

Pancreatic cancer in adults: diagnosis and management

Appendices A & B

Scope and Stakeholders

February 2018

Final

*Developed by the National Guideline Alliance, hosted by the Royal College of
Obstetricians and Gynaecologists*

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© NICE 2018. All rights reserved. Subject to [Notice of rights](#).

Contents

Appendix A: Scope	5
A.1 Guideline title:.....	5
A.2 Topic	5
A.3 Who the guideline is for	5
A.4 Equality considerations.....	5
A.5 What the guideline is about	5
A.5.1 Who is the focus?	5
A.5.2 Settings.....	6
A.5.3 Activities, services or aspects of care.....	6
A.5.4 Economic aspects	6
A.5.5 Key issues and questions	6
A.6 Main outcomes	7
A.7 Links with other NICE guidance, NICE quality standards and NICE Pathways	8
A.7.1 NICE guidance.....	8
A.7.2 NICE quality standards	8
A.7.3 NICE Pathways.....	8
A.8 Context.....	9
A.8.1 Key facts and figures	9
A.8.2 Current practice	10
A.8.3 Policy, legislation, regulation and commissioning.....	10
Appendix B: Stakeholders.....	10

Appendix A: Scope

A.1 Guideline title:

Pancreatic cancer in adults: diagnosis and management

A.2 Topic

The Department of Health in England and NHS England have asked NICE to develop a clinical guideline on the diagnosis and management of pancreatic cancer.

This guideline will also be used to develop the NICE quality standard for pancreatic cancer.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the context section (A.8).

A.3 Who the guideline is for

- Healthcare professionals in secondary and tertiary care who are involved in the diagnosis, treatment, care and support of people with pancreatic cancer.
- Commissioners of pancreatic cancer services (including clinical commissioning groups and NHS England specialised commissioning).
- Healthcare professionals in primary care.
- Healthcare professionals providing end-of-life care.
- People using pancreatic cancer services, their family members and carers, and the public.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#) and [Northern Ireland Executive](#).

A.4 Equality considerations

NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified, and how they have been addressed;
- explains why any groups are excluded from the scope.

A.5 What the guideline is about

A.5.1 Who is the focus?

Groups that will be covered

- Adults (18 and over) referred to secondary care with suspected pancreatic cancer.
- Adults (18 and over) with newly diagnosed or recurrent pancreatic ductal adenocarcinoma.

Groups that will not be covered

- Adults (18 and over) in primary care with suspected pancreatic cancer.
- People with confirmed tumours of the pancreas other than pancreatic ductal adenocarcinoma.

1 **A.5.2 Settings**

- 2 Settings that will be covered
- 3 • All settings in which NHS care is provided.

4 **A.5.3 Activities, services or aspects of care**

5 **Key areas that will be covered**

- 6 1. Information and support needs for people with pancreatic cancer and their families and
- 7 carers.
- 8 2. Referring people to specialist teams.
- 9 3. Diagnosing suspected pancreatic cancer.
- 10 4. Staging pancreatic cancer.
- 11 5. Managing pancreatic cancer.
- 12 6. Follow-up of people with pancreatic cancer.

13 **Areas that will not be covered**

14 Identifying people in primary care with suspected pancreatic cancer and referring them to

15 secondary care.

16 **A.5.4 Economic aspects**

17 We will take economic aspects into account when making recommendations. We will develop

18 an economic plan that states for each review question (or key area in the scope) whether

19 economic considerations are relevant, and if so whether this is an area that should be

20 prioritised for economic modelling and analysis. We will review the economic evidence and

21 carry out economic analyses, using an NHS and personal social services (PSS) perspective,

22 as appropriate.

