

**NATIONAL INSTITUTE FOR HEALTH AND CARE
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Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Pancreatic cancer

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for pancreatic cancer. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development sources

The key development sources referenced in this briefing paper are:

[Pancreatic cancer in adults: diagnosis and management](#) NICE guideline NG85 (2018). Guideline review is scheduled for February 2021.

[Suspected cancer: recognition and referral](#) NICE guideline NG12 (2015). No review schedule presented.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the diagnosis and management of pancreatic cancer in adults.

2.2 Definition

The pancreas is an organ in the upper abdomen. It is approximately 6 inches long and is located behind the stomach. The pancreas has 2 main functions:

- It makes pancreatic juices which contain substances called enzymes. These enzymes help to break down food so the body can absorb it. The pancreatic juices flow down a tube called the pancreatic duct, which runs the length of the pancreas and empties into the duodenum (the first part of the small intestines).

- The pancreas also makes hormones, including insulin, which control sugar levels in the blood¹.

Pancreatic cancer occurs when a malignant tumour forms in the pancreas. It includes carcinomas of the head of the pancreas, the ampulla of Vater, the common bile duct, and the duodenum. Tumours can develop in both the exocrine and the endocrine tissue of the pancreas, although 95% arise from the exocrine parenchyma (functional tissue) and are referred to as adenocarcinomas².

2.3 Incidence and prevalence

It's not fully understood what causes pancreatic cancer, but a number of risk factors for developing the condition have been identified:

- age – it mainly affects people aged 50-80
- being very overweight
- tobacco – around 1 in 3 cases are associated with smoking cigarettes, cigars or chewing tobacco
- having a history of certain health conditions such as diabetes, chronic pancreatitis (long-term inflammation of the pancreas), stomach ulcer and Helicobacter pylori infection (a stomach infection)
- genetics - in about 1 in 10 cases, pancreatic cancer is inherited. Certain genes also increase chances of getting pancreatitis, which in turn increases risk of developing cancer of the pancreas.

Pancreatic cancer is the 6th most common cause of cancer death in the UK, accounting for 6% of all cancer deaths (2016). There were 9,921 new cases of pancreatic cancer in UK in 2015 and 9,263 people died with this type of cancer in 2016. Since the late 1970s, pancreatic cancer mortality rates remained stable in the UK. However, this overall pattern masks increased rates in females (12%) and decreased rates in males (14%). Over the last decade, pancreatic cancer mortality rates have increased by less than a tenth (7%) in the UK. The increase is similar in males (6%) and females (7%). Mortality rates for pancreatic cancer are projected to fall by 3% in the UK between 2014 and 2035, to 17 deaths per 100,000 people by 2035. Pancreatic cancer deaths are more common in people living in the most deprived areas³.

2.4 Diagnosis and management

Pancreatic cancer often doesn't cause any signs or symptoms in the early stages which can make it hard to diagnose early. Some of the symptoms may include:

¹ [Pancreatic cancer UK](#) (2018)

² [Pancreatic cancer action](#) (2018)

³ [Cancer research UK](#) (2018)

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- abdominal pain
- back pain
- unexplained weight loss
- indigestion
- loss of appetite
- changes to bowel habits – including steatorrhoea (pale, smelly stools that may float), diarrhoea or constipation
- nausea and vomiting
- difficulty swallowing
- jaundice
- recently diagnosed diabetes.

Patients with symptoms that suggest they have pancreatic cancer need an urgent referral to secondary care for further investigations. Decisions about treatment should be taken by specialist pancreatic multidisciplinary teams (MDT) based on diagnosis and staging investigations⁴.

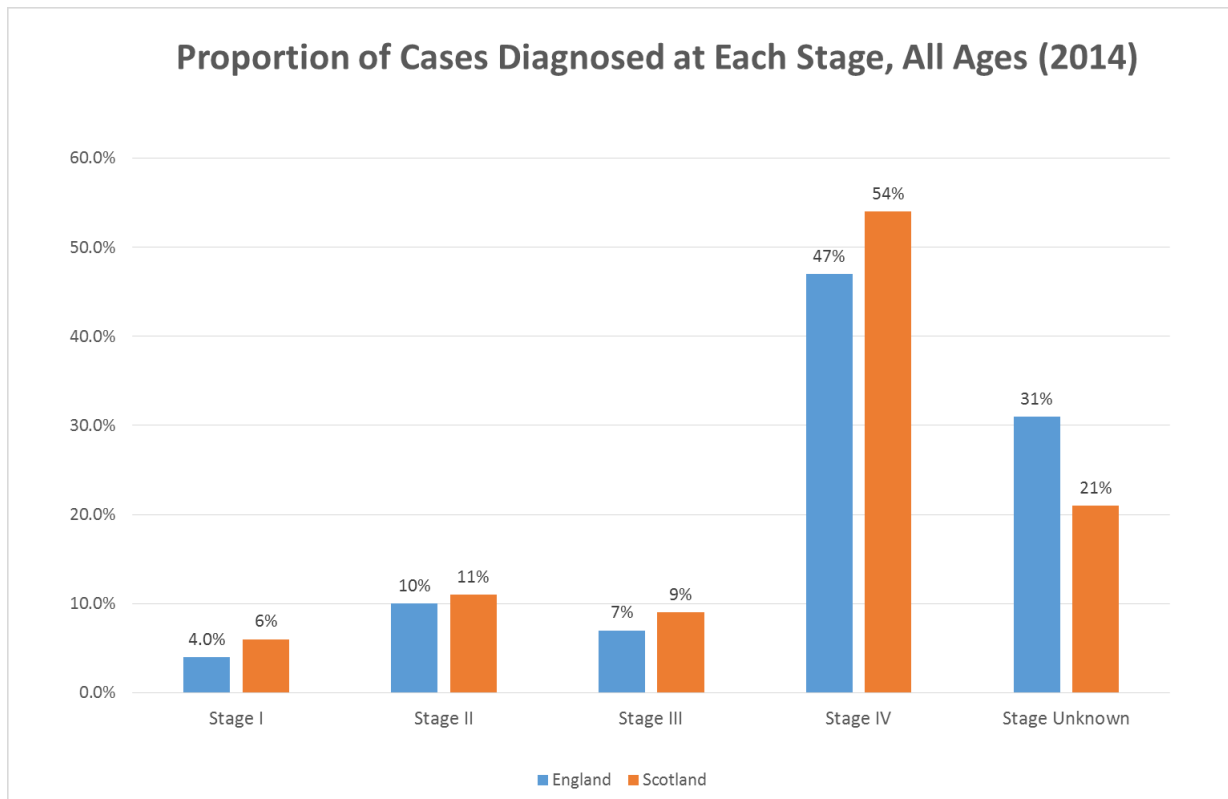
The 3 main treatments for pancreatic cancer are:

- surgery
- chemotherapy
- radiotherapy.

In 2013 – 14 only 10% of patients diagnosed with pancreatic cancer had the potentially curative surgery. Surgery is most effective for patients if their disease has been diagnosed early⁵.

⁴ [Pancreatic cancer action \(2018\)](#)

⁵ [Cancer research UK](#) (2018)



The UK has one of the worst survival rates in Europe, with average life expectancy on diagnosis just 4–6 months and a relative survival to 1 year of approximately 20%. Only 3% of people survive for 5 years or longer. This figure has not improved much in over 40 years, and the more recent effects of increased surgery and use of adjuvant chemotherapy on survival outcomes is not yet established. However, people have up to a 30% chance of surviving 5 years if their tumour can be surgically removed and they have adjuvant chemotherapy.

2.5 National outcome frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [NHS outcomes framework 2016–17](#)

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p>Improvement areas</p> <p>Reducing premature mortality from the major causes of death</p> <p>1.4 Under 75 mortality rate from cancer*</p> <p>i One- and ii Five-year survival from all cancers <i>v One- and vi Five-year survival from cancers diagnosed at stage 1 & 2**</i></p>
4 Ensuring that people have a positive experience of care	<p>Overarching indicators</p> <p>4a Patient experience of primary care</p> <p>i GP services ii GP Out-of-hours services</p> <p>4b Patient experience of hospital care</p> <p>4c <i>Friends and family test</i></p> <p>4d <i>Patient experience characterised as poor or worse</i></p> <p><i>I Primary care</i> <i>ii Hospital care</i></p> <p>Improvement areas</p> <p>Improving people’s experience of outpatient care</p> <p>4.1 Patient experience of outpatient services</p> <p>Improving hospitals’ responsiveness to personal needs</p> <p>4.2 Responsiveness to inpatients’ personal needs</p> <p>Improving people’s experience of accident and emergency services</p> <p>4.3 Patient experience of A&E services</p> <p>Improving the experience of care for people at the end of their lives</p> <p>4.6 Bereaved carers’ views on the quality of care in the last 3 months of life</p>
<p>Alignment with Public Health Outcomes Framework</p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

Table 2 [Public health outcomes framework for England, 2016–2019](#)

Domain	Objectives and indicators
2 Health improvement	<p>Objective People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p>Indicators 2.19 Cancer diagnosed at stage 1 and 2*</p>
4 Healthcare public health and preventing premature mortality	<p>Objective Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p>Indicators 4.05 Under 75 mortality rate from cancer *</p>
<p>Alignment with NHS Outcomes Framework * Indicator is shared</p>	

3 Summary of suggestions

3.1 Responses

In total 11 registered stakeholders and 6 specialist committee members responded to the 2-week engagement exercise (5 - 19 March 2018)

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Diagnosis and staging <ul style="list-style-type: none"> • Diagnosis • Staging 	BS, BSGAR, PCA, PCRF, PCUK, RCPATH, SCMs
Care planning <ul style="list-style-type: none"> • Specialist pancreatic multidisciplinary teams • Clinical nurse specialist 	BSG, PCA, PCRF, PCUK, RCGP, RCP SCMs
Cancer management <ul style="list-style-type: none"> • Resectable and borderline resectable pancreatic cancer • Unresectable pancreatic cancer 	BSR, RCGP, PCA, PCRF, PCUK, RCPATH, SCM
Support needs <ul style="list-style-type: none"> • Psychological support • Pain management • Nutritional management 	BSG, BSGAR, NHSE, RCGP, RCP, SCMs
Additional areas <ul style="list-style-type: none"> • Support for doctors and nurses • Clinical trials 	NHSE, PCA, PCRF, PCUK, RCGP, SCMs
BS, Boston Scientific BSG, British Society of Gastroenterology BSGAR, British Society of Gastrointestinal and Abdominal Radiology BSR, British Society of Radiologists NHSE, NHS England PCA, Pancreatic Cancer Action PCRF, Pancreatic Cancer Research Fund PCUK, Pancreatic Cancer UK RCGP, Royal College of General Practitioners RCPATH, Royal College of Pathologists RCP, Royal College of Physicians SCM, Specialist Committee Member	

3.2 *Identification of current practice evidence*

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 390 papers were identified for pancreatic cancer. In addition, 47 papers were suggested by stakeholders at topic engagement and 23 papers internally at project scoping.

