





Pancreatic Cancer – Information Toolkit

Working together | Improving together

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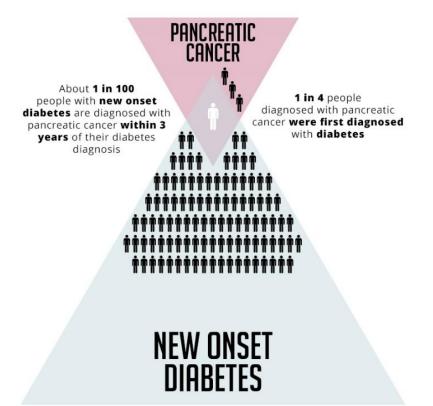


Purpose of this toolkit



This information toolkit aims to improve the awareness and understanding of the risk factors, signs and symptoms of pancreatic cancer. It is targeted towards primary and community care colleagues and includes a range of learning resources, guidance and supporting materials.

Key message throughout this toolkit: unexplained new-onset diabetes can be an early warning sign for pancreatic cancer.



Why is early diagnosis important?



If a cancer is diagnosed at an early stage, there is a much greater chance of being able to treat the disease successfully, often with less invasive procedures and fewer long-term side effects.

It is also important that we diagnose cancers as fast as possible so that treatment can start quickly and as accurately as possible - for example, identifying the genetic make-up of an individual's tumour tells us how best to treat it.

People diagnosed earlier with cancer are not only more likely to survive, but importantly also to have better experiences of care, lower treatment morbidity, and improved quality of life compared with those diagnosed late.

Early diagnosis of pancreatic cancer



Diagnosing pancreatic cancer is difficult and can take a long time; often with many visits to the doctor. Around 80%¹ of pancreatic cancer patients are not diagnosed until the cancer is at an advanced stage. At this late stage, surgery is usually not possible – and this is the only known treatment that has the potential to cure the disease.

For eligible patients, surgery is the best option for long-term survival of pancreatic cancer. It can increase a patient's survival by about ten-fold.

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Pancreatic Cancer UK

Pancreatic Cancer Action

Primary Care Top 10 Tips

Click below for training resources



National data



The importance of diagnosing pancreatic cancer early is further supported by the poor national position:

- Almost half of all patients are diagnosed as an emergency presentation
- Only 1% of people diagnosed with pancreatic cancer today are predicted to survive their disease for at least ten years
- Less than 8% of people survive beyond five years
- Pancreatic cancer survival in the UK has not improved in the last 40 years
- Patients diagnosed in time for surgery, the chances of surviving beyond five years increases tenfold



Half of all patients are diagnosed as an emergency



For those diagnosed in time for surgery their chance of surviving beyond five years increases tenfold



- Cancer Research UK Stats
- Pancreatic Cancer Facts

Surrey and Sussex Cancer Alliance data



The situation across the Surrey and Sussex Cancer Alliance (SSCA) further adds to the need for improvement:

- Only 21% of pancreatic cancer patients are diagnosed early (stages 1 or 2) (2019)¹
- 51% patients are diagnosed through emergency presentation (2022)²
- Over 60% of areas have a higher pancreatic cancer incidence rate than the England average (17.2 people per 100,000 population) (2016-2018 CCGs)³





- Cancer Research UK Stats
- Pancreatic Cancer Facts

^{1.} National Disease Registration Service, Cancer Data. (2019)

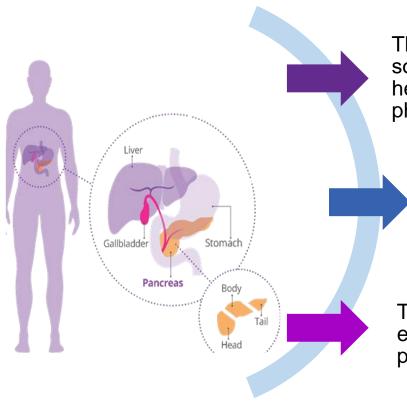
^{2.} Rapid Cancer Registration Dataset, CancerStats (2022)

^{3.} Rapid Cancer Registration Dataset, CancerStats (2016-2018)

