# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

# HEALTH AND SOCIAL CARE DIRECTORATE

# QUALITY STANDARD CONSULTATION

# SUMMARY REPORT

## 1 Quality standard title

Pancreatic cancer

Date of quality standards advisory committee post-consultation meeting:
19 September 2018

## 2 Introduction

The draft quality standard for pancreatic was made available on the NICE website for a 4-week public consultation period between 19 July and 16 August 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 16 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

# 3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

**General comments on the quality standard**

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Positive response to the draft quality standard.
- The quality standard should clarify that it only covers adenocarcinoma of the exocrine pancreas and does not apply to pancreatic neuroendocrine tumours (CRG).
- The quality standard is mainly relevant to secondary and tertiary care, primary care only mentioned in reference to prescribing enteric coated pancreatin.

- There may be a need to raise awareness of pancreatic cancer among GPs; MDTs could send a letter to the GPs about each patient diagnosed.
- Only statement 6 (placeholder) is patient focused.

## Consultation comments on data collection

- Stakeholders thought that the data should be available and data collection in secondary care not too burdensome considering small numbers involved.

## Consultation comments on resource impact

- Most of the systems and structures needed to implement the statements are already in place and should not require additional resources.

# 4 Summary of consultation feedback by draft statement

## *4.1 Draft statement 1*

Adults with suspected pancreatic cancer have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Statement should be achievable as cancer networks of centralised pancreatic cancer MDTs are already in place.
- It would be helpful to define members/roles that should be included within the MDT; suggestion for the MDT to include: endoscopist, pathologist, oncologist, radiologist, surgeon and palliative care specialist.

### Consultation comments on measures

- Process measure - stakeholders suggested that whilst not publicly available this data can be extracted from Hospital Episode Statistics.
- Outcome measure b - stakeholders suggested that whilst not publicly available this data can be extracted from the national Systemic Anti-Cancer Therapy Database.
- Outcome measure c - stakeholder suggested that it would be difficult to obtain meaningful data from National Cancer Patient Experience Survey as representation from people with pancreatic cancer is low and aggregated within all upper gastrointestinal cancers; they suggested using proxy measures based on holistic needs assessment.

## *4.2 Draft statement 2*

Adults with localised pancreatic cancer who can have cancer treatment have staging using fluorodeoxyglucose positron emission tomography/CT (FDG-PET/CT).

### Consultation comments

Stakeholders made the following comment in relation to draft statement 2:

- The statement should specify that the FDG-PET/CT should be carried out before commencing radical chemo-radiotherapy or surgical treatments otherwise many scans would be carried out unnecessarily in people too unwell to have curative or palliative treatments.

### Consultation comments on measures

Outcome measure b – stakeholders suggested that the information on unnecessary surgery or radical treatment is not currently collected by the National Cancer Registry and Analysis Service and suggested local data sources such as patient records and the Hospital Episode Statistics as alternative sources; stakeholders also highlighted defining “unnecessary surgery” as a potential challenge.

## *4.3 Draft statement 3*

Adults with resectable pancreatic cancer and obstructive jaundice do not have preoperative biliary drainage unless specifically indicated.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- The specific indications for pre-operative biliary drainage has to be refined to capture people that might benefit from the procedure. These include people:
  - with acute cholangitis,
  - with a bilirubin level below 250 μmol/l
  - with untreatable pruritus
  - with renal dysfunction as a consequence of obstructive jaundice
  - in whom the surgical procedure is delayed due to neoadjuvant therapy, need of nutritional support in cases of high risk of malnourishment, or due to logistic issues
- Stakeholders highlighted that although a person may be fit for surgery, it that does not mean that the hyperbilirubinaemia is not having an adverse effect on other organ functions (cardiac/kidney) which can deteriorate when compounded by surgical trauma.

### Consultation comments on measures

- Data can be collected from specialist MDTs and would not be associated with additional cost.
- Outcome measure a - stakeholders suggested that whilst not publicly available this data can be extracted from Hospital Episode Statistics and Cancer Waiting Times
- Stakeholders suggested including measures for:
  - disease free survival of people having surgery with and without biliary drainage,
  - people with pancreatic cancer who received surgery to remove the tumour
  - people intended for resection able to have the surgery after biliary drainage

  Treatment data published by the National Cancer Registration and Analysis Service.

## *4.4 Draft statement 4*

Adults with unresectable pancreatic cancer have a discussion about chemotherapy options available to them.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- The discussion should be clearly documented.
- The statement should be broader and include discussing participation in clinical trials and experimental treatments as well as interventions such as enzyme supplements, dietetic input, pain control and depression.

### Consultation comments on measures

- Process measure b - stakeholders suggested that whilst not publicly available this data can be extracted from the national Systemic Anti-Cancer Therapy Database.
- Outcome measure b - stakeholders highlighted that it would be difficult to obtain meaningful data from National Cancer Patient Experience Survey as representation from pancreatic cancer patients is low and aggregated within all upper gastrointestinal cancers; they suggested using proxy measures based on holistic needs assessment.

## *4.5 Draft statement 5*

Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- The statement should be broader and include
  - giving advice on how to use the enzymes; currently PERT if often ineffective because people do not use it appropriately
  - people with resectable pancreatic cancer.
- The equality and diversity section may cause confusion among people who do not eat pork but use pork based PERT due to lack of alternative; stakeholders were not familiar with effective beef based products.

### Consultation comments on measures

- Process measure - stakeholders suggested that whilst not publicly available this data can be extracted from the drug prescription database managed by the National Cancer Registration and Analysis Service and NHS Digital.

- Outcome measure - it would be helpful to define nutritional status.

## *4.6 Placeholder statement 6*

Effective interventions to address psychological needs.

**Consultation question:**

Do you know of any evidence-based guidance that could be used to develop this placeholder statement? If so, please provide details. If not, would new evidence based guidance relating to addressing psychological needs have the potential to improve practice? If so, please provide details.

