

Pancreatic Cancer Information Toolkit

October 2025

ST ERTH
ENZANCEO FALMOUTE



Contents

01	National Data	09 Inherited Risk of Pancreatic Cancer
02	Local Data	10 The European Registry of Hereditary Pancreatic Diseases (EUROPAC)
03 Main Risk Factors04 Other possible risk factors05 New onset diabetes and pancreatic cancer06 Ardens SystmOne and EMIS		
		11 Who should be referred to EUROPAC?
		12 EUROPAC Referral Process
		13 EUROPAC Referral Resources and
		Patient Posters
07	Ardens Cancer Symptom Analyser	14 Training Available
08	GatewayC Cancer Maps	15 Posters for Patients

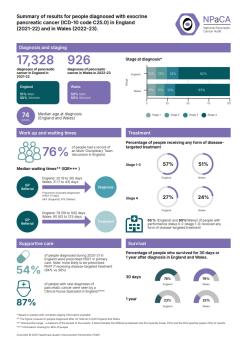


National Data

Pancreatic cancer affects 10,000 people a year in the UK and is the deadliest common cancer, with shocking five-year survival rates of just **7**%, which have barely changed in the last fifty years.

More than half of people with pancreatic cancer die within 3 months, while around 77% die within one year of diagnosis.

This makes pancreatic cancer **eight** times more deadly than other common cancers.



GIRFT launches new specialty review into services for pancreatic cancer patients

August 21, 2023 | Appointments, News



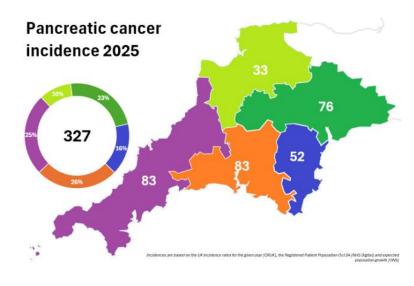


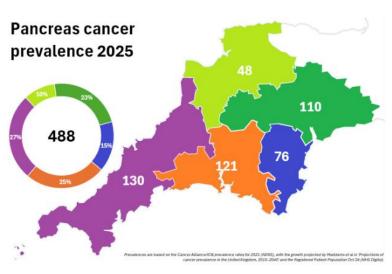


Local Data

Currently 31% of pancreatic cancer is diagnosed at stage 1 and 2 for the Peninsula but we predict that 158 patients a year would have an improved survival rate and better quality of life if 75% were caught at stage 1 and 2 by 2028.

We are currently just above the England average for earlier diagnosis, but we still do not meet the national early diagnosis target.







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.



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.



New onset diabetes and pancreatic cancer Alliance

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

Materials

- Fact Sheet -Explaining the NICE guidelines for diagnosing and managing pancreatic cancer
- Diabetes resources for health professionals
- Managing diabetes if you have pancreatic cancer
- <u>UK-EDI: protocol for establishing a national multicentre cohort of individuals with new-onset diabetes for early detection of pancreatic cancer</u>
- 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.



Arden Cancer Template in EMIS



Ardens Resources in SystmOne



Family History of Pancreatic cancer: SNOMED concept ID 429000004

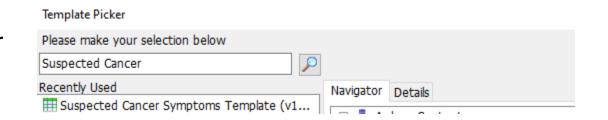


Ardens Cancer Symptom Analyser

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 Templateoffers the appropriate NICE NG12 suspected cancer guidance, depending on the symptoms recorded for the patient.





Ardens Cancer Symptom Analyser:

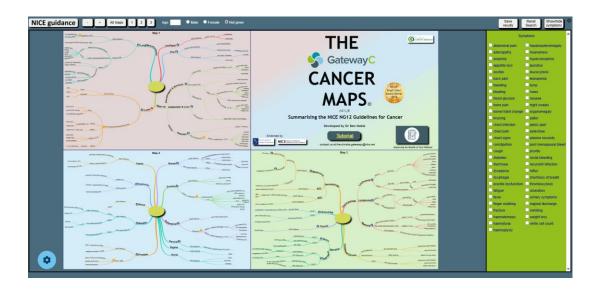
Ardens EMIS Web



GatewayC Cancer Maps

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.