Of these papers, 13 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 *Diagnosis and staging*

4.1.1 Summary of suggestions

Diagnosis

Stakeholders suggested early diagnosis as an area for quality improvement. They highlighted that diagnosis has an impact on resectability of the tumour, patient outcomes and patient satisfaction.

Stakeholders also suggested that to ensure accurate diagnosis and appropriate treatment, tissue sample from pancreatic tumours should be acquired by endoscopic ultrasound (EUS) before surgery is performed. They suggested that provision of EUS in the country is inadequate and causes delays within the diagnostic pathway.

Staging

Stakeholders highlighted staging as an area for quality improvement. They suggested that failure to perform all the key staging investigations prior to an intervention can compromise treatment options and cause delays.

Stakeholders suggested that carrying out a pancreatic protocol CT scan, followed by fluorodeoxyglucose-positron emission tomography/CT (FDG-PET/CT) and/or EUS with EUS –guided sampling is clinically indicated and cost saving as patients who cannot benefit from major radical surgery can avoid operation and go straight to other forms of management.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after the table to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Diagnosis	<p>Pancreatic cancer NICE NG12 Recommendation 1.2.4</p> <p>People with obstructive jaundice NICE NG85 Recommendations 1.1.1, 1.1.2</p> <p>People without jaundice who have pancreatic abnormalities on imaging NICE NG85 Recommendations 1.1.4 - 1.1.6</p>
Staging	<p>Staging NICE NG85 Recommendations 1.3.1,1.3.2</p>

Pancreatic cancer

NICE NG12 Recommendation 1.2.4

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for pancreatic cancer if they are aged 40 and over and have jaundice.

People with obstructive jaundice

NICE NG85 Recommendation 1.1.1

For people with obstructive jaundice and suspected pancreatic cancer, offer a pancreatic protocol CT scan before draining the bile duct.

NICE NG85 Recommendation 1.1.2

If the diagnosis is still unclear, offer fluorodeoxyglucose-positron emission tomography/CT (FDG-PET/CT) and/or endoscopic ultrasound (EUS) with EUS-guided tissue sampling.

People without jaundice who have pancreatic abnormalities on imaging

NICE NG85 Recommendation 1.1.4

Offer a pancreatic protocol CT scan to people with pancreatic abnormalities but no jaundice.

NICE NG85 Recommendation 1.1.5

If the diagnosis is still unclear, offer FDG-PET/CT and/or EUS with EUS-guided tissue sampling.

NICE NG85 Recommendation 1.1.6

If cytological or histological samples are needed, offer EUS with EUS-guided tissue sampling.

Staging

NICE NG85 Recommendation 1.3.1

For people with newly diagnosed pancreatic cancer who have not had a pancreatic protocol CT scan, offer a pancreatic protocol CT scan that includes the chest, abdomen and pelvis

NICE NG85 Recommendation 1.3.2

Offer fluorodeoxyglucose-positron emission tomography/CT (FDG-PET/CT) to people with localised disease on CT who will be having cancer treatment (surgery, radiotherapy or systemic therapy).

4.1.3 Current UK practice

Diagnosis

A clinical audit of cancer diagnosis carried out in 2014 in general practices in England found that 31.6% of people diagnosed with pancreatic cancer experienced avoidable delays to diagnosis. This was the second highest result out of all analysed cancer sites (Stomach cancer 34.4% was the highest)⁶.

A survey carried out by pancreatic cancer UK in 2015 found that 63% of respondents said they/their family member had to visit their GP three times or more before diagnosis. 23% said they had to visit seven times or more. The survey also found that in 41% of people, it took three months or longer from first going to their GP with symptoms until they were diagnosed⁷.

A small audit was carried out at the University Hospitals of Leicester NHS Trust, using data from 51 patients admitted with an emergency diagnosis of pancreatic cancer in 2013. As part of the audit, patient notes were evaluated to determine if any patients had consulted their GP within 6 months of presentation with symptoms which could have been an early warning of pancreatic cancer. The results showed:

- 51% of patients had presented to their GP within 6 months prior to diagnosis with such symptoms
- 39% of patients had previously undergone procedures to investigate upper abdominal pain performed within 6 months of presentation (11 patients had ultrasound scans, 7 had oesophagogastroduodenoscopy)

⁶ Swann R. et al. (2018) [Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit](#)

⁷ Pancreatic cancer UK (2015), [Results of symptoms and diagnosis survey](#)

The results from Leicester also confirmed that late diagnosis is an area of concern in pancreatic cancer:

- Only 10% of patients had resectable disease
- 49% of patients were found to have metastases
- 29% of patients were found to have locally advanced disease⁸

In 2011 a group working on behalf of The British Society of Gastroenterology reviewed service provision and training for endoscopic ultrasound in the UK. They found that the provision of EUS services in the UK was lower than in other large European countries. The main concerns raised by the review were around access and endoscopist training⁹.

No recent published studies, reviews or audits on current practice of using EUS for tissue acquisition were identified. This area is based on stakeholder's knowledge and experience.

Staging

In February 2018 The National Cancer Registration and Analysis Service (NCRAS) in partnership with Cancer Research UK (CRUK) published population-based statistics on the patients recorded to have received chemotherapy, radiotherapy and surgical tumour resections for their tumour. The data indicates that for 37.5% of the pancreatic tumours recorded to be treated, stage was recorded as unknown¹⁰.

4.1.4 Resource impact

When NG85 was published, the recommendations referring to the use of PET/CT scans were determined to cause an increase in costs due to an increase in the use of PET/CT, however this increase in costs was expected to be offset by a reduction in the number of pancreatectomies and the recommendations on diagnosis and staging were thought to be cost neutral overall.

⁸ Ojo D., Dennison A.R., Garcea G.(2016), [Audit of emergency presentation of pancreatic cancer.](#)

⁹ Meehan J et al. (2011) [Service provision and training for endoscopic ultrasound in the UK](#)

¹⁰ National Cancer Intelligence Network (2018), [Chemotherapy, Radiotherapy and Tumour Resection in England](#), 2013 – 2014

4.2 *Care planning*

4.2.1 Summary of suggestions

Specialist pancreatic multidisciplinary teams

Stakeholders highlighted the role of specialist pancreatic multidisciplinary teams as an area for quality improvement.

Stakeholders suggested that a specialist pancreatic cancer multidisciplinary team should decide what care is needed and involve the person with suspected or confirmed pancreatic cancer in the decisions. They also suggested that care should be delivered in partnership with local cancer units.

Clinical nurse specialist

Stakeholders highlighted access to specialist support from clinical nurse specialist as an area for quality improvement. They suggested that whilst there is good evidence of positive patient outcomes, such as patient experience, current access is variable.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Specialist pancreatic multidisciplinary teams	Specialist pancreatic multidisciplinary teams NICE NG85 Recommendation 1.2.1
Clinical nurse specialist	No recommendations identified in NICE NG85.

Specialist pancreatic multidisciplinary teams

NICE NG85 Recommendation 1.2.1

A specialist pancreatic cancer multidisciplinary team should decide what care is needed, and involve the person with suspected or confirmed pancreatic cancer in the decision. Care should be delivered in partnership with local cancer units.

4.2.3 Current UK practice

Specialist pancreatic multidisciplinary teams

Parliamentary enquiry into pancreatic cancer carried out in 2013 raised concerns about delays in referrals to specialist pancreatic cancer centres as well as multidisciplinary teams¹¹. The same year, NHS England stated in the standard contract for hepatobiliary and pancreas that in some cancer networks, up to 40% of patients were still not referred or discussed with the specialist pancreatic team¹².

Clinical nurse specialist

The 2016 National Cancer Patient Experience Survey found that 90.4% of respondents (all upper GI cancers) said that they had been given the name of a Clinical Nurse Specialist who would support them through their treatment. Also, 80% of respondents said it had been 'quite easy' or 'very easy' to contact the Clinical Nurse Specialist¹³.

4.2.4 Resource impact

This area of the guidance was not anticipated to be an area of significant resource use during the development of the guideline.

¹¹ [All Party Parliamentary Group on pancreatic cancer 2013](#)

¹² NHS England (2013) 2013/14 [NHS standard contract for hepatobiliary and pancreas \(adult\)](#)

¹³ Quality Health Ltd. (2017) [National Cancer Patient Experience Survey 2016](#)

4.3 Cancer management

4.3.1 Summary of suggestions

Resectable and borderline resectable pancreatic cancer

Stakeholders highlighted managing resectable and borderline resectable pancreatic cancer as an area for quality improvement. They suggested that people who have resectable pancreatic cancer and obstructive jaundice, are well enough for the procedure and are not enrolled in a clinical trial that requires preoperative biliary drainage, should be offered resectional surgery rather than preoperative biliary drainage. They suggested that biliary drainage may cause unnecessary delays and compromise interpretation of resectability.

Stakeholders also suggested that adjuvant therapy should be started post-surgery as soon as people are well enough to tolerate all 6 cycles which are required for optimal benefit. Stakeholders highlighted neoadjuvant therapy and minimally invasive pancreatectomy as developmental areas of emergent practice.