**Stakeholders made the following comments:**

- The statement should not be a placeholder but a standard quality statement as the need for effective interventions is an unmet need.
- Whilst depression and anxiety are known side effects of cancer diagnosis, there is no evidence-based guidance on the psychological needs of people with pancreatic cancer.

# 5 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements:

- Palliative care
- End of life care
- Pain management
- Local accurate staging (by multiphase CT) should be performed prior to stenting.
- Endoscopic ultrasound in local staging of pancreatic cancer.
- Development of a proforma for standardising radiology report in pancreatic cancer.
- MRI of liver to detect occult liver metastasis too small for CT and PET/CT as part of staging.

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## Appendix 1: Quality standard consultation comments table – registered stakeholders

| ID | Stakeholder | Statement number | Comments[1] |
|---|---|---|---|
| 1 | NHS England | General | These standards relate to secondary & tertiary care.  There is no mention of primary care except for the need to prescribe enteric coated pancreatin on page 17.  There may be a need to raise awareness in GPs.  This could be done by the MDT in a letter to the GP about each patient diagnosed. (RP) |
| 2 | NHS England | General | The document is dealing only with adenocarcinoma of the exocrine pancreas and should somewhere make it explicit that this is the case and that the guidance does not apply to pancreatic neuroendocrine tumours (CRG) |
| 3 | Royal College of Radiologists | General | RCR are generally supportive of the Quality Standard |
| 4 | The Royal College of Surgeons of Edinburgh | General | All the quality statements in the draft document are important for improving care in pancreatic cancer. However a number of these measures would require significant financial funding. Systems such as dietary and psychological input are best served as close to the patient's home as possible. The specialist centre may not necessarily be the best place to implement or follow this up. Local measures will then need to be funded for this either at the patient's base hospital or local GP practice/social service |
| 5 | Royal College of General Practitioners | Question 1 | These are predominately focused on processes in secondary care and not direct patient related outcomes. Only statement 6 (placeholder) Effective interventions to address psychological needs is patient focused.<br>There is no quality of end of life care statements in patients with pancreatic cancer and whether they should receive on-demand early palliative care at diagnosis to help them as well as their main care givers<br>There is no statement on the analgesic control in patients with pancreatic cancer |
| 6 | Royal College of Pathologists | Question 1 | The document is focussed on and reflects key areas of quality improvement. Data collection for statements 1-5 should be possible. I am not able to provide an example of implementation of NICE guidelines from practice. |
| 7 | Royal College of General Practitioners | Question 2 | These are predominantly dependent on secondary care clinical systems |
| 8 | Royal College of General Practitioners | Question 3 | Not known |
| 9 | British Society of Interventional Radiology | Statement 1 | The MDT should include an endoscopist, pathologist, oncologist, radiologist, surgeon & palliative care specialist, in order to truly have multidisciplinary panel that should reduce any regional fluctuations in care. |

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

| ID | Stakeholder | Statement number | Comments[1] |
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| | (BSIR) | | |
| 10 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 1 | We are pleased to see this statement and support it. We would like it to state that the Specialist MDT includes access to nutritional support rather than it can include access to nutritional support. |
| 11 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 1 | We feel it would be helpful if the Specialist MDT members could be defined. If this cannot then we would like the job roles of the members of the SMDT to be recorded when data is collected to audit against these standards so people can see who they consist of. |
| 12 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 1 | This is a very important quality measure and we support that this should be included as a Quality Statement. Pancreatic cancer is a complex disease and specialised care and treatment are needed to ensure that patients receive the best care and treatment possible.<br>The specialist MDT can also ensure that patients have access to specialists for the management of pain, nutritional symptoms and psychological symptoms to ensure people can maintain a good quality of life. Data from callers to the Pancreatic Cancer UK Support Line, shows that 47.5% of callers request information about supportive care such as symptom control, practical support, emotional support, side effects and palliative care, demonstrating the need for specialist support in these areas.<br>The importance of diagnosis and care being determined by a specialist pancreatic multidisciplinary team was also acknowledged 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.<br>In support of this 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 (elderly and low performance status patients).  This shows the significance of a specialist MDT in care and treatment for pancreatic cancer patients https://www.ncbi.nlm.nih.gov/pubmed/28081546 . |
| 13 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 1 | An additional suggestion in measurement of this standard is that besides the proposed data source 'Local data collection, for example, patient records or specialist pancreatic cancer MDT reports', it is also possible to obtain data from patient records in the Hospital Episode Statistics database from the NHS Digital (https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics). Data for pancreatic cancer is not publicly available, but it can be accessed by NHS staff and civil service stakeholders |

| ID | Stakeholder | Statement number | Comments[1] |
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| | | | through the N3 connection. |
| 14 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 1 | We would like to highlight an additional data source to collect this data. Besides the proposed data source 'Local data collection, for example, records from the specialist pancreatic cancer multidisciplinary team', this information can be also obtained from the national Systemic Anti-Cancer Therapy Database (http://www.chemodataset.nhs.uk/home). Data for pancreatic cancer is not publicly available, but it can be accessed by NHS staff and stakeholders through the N3 connection. |
| 15 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 1 | As we believe that the Quality Statement to ensure that patients have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team is crucial to improving pancreatic cancer care and outcomes, we agree that the proportion of adults with pancreatic cancer given enough care and support from health and social services should be an outcome measured. However, it may be hard to measure this outcome through the National Cancer Patient Experience Survey as pancreatic cancer responses are given as part of UGI cancers in the current format. Moreover, looking at data for pancreatic cancer, only around 5% of newly diagnosed cases fill in the survey and therefore there is high risk of biased data (data obtained after private communications with Quality Health).<br>Enough care and support from health and social care services might be measured from the number of patients with pancreatic cancer who have a care and support plan based on a holistic needs assessment undertaken at diagnosis (numerator) against the number of patients diagnosed with pancreatic cancer (denominator).<br>Macmillan Cancer support has developed a straightforward tool for Holistic Needs Assessment as part of the quality of life metric to be developed and rolled out in England as part of the Cancer Strategy. This is an assessment that the specialist multidisciplinary team can use to identify supportive care that patients need and develop a care plan. Details and guidance of this assessment tool can be found here https://www.macmillan.org.uk/information-and-support/treating/after-treatment/finishing-treatment/holistic-needs-assessment.html<br>and https://www.macmillan.org.uk/_images/sign-up-to-use-the-ehna_tcm9-297776.pdf<br>Collection of data from local patient records based on the care plan developed after the holistic needs assessment can be used to measure a) Patient satisfaction with support offered and b) Patient satisfaction with support received similar to the quality statement 5 for lung cancer (https://www.nice.org.uk/guidance/qs17/chapter/Quality-statement-5-Holistic-needs-assessment) |
| 16 | The British Society of Gastroenterology | Statement 1 | We would agree that it a key area for quality improvement that all pancreatic cancer diagnoses and care is determined by a specialist pancreatic cancer multidisciplinary team (MDT). There is already a cancer network of centralised pancreatic cancer MDTs. The resources are therefore in place to report the confirmed diagnosis and collect the data in this setting even with those patients requiring best supportive care where specialised advice is helpful. This standard in achievable by the network services in place. |

