NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Pancreatic cancer

NICE quality standard

Draft for consultation

July 2018

This quality standard covers diagnosis and management of pancreatic cancer in adults aged over 18. It describes high-quality care in priority areas for improvement. It does not cover national initiatives, such as cancer screening or audit.

It is for commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 19 July to 16 August 2018). The final quality standard is expected to publish in December 2018.

Quality statements

Statement 1 Adults with suspected pancreatic cancer have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.

Statement 2 Adults with localised pancreatic cancer who can have cancer treatment have staging using fluorodeoxyglucose positron emission tomography/CT (FDG-PET/CT).

Statement 3 Adults with resectable pancreatic cancer and obstructive jaundice do not have preoperative biliary drainage unless specifically indicated.

Statement 4 Adults with unresectable pancreatic cancer have a discussion about chemotherapy options available to them.

Statement 5 Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.

Statement 6 (placeholder) Effective interventions to address psychological needs.

NICE has developed guidance and a quality standard on patient experience in adult NHS services (see the NICE pathway on patient experience in adult NHS services), which should be considered alongside these quality statements. Statements 4, 5 and 10 in patient experience in adult NHS services (QS15) are particularly relevant in the context of supporting adults with pancreatic cancer.

Other quality standards that should be considered when commissioning or providing pancreatic cancer services include: suspected cancer (QS124) and end of life care for adults (QS13)

A full list of NICE quality standards is available from the quality standards topic library.

Questions for consultation

Questions about the quality standard

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

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

Question 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.

Local practice case studies

Question 4 Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to NICE local practice case studies on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Specialist pancreatic multidisciplinary teams

Quality statement

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

Rationale

Early input from a specialist pancreatic cancer multidisciplinary team (MDT) can minimise delays to diagnosis, optimise staging strategy and ensure that all management options are considered. The specialist MDT can provide access to psychological support, nutritional support and pain management for adults with pancreatic cancer. They can also provide specific expertise, including knowledge of novel treatments and ongoing clinical trials, which may not be available within a local MDT.

Quality measures

Structure

a) Evidence of specialist pancreatic cancer multidisciplinary teams in the area.

Data source: Local data collection, for example, service protocols or regional network arrangements.

b) Evidence of clear care pathways put in place between local cancer units and specialist pancreatic cancer multidisciplinary teams.

Data source: Local data collection, for example, regional network arrangements, documented local referral policies or agreed patient pathways.

Process

Proportion of adults with suspected pancreatic cancer who have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.

Numerator – the number in the denominator who have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.

Denominator – the number of adults with suspected pancreatic cancer.

Data source: Local data collection, for example, patient records or specialist pancreatic cancer MDT reports.

Outcome

a) Proportion of adults with pancreatic cancer receiving treatment.

Data source: National Cancer Registration and Analysis Service.

b) Proportion of adults with pancreatic cancer offered access to clinical trials.

Data source: Local data collection, for example, records from the specialist pancreatic cancer multidisciplinary team.

c) Proportion of adults with pancreatic cancer given enough care and support from health and social services

Data source: National Cancer Patient Experience Survey

What the quality statement means for different audiences

Service providers (local cancer networks, secondary care, community imaging services and specialist cancer centres) ensure that pathways and systems are in place for specialist pancreatic cancer multidisciplinary teams to review all cases of suspected pancreatic cancer.

Healthcare professionals (such as members of the local cancer network, clinical oncologists and radiologists) are aware of local pathways for pancreatic cancer and ensure that specialist pancreatic cancer multidisciplinary teams provide them with guidance on further investigations necessary to establish accurate diagnosis and plan care for adults with suspected pancreatic cancer.

Commissioners (NHS England and clinical commissioning groups) ensure that they commission standardised pancreatic cancer care in which adults with suspected pancreatic cancer have diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.

Adults who may have pancreatic cancer have their case reviewed by a team of specialists called a pancreatic cancer multidisciplinary team. This team has special expertise in diagnosing and treating pancreatic cancer. They can also help adults who are diagnosed with pancreatic cancer get pain relief, psychological support and help with nutrition.