23 **A.5.5 Key issues and questions**

24 While writing this scope, we have identified the following key issues and draft review

25 questions related to them:

- 26 1. Information and support needs for people with pancreatic cancer and their families
- 27 ○ What are the specific information and support needs of people who are diagnosed with
- 28 pancreatic cancer and their families or carers (as appropriate) throughout the care
- 29 pathway?
- 30 2. Referral to specialist teams
- 31 ○ Does referral of all people with suspected pancreatic cancer to a regional centre or
- 32 multidisciplinary team for review improve patient management and outcomes?
- 33 3. Diagnosing suspected pancreatic cancer
- 34 ○ What is the most effective diagnostic pathway (including CA 19–9, histology, cytology
- 35 and imaging investigations) for people with suspected pancreatic cancer in secondary
- 36 care who have obstructive jaundice?
- 37 ○ What is the most effective diagnostic pathway (including CA 19–9, histology, cytology
- 38 and imaging investigations) for people with suspected pancreatic cancer in secondary
- 39 care who have no jaundice with pancreatic lump(s)?
- 40 ○ What is the most effective diagnostic pathway (including CA 19–9, histology, cytology
- 41 and imaging investigations) for people with suspected pancreatic cancer in secondary
- 42 care who have pancreatic cysts?

- 1 ○ What is the most effective diagnostic pathway (including CA 19–9, histology, cytology
- 2 and imaging investigations) for people with suspected pancreatic cancer in secondary
- 3 care who are from other high risk groups, for example, familial pancreatic cancer and
- 4 hereditary pancreatitis (PRSS1 mutations)?
- 5 4. Staging pancreatic cancer
- 6 ○ What is the most effective investigative pathway (for example, combinations of CA19-9,
- 7 endoluminal ultrasound, CT, MRI, positron emission tomography (PET)-CT, tissue
- 8 diagnosis, laparoscopy with or without ultrasound) for staging pancreatic cancer as
- 9 resectable, borderline resectable, locally advanced and metastatic disease?
- 10 5. Management of pancreatic cancer
- 11 ○ What is the most effective surgery for people with resectable and borderline resectable
- 12 pancreatic cancer?
- 13 ○ What are the most effective neoadjuvant therapies (chemotherapy, chemoradiotherapy,
- 14 do nothing) for people with resectable and borderline resectable pancreatic cancer?
- 15 ○ What is the most effective adjuvant therapy (chemotherapy, chemoradiotherapy or
- 16 radiotherapy) for people who have had resection of pancreatic cancer?
- 17 ○ What is the most effective treatment (chemotherapy, chemoradiotherapy or other local
- 18 therapies) for people with locally advanced pancreatic cancer?
- 19 ○ Do sympathectomy or neurolytic techniques effectively manage pain from locally
- 20 advanced pancreatic cancer?
- 21 ○ What is the most effective management of metastatic pancreatic cancer (for example,
- 22 chemotherapy [excluding interventions covered by NICE technology appraisals],
- 23 symptom control, surgery for isolated metastases)?
- 24 ○ What is the most effective management of duodenal obstruction?
- 25 ○ What is the most effective management of biliary obstruction?
- 26 ○ What nutritional interventions (for example, pancreatic enzyme replacement therapy,
- 27 liquid nutritional supplements, dietetic assessment) improve outcomes for people with
- 28 pancreatic cancer?
- 29 6. Follow-up of people with pancreatic cancer
- 30 ○ What is the most effective follow-up protocol for people with resected pancreatic
- 31 cancer?

32 The key questions may be used to develop more detailed review questions, which guide the
33 systematic review of the literature.

34 **A.6 Main outcomes**

35 The main outcomes that will be considered when searching for and assessing the evidence
36 are:

- 37 1. Overall survival.
- 38 2. Disease-free survival.
- 39 3. Nutritional status.
- 40 4. Pain.
- 41 5. Disease-related morbidity.
- 42 6. Treatment-related morbidity.
- 43 7. Treatment-related mortality.
- 44 8. Health-related quality of life.
- 45 9. Patient reported outcome measures.