Unresectable pancreatic cancer

Stakeholders highlighted managing unresectable pancreatic cancer as an area for quality improvement. They suggested that people who cannot have their cancer removed surgically should be offered appropriate first and second line chemotherapy because palliative chemotherapy can prolong survival and improve quality of life.

Stakeholders also suggested offering FOLFIRINOX chemotherapy regimen to people with metastatic pancreatic cancer and an Eastern Cooperative Oncology Group (ECOG) performance status of 0–1 because it improves fitness and survival.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Resectable and borderline resectable pancreatic cancer	Biliary obstruction NICE NG85 Recommendation 1.7.1 Adjuvant treatment NICE NG85 Recommendation 1.8.5
Unresectable pancreatic cancer	Locally advanced pancreatic cancer NICE NG85 Recommendation 1.9.1 Metastatic pancreatic cancer NICE NG85 Recommendation 1.9.4

Biliary obstructionNICE NG85 Recommendation 1.7.1

Offer resectional surgery rather than preoperative biliary drainage to people who:

- have resectable pancreatic cancer and obstructive jaundice
- are well enough for the procedure
- are not enrolled in a clinical trial that requires preoperative biliary drainage.

Adjuvant treatmentNICE NG85 Recommendation 1.8.5

Give people time to recover from surgery before starting adjuvant therapy. Start adjuvant therapy as soon as they are well enough to tolerate all 6 cycles.

Locally advanced pancreatic cancerNICE NG85 Recommendation 1.9.1

Offer systemic combination chemotherapy to people with locally advanced pancreatic cancer who are well enough to tolerate it.

Metastatic pancreatic cancerNICE NG85 Recommendation 1.9.4

Offer FOLFIRINOX to people with metastatic pancreatic cancer and an Eastern Cooperative Oncology Group (ECOG) performance status of 0–1.

Please note: Although this use is common in UK clinical practice, at the time of publication (February 2018) FOLFIRINOX did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

4.3.3 Current UK practice

In February 2018 The National Cancer Registration and Analysis Service (NCRAS) in partnership with Cancer Research UK (CRUK) published population-based statistics on the patients recorded to have received chemotherapy, radiotherapy and surgical tumour resections for their tumour in England. The results are presented in table 7¹⁴.

Table 7 Percentage of pancreas tumours diagnosed in 2013-2014 and recorded to have been treated with chemotherapy, tumour resection and radiotherapy in England

	All stages	Stage 1	Stage 2	Stage 3	Stage 4	Unknown
Chemotherapy only	19.7	13.4	12.9	37.1	24.5	13.4
Tumour resection only	4.6	15.9	18.1	3.2	1.0	4.7
Radiotherapy only	1.3	1.1	0.3	1.8	1.6	1.1
Chemotherapy + Radiotherapy	3.4	4.8	3.7	8.9	2.4	3.5
Tumour resection + Chemotherapy	4.9	4.7	34.1	4.0	1.0	2.8
Tumour resection + Radiotherapy	0.1	0.3	0.3	0.1	0.0	0.1
Chemotherapy + Tumour resection + Radiotherapy	0.2	0.3	1.2	0.3	0.1	0.1
Other care	65.8	59.4	29.4	44.6	69.3	74.2

Resectable and borderline resectable pancreatic cancer

A study carried out in Birmingham hospital found that out of 93 patients who underwent pancreatoduodenectomy, 61 patients had preoperative biliary drainage¹⁵.

No published studies on current practice were highlighted in regards to proportion of patients receiving post-operative adjuvant treatment. This area is based on stakeholder's knowledge and experience.

¹⁴ National Cancer Intelligence Network (2018), [Chemotherapy, Radiotherapy and Tumour Resection in England](#), 2013 – 2014

¹⁵ Prasad Pooja et al. (2017) [Pancreatoduodenectomy for periampullary cancer and biliary obstruction: impact of a pathway to avoid preoperative biliary drainage](#).

Unresectable pancreatic cancer

No published studies on current practice were highlighted in regards to proportion of patients receiving first and second line chemotherapy. This area is based on stakeholder's knowledge and experience.

No published studies on current practice were highlighted in regards to proportion of patients with metastatic pancreatic cancer receiving FOLFIRINOX. This area is based on stakeholder's knowledge and experience.

4.3.4 Resource impact

This was not anticipated to be an area of significant resource impact when the guideline was developed.

4.4 *Support needs*

4.4.1 **Summary of suggestions**

Psychological support

Stakeholders highlighted psychological support as an area for quality improvement. They suggested that patients with pancreatic cancer experience high prevalence of depression and anxiety and their needs are often not met. They also suggested that relatives and carers should have access to this support as well.

Pain management

Stakeholders highlighted improving access to coeliac plexus block for pain management in people with pancreatic cancer as an area for quality improvement. They suggested that the procedure should be considered as part of the early multidisciplinary decision process rather than later in the pain management pathway.

Nutritional management

Stakeholder highlighted nutritional management as an area for quality improvement. They suggested that appropriate nutritional support increases quality of life and survival in pancreatic cancer patients and suggested that people should have access to a specialist dietitian. The stakeholders also suggested that pancreatic cancer patients should be offered pancreatic enzyme replacement tablets (PERT). They suggested that optimal nutrition support improves fitness to undergo surgery and other treatments, improves quality of life through symptom improvement and may also contribute to survival.

4.4.2 **Selected recommendations from development source**

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Psychological support	Psychological support NICE NG85 Recommendations 1.4.1, 1.4.2
Pain management	Pain management NICE NG85 Recommendation 1.5.1
Nutritional management	Nutritional management NICE NG85 Recommendation 1.6.1

Psychological support

NICE NG85 Recommendation 1.4.1

Throughout the person's pancreatic cancer care pathway, specifically assess the psychological impact of:

- fatigue
- pain
- gastrointestinal symptoms (including changes to appetite)
- nutrition
- anxiety
- depression.

NICE NG85 Recommendation 1.4.2

Provide people and their family members or carers (as appropriate) with information and support to help them manage the psychological impact of pancreatic cancer on their lives and daily activities. This should be:

- available on an ongoing basis
- relevant to the stage of the person's condition
- tailored to the person's needs.

Pain management

NICE NG85 Recommendation 1.5.1

Consider EUS-guided or image-guided percutaneous neurolytic coeliac plexus block to manage pain for people with pancreatic cancer who:

- have uncontrolled pancreatic pain or
- are experiencing unacceptable opioid adverse effects or
- are receiving escalating doses of analgesics.

Nutritional management

NICE NG85 Recommendation 1.6.1

Offer enteric-coated pancreatin for people with unresectable pancreatic cancer.

4.4.3 Current UK practice

Psychological support

The 2016 National Cancer Patient Experience Survey found that 66.9% of respondents (all upper GI cancers) said that hospital staff had provided information about support or self-help groups for people with cancer¹⁶.

No studies, reviews or audits indicating what psychological support is available to people with pancreatic cancer in the UK have been identified. This area is based on stakeholder's knowledge and experience

Coeliac plexus blockPain management

No studies, reviews or audits indicating how often coeliac plexus block is offered or used to manage pain have been identified. This area is based on stakeholder's knowledge and experience.

Nutritional management

A very small survey carried out with clinical nurse specialists found that 19% had access to pancreatic specialist dietitian and another 9.5% had access to Hepato-Pancreato-Biliary (HPB) specialist dietitian. The same survey found that 4% had no access to any dietetic support¹⁷.

4.4.4 Resource impact

This area was not considered to have a significant impact on resource use for the NHS during the production of the guidance.

¹⁶ Quality Health Ltd. (2017) [National Cancer Patient Experience Survey 2016](#)

¹⁷ Pancreatic cancer UK (2015) [Clinical Nurse Specialist Survey](#)

4.5 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 16 May 2018.

Support for doctors and nurses

Educational support and advice for GPs and primary care professionals on symptoms of pancreatic cancer and diagnostics was suggested as an area of quality improvement.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the education and advice that enables the actions to take place. However, support for GPs and primary care professionals may be referred to in the audience descriptors.