Source guidance

Pancreatic cancer in adults: diagnosis and management (2018) NICE guideline NG85, recommendation 1.2.1.

Definitions of terms used in this quality statement

Suspected pancreatic cancer

Pancreatic cancer is suspected based on findings from a standard CT and/or a pancreatic protocol CT. Pancreatic cysts with high-risk features of pancreatic cancer should also be included. [Expert opinion]

Quality statement 2: Staging using FDG-PET/CT

Quality statement

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

Rationale

FDG-PET/CT adds information to CT imaging and allows for more accurate staging, particularly with respect to detecting metastatic disease. It is likely to influence the management of the disease and can help to avoid unnecessary surgery or radical local treatment for cancer that has already spread.

Quality measures

Structure

Evidence of local arrangements to ensure that FDG-PET/CT is used for staging in adults with localised pancreatic cancer who can have cancer treatment.

Data source: Local data collection, for example, service protocols.

Process

Proportion of adults with localised pancreatic cancer who had FDG-PET/CT before receiving cancer treatment.

Numerator – the number in the denominator who had FDG-PET/CT staging before the treatment.

Denominator – the number of adults with localised pancreatic cancer who received cancer treatment.

Data source: Local data collection, for example, patient records.

Outcome

a) Proportion of adults with pancreatic cancer who have staging recorded at diagnosis.

Data source: National Cancer Registration and Analysis Service.

b) Proportion of adults with pancreatic cancer who have unnecessary surgery or radical local treatment.

Data source: National Cancer Registration and Analysis Service.

What the quality statement means for different audiences

Service providers (specialist regional centres) have processes in place to ensure that adults with localised pancreatic cancer who can have cancer treatment have FDG-PET/CT for staging.

Healthcare professionals (surgeons and oncologists) use FDG-PET/CT for accurate staging in adults with localised pancreatic cancer who can have cancer treatment.

Commissioners (NHS England and clinical commissioning groups) ensure that they commission services in which adults with localised pancreatic cancer who can have cancer treatment have FDG-PET/CT for accurate staging.

Adults with pancreatic cancer have a special scan called an FDG-PET-CT scan. This scan gives doctors information that helps them decide the best treatment. It shows exactly where the cancer is, and how far advanced it is (the stage of the cancer).

Source guidance

Pancreatic cancer in adults: diagnosis and management (2018) NICE guideline NG85, recommendation 1.3.2.

Definitions of terms used in this quality statement

Localised pancreatic cancer

Cancer limited to the place where it started, that is, the pancreas, with no sign that it has spread to distant sites. [Expert opinion]

Cancer treatment

Pancreatic cancer treatment includes:

- surgery
- radiotherapy
- systemic therapy.

[NICE's guideline on pancreatic cancer in adults: diagnosis and management recommendation 1.3.2]

Quality statement 3: Biliary obstruction and resectable pancreatic cancer

Quality statement

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

Rationale

Resectional surgery performed without unnecessary delays contributes to positive outcomes for adults with pancreatic cancer. For those sufficiently fit and not enrolled in a clinical trial that requires biliary drainage, 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. Carrying out the resection without performing biliary drainage also reduces costs.

Quality measures

Structure

Evidence of local care pathways which ensure that adults with resectable pancreatic cancer and obstructive jaundice do not have preoperative biliary drainage unless specifically indicated.

Data source: Local data collection, for example, service protocols, regional network arrangements, documented local referral policies or agreed patient pathways.

Process

Proportion of adults with resectable pancreatic cancer and obstructive jaundice who had no specific indication for biliary drainage who had preoperative biliary drainage.

Numerator – the number in the denominator who had preoperative biliary drainage

Denominator – the number of adults with resectable pancreatic cancer and obstructive jaundice who had no specific indication for biliary drainage.

Data source: Local data collection, for example, patient records.

Outcome

a) Time to surgery for adults with resectable pancreatic cancer.