| ID | Stakeholder | Statement number | Comments[1] |
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| 17 | The Royal College of Surgeons of Edinburgh | Statement 1 | There are regional pancreatic MDTs across the country usually held once weekly to discuss all referrals with suspected pancreatic cancer or pancreatic cysts. All MDT outcomes should be uploaded onto a national database.<br>There are referral policies and pathways within each region. Some regions have more refined policies and pathways than others. These policies and pathways should be standardised to allow best practice to be consistent across the UK.<br>It is difficult to collect data on the denominator. There is a distinct possibility that not all suspected pancreatic cancers are being referred to the local HPB MDT. Policing this would be challenging. |
| 18 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 2 | We welcome this Quality statement as it is critical for patients with pancreatic cancer to have an accurate diagnosis and staging in order to have determined the best treatment and care plan.<br>This was also considered a priority by 57% of 154 respondents in a survey that Pancreatic Cancer UK carried out which asked healthcare professionals, patients and carers to prioritise five areas of the NICE guidelines that they believed would most improve care.<br>Accurate staging of the disease is essential to implementing the best treatment and care option for an individual and avoiding unnecessary delays and complications.<br>National staging data published from the National Cancer Registry and Analysis Service shows that 20% of pancreatic cancer patients were missing stage at diagnosis (http://www.ncin.org.uk/publications/survival_by_stage). Moreover, from pancreatic cancer patients with unknown stage (4,563 patients), 74.2% did not receive any active treatment in the calendar period 2013-2014 (http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments). We worry that too many patients do not receive treatment because they do not have their disease accurately diagnosed and staged.<br>In support of this, a study in England has demonstrated that accurate staging at cancer diagnosis can influence treatment pathways because it is a key predictor of overall cancer outcomes (https://www.ncbi.nlm.nih.gov/pubmed/25734389).<br>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 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4750230/). This indicates the need for accurate diagnosis and staging to ensure the best treatment pathway for patients. |

| ID | Stakeholder | Statement number | Comments[1] |
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| 19 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 2 | We are in agreement that it would be helpful to measure the proportion of adults with pancreatic cancer who have unnecessary surgery or radical local treatment as part of this statement's outcome. However, we believe that measuring this outcome with treatment data published by the National Cancer Registry and Analysis Service will not sufficiently address this outcome. There is not a database (at least publicly) giving information about unnecessary surgery or radical treatment. The National Cancer Registry and Analysis Service provides data on treatment by stage of diagnosis (including unknown stage) but it is not clear with the information provided in the draft quality standard of how unnecessary treatment will be defined in this dataset.<br>We suggest that this data to be obtained from local data sources in patient records and also from the national database of Hospital Episode Statistics in NHS Digital (https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics). Data for pancreatic cancer is not publicly available, but it can be accessed by NHS staff, NCRAS and civil service stakeholders through the N3 connection. |
| 20 | The British Society of Gastroenterology | Statement 2 | The wording of this statement may need addressing as many patients with localised pancreatic cancer become unable to have for curative or palliative treatments due to general ill health (mainly from the disease), and therefore many PET CTs will be performed unnecessarily (and sometimes to address audit rather than patient needs). The quality statement should qualify this at the end by adding '….PET/CT) before commencing radical chemo-radiotherapy or surgical treatments'. Without this qualifying statement there is likely to be a significant increase in PET CT use without the benefit of preventing unnecessary surgery. |
| 21 | The Royal College of Surgeons of Edinburgh | Statement 2 | PET/CT should definitely be part of the staging process of resectable pancreatic cancer. However, not all patients who have localised pancreatic cancer should have PET/CT. If the disease is localised but advanced and the patient is only going to be receiving palliative treatment then PET/CT will not add any value. In the context of clinical trials where patients are receiving attempted downstaging chemotherapy then PET/CT will be of value. |
| 22 | Boston Scientific | Statement 3 | The Quality Statement states that adults with resectable pancreatic cancer and obstructive jaundice do not have preoperative biliary drainage unless specifically indicated. It further defined adults with resectable pancreatic cancer and obstructive jaundice with a specific indication for biliary drainage:<br>• adults who are not well enough for the resectional surgery<br>• adults enrolled in a clinical trial that requires preoperative biliary drainage<br>We believe this definition does not accurately capture relevant patient groups that might benefit from biliary drainage.<br>The ESMO guidelines - European Society of Medical Oncology report the following recommendation:<br>"A recent prospective and randomised trial demonstrated an increased complication rate associated with routine preoperative biliary drainage. However, patients in the trial had a total bilirubin level below 250 µmol/l. Therefore, |