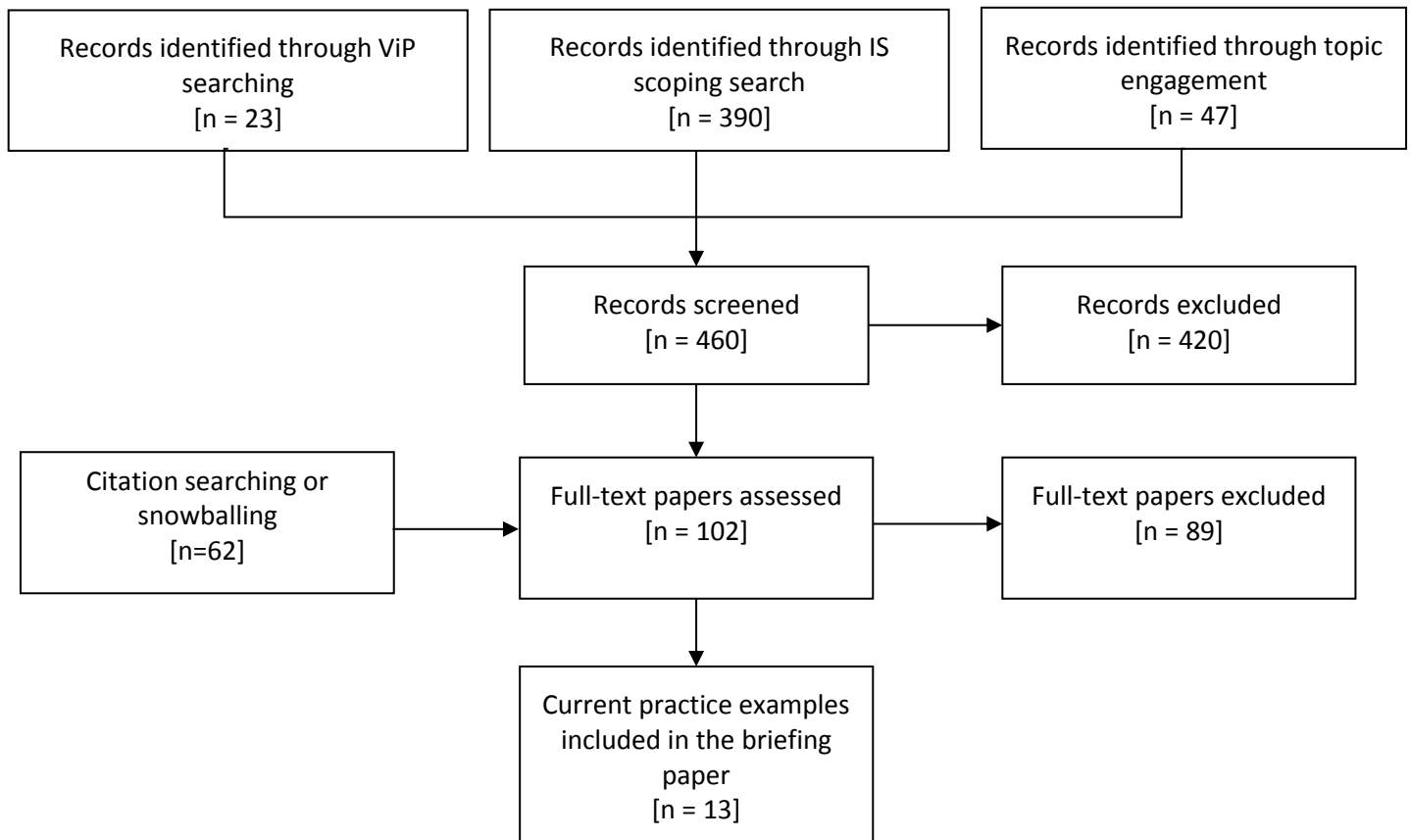
Clinical trials

Stakeholders highlighted access to clinical trials as an area for quality improvement.

They suggested that due to poor patient outcomes and the need to identify better treatments all eligible patients should be offered access to clinical trials when possible. This suggestion has not been progressed. Increasing the opportunities for patients and the public to participate in research is within the remit of the National Institute for Health Research.

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Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
1	SCM4	Provide timely and accurate diagnosis and staging of pancreatic cancer	Pancreatic cancer has a poor prognosis, 80% are diagnosed with advanced disease when treatment options are limited and it may be too late for them to receive surgery, the only potential cure. Many are diagnosed through an emergency presentation route, which is associated with poorer survival. People diagnosed also report going back to their GP multiple times before being referred for tests and diagnosed. Timely diagnosis is essential to provide people with the best chance of being able to receive treatment to prolong life and improve quality of life. Accurate staging of the disease will ensure patients get the most appropriate treatment option for them. For example detect spread of the disease pre surgery so that they do not have surgery if they are going to recur quickly. This staging must be carried out quickly so treatment can begin before health deteriorates. Recommended in NICE guidelines.	Data from NCRAS on routes to diagnosis demonstrates that 44% of pancreatic cancer patients are diagnosed via an emergency route. A paper by Keane, Horsfall, Rait and Pereira in BMJ Open demonstrated that people with pancreatic cancer visit their GP multiple times before being diagnosed.	National Cancer Registration and Analysis service - http://www.ncin.org.uk/publications/routes_to_diagnosis A paper by Keane, Horsfall, Rait and Pereira in BMJ Open A case-control study comparing the incidence of early symptoms in pancreatic and biliary tract cancer http://bmjopen.bmj.com/content/4/11/e005720.full?keytype=ref&ijkey=Of2zmYEB6srnZgd

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2	Boston Scientific	<p>Diagnosis : People with obstructive jaundice (1.1.3 - NICE Guideline. Pancreatic cancer in adults: diagnosis and management)</p>	<p>We would like to suggest replacing biliary brushing for cytology with targeted Biopsy and biliary brush Cytology if endoscopic retrograde cholangiopancreatography (ERCP) is being used to relieve the biliary obstruction and there is no tissue diagnosis. We think this is important because targeted biopsy show higher sampling yields of 86% sensitivity and 100% specificity (1) and adequate specimen for histologic evaluation in 97.7% of cases (2) compared to lower cytological sensitivities for diagnosing biliary cancer of 32% -70% (3).</p>	<p>Quality improvement in diagnostic care for people with obstructive jaundice is needed due to the low sampling yield sensitivity and the low histologic specificity of biliary brushing.</p>	<p>References: 1.Performance of a fully disposable, digital, single-operator cholangiopancreatoscope, Shah et al, Published online: 16.5.2017 Endoscopy 2017; 49: 651–658) 2.Digital, single-operator cholangiopancreatoscopy in the diagnosis and management of pancreatobiliary disorders: a multicenter clinical experience. Authors Navaneethan et al. Article in Press, GIE http://dx.doi.org/10.1016/j.gie.2016.03.789 3. Diagnosis of bile duct cancer by bile cytology: usefulness of post-brushing biliary lavage fluid Authors Sugimoto et al. http://dx.doi.org/10.1055/s-0034-1391666 Published online: 7.5.2015 Endosc Int Open 2015; 03:E323–E328.</p>
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3	British Society of Gastrointestinal and Abdominal Radiology	Length of the diagnostic imaging pathway	As described, diagnostic pathway for pancreatic cancer is complex and can take several weeks to complete variably including US, CT, MRI, EUS (+/- FNA) and PET/CT. Delays to diagnosis and delays between staging investigations and surgery can affect resectability, outcomes and patient satisfaction.	The proportion of patients who are amenable to curative treatment remains low, and the surgical rates for potentially operable patients can also be improved. Shortened diagnostic pathways may improve resectability, outcomes and patient satisfaction.	National Cancer Intelligence Network (NCIN) collects data on incidence, prevalence and morbidity. NHS England collects data on diagnostic pathways. Diagnostic Imaging Dataset collects data on diagnostic imaging. Commentary on the diagnosis pathway: https://www.bmj.com/content/349/bmj.g5261 Pancreatic Cancer UK Policy Briefing: https://www.pancreaticcancer.org.uk/media/86662/every-lm_policybriefing-final.pdf
4	British Society of Gastrointestinal and Abdominal Radiology	Assessment and documentation of diagnostic imaging	CT is central to the assessment of resectability in pancreatic cancer. However, formal review and documentation of the relevant criteria for resectability is variable.	Clear documentation of the radiological assessment will support clinical decision making at diagnosis, following neoadjuvant treatment and facilitate retrospective audit. This may also help support entry into much-needed clinical trials. A minimum data set for pancreatic cancer staging CT may improve consistency of documentation	Minimum datasets are required for e.g. CTCs performed in the BCSP. An example reporting template is found at https://www.tri-kobe.org/nccn/guideline/pancreas/english/pancreatic.pdf (pages 21-24)
5	SCM1	Improved access to EUS which currently causes bottle necks in service	The NICE Guidelines for Pancreatic Cancer recognise EUS as a method of tissue sampling prior to treatment. Current provision appears inadequate in some areas around the country.		Please see the NICE Guidelines for Pancreatic Cancer February 2018 www.nice.org.uk/guidance/ng85/resources/pancreatic-cancer

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6	SCM1	Management of pancreatic cysts	Current management of pancreatic cysts often requires referral to tertiary centres. This results in monitoring which is not carried out locally.		Please see the NICE Guidelines for Pancreatic Cancer February 2018 www.nice.org.uk/guidance/ng85/resources/pancreatic-cancer
7	SCM2	Tissue core acquisition before operation by endoscopic ultrasound in patients with pancreatic cancer	In the near future (and at present in research studies) preoperative tissue from the pancreatic tumours is needed for genomic analysis. This is key to the personalised approach to this disease.	The optimum way of obtaining core histological material and hence material suitable for genomic analysis is endoscopic ultrasound with core biopsy. This is a difficult technique to learn and at present the yield even of cytology from these procedures is low in many centres. There requires to be very significant up-skilling in the performance of EUS and biopsy in the UK and the recognition that this is a specialist area, requiring practitioners to be undertaking this regularly, not on an occasional basis.	European Guidelines are available: https://www.thieme-connect.com/products/ejournals/html/10.1055/s-0043-119219 However there are little data on the quality of EUS adntissue acquisition in the UK although anecdotally it is highly variable in specialist centres.
8	Royal College of Pathologists	Direct histological processing of EUS guided tissue samples	There is clear evidence that direct histological processing of EUS guided fine needle aspiration and fine needle core biopsies allows improved diagnosis and additional diagnostic tests including molecular analysis that could not be reliably performed on conventional cytology preparations. Additional ancillary tests on tissue samples will contribute to diagnostic certainty and accuracy and will be prerequisite for evaluating biomarkers in the context of treatment stratification and trials	Comparison of conventional cytology processing with formalin fixed histology processing of EUS samples showed superiority in terms of time needed for diagnosis, cost and suitability for molecular tests. Centres across the UK differ in their practice of EUS tissue sampling and laboratory processing with many centres maintaining cytology processing as expertise in interpretation of EUS samples has been maintained by cytopathologists	Direct histological processing of EUS biopsies enables rapid molecular biomarker analysis for interventional pancreatic cancer trials. Pancreatology. 2012 Jan-Feb;12(1):8-15. Audit information of pathological evaluation of EUS centres across UK not available