Data source: Local data collection, for example, patient records.

b) Complications related to surgery in adults with pancreatic cancer.

Data source: Local data collection, for example, patient records.

c) Overall survival in adults with resectable pancreatic cancer.

Data source: Local data collection, for example, patient records.

d) Health-related quality of life in adults with pancreatic cancer.

Data source: National cancer patient experience survey.

What the quality statement means for different audiences

Service providers (secondary and tertiary services, specialist regional centres) ensure that systems are in place for adults with resectable pancreatic cancer and obstructive jaundice who are well enough for resectional surgery, and are not enrolled in a clinical trial that requires preoperative biliary drainage, to have resectional surgery without preoperative biliary drainage.

Healthcare professionals (such as gastroenterologists, surgeons and interventional radiologists) are aware of the local pathways for pancreatic cancer and understand that adults with resectable pancreatic cancer and obstructive jaundice who are well enough for resectional surgery, and are not enrolled in a clinical trial that requires preoperative biliary drainage, should have resectional surgery without unnecessary delays such as performing preoperative biliary drainage.

Commissioners (NHS England and clinical commissioning groups) ensure that they commission services that carry out resectional surgery in adults who have pancreatic cancer without unnecessary delays. They ensure that preoperative biliary drainage is not carried out unnecessarily in adults with pancreatic cancer and obstructive jaundice who are well enough for resectional surgery.

Adults with pancreatic cancer and jaundice who are well enough to have an operation to remove their tumour can have the operation without needing to have their jaundice treated first, unless they are in a clinical trial that requires the jaundice to be treated.

Source guidance

Pancreatic cancer in adults: diagnosis and management (2018) NICE guideline NG85, recommendation 1.7.1.

Definitions of terms used in this quality statement

Adults with resectable pancreatic cancer and obstructive jaundice with a specific indication for biliary drainage:

- adults who are not well enough for the resectional surgery
- adults enrolled in a clinical trial that requires preoperative biliary drainage

[NICE's guideline on Pancreatic cancer in adults: diagnosis and management recommendation 1.7.1]

Quality statement 4: Unresectable pancreatic cancer

Quality statement

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

Rationale

Some adults with unresectable pancreatic cancer do not receive any form of active treatment even though systemic chemotherapy can potentially improve quality of life, help them manage some of the symptoms and extend life expectancy. Chemotherapy should be a personal choice based on a discussion with the specialist pancreatic cancer multidisciplinary team (MDT) about feasibility, potential benefits and risks.

Quality measures

Structure

Evidence of local arrangements and written clinical protocols to ensure that adults with unresectable pancreatic cancer have a discussion about chemotherapy options available to them.

Data source: Local data collection, for example, service specification or local protocols.

Process

a) Proportion of adults with unresectable pancreatic cancer who had a discussion about chemotherapy options available to them.

Numerator – the number in the denominator who had a discussion about chemotherapy options available to them.

Denominator – the number of adults with unresectable pancreatic cancer.

Data source: Local data collection, for example, patient records.

b) Proportion of adults with unresectable pancreatic cancer who received chemotherapy.

Numerator – the number in the denominator who received chemotherapy.

Denominator – the number of adults with unresectable pancreatic cancer who accepted chemotherapy.

Data source: National Cancer Registration and Analysis Service

Outcome

a) Survival among adults with unresectable pancreatic cancer

Data source: National Cancer Registration and Analysis Service.

b) Patient satisfaction with pancreatic cancer care.

Data source: National cancer patient experience survey.

What the quality statement means for different audiences

Service providers (secondary and tertiary services, specialist regional centres) ensure that systems are in place to discuss chemotherapy options with adults who have unresectable pancreatic cancer.

Healthcare professionals (such as members of the local cancer network and oncologists) are aware that chemotherapy can be beneficial for some adults with unresectable pancreatic cancer. They agree potential chemotherapy options with the specialist pancreatic cancer MDT and have a discussion with the adult about the pros and cons of each option.