| ID | Stakeholder | Statement number | Comments[1] |
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| | | | the correct approach in patients with higher levels remains undefined. If jaundice is present at diagnosis of pancreatic carcinoma, endoscopic drainage should only be carried out preoperatively in patients with active cholangitis, or in those whom resection for cure cannot be scheduled within 2 weeks of diagnosis, and in those with a bilirubin level below 250 µmol/l."<br>J. Enrique Domínguez, Julio Iglesias, et al (Endosc Ultrasound. 2017 Dec; 6 (Suppl 3): S119–S121) describe that: Preoperative biliary drainage is reported to increase complications compared with surgery without preoperative drainage. Nevertheless some patients may benefit from preoperative relief of jaundice; these include patients with untreatable pruritus, acute cholangitis, or renal dysfunction as a consequence of obstructive jaundice. In addition, patients in whom the surgical procedure is delayed due to neoadjuvant therapy, need of nutritional support in cases of high risk of malnourishment, or due to logistic issues, also require a preoperative biliary stenting.<br>We respectfully ask NICE to take into consideration the above references when defining the patient population that might benefit from biliary drainage. |
| 23 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 3 | We welcome this Quality Statement and we are in agreement with what is stated in the 'Rationale' section that performing preoperative biliary drainage is associated with an increased delay to surgery, more complications, more hospitalisations and higher prevalence of pre-surgery pancreatitis compared with surgery alone. Moreover, there is evidence that delays and complications because of biliary drainage can also prevent the patients from being resected https://www.ncbi.nlm.nih.gov/pubmed/26572509 and http://www.hpbonline.org/article/S1365-182X(17)31130-9/fulltext). In a disease with such a poor prognosis and where very few patients are diagnosed at an early stage (20%) when they can receive potentially curative surgery, it is crucial to try to increase the number of patients receiving surgery. Currently less than 10% receive surgery (http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments).<br>A study led by Mr Keith Roberts and his team at the Queen Elizabeth hospital in Birmingham has demonstrated that this is possible in the NHS. In this pathway, it was shown that avoiding preoperative biliary drainage reduced time to surgery from 65 to 16 days, significantly more patients underwent potentially curative surgery (97% vs 75%) and implementing the pathway had a cost benefit of £3,200 per patient (https://www.pancreaticcancer.org.uk/media/1246432/6136_pcuk_fast-track_surgery_showcase.pdf ; https://www.ncbi.nlm.nih.gov/pubmed/285662390).<br>Moreover, we anticipate that by avoiding the complications of preoperative biliary drainage will also improve patient experience and quality of life. |
| 24 | Pancreatic Cancer UK, Pancreatic Cancer Action, | Statement 3 | We agree that local data collection, for example, from patient records to measure this outcome is sensible. Additionally, measuring the outcome from data recorded in centralised databases such as Hospital Episode Statistics |

| ID | Stakeholder | Statement number | Comments[1] |
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| | Pancreatic Cancer Research Fund | | (https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics) and Cancer Waiting Times (https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/) in NHS Digital would be additional options. This will allow the collection of evidence on the impact of biliary drainage not only on time to surgery but also on whether the patient intended for resection was able to have a surgery after biliary drainage.<br>Data for pancreatic cancer is not publicly available, but it can be accessed by NHS staff and civil service stakeholders through the N3 connection. |
| 25 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 3 | In support of this quality statement, monitoring overall survival for resectable pancreatic cancers is a sensible measure. Estimates for overall survival are not straightforward as a method and this should be taken into account in timelines, especially in early years of the guideline implementation. It will be useful to include a quality measure for disease free survival of patients having surgery with and without biliary drainage, as this will give a good picture of the impact of surgery without biliary drainage.<br>An additional quality outcome measure is to also look at the number of patients with pancreatic cancer who received surgery to remove the tumour. As referred to in the 'Rationale' section, performing preoperative biliary drainage is associated with an increased delay to surgery, more complications, more hospitalisations and higher prevalence of pre-surgery pancreatitis compared with surgery alone. Moreover, there is evidence that delays and complications because of biliary drainage can also prevent the patients from being resected (https://www.ncbi.nlm.nih.gov/pubmed/26572509 and http://www.hpbonline.org/article/S1365-182X(17)31130-9/fulltext).<br>Treatment data published by the National Cancer Registry and Analysis Service can be used as data source for this information (http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments). |
| 26 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 3 | We agree that measuring health-related quality of life in adults with pancreatic cancer should be measured as an outcome of this quality statement.<br>As mentioned above, in its current format, the National Cancer Patient Experience Survey is not the ideal data source to measure quality of life as only 5% of new diagnosed patients fill in the survey. Also, although there is a question in the survey about type of treatment received, responses in satisfaction are not broken down by treatment type. So, it is unlikely that this measure will directly address quality of life for people resected with no biliary drainage.<br>We recommend as an alternative data source to measure quality of life in adults and link it to surgery with no biliary |