9	SCM3	Proportion of pancreatic cancer diagnosed as early stage disease	Only 20% of patients are diagnosed at an early stage disease when resection is possible. Resectable disease has best survival outcomes (median survival ~ 27months vs 14 -18 months for locally advanced disease, and ~6-8 months for metastatic cancer. Early diagnosis is therefore critical in improving patient outcomes in this disease site	<p>63% visit GP 3 times or more, and 23% 7 times or more before diagnosis is made. 41% reported first symptom to diagnosis of 3 months or more</p> <p>https://www.pancreaticcancer.org.uk/media/409005/3047_pcuk_symptomsdiagnosis_survey.pdf</p> <p>The principles outlined in the NICE guideline NG12 (suspected cancer: recognition and referral) is also relevant for this Quality Standards Indicator</p>	<p>https://www.pancreaticcancer.org.uk/media/409005/3047_pcuk_symptomsdiagnosis_survey.pdf</p> <p>https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-on-patient-support-safety-netting-and-the-diagnostic-process#upper-gastrointestinal-tract-cancers</p>
10	British Society of Gastrointestinal and Abdominal Radiology	Consistency and timing of pancreatic protocol staging CT	NICE guidelines recommend that pancreatic protocol CT should be offered to patients with suspected pancreatic cancer. Accurate staging investigations, particularly CT, are important to allow surgical resectability to be assessed. Implementation is variable, which can introduce delays in decision-making. Where possible, staging investigations should be completed prior to biliary intervention to avoid imaging compromised by artefact or complications of intervention.	<p>Inconsistency in the diagnostic imaging pathway can lead to delays, and failure to perform all the key staging investigations prior to biliary intervention can compromise interpretation of resectability.</p> <p>It is recommended that time between staging investigations and surgery is less than 30 days.</p>	Impact of delays to surgery on resectability: https://www.ncbi.nlm.nih.gov/pubmed/26572509
11	SCM5	FDG-PET/CT Offer fluorodeoxyglucose -positron emission tomography/CT (FDG-PET/CT) to people with localised disease on CT who will be having cancer treatment.	Optimally correct staging ensures that a person with pancreatic cancer gets the correct treatment, e.g. chemotherapy rather than surgery.	FDG-PET/CT is not yet part of routine staging practice. Its availability and timeliness of provision will be challenging to implement.	PET-Panc study (HTA)

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12	SCM2	The provision of per-operative PET-CT to all patients having elective surgery for pancreatic cancer	It has been demostated in the PET-PANC study funder by NIHR HTA programme that pre-opearative CT-PET is clinically indicated and cost saving as patients who cannot benefit from major radical surgery can avoid operation and go straight to oncological managment	CT-PET is not run as with most conventional imaging within the NHS but provided through a contact with a private provider, Alliance Medical. At present it is not clear that PET-CT can be provided within the present Cancer Targets timelines in patients with pancreatic cancer. Reasons include the current wait times and also the complexity of the request process which is parallel to NHS request sytems but not integrated.	The PET-PANC study can be found at: Health Technol Assess. 2018 Feb;22(7):1-114. doi: 10.3310/hta22070.
13	SCM6	Give accurate diagnosis of pancreatic cancer tumour i.e. pancreatic cancer subtype and stage.	An accurate diagnosis of the cancer subtype and stage is needed to ensure that the best treatment options are put forward to the patient Based on the feedback from the support group feedback this is a priority area for This is part of NICE guidance		
14	Pancreatic Cancer UK, Pancreatic Cancer Action & Pancreatic Cancer Research Fund	Give accurate diagnosis of pancreatic cancer tumour i.e pancreatic cancer subtype and stage.	Accurate diagnosis of the subtype and stage of the disease are essential to implementing the best treatment and care option for an individual and avoiding unnecessary delays and complications.Pancreatic Cancer UK carried out a survey which asked healthcare professionals, patients and carers to prioritise five areas of the NICE guidelines that they believed would most improve care. Accurate diagnosis and staging was considered a priority by 57% of 154 respondents. This was identified as the top priority for patients and carers. Accurate diagnosis/staging is recommended within NICE guidance. If the diagnosis is still unclear, offer fluorodeoxyglucose-positron emission	The National Cancer Registration and Analysis Service (NCRAS) produced a population-based analysis which found that in the period 2013-2014, 37.5 % of pancreatic cancer cases were recorded as stage unknown compared to 21.5% of unknown stage of other common cancers. This highlights that currently accurate staging data for pancreatic cancer is lacking at diagnosis. A study in England has demonstrated that accurate staging at cancer diagnosis can influence treatment pathways because it is a key predictor of	The National Cancer Registration and Analysis Service (NCRAS) in partnership with Cancer Research UK (CRUK) has, for the first time, produced population-based statistics on the patients recorded to have received chemotherapy, radiotherapy and surgical tumour resections for their tumour in England http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments McPhail, S., et al. (2018) Stage at diagnosis and early

			<p>tomography/CT (FDG-PET/CT) and/or endoscopic ultrasound (EUS) with EUS-guided tissue sampling. Offer fluorodeoxyglucose-positron emission tomography/CT (FDG- PET/CT) to people with localised disease on CT who will be having cancer treatment (surgery, radiotherapy or systemic therapy).</p>	<p>overall cancer outcomes. This is further supported by research showing that many patients who have surgery have poor survival due to increased resection margin and micro-metastasis. The median survival for R0, R1 and R2 was found to be 17 months, 12 months and 8 months, respectively and 1 year survival was 64%, 50% and 36%, respectively. Many of these patients would have been diagnosed using a CT scan which is not as sensitive at detecting micro-metastasis. Undergoing a major surgery when the cancer has already spread can dramatically reduce the patient's quality of life without increasing the chance of overall survival. This indicates the need for accurate diagnosis and staging to ensure the best treatment pathway for patients.</p>	<p>mortality from cancer in England Br J Cancer 112.Suppl 1 (2015): S108–S115. Johnston WC, et. al, (2016) Total pancreatectomy for pancreatic ductal adenocarcinoma: review of the national cancer data base HPB (Oxford).18(1):21-8.</p>
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<p>15</p>	<p>SCM4</p>	<p>A specialist pancreatic cancer multidisciplinary team should decide what care is needed, and involve the person with suspected or confirmed pancreatic cancer in the decision. Care should be delivered in partnership with local cancer units.</p>	<p>Through my role at Pancreatic Cancer UK I hear through the charity's services and talking to those affected about variations in the treatment and care provided, this includes variation in the treatment options provided. In a disease with such a poor prognosis and where poor quality of life is often reported it is essential that all patients receive the most effective treatment and care options for them. This could best be achieved if specialist MDTs were involved in deciding the care of each patient. There is a recommendation on this in the NICE diagnosis and management of pancreatic cancer guidelines.</p>	<p>Pancreatic cancer mortality between cancer alliances ranges from a lowest mortality rate of 13.6 people per 100,000 population to the highest mortality rate of 19.7 people per 100,000 of the population. This suggests regional disparities in care standards. This may be impacted on by the level of involvement of specialist MDTs in the care of patients. A recent analysis of data published by Public Health England (PHE) revealed that around 7 in 10 pancreatic cancer patients received no active treatment for their cancer. A recent study focusing on care and treatment of unresectable pancreatic cancer patients showed that care in pancreatic cancer dedicated oncology clinics led to better outcomes.</p>	<p>Mortality by CCG is published on the NHS for England cancer data website (https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview http://geoportal.statistics.gov.uk/) CCG to Cancer Alliance mapping was taken from https://www.england.nhs.uk/wp-content/uploads/2017/02/cancer-alliance-guidance.pdf Cancer Alliance specific mortality data was calculated by averaging CCG mortality. Public Health England (PHE)/National Cancer Registration and Analysis Service (NCRAS) published population-based statistics on care and treatments that patients have received in 2013-2014 by cancer site in England. Data can be seen here http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments Faluyi OO, et al., (2017). Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional cancer centre. <i>Br J Cancer</i> 116 (4):424-431.</p>
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16	SCM6	A specialist pancreatic cancer multidisciplinary team should decide what care is needed, and involve the person with suspected or confirmed pancreatic cancer in the decision.	Running the local Staffordshire support group there are often patients who come from hospitals which are not a specialist centre. There is variance in the access to specialist knowledge and this can influence the effectiveness of the treatment plan. This is part of the current guidance		
17	Pancreatic Cancer UK, Pancreatic Cancer Action & Pancreatic Cancer Research Fund	A specialist pancreatic cancer multidisciplinary team should decide what care is needed, and involve the person with suspected or confirmed pancreatic cancer in the decision.	Multidisciplinary teams (MDT) are recommended within NICE guidance. A specialist pancreatic cancer MDT should decide what care is needed, and involve the person with suspected or confirmed pancreatic cancer in the decision. Care should be delivered in partnership with local cancer units. Pancreatic cancer is a complex disease and specialised care and treatment are needed for best outcomes. Therefore, the role of the specialist MDT is critical. This was also identified in a survey that Pancreatic Cancer UK carried out in which healthcare professionals, patients and carers were asked to prioritise five areas of the NICE guidelines that they believed would most improve care. Having a specialist MDT decide on treatment was considered a priority by 79% of 154 respondents. This was the recommendation that was ranked as the most important factor that respondents believed would improve care.	Pancreatic cancer mortality between cancer alliances ranges from a lowest mortality rate of 13.6 people per 100,000 population to the highest mortality rate of 19.7 people per 100,000 of the population. Such variations in mortality are suggestive of regional disparities in care standards. Differences in the role and level of involvement of MDTs in care of patients could be a contributing factor. In 2015 the National Cancer Patient Experience Survey (NCPES) in England reported that only 30% of upper gastrointestinal cancers, which include pancreatic cancer patients, were given a care plan. A recent analysis of data published by Public Health England (PHE) revealed that around 7 in 10 pancreatic cancer patients received no active treatment for their cancer as opposed to 3 in 10 people with other common cancers. A	Mortality by CCG is published in the NHS for England cancer data website (https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview http://geoportal.statistics.gov.uk/) CCG to Cancer Alliance mapping was taken from https://www.england.nhs.uk/wp-content/uploads/2017/02/cancer-alliance-guidance.pdf Cancer Alliance specific mortality data was calculated by averaging CCG mortality. You can see NCPES data for 2015 here https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey . Public Health England (PHE)/National Cancer Registration and Analysis Service (NCRAS) published for the first time population-based statistics on care and treatments that patients have received in 2013-2014 by cancer site in England. Data can be seen here http://www.ncin.org.uk/cancer_type

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				<p>factor that could contribute to this could be the lack of sufficient involvement of specialist MDT teams. A recent study focusing on care and treatment of unresectable pancreatic cancer patients showed that care in pancreatic cancer dedicated oncology clinics led to better outcomes. This involved earlier initiation of treatment from diagnosis by 10 days, increased number of patients having access to chemotherapy and better survival outcomes for frail patients. This shows the significance of a specialist MDT in care and treatment for pancreatic cancer patients.</p>	<p>and topic specific work/topic specific work/main cancer treatments Faluyi OO, et al., (2017). Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional cancer centre. <i>Br J Cancer</i> 116 (4):424-431.</p>
18	Royal College of General Practitioners	Centralised care for advanced pancreatic cancer	Pancreatic Cancer UK has called for this innovative practice		
19	British Society of Gastroenterology	Patient Access to Named Clinical Nurse Specialist	There is good evidence that patient benefit from CNS support.	The ratio of nurses is variable among specialties and not been assessed and varies. The significant impact of a named nurse should make it an auditable outcome	https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005
20	SCM1	CNS support for patients and families following a diagnosis of pancreatic cancer	CNS provision for this group is often restricted to tertiary care centres, despite many palliative treatments being offered in district general hospitals.		Please see Clinical Nurses – Pancreatic Cancer UK www.pancreaticcancer.org.uk/media/405277/pancreatic-cancer...