Challenges in early diagnosis



Pancreatic cancer is hard to diagnose early. The main challenges in early diagnosis are:



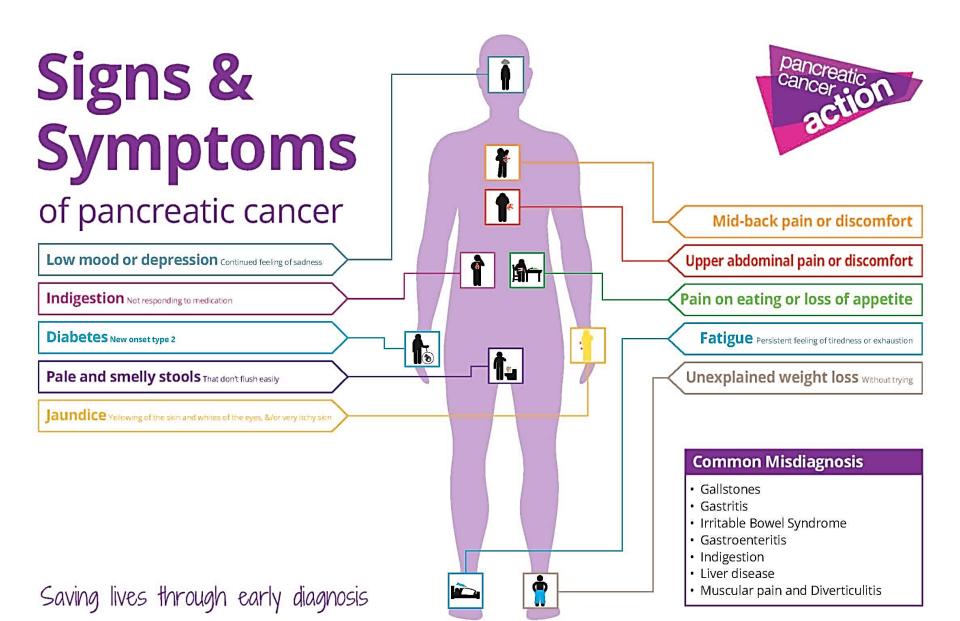
The pancreas is deep inside the body, so early tumours can't be seen or felt by health care providers during routine physical exams.

People usually have no symptoms until the cancer has become very large or has already spread to other organs.

There is no standard diagnostic tool or established early detection method for pancreatic cancer.



- Why is pancreatic cancer diagnosed late?
- Pancreatic Cancer UK: Early Diagnosis Challenge
- Early Detection Information and Research



Main risk factors



Age

Pancreatic cancer is more common in older people. In the UK, 47% of people diagnosed are over 75 years old. It is uncommon in people under 40 years old.

Smoking

Smoking increases the risk of pancreatic cancer. The risk increases the longer someone has smoked and the amount smoked. In the UK, one in five pancreatic cancers are caused by smoking.

Being overweight

Being overweight or obese increases the risk of pancreatic cancer. In the UK, approximately, 12% of pancreatic cancers are caused by people being over weight.

Family history of pancreatic cancer

In the UK, 5-10% of people diagnosed with pancreatic cancer have a family history. The risk increases further if more than one first degree relative has been diagnosed with pancreatic cancer or if the first degree relative was diagnosed at a young age.

Pancreatitis

People with chronic pancreatitis have increased risk of pancreatic cancer. If the chronic pancreatitis is hereditary the risk of pancreatic cancer is higher.

Diabetes

Diabetes can be a risk factor and a symptom of pancreatic cancer. People with diabetes have a higher risk of developing pancreatic cancer.

More than one of the above risk factors increases the overall risk of pancreatic cancer.

Other possible risk factors



Some research has suggested that the following things may increase your risk of pancreatic cancer. But more research is needed.

History of cancer

The risk of pancreatic cancer can be higher if an individual has already had other cancers.

Alcohol

There is some evidence that drinking a lot of alcohol may increase the risk of pancreatic cancer and of getting it at a younger age, but it's not clear exactly how much alcohol may increase the risk.