| ID | Stakeholder | Statement number | Comments[1] |
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| | | | drainage collection of local data from the cancer specialist multidisciplinary team by the use of the holistic needs assessment tool introduced by Macmillan. Details and guidance of this assessment can be found here<br>https://www.macmillan.org.uk/information-and-support/treating/after-treatment/finishing-treatment/holistic-needs-assessment.html<br>and https://www.macmillan.org.uk/_images/sign-up-to-use-the-ehna_tcm9-297776.pdf and<br>https://www.nice.org.uk/guidance/qs17/chapter/Quality-statement-5-Holistic-needs-assessment<br>This can be done at various stages of the care pathway and it is a very straightforward tool. |
| 27 | The British Society of Gastroenterology | Statement 3 | We agree that patient with resectable disease do not require preoperative biliary drainage. This data is collectable form the specialised MDTs. Given the low numbers that are resectable at presentation this information is available without any specific resource cost. |
| 28 | The Royal College of Surgeons of Edinburgh | Statement 3 | This should be the default mode<br>The specific indications for pre-operative biliary drainage has to be refined<br>It should be noted that although a patient may be fit for surgery that does not mean that the hyperbilirubinaemia in not having an adverse effect on other organ functions (cardiac/ kidney) which can deteriorate when compounded by surgical trauma.<br>NG85 says: 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<br>It does not define what “well enough” means and this should be clarified |
| 29 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | We welcome this quality statement as it is really crucial for patients with unresectable pancreatic cancer to be aware of the chemotherapy options available to them as well as benefits and risks. In a survey that Pancreatic Cancer UK carried out March 2018, offering appropriate chemotherapy was considered a priority for 55% of health professionals, patients and carers. Moreover, at Pancreatic Cancer UK, we hear through our Support Line that patients have not always been told about different chemotherapy options or had the opportunity to fully discuss the pros and cons of chemotherapy treatment. Analysis of calls to the Pancreatic Cancer UK Support Line in 2016/2017 shows that about 40% of patients mainly call to ask about treatment options as well as risks and benefits..<br>We worry that patients who could potentially receive life-extending chemotherapy, do not always have it because they are not made aware of this treatment as an option or they are often told that it may ‘only give them two months’ or that treatment will cause ‘more harm than good’. In support of this concern, national data published by the National Cancer Registry and Analysis Service in England has shown that 66% of patients with pancreatic cancer will not receive any active treatment (surgery or chemotherapy) and that only around 20% of patients with pancreatic cancer receive chemotherapy. Among these patients, the same dataset has shown that a significant |

| ID | Stakeholder | Statement number | Comments[1] |
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| | | | proportion of stage 1 (59.4%), stage 2 (29.4%) and stage 3 (44%) patients did not receive any type of active treatment. This represents 1258 patients in the calendar period 2013-2014 (https://www.cancerdata.nhs.uk/treatments).<br>We also feel that within this statement it is vital to include access and availability of clinical trials appropriate for them. Given the appalling survival of pancreatic cancer that has hardly seen any progress in the last 45 years at least, it is important that patients are aware of clinical trials might benefit them, if we are to see any improvement in disease outcomes.<br>As mentioned above, national data shows that 66% of pancreatic cancer patients do not receive treatment (http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments) and data obtained privately from National Health Research Institute shows that only 4.6% of patients with pancreatic cancer participate in clinical trials. This is also supported by data from the National Cancer Patient Experience Survey which has shown that 61% of patients with pancreatic cancer have not had discussions about participation in experimental treatments (breakdown of data was obtained after private communications with Quality Health). Lack of discussions about participation in research is a common issue highlighted for all cancers in the survey. It is therefore vital to include clinical trial and experimental treatments as part of statement 4. |
| 30 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | As mentioned above, we welcome this quality standard as it is really crucial for patients with unresectable pancreatic cancer to be aware of the chemotherapy options available to them as well as benefits and risks.<br><br>However we believe that with a disease with such a poor prognosis, it is crucial to also include discussions about experimental and clinical trials available to patients that they are able to tolerate. Refer to comment 1 above for more information. |
| 31 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | As mentioned in comment 1, we welcome this quality statement as it is crucial for patients with unresectable pancreatic cancer to be aware of the chemotherapy options available to them as well as benefits and risks. The rationale of this statement could be strengthened by including that patients should have access to the most effective treatment options that they are able to tolerate. Chemotherapy should be a personal choice based on the options available and on a discussion with the specialist pancreatic cancer multidisciplinary team (MDT) about feasibility, potential benefits and risks. |
| 32 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | We agree that this is a very sensible quality measure for this quality statement. In addition to the data source of the National Cancer Registration and Analysis Service, this data can be also obtained from the national SACT Systemic Anti-Cancer Therapy Database (http://www.chemodataset.nhs.uk/home). Data for pancreatic cancer is not publicly available, but it can be accessed by NHS staff, National Cancer Registry and Analysis Service and civil service |

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| | | | stakeholders through the N3 connection. |
| 33 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | We agree that this is a very sensible quality measure for this quality statement. As mentioned above, it is hard to robustly measure this outcome through the National Cancer Patient Experience Survey as pancreatic cancer responses are given as part of UGI cancers in the current format. Moreover, looking at data for pancreatic cancer, only around 5% of newly diagnosed cases fill in the survey and therefore there is high risk of biased data (data obtained after private communications with Quality Health). There is the risk that mainly patients with good prognosis (i.e. resected patients) will fill in the survey.<br><br>Measurement through local data on Holistic Needs Assessment is another possibility. Details and guidance of this assessment can be found here https://www.macmillan.org.uk/information-and-support/treating/after-treatment/finishing-treatment/holistic-needs-assessment.html<br>and https://www.macmillan.org.uk/_images/sign-up-to-use-the-ehna_tcm9-297776.pdf and<br>https://www.nice.org.uk/guidance/qs17/chapter/Quality-statement-5-Holistic-needs-assessment |
| 34 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 4 | As mentioned above, we welcome the quality statement 4 where adults with unresectable pancreatic cancer have a discussion about chemotherapy options available to them as it is really crucial for patients with unresectable pancreatic cancer to be aware of the chemotherapy options available to them as well as benefits and risks.<br>As per comment 1, we also suggest that this quality statement can be expanded to discussions about available experimental treatments and clinical trials that patients with unresectable disease can participate in. Therefore, we propose a process quality measure for this where the proportion of patients who had discussions about availability of experimental treatments and clinical trials (numerator) as opposed to the number of unresectable patients (denominator) to be monitored. Local data collection, for example, patient records can be used as the data source. Moreover, the number of patients participated to experimental treatments and clinical trials (numerator) compared to the number of patients accepted to participate (denominator) is recommended to be used as an Outcome quality measure. National Cancer Registration and Analysis Service, Systemic Anti-Cancer Therapy and Hospital Episode Statistics can be used as data sources for this outcome. |
| 35 | Royal College of Pathologists | Statement 4 | Discussion about chemotherapy options in unresectable pancreatic cancer can only be measured and data collected if that discussion and the presented options are clearly documented. Is it therefore worth considering specifying the discussion as “clearly documented discussion”? |
| 36 | Royal College of Radiologists | Statement 4 | The guidance mentions the proportion of patients having a discussion about palliative chemotherapy and the quality standard measures the proportion receiving chemotherapy. This is a common proxy used, but is not an accurate measure, especially in those diseases where the incident population do not strongly resemble trial populations (due |