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21	SCM3	All patients should be offered support from cancer specialist nurses (including palliative care) and dietician	Patients, even with 'curable' disease have limited life expectancy, rapid deterioration in health, nutritional issues, symptom control is a major issue for this patient group.	Survey of specialist nurses suggest need for further nursing resources to support patient needs https://www.pancreaticcancer.org.uk/media/405277/pancreatic-cancer-uk-clinical-nurse-survey.pdf	
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<p>22</p>	<p>SCM4</p>	<p>Offer resectional surgery rather than preoperative biliary drainage to people who have resectable pancreatic cancer and obstructive jaundice and are well enough for the procedure and are not enrolled in a clinical trial that requires preoperative biliary drainage</p>	<p>In a disease like pancreatic cancer with a poor prognosis it is important that if patients are eligible for surgery they can access it quickly, so the disease does not progress while they wait for this treatment. Biliary drainage can delay surgery and cause additional complications which further delay surgery. Pathways must allow patients to access surgery rather than preoperative biliary drainage if they are well enough and not enrolled in a trial that requires drainage. This is a recommendation within the NICE diagnosis and management of pancreatic cancer guidelines.</p>	<p>Emerging evidence demonstrates that an increase in waiting times from referral to diagnosis and from diagnosis to surgery can reduce the chance of tumour resectability because of tumour growth or metastasis. It has been shown that an imaging-to-resection interval over 22 days is associated with increased frequency of unresectability. Endoscopic stenting of the bile duct (ERCP) is associated with clinical complications, especially cholangitis and pancreatitis, that may delay surgery or preclude resection. For example, studies have associated biliary stenting with serious morbidities as opposed to patients who had direct surgery (73.5% vs 39%) In a fast-track pathway developed at University Hospitals Birmingham, the time to surgery was reduced from 65 to 16 days. Significantly more patients underwent potentially curative surgery in the fast-track group (97% vs 75%). Moreover, the implementing pathway had a cost benefit of £3,200 per patient. Similar pathways implemented in Manchester and Leicester.</p>	<p>Sanjeevi, S. et al. Impact of delay between imaging and treatment in patients with potentially curable pancreatic cancer. <i>British Journal of Surgery</i> 103, 267-275, doi:10.1002/bjs.10046 (2016). Fang, Y. et al. Pre-operative biliary drainage for obstructive jaundice. <i>Cochrane Database Systematic Reviews</i>, doi:10.1002/14651858.CD005444.pub3 (2012) van der Gaag, N. A. et al. Preoperative biliary drainage for cancer of the head of the pancreas. <i>New England Journal of Medicine</i> 362, 129-137, doi:10.1056/NEJMoa0903230 (2010). Roberts, K. J. et al. A reduced time to surgery within a 'fast track' pathway for periampullary malignancy is associated with an increased rate of pancreatoduodenectomy. <i>HPB (Oxford)</i>, doi:10.1016/j.hpb.2017.04.011 (2017)</p>
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<p>23</p>	<p>British Society of Radiologists</p>	<p>Percutaneous biliary drainage (PTBD) +/- stent insertion for pancreatic cancer</p>	<p>In patients who have obstructive jaundice due to a pancreatic neoplasm and are either unable to undergo ERCP or this is unsuccessful Percutaneous biliary drainage is a useful alternative. There is evidence to support that this is a safe way to relieve jaundice and related symptoms in palliation and extend median survival and enable chemotherapy by improving bilirubin. The percutaneous route facilitates internal-external biliary drainage or preferably stent insertion. Covered or uncovered self-expandable metallic stents and plastic stents are all possible. It's role in preoperative management is debatable.</p>	<p>The NICE guidelines do not suggest a role for percutaneous drainage in pancreatic cancer. The uptake of this technique for this indication is variable across the country and although it is not first line it is very likely to be too low. It may be more commonly seen in tertiary centres. There are complications associated with PTBD but these are acceptable in the right clinical scenario. A relatively small but significant group of patients will not be afforded all treatment options if PTBD is not recognised in the NICE guidelines. Professionals may unwittingly be withholding the correct treatment for fear of not adhering to guidance</p>	<p>There is a lot of evidence to suggest a role for PTBD in pancreatic cancer some studies are included below. Piñol V, Castells A, Bordas JM, Real MI, Llach J, Montañà X, Feu F, Navarro S. Percutaneous self-expanding metal stents versus endoscopic polyethylene endoprosthesis for treating malignant biliary obstruction: randomized clinical trial. Radiology. 2002;225:27–34. Mahgerefteh S, Hubert A, Klimov A, Bloom AI. Clinical Impact of Percutaneous Transhepatic Insertion of Metal Biliary Endoprosthesis for Palliation of Jaundice and Facilitation of Chemotherapy. Am J Clin Oncol. 2013;Sep 21; Briggs CD, Irving GR, Cresswell A, Peck R, Lee F, Peterson M, Cameron IC. Percutaneous transhepatic insertion of self-expanding short metal stents for biliary obstruction before resection of pancreatic or duodenal malignancy proves to be safe and effective. Surg Endosc. 2010;24:567–571.</p>
<p>24</p>	<p>SCM5</p>	<p><u>Fast-track surgery</u> Offer resectional surgery rather than preoperative biliary drainage to people who have resectable pancreatic cancer</p>	<p>Speedier provision of treatment reduces overall complications by avoiding unnecessary procedures (i.e. endoscopic stenting); may improve resectability rates and improve overall survival.</p>	<p>Fast-track surgery is not yet routinely provided in the UK due to the logistical demands of providing a whole day operating list at short notice.</p>	<p>All Party Parliamentary Group on Pancreatic Cancer. RICOCHET study (a trainee-led national audit).</p>

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		and obstructive jaundice			
25	SCM5	<u>Adjuvant therapy</u> Start adjuvant therapy as soon as they are well enough to tolerate all 6 cycles.	Adjuvant therapy prolongs overall survival but all 6 cycles are required for optimal benefit.	Adequate time to recover from surgery and maintenance of fitness during this recovery period is necessary in order to tolerate the full course of chemotherapy.	
26	SCM5	Additional developmental areas of emergent practice <u>Neoadjuvant therapy</u> Only consider neoadjuvant therapy for people with borderline or resectable pancreatic cancer as part of a clinical trial. <u>Minimally invasive pancreatectomy</u> Minimally invasive pancreatectomy or pancreatoduodenectomy (laparoscopic or robotic) compared with open.	Neoadjuvant therapy may improve overall survival in those with operable pancreatic cancer. Minimally invasive pancreatic surgery may reduce complications, length of stay and improve quality of life.	Greater provision of neoadjuvant therapy will mean that more patients are being enrolled into clinical trials or that more patients are receiving it if trials report a survival benefit. Minimally invasive pancreatic surgery is technically challenging and pancreatoduodenectomy not adopted because of unproven benefit. Increased adoption will likely reflect technical advances and improved evidence of its value.	
27	Royal College of General Practitioners	Development of Neoadjuvant treatment protocol in localised pancreatic cancer	Pancreatic Cancer UK has called for this innovative practice		