Red and processed meat

Eating red meat or processed meat may increase the risk of pancreatic cancer, particularly meat cooked at high temperatures.

Gallstones and gall bladder surgery

Some evidence suggests that people who have gallstones or have had their gall bladder removed (cholecystectomy) may have an increased risk of pancreatic cancer.

Click below for training resources





New-onset diabetes and pancreatic cancer



Diabetes, especially Type 2, is common among the general population. However, unexplained new-onset diabetes should be investigated as a possible indicator of pancreatic cancer. It is also important to ask patients about other symptoms of pancreatic cancer such as steatorrhea, back pain and weight loss.

NICE NG12 guidelines recommend an urgent direct access CT scan (to be performed within 2 weeks), or an urgent ultrasound scan if CT is not available, to assess for pancreatic cancer in people aged 60 and over with weight loss any of the following: diarrhoea, back pain, abdominal pain, nausea, vomiting, constipation, new-onset diabetes.

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

- NICE NG12 guidelines
- <u>Fact Sheet Explaining the NICE guidelines for diagnosing and managing pancreatic cancer</u>
- -Ώ-
- Diabetes resources for health professionals
- Managing diabetes if you have pancreatic cancer
- University of Liverpool Overview of the pancreatic cancer risk in people with New Onset Diabetes
- Pancreatic cancer could be diagnosed up to three years earlier

Ardens SystmOne and EMIS



Ardens has created a variety of cancer resources to assist with identifying patients who may have a potential cancer diagnosis, and to support their ongoing management once diagnosed.

The new Diabetes alert will be displayed if you are adding a new diagnosis of diabetes to a patients record and they are over the age of 60, advising the user to consider the possibility

of pancreatic cancer.





QCancerScore



QCancer scores offer a host of tools that can calculate and display the risk of cancer across a range of tumour sites. There are several scores under the QCancer banner. QCancer is fully integrated into EMIS web, further information on this is on the link below.

QCancer works out the risk of a patient having a current but as yet undiagnosed cancer taking account of their risk factors and current symptoms. It does not give a diagnosis of cancer, but a risk of having one as yet undiagnosed.

Other tools include 10 year, which works out the risk of a patient developing cancer over the next 10 years given their individual risk factors.

Ardens Cancer Symptom Analyser



The Ardens Cancer Symptom Analyser supports clinicians in identifying whether a patient's symptoms and findings meet the criteria for referral based on NICE NG12 Suspected
Cancer Guidelines.

The Cancer Symptom Analyser consist of the following resources:

- Suspected Cancer Symptoms Template designed to record details of the patients presenting symptoms.
- Suspected Cancer Analyser Template offers the appropriate NICE NG12 suspected cancer guidance, depending on the symptoms recorded for the patient.

Know your codes:



Family History of Pancreatic cancer: **SNOMED concept ID 429000004**

This code is now available on EMIS and SystmOne

Cancer Research UK Symptom Reference Guide

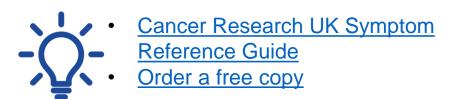


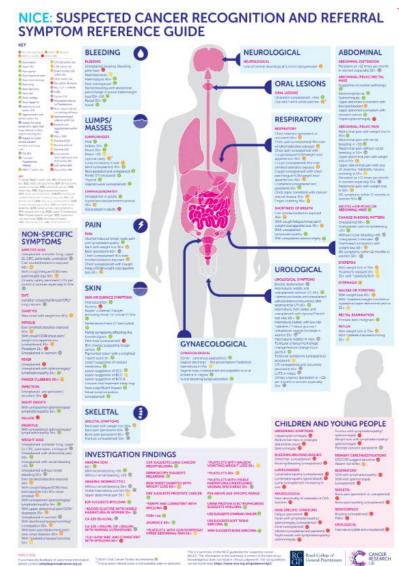
This symptom reference guide for suspected cancer recognition and referral has been developed by Cancer Research UK and the Royal College of General Practitioners to summarise NICE Guideline 12 Suspected cancer: recognition and referral.