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| | | | to age and co-morbidities), or where the small benefit of palliative chemotherapy means many patients decline therapy. |
| 37 | The British Society of Gastroenterology | Statement 4 | Patients with un-resectable cancer can benefit from multiple interventions. Palliative chemotherapy is only one of these that should be discussed or explained why it would not be a good idea. Other interventions are also beneficial – to quality of life including pancreatic enzyme supplements (PES) (Statement 5), but also dietetic input analgesia including coeliac nerve blocks, and depression given the current limited improvement from chemotherapy this and PES should not be the only 2 standards in the palliative statements. The statement (or additional statements) should consider additional discussions of pain control [Kaufman M, et al. J Clin Gastroenterol2010;44:127-34] mood [Joffe RT, et al. Gen Hosp Psychiatry 1986;8:241-45] and dietitian review. [Witvliet-van Nierop JE, Gastroenterol Res Pract 2017:6193765] |
| 38 | The Royal College of Surgeons of Edinburgh | Statement 4 | No arguments with this one. |
| 39 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 5 | We support the use of PERT with people with unresectable pancreatic cancer. |
| 40 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 5 | One outcome measure in this section is ‘Nutritional status of adults with unresectable pancreatic cancer’. It would be helpful if how this was measured was defined. |
| 41 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 5 | We feel being prescribed PERT is important for this group of people. However in our experience it is also very important for people to be taught how to take them. If they are not then PERT are often taken ineffectively. |
| 42 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 5 | We are not aware of any effective beef derived PERT available. We feel it should just say from pork products. We have many patients who do not usually consume pork who take PERT as there is no suitable alternative available. Having the statement as it is may be confusing for these people. |
| 43 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 5 | We welcome this quality statement as 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, the 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 high unmet need in different care settings and can also affect quality of life due to reduced functional status that may subsequently affect treatment options. |

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| | | | We would recommend that this quality statement is extended to adults with resectable disease as well. We acknowledge that NICE guidance recommends that enteric-coated pancreatin should be considered for resectable disease rather than to be offered, however it is crucial that nutritional malabsorption is managed for resectable patients who may need it to tolerate surgery, to recover faster and also be able to receive life-extending post-operative treatment (e.g. adjuvant chemo). It is important that use of enzyme replacement therapy in resectable patients is measured. A recent peer-reviewed publication has convincingly demonstrated that resectable patients who receive enteric-coated pancreatin have better survival (Roberts, K. et al., (2017) https://www.ncbi.nlm.nih.gov/pubmed/28711377). Moreover, based on peer-reviewed evidence, pancreatic enzyme replacement therapy is indicated post-surgery in patients with clinically evident steatorrhoea, weight loss or maldigestion-related symptoms. Given its favourable safety profile, enteric-coated pancreatin is also appropriate in asymptomatic patients when at high risk for nutritional deficits resulting from upper-gastrointestinal surgery, such as pancreatic cancer surgery (Dominguez-Munoz, 2009; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2798169/). Therefore, it will be important to have a quality measure in place to ensure that enteric-coated pancreatin is prescribed in at least resectable patients with evident nutritional symptoms pre- or post-operatively. |
| 44 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 5 | As mentioned in comment 2, we welcome this quality statement as dietary deprivation and weight loss are common symptoms in pancreatic cancer and we agree with the process suggested as a quality measure.<br>We recommend that in addition to the 'Local data collection, for example, patient record' as a source of data, that it can be also measured from the drug prescription database managed by the National Cancer Registration and Analysis Service and NHS Digital. |
| 45 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 5 | We believe that the National Cancer Patient Experience Survey will not give robust data for this measure. It is recommended that quality of life be measured through local data collection and patient records as part of the Holistic Needs Assessment tool introduced by Macmillan. Details and guidance of this assessment can be found here https://www.macmillan.org.uk/information-and-support/treating/after-treatment/finishing-treatment/holistic-needs-assessment.html<br>and https://www.macmillan.org.uk/_images/sign-up-to-use-the-ehna_tcm9-297776.pdf and https://www.nice.org.uk/guidance/qs17/chapter/Quality-statement-5-Holistic-needs-assessment<br>This can be done at various stages of the care pathway and it is a very straightforward tool. |
| 46 | The British Society of Gastroenterology | Statement 5 | See above |
| 47 | The Royal College of | Statement 5 | Again no arguments with this one. |