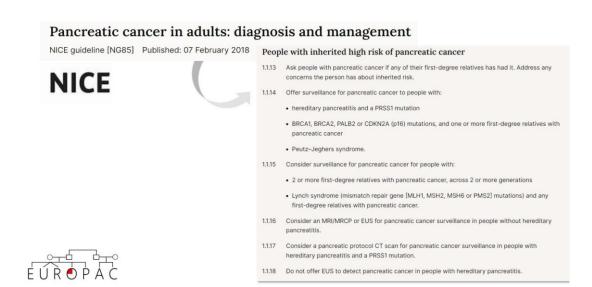


Introduction to Cancer Care Map



Inherited Risk of Pancreatic Cancer

This guideline covers diagnosing and managing pancreatic cancer in adults aged 18 and over. It aims to improve care by ensuring quicker and more accurate diagnosis, and by specifying the most effective treatments for people depending on how advanced their cancer is.



Overview | Pancreatic cancer in adults: diagnosis and management | Guidance | NICE

The European Registry of Hereditary Pancreatic Diseases (EUROPAC)



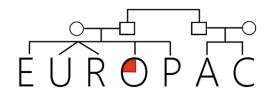
EUROPAC is a registry for families with histories of Familial Pancreatic Cancer and Hereditary Pancreatitis.

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.





South West Cancer Alliances
EUROPAC Webinar



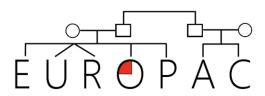
Who should be referred to EUROPAC?

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-Jegherssyndrome
- 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 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

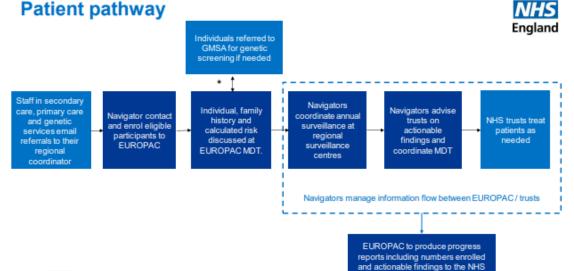


- Refer those who have a known mutation and relative with pancreatic cancer
- Link with BRCA & Lynch Syndrome programmes



Primary care

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





South West Cancer Alliances
EUROPAC Webinar





Cancer Programme

^{*} Patients do not need to have an identified mutation to be eligible for surveillance

EUROPAC Referral Resources and Patient Posters



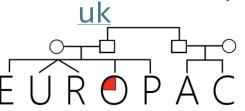




EUROPAC have developed a referral form and information sheet for healthcare professionals to refer patients to the registry here EUROPAC, which can be found on the Peninsula Cancer Alliance website.

For **general enquiries**, please email <u>europac@liv.ac.uk</u>

For **referrals and queries** with sensitive information, please email <u>europac.study@liverpoolft.nhs.</u>



Have you, or someone in your family, been diagnosed with pancreatic cancer?

Are you worried about the risks of hereditary pancreatic cancer?



Around 10% of pancreatic cancers are caused by inherited risk factors.

These can occur in families with a history of either pancreatic cancer or hereditary pancreatitis or in people who carry an at-risk genetic mutation.

Anyone with a family history of pancreatic cancer can now register themselves to the European Registry of Hereditary Pancreatic Diseases (EUROPAC) for annual surveillance.

If you would like further information or would like to register, please visit www.europactrial.com, call 0151 795 1256 or email beata.gubacsi@liverpoolft.nhs.uk





Training Available

Introduction to pancreatic cancer course | Pancreatic Cancer UK - Courses

<u>Diabetes and pancreatic cancer six-part online</u> <u>course | Pancreatic Cancer UK – Courses</u>

> Pancreatic Cancer U

Summary of Pancreatic Cancer: Early Diagnosis in General Practice | RCGP Learning



Pancreatic Cancer - GatewayC

Pancreatic cancer: Tips to aid early recognition and referral – GatewayC

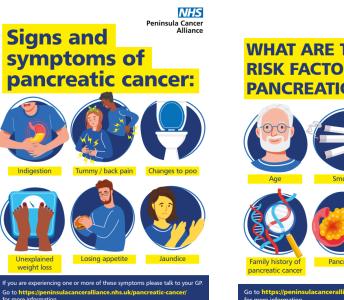
Pancreatic cancer Podcast - GatewayC





Posters for Patients

 Peninsula Cancer Alliance Posters





 Awareness Packs from Pancreatic UK can be ordered here.



Acknowledgements

This information was collated in October 2025 using resources from Pancreatic UK, CRUK and various NHS Websites, including information gathered by the Surrey and Sussex Cancer Alliance.

If you have any questions, please reach out to the team at: peninsula.ca@nhs.net

Feedback about this toolkit will be helpful for future work. Please complete this **form** to let us know what you think.