1 **A.7 Links with other NICE guidance, NICE quality standards** 2 **and NICE Pathways**

3 **A.7.1 NICE guidance**

4 **NICE guidance about the experience of people using NHS services**

5 NICE has produced the following guidance on the experience of people using the NHS. This
6 guideline will not include additional recommendations on these topics unless there are
7 specific issues related to pancreatic cancer:

- 8 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 9 • [Medicines adherence](#) (2009) NICE guideline CG76

10 **NICE guidance in development that is closely related to this guideline**

11 NICE is currently developing the following guidance that is closely related to this guideline:

- 12 • [Care of the dying adult NICE guideline](#). Publication expected December 2015
- 13 • [Improving supportive and palliative care in adults \(update\)](#) NICE guideline. Publication
14 expected January 2018.
- 15 • [Pancreatic cancer \(metastatic, untreated\) – liposomal cisplatin \(with gemcitabine\)](#) NICE
16 technology appraisal. Publication date to be confirmed.
- 17 • [Pancreatic cancer \(metastatic\)](#) - nimotuzumab (1st line) NICE technology appraisal.
18 Publication date to be confirmed.

19 **A.7.2 NICE quality standards**

20 NICE quality standards that may use this guideline as an evidence source when they are
21 being developed

- 22 • Pancreatic cancer NICE quality standard. Publication date to be confirmed.

23 **A.7.3 NICE Pathways**

24 NICE Pathways bring together all related NICE guidance and associated products on a topic
25 in an interactive topic-based flow chart. When this guideline is published, the
26 recommendations will be added to [NICE Pathways](#).

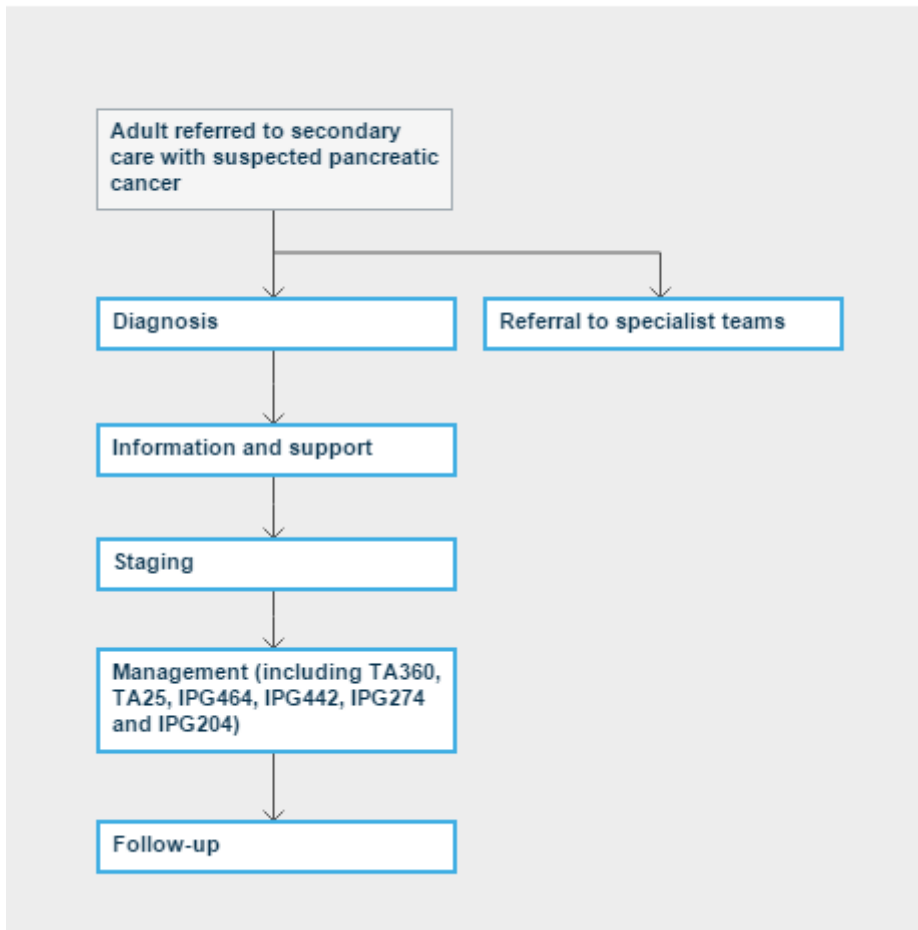
27 Other relevant NICE guidance will also be added to the NICE Pathway, including:

- 28 • [Suspected cancer: recognition and referral](#) (2015) NICE guideline 12
- 29 • [Paclitaxel as albumin-bound nanoparticles in combination with gemcitabine for previously](#)
30 [untreated metastatic pancreatic cancer](#) (2015) NICE technology appraisal guidance 360
- 31 • [Guidance on the use of gemcitabine for the treatment of pancreatic cancer](#) (2001) NICE
32 technology appraisal guidance 25
- 33 • [Endoscopic bipolar radiofrequency ablation for treating biliary obstruction caused by](#)
34 [cholangiocarcinoma or pancreatic adenocarcinoma](#) (2013) NICE interventional procedure
35 guidance 464
- 36 • [Irreversible electroporation for treating pancreatic cancer](#) (2013) NICE interventional
37 procedure guidance 442
- 38 • [Autologous pancreatic islet cell transplantation for improved glycaemic control after](#)
39 [pancreatectomy](#) (2008) NICE interventional procedure guidance 274
- 40 • [Laparoscopic distal pancreatectomy](#) (2007) NICE interventional procedure guidance 204

1
2
3
4
5

A draft pathway outline on pancreatic cancer, based on the draft scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development. The pancreatic cancer pathway will be accessible from the [gastrointestinal cancers pathway](#).

Pancreatic cancer overview



6

7 **A.8 Context**

8 **A.8.1 Key facts and figures**

9 Pancreatic cancer is the fifth leading cause of cancer death in the UK. On average, 23
10 people die each day from the disease. The UK has one of the worst survival rates in Europe,
11 with average life expectancy on diagnosis just 4–6 months and a relative survival to 1 year of
12 approximately 20%.

13 Only 3% of people survive for 5 years or longer. This figure has not improved much in over
14 40 years, and the more recent effects of increased surgery and adjuvant chemotherapy on
15 survival outcomes are not yet established.

16 Because of late diagnosis only 4–10% of people with pancreatic cancer are eligible for
17 potentially curative surgery. People who are able to have surgery to remove the tumour and
18 be given adjuvant chemotherapy have up to a 30% chance of surviving 5 years.

1 **A.8.2 Current practice**

2 The symptoms of pancreatic cancer are non-specific. One survey found that 40% of people
3 diagnosed with pancreatic cancer in England had visited their GP 3 or more times before the
4 diagnosis was made. Fifty per cent of people are diagnosed as an emergency in the A&E
5 system. Even after diagnosis of pancreatic cancer there is evidence from the National
6 Cancer Intelligence Network of wide variation in practice throughout England.

7 **A.8.3 Policy, legislation, regulation and commissioning**

8 **Policy**

9 Department of Health (2014) [Improving outcomes: a strategy for cancer fourth annual report](#)

10 Department of Health (2012) [Commissioning Cancer Services](#)

11 Department of Health (2015) [Achieving world-class cancer outcomes – A strategy for](#)
12 [England 2015–2020](#)

13 **Legislation, regulation and guidance**

14 Department of Health (2001) [Improving outcomes in upper gastro-intestinal cancers](#)

15 European Society of Medical Oncology (2015) [Cancer of the Pancreas: ESMO Clinical](#)
16 [Practice Guidelines](#)

17 British Society of Gastroenterology (2005) [Guidelines for the Management of Patients with](#)
18 [Pancreatic Cancer, Periampullary and Ampullary Carcinomas](#)

19 National Comprehensive Cancer Network (2014) [Guidelines for Patients: Pancreatic Cancer](#)

20 Royal College of Pathologists (2010) [Dataset for the histopathological reporting of](#)
21 [carcinomas of the pancreas, ampulla of Vater and common bile duct](#)

22 **Further information**

This is the final scope, incorporating comments from registered stakeholders during consultation. The guideline is expected to be published in January 2018.