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| | Surgeons of Edinburgh | | The use of pancreatic enzyme replacement therapy (PERT) should not be restricted to those with unresectable pancreatic cancer. Any patient undergoing a pancreaticoduodenectomy should also be placed on PERT starting pre-operatively and should ideally be seen by a dietition either before or at the very least after surgery.<br>All patients with inoperable pancreatic cancer should also be offered the opportunity to see a dietition with a specialist interest in pancreatic disease. |
| 48 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 6 | We are not sure there are always systems in place to address patient's psychological needs, it depends what those needs are. |
| 49 | Pancreatic Cancer UK, Pancreatic Cancer Action, Pancreatic Cancer Research Fund | Statement 6 | We welcome the consideration of 'Effective interventions to address psychological needs' to be included in the quality standard for pancreatic cancer patients. We believe that this is a very important statement for pancreatic cancer patients and their loved ones who have to cope with a disease with such a poor prognosis and complex symptoms.<br>We strongly believe that this statement should be included as a main quality statement as it has been recognised as a highly unmet need. In support of this, a survey that Pancreatic Cancer UK carried out to collect evidence from healthcare professionals, patients and carers for 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, suggesting that patients and their loved ones will benefit from having access to psychological interventions.<br>Pancreatic cancer has the lowest survival among all cancers; at least 60% of patients will be diagnosed at a late stage (stage 3 and stage 4), 45% of patients as an emergency and around 80% of the patients will die within a year (Stage data 2016, http://www.ncin.org.uk/view?rid=3006 and Routes to Diagnosis, 2006-2015 workbook; http://www.ncin.org.uk/view?rid=3549).<br>Cancers with such a poor prognosis and complex symptoms such as pain, fatigue, weight loss and malnutrition have a psychological impact on both patients and their families and therefore depression and anxiety are common symptoms among pancreatic cancer patients and occur more frequent than in other malignancies (Akizuki et al, 2016; https://www.ncbi.nlm.nih.gov/pubmed/26590013); Clark et al., 2010; https://www.ncbi.nlm.nih.gov/pubmed/20119937). Cancer of the pancreas is associated with a strikingly high incidence of depression (Mayr et al., 2010; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2976753/). In support to this, a population-based study in England conducted by the National Cancer Registry and Analysis Service demonstrated that pancreatic cancer is the second highest cancer where patients are at an increased risk of suicide after their diagnosis (Henson et al., 2018; https://www.phe-events.org.uk/hpa/frontend/reg/tDailyAgendaAlt.csp?pageID=306989&ef_sel_menu=2942&eventID=728&mode= ). |

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| | | | An Australian study has shown that 52% of pancreatic cancer patients reported an unmet psychological need (Beesley et al., 2015; https://onlinelibrary.wiley.com/doi/abs/10.1002/pon.3887). 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 (Deng et al., 2018; https://www.ncbi.nlm.nih.gov/pubmed/29413686).<br>Besides the impact of pancreatic cancer in the mental wellbeing of the patients, there is also evidence suggesting that depression is a symptom of the disease itself. A literature review meta-analysis found that symptoms of depression and/or anxiety may appear in approximately 50% of patients with pancreatic cancer before the diagnosis is made (Green and Austin, 1993; https://www.ncbi.nlm.nih.gov/pubmed/8493302) and this was further supported in a more recent review by Mayr and Schmid (2010; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2976753/#B26).<br>All the above highlights that it is critical for pancreatic cancer patients to have access to psychosocial support and interventions. Patients with pancreatic cancer and loved ones affected should be able to easily access appropriate supportive and psychological care, which forms a normal part of the overall care package.<br>Cancer Networks such as the East Anglia Cancer Network and the West of Scotland Cancer Network have developed guidelines and frameworks for psychosocial support for patients with cancer. Both frameworks include initial assessment of psychological needs through holistic needs assessment and mental health assessment and how this changes within a specific timeframe (e.g two weeks). Depending on the level of severity, a referral to specialist onco-psychologist/ psychiatrist or qualified Mental Health Services is recommended. The patients will have access to a number of interventions (evidence-based) tailored to their needs. Assessment of quality of life and reported needs pre-, peri- and post-intervention enables monitoring of patients well-being.<br>We acknowledge that there are limitations in peer-reviewed evidence of psychosocial interventions specifically for pancreatic cancer. Overall symptom care has been a neglected area in pancreatic cancer compared to other cancers and there is a need for more symptom management to be put in place. Despite the limited resources, a number of interventions in the literature have shown positive outcomes and could be potentially be provided by psychology specialists in the care setting of England.<br>A systematic analysis published by Steven D Passik in 1996 reports that besides somatic complaints, pancreatic cancer patients should be assessed for dysphoric mood for two or more weeks and also hopelessness, helplessness, and a sense of worthlessness or despair. Inability to feel pleasure and suicidal ideation are also dependable diagnostic markers for depression in patients with pancreatic cancer and should be assessed (http://www.cancernetwork.com/gastrointestinal-cancer/supportive-care-patient-pancreatic-cancer-role-psycho- |

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| | | | oncologist).<br>Examples of psychological interventions relevant to pancreatic cancer are listed below.<br>For patients who meet the Diagnostic and Statistical Manual-IV (DSM-IV) criteria for mood disorders or adjustment disorders, a combination of supportive psychotherapy and cognitive-behavioural techniques has been shown to decrease psychological distress and depressive symptoms (http://www.cancernetwork.com/gastrointestinal-cancer/supportive-care-patient-pancreatic-cancer-role-psycho-oncologist).<br>Interdisciplinary crisis intervention therapy has been reported as a potentially promising intervention for poor prognosis cancers such as pancreatic cancer. It is an intervention that aims to restore the patient's baseline (precancer) psychological functioning by using hypnosis, relaxation therapy, and other psychotherapeutic techniques and modalities that reduce pain and distress. A study on an intervention group of 30 participants with advanced disease showed improvement across all areas assessed such as hospital adjustment, communication with others, disease information, death perceptions, and self-concept within two weeks (Ferlic et al, 1979 cited in Andersen, 1992 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2743106/).<br>This model in combination with flexible and individually tailored psychological support is recommended for patients who approach end of life (Akechi 2012, https://academic.oup.com/jjco/article/42/12/1113/939814).<br>Another intervention that has been proposed in the literature for patients with advanced pancreatic cancer who receive active treatment is Dignity Therapy (Dose et al, 2018, https://link.springer.com/article/10.1007%2Fs00520-017-3833-2 and https://clinicaltrials.gov/ct2/show/NCT02132325).<br>Dignity Therapy has been historically used in end of life care and is based on the novel psychotherapeutic approach by Harvey Max Chochinov's in which patients receiving home-based palliative services are tape recorded while discussing issues that matter most or subjects they want to remember (Chochinov 2005; http://ascopubs.org/doi/pdf/10.1200/JCO.2005.08.391). In the study by Dose and colleagues, ten patients with pancreatic cancer pursuing chemotherapy were included and they reported improved quality of life after completing a brief psychotherapeutic intervention consisting a focused life review/values clarification delivered during three outpatient oncology clinic visits (Dose 2015, http://ascopubs.org/doi/abs/10.1200/jco.2015.33.29_suppl.225).<br>Interdisciplinary Supportive Care Planning intervention has shown improvement in quality of life in pancreatic cancer and it is a very easy and acceptable intervention in the care setting. The intervention includes assessment of comprehensive quality of life, case presentation at interdisciplinary care meetings, and two nurse-administered educational sessions on quality of life concerns. Discussions were largely focused on physical and psychosocial needs. A total of 10 pancreatic cancer patients were enrolled during a four-month period in the intervention study. |