Scan the QR code or click the link to view the comprehensive guide.



SCAN ME





GatewayC Cancer Maps

Surrey and Sussex
Cancer Alliance

Background and Risks for Pancreatic Cancer

more common in white and black people than Asian people survival (all stages) 1 year - 20% 5 year - 5% higher for pancreatic endocrine tumours

96% diagnosed in people > 50y/o
50% cases in women, 50% in men

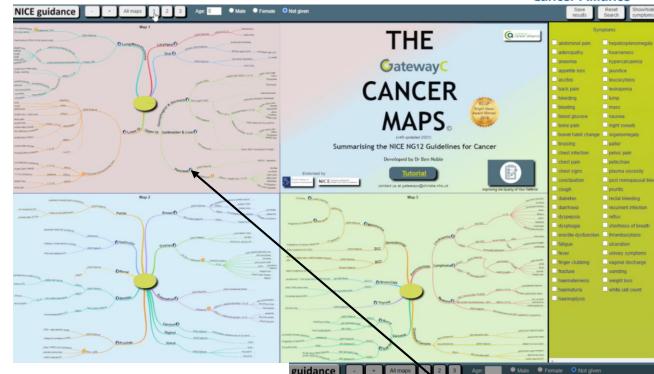
31% cases preventable

o smoking (30% cases)

o alcohol, ≥6 units/day (70% cases)

The Cancer Maps are an RCGP award-winning interactive reference tool which summarise the NICE NG12 guidelines.

The three maps allow healthcare professionals to quickly reference NG12 guidelines in just a few clicks, acting as a reassuring referral guide and a helpful safety-netting tool in discussion with patients.





GatewayC – Introducing
Cancer Maps
Cancer Maps Tool and
Tutorial

Inherited Risk of Pancreatic Cancer



About 10% of pancreatic cancers are hereditary meaning that for every 10 people with the disease, one likely had increased risk due to genetic mutations. Mutations that happen during a person's lifetime, rather than inherited mutations, cause most pancreatic cancers.

Mutated DNA can pass from generation to generation (germline mutations). These mutations may lead to hereditary pancreatic cancer. This is the only way the disease can be inherited.

Most individuals with inherited and other risk factors for developing pancreatic cancer are <u>not aware of their risk</u> or involved in any surveillance.

As early diagnosis plays such an important role in outcomes and survival for pancreatic cancer, understanding and monitoring risk factors is a key area for improvement.

NICE guidance NG85 Pancreatic cancer in adults: diagnosis and management recommends surveillance for people with an inherited high-risk, to detect pancreatic cancer earlier.



Image credit: https://arielmedicine.com/patientsv1/quide-pancreatic-cancer/

Read more about Family History of Pancreatic Cancer from Pancreatic Cancer UK.



Pancreatic Cancer Surveillance – NG85 Recommendations for Inherited Risk



Pancreatic cancer in adults: diagnosis and management

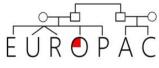
NICE guideline [NG85] Published: 07 February 2018





People with inherited high risk of pancreatic cancer

- 1.1.13 Ask people with pancreatic cancer if any of their first-degree relatives has had it. Address any concerns the person has about inherited risk.
- 1.1.14 Offer surveillance for pancreatic cancer to people with:
 - · hereditary pancreatitis and a PRSS1 mutation
 - BRCA1, BRCA2, PALB2 or CDKN2A (p16) mutations, and one or more first-degree relatives with pancreatic cancer
 - · Peutz-Jeghers syndrome.
- 1.1.15 Consider surveillance for pancreatic cancer for people with:
 - 2 or more first-degree relatives with pancreatic cancer, across 2 or more generations
 - Lynch syndrome (mismatch repair gene [MLH1, MSH2, MSH6 or PMS2] mutations) and any first-degree relatives with pancreatic cancer.
- 1.1.16 Consider an MRI/MRCP or EUS for pancreatic cancer surveillance in people without hereditary pancreatitis.
- 1.1.17 Consider a pancreatic protocol CT scan for pancreatic cancer surveillance in people with hereditary pancreatitis and a PRSS1 mutation.
- 1.1.18 Do not offer EUS to detect pancreatic cancer in people with hereditary pancreatitis.