You can follow progress of the [guideline](#).

Our website has information about how NICE [guidelines](#) are developed.

23 **Appendix B: Stakeholders**

24 Royal College of Obstetricians and Gynaecologists

25 NICE - Implementation

26 Social Care Institute for Excellence

27 National Collaborating Centre for Cancer

28 Welsh Government

29 NICE - Topic selection

30 Royal College of Nursing

31 NET Patient Foundation

- 1 Royal College of Anaesthetists
- 2 National Deaf Children's Society
- 3 Belfast Health and Social Care Trust
- 4 National Collaborating Centre for Mental Health
- 5 NICE - Evidence Services
- 6 NICE - Topic selection
- 7 Welsh Government
- 8 Southern Health & Social Care Trust
- 9 Royal College of Psychiatrists
- 10 Department of Health, Social Services and Public Safety - Northern Ireland
- 11 Healthcare Improvement Scotland
- 12 Deltex Medical
- 13 NICE - CPHE
- 14 Royal College of Surgeons of England
- 15 NHS Choices
- 16 Association of Anaesthetists of Great Britain and Ireland
- 17 Care Quality Commission
- 18 Health and Care Professions Council
- 19 Healthcare Quality Improvement Partnership
- 20 Medicines and Healthcare Products Regulatory Agency
- 21 Ministry of Defence
- 22 NHS England
- 23 National Institute for Health Research
- 24 Northern Health and Social Care Trust
- 25 Public Health England
- 26 NICE - PIP
- 27 Royal Pharmaceutical Society
- 28 Department of Health
- 29 Royal College of Radiologists
- 30 British Medical Association
- 31 National Clinical Guideline Centre
- 32 NICE - Clinical Guidelines Surveillance
- 33 Royal College of Midwives

- 1 NICE - Implementation
- 2 NICE - Technology Appraisals & HST
- 3 NICE - Quality Programme
- 4 Belfast Health and Social Care Trust
- 5 NHS Somerset CCG
- 6 British Psychological Society
- 7 National Collaborating Centre for Cancer
- 8 Health and Social Care Information Centre
- 9 NICE - Medicines and Prescribing Centre
- 10 NICE - Medicines and Prescribing Centre
- 11 UCL Partners
- 12 UCL Partners
- 13 Royal College of Radiologists
- 14 British Red Cross
- 15 British Nuclear Cardiology Society
- 16 NICE - MTEP
- 17 South Eastern Health and Social Care Trust
- 18 Royal College of Midwives
- 19 British Medical Journal
- 20 Western Health and Social Care Trust
- 21 Royal College of Pathologists
- 22 National Collaborating Centre for Mental Health
- 23 Ministry of Defence
- 24 National Collaborating Centre for Women's and Children's Health
- 25 NICE - Scientific Advice
- 26 NICE - Social Care
- 27 Royal College of General Practitioners in Wales
- 28 Royal College of Pathologists
- 29 NICE - Clinical Guideline Updates team
- 30 British Nuclear Cardiology Society
- 31 NICE - CPHE
- 32 Royal College of Speech and Language Therapists
- 33 County Durham and Darlington NHS Foundation Trust

- 1 Nursing and Midwifery Council
- 2 NHS England
- 3 NICE - Scientific Advice
- 4 NICE - DAP
- 5 Welsh Scientific Advisory Committee
- 6 Scottish Intercollegiate Guidelines Network
- 7 Royal Pharmaceutical Society
- 8 Royal Pharmaceutical Society
- 9 NICE - Interventional Procedures
- 10 Royal College of General Practitioners
- 11 Royal College of Paediatrics and Child Health
- 12 Scottish Intercollegiate Guidelines Network
- 13 Public Health Wales
- 14 Public Health Wales
- 15 Royal College of Physicians
- 16 NICE - Internal Clinical Guidelines Programme
- 17 Manchester Cancer
- 18 Royal College of Speech and Language Therapists
- 19 NHS Health at Work