Commissioners (NHS England and clinical commissioning groups) ensure that they commission services in which adults with unresectable pancreatic cancer have an opportunity to discuss chemotherapy options available to them.

Adults with pancreatic cancer that cannot be treated with surgery have a conversation with a healthcare professional about options for chemotherapy to help relieve the cancer symptoms. Chemotherapy may also increase their life expectancy.

Source guidance

Pancreatic cancer in adults: diagnosis and management (2018) NICE guideline NG85, recommendations 1.9.1, 1.9.4 and 1.9.6.

Equality and diversity considerations

To have an informed discussion with a healthcare professional people need to understand the options available and be able to ask questions. People who do not speak English should be supported by an interpreter or advocate to ensure that they can communicate effectively with healthcare professionals.

Quality statement 5: Pancreatic enzyme replacement therapy

Quality statement

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

Rationale

Pancreatic cancer inhibits the ability of the pancreas to deliver pancreatic enzymes, which assist digestion and absorption of fat, carbohydrates and proteins. Enteric-coated pancreatin can improve the nutritional status and wellbeing of people with pancreatic cancer and, as a result, their ability to tolerate treatment.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.

Data source: Local data collection, for example, service specification or local protocols.

Process

Proportion of adults with unresectable pancreatic cancer prescribed enteric-coated pancreatin.

Numerator – the number in the denominator prescribed enteric-coated pancreatin.

Denominator – the number of adults with unresectable pancreatic cancer.

Data source: Local data collection, for example, patient records.

Outcome

a) Nutritional status of adults with unresectable pancreatic cancer.

Data source: Local data collection, for example, patient records.

b) Adults with unresectable pancreatic cancer able to tolerate treatment.

Data source: Local data collection, for example, patient records.

c) Health-related quality of life in people with pancreatic cancer.

Data source: National cancer patient experience survey.

What the quality statement means for different audiences

Service providers (secondary and tertiary services, dietetics services, specialist regional centres) ensure that adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.

Healthcare professionals (such as GPs, dieticians and members of the local cancer network) prescribe enteric-coated pancreatin to adults with unresectable pancreatic cancer.

Commissioners (clinical commissioning groups) ensure that they commission services in which adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.

Adults with pancreatic cancer that cannot be treated with surgery are given tablets of a medicine called pancreatin that makes it easier to digest food and absorb nutrients. This medicine can help them to keep their weight stable, feel better, have more energy for normal daily activities and cope with their cancer treatment.

Source guidance

Pancreatic cancer in adults: diagnosis and management (2018) NICE guideline NG85, recommendation 1.6.1.

Equality and diversity considerations.

All pancreatic enzyme supplements are made from pork or beef products that may be unacceptable for some people because of their religion or beliefs. People with pancreatic cancer need to be made aware of the ingredients and make an informed decision about taking or declining these supplements.

Quality statement 6 (placeholder): Effective interventions to address psychological needs

What is a placeholder statement?

A placeholder statement is an area of care that has been prioritised by the quality standards advisory committee but for which no source guidance is currently available. A placeholder statement indicates the need for evidence‑based guidance to be developed in this area.

Rationale

Adults with pancreatic cancer often have unmet psychological support needs that affect their quality of life. These can be related to anxiety and depression, and to the psychological impact of fatigue, pain, gastrointestinal symptoms (particularly changes to appetite) and nutritional status. Adults with pancreatic cancer and their families and carers need effective interventions that can improve their quality of life, psychological wellbeing and ability to carry out normal activities.

Question for consultation

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.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See quality standard advisory committees on the website for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage

This quality standard will be included in the NICE Pathway on pancreatic cancer, which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references

to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- cancer staging
- pancreatic cancer survival rate
- pancreatic cancer mortality rate
- nutritional status of adults with pancreatic cancer
- health-related quality of life
- patient satisfaction with their care

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- NHS outcomes framework
- Public health outcomes framework for England.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact tool for the NICE guideline on pancreatic cancer in adults to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations.

Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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