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| | | | Improvement in quality of life and positive feedback from the patients was reported (Sun et al., 2016; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4919144/).<br>A communication support intervention provided by mental health nurses has been also suggested for older patients with advanced cancer (including pancreatic cancer) who are offered an in-home meeting and a follow-up telephone contact (reviewed by Raingruber, 2011, https://www.hindawi.com/journals/isrn/2011/638218/).<br><br>Meaning Centered Group Psychotherapy has been suggested as a treatment for psychological and existential or spiritual distress in patients with advanced cancer. A randomized controlled study of 253 patients with advanced cancer (including 45 pancreatic cancer patients) showed that Meaning Centered Group Psychotherapy had positive outcomes, especially for quality of life, depression, and hopelessness (Breitbart et al., 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4334778/). Details of the full protocol can be found in https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4334778/bin/supp_33_7_749__index.html.<br>Based on the above, the following quality statement is suggested:<br>Quality Statement- Patients with pancreatic cancer have access to specialist psychosocial services where a combination of interventions can be accessed based on their needs.<br>Process:<br>a) Number of patients referred to specialist psychosocial services (numerator) against all patients diagnosed with the disease (denominator). Data to be collected local patient records and Hospital episode Statistics.<br>b) Number of patients with pancreatic cancer who attended and had initial assessment in specialist psychosocial services (numerator) against the number of patients who were referred (denominator). Data to be collected by local patient records and Hospital Episode Statistics.<br>c) Number of patients who had psychological interventions (numerator) compared to patients who attended specialist psychosocial services. Data to be collected by local patient records and Hospital Episode Statistics.<br>Outcomes:<br>a) Improvement of quality of life through holistic needs assessment by specialist MDT. Data to be collected by local patient records and Hospital Episode Statistics<br>b) Improvement in intervention-specific measures before and after the intervention assessed by psychosocial services. Data to be collected by local patient records and Hospital Episode Statistics |
| 50 | Royal College of Pathologists | Statement 6 | I do not know of any evidence based guidance that could be used to develop this placeholder statement. I am not in a position to comment whether new evidence-based guidance relating to addressing psychological needs has the potential to improve practice. |

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| 51 | The British Society of Gastroenterology | Statement 6 | See above |
| 52 | The British Society of Gastrointestinal and abdominal radiology (BSGAR) | Statement 6 | BSGAR Committee agrees the draft QS accurately reflects the key area for quality improvement.<br>General comment that effective intervention should also be made to address symptomatic needs. |
| 53 | The Royal College of Surgeons of Edinburgh | Statement 6 | There is no evidence-based guidance on the psychological needs of patients with pancreatic cancer. However depression and anxiety is a well known side-effect of being diagnosed with cancer (patient and relatives). Both depression and anxiety affect quality of life. It is possible that addressing these issues may affect quality of life and survival but it is as yet an unexplored area of this disease. Putting systems in place to address this may help but this would require a clinical trial |
| 54 | Nutrition Interest Group of the Pancreatic Society (NIGPS) | Statement 6 | We feel new evidence-based guidance relating to addressing psychological needs would have the potential to improve practice and the experience of those with pancreatic cancer. Unmet psychological needs have an impact on people's experience and ability to tolerate treatment, therefore potentially the efficacy of it, their survival and certainly quality of life. Specifically from our area, psychological symptoms have an impact on people's nutritional intake and therefore nutritional status. |
| 55 | Royal College of General Practitioners | Statement 6 | None identified |
| 56 | The British Society of Gastrointestinal and abdominal radiology (BSGAR) | Additional areas | BSGAR agrees the draft QS accurately reflects the key areas for quality improvement.<br>A few additional points were raised as suggestions for further discussion and consideration:<br>1) Consider specifying local accurate staging (by multiphase CT) should be performed prior to stenting.<br>2) Consider recommending endoscopic ultrasound in local staging of pancreatic cancer.<br>3) Consider recommending development of a proforma for standardising radiology report in pancreatic cancer.<br>4) Consider recommending MRI of liver to detect occult liver metastasis too small for CT and PET/CT as part of staging.<br>5) Access to PET/CT could potentially have resource implication |
| 57 | Department of Health and Social Care | No comments | Thank you for the opportunity to comment on the draft for the above quality standard.<br>I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation. |
| 58 | Royal College of Nursing | No comments | Nurses caring for people with Pancreatic Cancer were invited to review the draft quality standard. There are no further comments to make on this document on behalf of the Royal College of Nursing. |

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| | | | Thank you for the opportunity to participate |
| 59 | Royal College of Physicians | Support | The NCRI-ACP-RCR-RCR is grateful for the opportunity to respond to the above consultation. We have liaised with our experts and would be happy to support the quality standard. |

## *Registered stakeholders who submitted comments at consultation*

- Boston Scientific
- British Society of Gastroenterology
- British Society of Gastrointestinal and Abdominal Radiology
- British Society of Interventional Radiology
- Department of Health and Social Care
- NHS England
- Nutrition Interest Group of the Pancreatic Society
- Pancreatic Cancer Action
- Pancreatic Cancer Research Fund
- Pancreatic Cancer UK
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Pathologists
- Royal College of Physicians
- Royal College of Radiologists
- Royal College of Surgeons of Edinburgh