<p>28</p>	<p>Royal College of Pathologists</p>	<p>Standardised pathological assessment of pancreatoduodenectomy specimens</p>	<p>There is evidence that standardised, meticulous assessment of pancreatoduodenectomy specimens by axial slicing and extensive, methodical sampling increases rate of incomplete resection (R1) of pancreatic ductal adenocarcinoma to 70% and more. Resection margin status has a significant impact on outcome.</p>	<p>RCPATH dataset on histopathological reporting of carcinomas of the pancreas, ampulla of Vater and common bile duct recommends standardised assessment of pancreatoduodenectomy specimens. National survey of pathology practice in the UK showed considerable variation in dissection methodology and resection margin assessment. National and international studies using standardised pathology assessment consistently confirm impact on outcome</p>	<p>Royal College of Pathologists. Dataset for the histopathological reporting of carcinomas of the pancreas, ampulla of Vater and common bile duct March 2017. Feakins R, Campbell F, Verbeke CS. Survey of UK histopathologists' approach to the reporting of resection specimens for carcinomas of the pancreatic head. J Clin Pathol 2013; 66:715-717. Resection margin involvement and tumour origin in pancreatic head cancer. Br J Surg. 2012;99:1036-49. Prognostic Value of Resection Margin Involvement After Pancreaticoduodenectomy for Ductal Adenocarcinoma: Updates From a French Prospective Multicenter Study. Ann Surg. 2017; 266:787-796. R0 Versus R1 Resection Matters after Pancreaticoduodenectomy, and Less after Distal or Total Pancreatectomy for Pancreatic Cancer. Ann Surg. 2017 Pancreatic Cancer Surgery: The New R-status Counts. Ann Surg. 2017;265:565-573. The Impact of Positive Resection Margins on Survival and Recurrence</p>
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					Following Resection and Adjuvant Chemotherapy for Pancreatic Ductal Adenocarcinoma.
29	SCM4	Ensure inoperable pancreatic cancer patients are receiving the most effective first and second line chemotherapy that they can tolerate, and involve them in this treatment decision.	Through my role at Pancreatic Cancer UK and managing it's services I hear about variations in the chemotherapy options provided to people with pancreatic cancer. In a disease with such a poor prognosis it is important that people are receiving the most effective treatment option for them, which they can tolerate, to improve their length of life and quality of life. Those diagnosed should also be involved in decisions about whether to have chemotherapy and which option to have. First and second line chemotherapy options are recommended within the NICE diagnosis and management of pancreatic cancer guidelines.	The National Cancer Registration and Analysis Service (NCRAS) carried out a population-based analysis showing that only 20% of pancreatic cancer patients received chemotherapy in 2013-2014. Studies have described how appropriate chemotherapy can prolong survival and can also improve quality of life. A recent study on unresectable pancreatic cancer patients found that patients receiving 2 nd line chemotherapy had a median survival of 11 months compared to a median survival of 8 months if they received only 1 st line chemotherapy. It is therefore important that if they are well enough to tolerate second line treatment that patients have access to it to improve length of life and symptom control.	Service (NCRAS) in partnership with Cancer Research UK (CRUK) has, for the first time, produced population-based statistics on the patients recorded to have received chemotherapy, radiotherapy and surgical tumour resections for their tumour in England http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments Kleeff J, et al., (2016) Pancreatic cancer. Nat Rev Dis Primers 2:16022 Faluyi, O. O., et al. (2017) Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional Cancer Centre Br J Cancer 116(4): 424-431.
30	Pancreatic Cancer UK, Pancreatic Cancer Action & Pancreatic Cancer Research Fund	Offer appropriate first and second line chemotherapy for people who cannot have their cancer removed surgically.	First and second line chemotherapy is recommended within NICE guidance for both metastatic and locally advanced pancreatic cancer. It is well established that appropriate chemotherapy improves survival of patients with cancer. Offering appropriate chemotherapy is considered a priority among health professionals, patients and carers as shown in a survey	The National Cancer Registration and Analysis Service (NCRAS) carried out a population-based analysis showing that only 19.7% of pancreatic cancer patients received palliative chemotherapy in 2013-2014. Studies have described how	The National Cancer Registration and Analysis Service (NCRAS) in partnership with Cancer Research UK (CRUK) has, for the first time, produced population-based statistics on the patients recorded to have received chemotherapy,

			<p>that Pancreatic Cancer UK carried out where 55% of the respondents ranked the guideline for offering appropriate chemotherapy as a priority.</p>	<p>appropriate palliative chemotherapy can prolong survival and can also improve quality of life. Around 7 in 10 pancreatic cancer patients in England received 'Other Care' defined as the group of patients who had no record of chemotherapy, tumour resection, or radiotherapy. This is more than twice the number of patients with all other common cancers receiving other care. This highlights that only a third of pancreatic cancer patients are receiving active life-extending treatment for their cancer. This is not only relevant to patients who were diagnosed at a late stage, but also to earlier stage patients. Precisely, 60% of stage 1 and 30% of stage 2 pancreatic cancer patients received 'Other Care' as opposed to other treatment. A recent study on unresectable pancreatic cancer patients found that patients receiving 2nd line chemotherapy had a median survival of 11 months compared to a median survival of 8 months if received only 1st line chemotherapy. It is therefore important to condition patients to tolerate sequential treatments to improve disease outcomes and care experience.</p>	<p>radiotherapy and surgical tumour resections for their tumour in England http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments Kleeff J, et al., (2016) Pancreatic cancer. Nat Rev Dis Primers 2:16022 Faluyi, O. O., et al. (2017) Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional Cancer Centre Br J Cancer 116(4): 424-431.</p>
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31	SCM5	<u>Metastatic pancreatic cancer</u> Offer FOLFIRINOX to people with metastatic pancreatic cancer and an ECOG performance status of 0–1.	Overall survival is best improved with this triple combination in people with metastatic cancer.	Greater provision of this combination will reflect better patient fitness to receive it.	
32	Royal College of General Practitioners	Fast track for pancreatic cancer	It has the lowest survival among the 21 most common cancers in the UK and it is predicted to become the 4th biggest cancer killer in less than a decade. More than 80% of patients are diagnosed at an advanced stage when they cannot receive curative surgery,		
33	SCM4	Provide care to manage the impact and symptoms of pancreatic cancer. Particularly the psychological impact, nutritional symptoms and pain.	Through my role at Pancreatic Cancer UK and managing it's services I hear about the impact of pancreatic cancer on quality of life. In particular people with pancreatic cancer report substantial problems managing the nutritional symptoms of the disease, pain and the psychological impact of being diagnosed with a disease with a poor prognosis as well as coping with the disease symptom. The care and support provided for these symptoms varies and needs to be improved. Evidence suggests managing these symptoms can improve quality of life and may also impact on survival outcomes. Needs for support around psychological impact, managing nutritional impact and pain management must be assessed and appropriate care to manage symptoms provided. There are recommendations on managing these symptoms in the NICE diagnosis and management of pancreatic cancer guidelines.	Depression and anxiety have been reported as more prevalent in pancreatic cancer patients in studies. 12.5% of people who called the Pancreatic Cancer UK support line with inquiries about supportive care requests required emotional support. A recent study shows patient's quality of life (QOL) can have a significant impact on how they're feeling and how long they survive after being diagnosed with the pancreatic cancer. An Australian study found 52% of pancreatic cancer patients reported an unmet psychological need. A survey by Pancreatic Cancer UK of 96 patients/carers found only 40% reported receiving enzyme replacement therapy (PERT) and 50% identified this as a priority area	Depression and anxiety references - (2013) Torgerson S. Wiebe L. A. (2013) Supportive care of the patient with advanced pancreatic cancer. <i>Oncology (Williston Park, N.Y.)</i> 27 , 183-190. and Akizuki N., Shimizu K., Asai M., Nakano T., Okusaka T., Shimada K., Inoguchi H., Inagaki M., Fujimori M., Akechi T. & Uchitomi Y. (2016) Prevalence and predictive factors of depression and anxiety in patients with pancreatic cancer: a longitudinal study. <i>Japanese journal of clinical oncology</i> 46 , 71-77 Yang Deng , Huakang Tu, Jeanne A. Pierzynski , Ethan D. Miller et al (2018) Determinants and prognostic value of quality of life in patients with pancreatic ductal adenocarcinoma <i>European Journal of Cancer</i> 92 (2018) 20e32 Beesley, V. L., et al. (2016). A

				to improve care. The use of PERT has been shown to improve symptoms of pancreatic cancer and can even improve survival. Another recent study on a group of resected patients demonstrated that prescription of PERT after surgery was associated with improved survival.	tsunami of unmet needs: pancreatic and ampullary cancer patients' supportive care needs and use of community and allied health services <i>Psychooncology</i> 25(2): 150-157. Pancreatic Cancer UK NICE top 5 priorities survey, 2018 Barkin, J. A., et al., (2017). Frequency of appropriate use of Pancreatic Enzyme Replacement Therapy (PERT) and symptomatic response in pancreatic cancer patients <i>Pancreas</i> 46:10. Roberts, K. et al., (2017) Pancreas exocrine replacement therapy is associated with increased survival following pancreatoduodenectomy for periampullary malignancy <i>HPB</i> 19 (10): 859-867.
34	SCM1	Improvement in the psychological and quality of life support for pancreatic cancer patients and their families/carers	Psychological and quality of life support for these patients is recognised as particularly important. However, it is often provided to different degrees, does not cover all aspects of nutrition, symptom control and psychological support and is sporadic throughout the patient journey		Please see the NICE Guidelines for Pancreatic Cancer February 2018 www.nice.org.uk/guidance/ng85/resources/pancreatic-cancer

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35	SCM6	Provide care to manage the impact and symptoms of pancreatic cancer. Particularly the psychological impact, nutritional symptoms and pain.	In the local support group and via the contacts I get from people who are affected by pancreatic cancer there is a gap in provision for support for patients and their families. There are often issues with anxiety depression and fatigue which affect a person social and associational life. They also explain the impact of nutritional advice and the role of enzymes and this a big impact for resect able patients post-surgery as well as those with un rsectable disease and those who survive post whipple This is part of NICE guidance	Pancreatic cancer UK did some research on the effect of nutritional supplements	
36	SCM6	Assess the psychological impact of pancreatic cancer and provide ongoing information and support to people and their family members or carers	The poor survival rates over 12 months mean that many people will be faced with a devastating diagnosis with a relatively poor prognosis. The effect of this can cause emotional turmoil and prompt the need for psychological support for both the patient and their family/carer. There is also significant feedback from survivors of the disease about survivor guilt and the on going affect of worrying that the disease will recur.		
37	NHS England	Role of primary care in cancer pathway	The standard should describe the role of primary care in the following areas of a person's cancer care pathway <ul style="list-style-type: none"> - psychological and mental health support - nutritional management and advice - pain management - terminal and palliative care 		