The European Registry of Hereditary Pancreatic Diseases (EUROPAC)

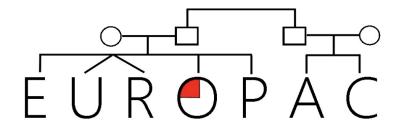


In order to ensure people with inherited risk factors have access to a high-risk surveillance pathway aligned to NG85 NICE guidance, NHS England and Cancer Alliances nationally have partnered with **The European Registry of Hereditary Pancreatic Diseases** (EUROPAC).

EUROPAC is a registry for families with histories of Familial Pancreatic Cancer and Hereditary Pancreatitis. They recruit people with a family history of pancreatic cancer and people who have been diagnosed with hereditary pancreatitis, with over 2000 families registered since 2007. They offer secondary pancreatic cancer screening to those who are at a higher risk of developing pancreatic cancer, with other 700 individuals undergoing active annual surveillance.

Using the family history that individuals provide, EUROPAC can assess their lifetime risk of developing pancreatic cancer. Surveillance is offered on a yearly basis, and use a combination of CT, EUS, MRI and blood tests.

EUROPAC's aim is to develop early detection methods for pancreatic cancer, by better understanding risk and offering surveillance to those who take part and to continuously refine who to and how they provide surveillance to individuals.



Who should be referred to EUROPAC?



Familial Pancreatic Cancer

- Two or more first-degree relatives with pancreatic cancer (with first-degree kinship)
- Three or more relatives with pancreatic cancer (on the same side of the family)
- Carrier of known genetic mutation BRCA1, BRCA2, PALB2, CDKN2A (p16), ATM or Lynch syndrome (mismatch repair gene [MLH1, MSH2, MSH6 or PMS2] mutations) and one or more relatives with pancreatic cancer
- Carrier of Peutz-Jeghers syndrome
- Hereditary Non-Polyposis Colorectal Cancer (HNPCC)
- Familial atypical multiple mole melanoma (FAMMM)

Hereditary Pancreatitis

- Families with two or more relatives with idiopathic pancreatitis
- Families with at least one case of pancreatitis and a confirmed causative mutation in the PRSS1 gene

EUROPAC Regional Surveillance Navigators



Regional Surveillance Navigators are the central point for referrals from providers and main contact for new and existing participants at their delegated surveillance centres, enrolling eligible individuals into EUROPAC and assisting with all aspects of surveillance.



The Surveillance Navigator covering the Surrey & Sussex Cancer Alliance region is **Beata Gubacsi.**

Beata is the first point of contact for study participants and healthcare professionals, providing information about EUROPAC, processing referrals to registration, and providing support for navigating surveillance appointments.

Beata can be contacted for queries and referrals as below: Secure NHS email: Beata.Gubacsi@liverpoolft.nhs.uk

Telephone: 0151 794 0717



The nearest surveillance centres for most SSCA patients are currently likely to be Southampton and London but additional sites are being explored.

EUROPAC Referral Process



There are three main referral routes into the regional navigators.



Secondary care

- Familial cascading from those diagnosed
- We expect most patients to come via this route



Genetic services

- Refer those who have a known mutation and relative with pancreatic cancer
- Link with BRCA & Lynch Syndrome programmes

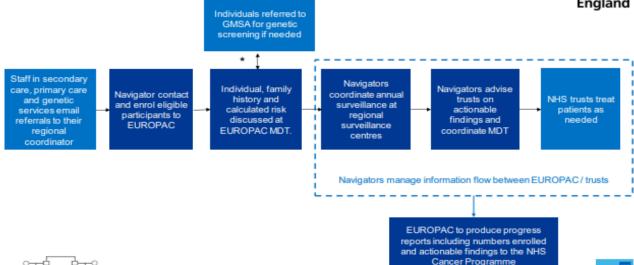


Primary care

- GPs refer individuals with known family history of pancreatic cancer
- SNOMED code: Family history of malignant neoplasm of pancreas (429000004)