<p>38</p>	<p>Pancreatic Cancer UK, Pancreatic Cancer Action & Pancreatic Cancer Research Fund</p>	<p>Assess the psychological impact of pancreatic cancer and provide ongoing information and support to people and their family members or carers.</p>	<p>Pancreatic cancer has a very poor prognosis and can have a significant impact on patients and their loved ones' lives. It is important to provide emotional and psychological support to patients and families. Pancreatic Cancer UK carried out a survey to collect evidence from healthcare professionals, patients and carers for the five key areas of the NICE guidelines that would most improve care. Emotional support for both patient and family was considered a priority by 62% of 154 respondents. Survey participants ranked psychosocial support as the second most likely recommendation to improve pancreatic cancer care. This indicates that psychological support was either important or not offered in the individual experiences of pancreatic cancer. Assessing the psychological impact of pancreatic cancer and providing ongoing information and support to people and their family members or carers is recommended in the NICE guidelines.</p>	<p>Pancreatic cancer has devastatingly low survival and on average only 24% of patients will survive a year after diagnosis. Moreover, 44% of patients will be diagnosed as an emergency and this is associated with even lower survival. 92% of patients diagnosed as an emergency will die within a year. Cancers with such a poor prognosis have a psychological impact on both patients and their families and depression and anxiety are common amongst patients. 12.5% of people who called Pancreatic Cancer UK support line with inquiries about supportive care requests required emotional support. This implies that psychological support varies across the nation and that some people may not be offered any support, or may not be offered support consistently throughout their care. Moreover, an Australian study reported that 52% of pancreatic cancer patients reported an unmet psychological need. A more recent study on pancreatic cancer showed that poor prognosis was associated with low mental component summary, implying lower quality of life. Quality of life was found to be a significant prognostic factor for overall survival.</p>	<p>1-year survival data can be seen here https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed Data on routes to diagnosis can be seen here http://www.ncin.org.uk/publications/routes_to_diagnosis Beesley, V. L., et al. (2016). A tsunami of unmet needs: pancreatic and ampullary cancer patients' supportive care needs and use of community and allied health services <i>Psychooncology</i> 25(2): 150-157. Deng, Y., et al. (2018) Determinants and prognostic value of quality of life in patients with pancreatic ductal adenocarcinoma <i>Eur J Cancer</i> 92:20-32.</p>
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39	British Society of Gastroenterology	Early Coeliac plexus block in pancreatic cancer	Coeliac plexus block in pancreatic cancer is recommended within NICE guidance. Consider EUS-guided or image-guided percutaneous neurolytic coeliac plexus block to manage pain is recommended but often occurs late when analgesia has failed. Coeliac block should be considered as part of the staging process if tumour not resectable	Coeliac plexus block to manage pain is recommended but often occurs late when analgesia has failed and Coeliac block should be considered as part of multi disciplinary decision process.	https://www.nice.org.uk/guidance/cg32 Wyse JM, Chen YI, Sahai AV. Celiac plexus neurolysis in the management of unresectable pancreatic cancer: when and how? World J Gastroenterol. 2014 Mar 7;20(9):2186-92.
40	British Society of Gastrointestinal and Abdominal Radiology	EUS-CPN for pain associated with pancreatic cancer	NICE guidelines recommend that EUS-guided or image-guided percutaneous neurolytic coeliac plexus block is considered to manage pain for people with pancreatic cancer and there is evidence of its efficacy in this setting. The availability of this treatment is variable and it is often considered late in the pain management pathway. There are not mechanisms to ensure all patients are considered for, or have access to this, treatment.	Pain affects 80% of patients with pancreatic cancer. There is evidence that pain management from pancreatic cancer is an ongoing problem area. Clinical trials in this area are also required	Efficacy of EUS-CPN: https://www.ncbi.nlm.nih.gov/pubmed/19137428 Scope of EUS availability: https://www.bsg.org.uk/asset/CFB-F06EC-2E65-4C27-AAFC9D94226F23F2/
41	Royal College of General Practitioners	Offer coeliac plexus block for uncontrolled pain.	Pain is often left to primary care to deal with. When there are problems, we can refer to palliative care services. They need the support of a NICE quality standard to ensure that this valuable technique is available to all who need it.		
42	British Society of Gastroenterology	Palliative - Patient Access to Specialist Pancreatic Dietician	Appropriate nutritional support recommended within NICE guidance and increases quality of life and survival in patients with inoperable disease.	Although patients are seen by a dietician – links to a specialist in pancreatic disease is limited if not treated in a centre where surgery is performed.	https://www.nice.org.uk/guidance/cg32 . Vujasinovic M, Valente R, Del Chiaro M, Permert J, Löhner JM. Pancreatic Exocrine Insufficiency in Pancreatic Cancer. Nutrients. 2017 Feb 23;9(3).

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43	British Society of Gastroenterology	Operative - Patient Access to Specialist Pancreatic Dietitian	Appropriate nutritional support recommended within NICE guidance quality of life and survival in patients with operable disease.	The number of specialist trained pancreatic dieticians is crucial to support patient pre and post operatively in a timely manner.	https://www.nice.org.uk/guidance/cg32 Afaneh C, Gerszberg D, Slattery E, Seres DS, Chabot JA, Kluger MD. Pancreatic cancer surgery and nutrition management: a review of the current literature. <i>Hepatobiliary Surg Nutr.</i> 2015 Feb;4(1):59-71.
44	SCM1	Increased access to dedicated HPB dietetic services for all patients diagnosed with pancreatic cancer who, in many cases suffer from cachexia	Expert HPB nutritional support is limited and often only available in tertiary centres. Further support for those unresectable patients receiving palliative treatments may support nutrition and decrease symptoms of pancreatic insufficiency.		Please see NICE guidelines for Patient experience in adult NHS services: improving the experience of care for people using adult NHS services NICE Guidelines for Pancreatic Cancer February 2018 www.nice.org.uk/guidance/ng85/resources/pancreatic-cancer
45	SCM5	<u>Nutrition</u> Offer enteric-coated pancreatin for people with unresectable pancreatic cancer and consider before and after pancreatic cancer resection.	Optimal Nutrition support will improve fitness to undergo surgery and other treatments and improve quality of life through symptom improvement. May also contribute to survival.	Provision of this type of nutritional support (i.e. pancreatic enzyme replacement therapy) is known to be variable and sub-optimal, especially outside of specialist centres.	PCUK, BDA or NIGPS may have data about current usage.
46	SCM6	Offer pancreatic enzyme replacement tablets (PERT) to pancreatic cancer patients at all stages of treatment	The impact of weight loss physically and psychologically is a burden for pancreatic cancer patients. They worry about the weight loss and are often pressured by family and carers to eat more, which creates a tension. Without the enzyme the weight loss will not be replaced by eating more food so the PERT helps physically and relieves some of the emotional tensions. This is part of NICE guidance		

47	Pancreatic Cancer UK, Pancreatic Cancer Action & Pancreatic Cancer Research Fund	Offer pancreatic enzyme replacement therapy (PERT) to pancreatic cancer patients at all stages of treatment	Dietary deprivation and weight loss are common symptoms in pancreatic cancer. This issue is commonly raised through the Pancreatic Cancer UK national support line. From people asking about dietary advice, 87.7% were inquiring about PERT in 2016/17. In support of this, prescription of PERT was identified as a key priority for 55% of respondents in the survey that Pancreatic Cancer UK carried out to identify the key areas in the NICE guideline that will make the biggest difference in care and treatment of affected patients. It is therefore recognised as a highly unmet need in different care settings and can also affect quality of life due to reduced functional status. PERT is recommended within NICE guidance. Offer enteric-coated pancreatin for people with unresectable pancreatic cancer. Consider enteric-coated pancreatin before and after pancreatic cancer resection.	The recent patient and carer survey that Pancreatic Cancer UK carried out showed that only 40% of the patients/carers respondents received PERT as a treatment. This suggests that currently not all pancreatic cancer patients are offered PERT suggesting inconsistencies in care. The use of PERT has been shown to improve symptoms of pancreatic cancer and can even improve survival. A recent study revealed that of the 76% of pancreatic cancer patients prescribed PERT, 65% were prescribed PERT appropriately with all meals & snacks. Overall compliance with PERT administration guidelines was low (38%; 44/104). Improvement in symptoms significantly correlated with appropriate use of PERT. Another recent study on a group of resected patients demonstrated that prescription of PERT after surgery was associated with improved survival.	Pancreatic Cancer UK NICE top 5 priorities survey, 2018 Barkin, J. A., et al., (2017). Frequency of appropriate use of Pancreatic Enzyme Replacement Therapy (PERT) and symptomatic response in pancreatic cancer patients <i>Pancreas</i> 46:10. Roberts, K. et al., (2017) <i>Pancreas</i> exocrine replacement therapy is associated with increased survival following pancreatoduodenectomy for periampullary malignancy <i>HPB</i> 19 (10): 859-867.
48	SCM6	Improved support for GP practices, doctors and nurses in the referral and diagnosis of suspected pancreatic cancer	Pancreatic cancer is of often insidious in its onset and has progressed significantly on initial presentation. An online educational support for both doctors and nurses may help with the management of spurious symptoms		Please see the NICE Guidelines for Pancreatic Cancer February 2018 www.nice.org.uk/guidance/ng85/resources/pancreatic-cancer

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49	NHS England	Advice for GPs & primary care professionals	The quality standard needs to include advice to GPs & primary care professionals on when to suspect pancreatic cancer, what diagnostics to use, and emphasis on early diagnosis and referral as the disease is invariably picked up after three or more visits to the GP.		
50	SCM3	Patients should be offered clinical trials wherever available	Given poor outcomes and resistance to chemo(radio)therapy, novel therapies are desperately required. 8000 cases of pancreatic cancers are diagnosed in the UK each year (and as many die from the disease), about half of patients are suitable for active treatment. It is therefore important that (1) patients have access to clinical trials given the poor outcomes from current treatment and (2) as many patients as possible are entered into clinical trials that will enable finding better treatments	Given the lack of good treatment options, offering entry into clinical trials should be considered as the 'best standard of care' – and therefore this is an important quality standard metric	
51	NHS England		I would request that the guidance considers the opportunities for diagnosis and management of pancreatic cancer within the context of the GP Forward View, New Models of Care and Integrated Care including social services.		
52	Royal College of General Practitioners	Additional developmental areas of emergent practice	Development of a blood test for the detection of pancreatic cancers	CancerSEEK test looks for mutations in 16 genes that regularly arise in cancer and eight proteins that are often released Cohen JD, Li L, Wang Y, Thoburn C, Afsari B, Danilova L, et al. Detection and localization of surgically resectable cancers with a multi-analyte blood test. Science [Internet]. 2018 Jan 18	

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53	Royal College of Nursing	This is to inform you that the Royal College of Nursing have no comments to submit to inform on the NICE pancreatic cancer topic engagement at this time.			
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