NHS England





CANCER PRODUMENT

EUROPAC Referral Resources



EUROPAC have developed a referral form and information sheet for healthcare professionals to refer patients to the registry here <u>EUROPAC</u>, which can be found on the Surrey & Sussex Cancer Alliance website. Or download them here:

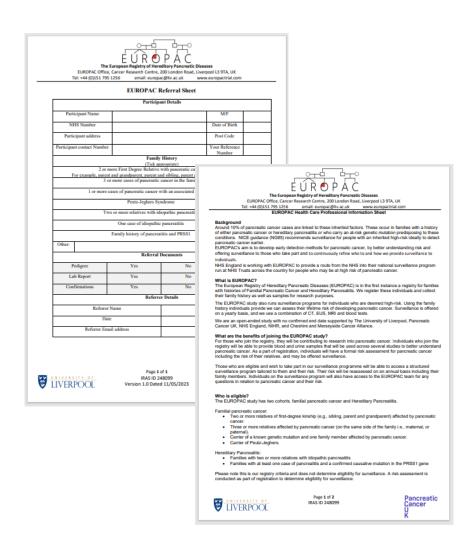
EUROPAC referral form HCP information sheet

EUROPAC website

https://www.europactrial.com/

EUROPAC participant Information sheets for familial pancreatic cancer and hereditary pancreatitis below:

EUROPAC Familial Pancreatic Cancer
EUROPAC Hereditary Pancreatitis



Further Resources



T dittion it documents		Cancer Alliance
Source	Resource	
Pancreatic	Symptoms of pancreatic cancer Z-card	
Cancer U K	Order free materials	
	Fact Sheet - Explaining the NICE guidelines for diagnosing and pancreatic cancer	<u>managing</u>
	Risk Factors	
	Diabetes resources for health professionals	
	Managing diabetes if you have pancreatic cancer	
	Diabetes and pancreatic cancer	
	Pancreatic Cancer UK: Early Diagnosis Challenge	
	Cancer Research UK Stats	
CANCER RESEARCH UK	Cancer Research UK Symptom Reference Guide	



Order a free copy

<u>University of Liverpool - Overview of the pancreatic cancer risk in people with New Onset Diabetes</u>

Further Resources



Source
pancreatic cancer action

Resource

Order free awareness materials

Living with pancreatic cancer/Type 3C diabetes

Resources for Healthcare Professionals

Pancreatic Cancer Facts

Why is pancreatic cancer diagnosed late?



NICE NG12 Guidance



New-onset Diabetes: A Potential Clue to the Early Diagnosis of Pancreatic Cancer

New-onset diabetes in pancreatic cancer: a study in the primary care setting

New onset diabetes and pancreatic cancer

Pancreatic cancer could be diagnosed up to three years earlier

PANCREATIC CANCER ACTION NETWORK Pancreatic cancer risk factors

Diabetes and Pancreatic Cancer - Diet and Nutrition

Early Detection Information and Research

Further Resources



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Resource



Ardens Cancer Resources

Ardens Cancer Symptom Analyser and How It Works

QCancer

QCancer Calculator and Guidance



Macmillan QCancer information

Primary Care Top 10 Tips



GatewayC – Introducing Cancer Maps

Cancer Maps Tool and Tutorial

Training



Source	Resource		
G ateway C	Access GatewayC's 'Pancreatic Cancer – Early Diagnosis' course		
	Cancer Keys - New onset diabetes and pancreatic cancer		
Pancreatic Cancer U K	Introduction to pancreatic cancer- Online course for GPs		
RC Royal College of General Practitioners	Pancreatic Cancer: Early Diagnosis in General Practice		

How we developed this toolkit



We have created this guidance and resource pack in collaboration with a number of partners and would like to thank them for providing information and insight.



Please note: the information in this pack is up to date as of October 2023 but may be subject to change. It is advisable to check sources for further updates.



We hope that you find this toolkit useful. If you have any questions, please contact us through our email: rsch.sscaadmin@nhs.net

Click here for more information on earlier diagnosis of pancreatic cancer on our website