Herefordshire and Worcestershire Integrated Care System

NHS Herefordshire and Worcestershire

Pancreatic Cancer Information Pack for Primary Care

Information Pack Contents

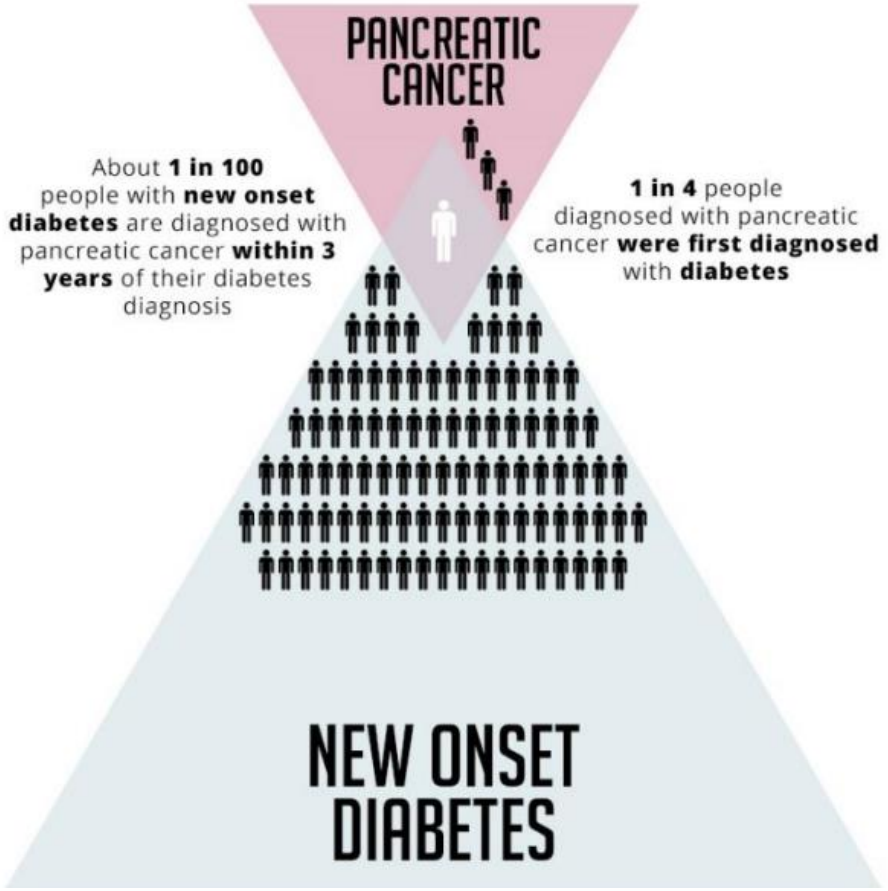
Look out for this icon
for further information

Look out for this icon
for training resource

Purpose of this information pack

This information pack 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 information pack:

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.

- Pancreatic Cancer UK
- Pancreatic Cancer Action
- Primary Care Top 10 Tips

Click the icon to access the training resources

1. Rawla, P., Sunkara, T. and Gaduputi, V. (2019) "Epidemiology of pancreatic cancer: Global trends, etiology and risk factors," World Journal of Oncology, 10(1), pp. 10–27. Available at: https://doi.org/10.14740/wjon1166. 5

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 4 years**
- Patients **diagnosed in time for surgery**, the chances of surviving beyond five years **increases tenfold**

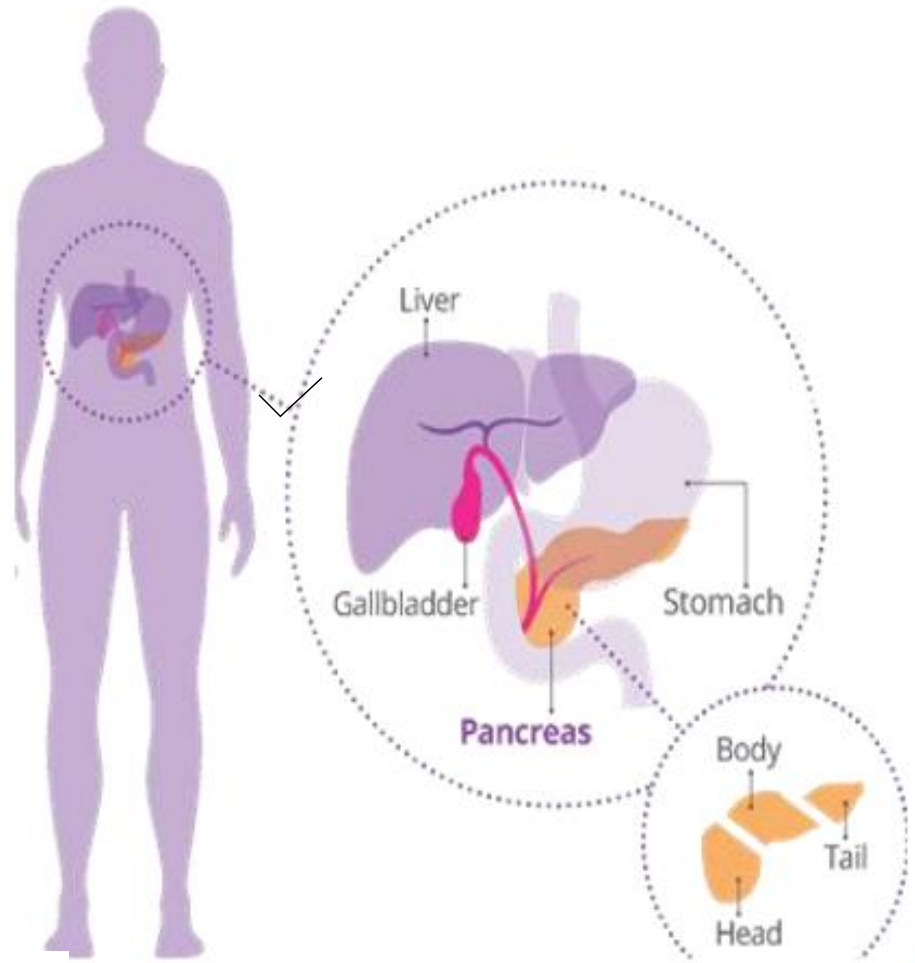
West Midlands Cancer Alliance Data

- Pancreatic cancer diagnosed at stage 1 or 2
  - England 28%
  - West Midlands Cancer Alliance 26%
  - Hereford and Worcester 19%

  Route to diagnosis
- Emergency presentation is over 40%

Pancreatic Cancer Facts
Cancer Research UK Pancreatic Info

Challenges in early diagnosis



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.

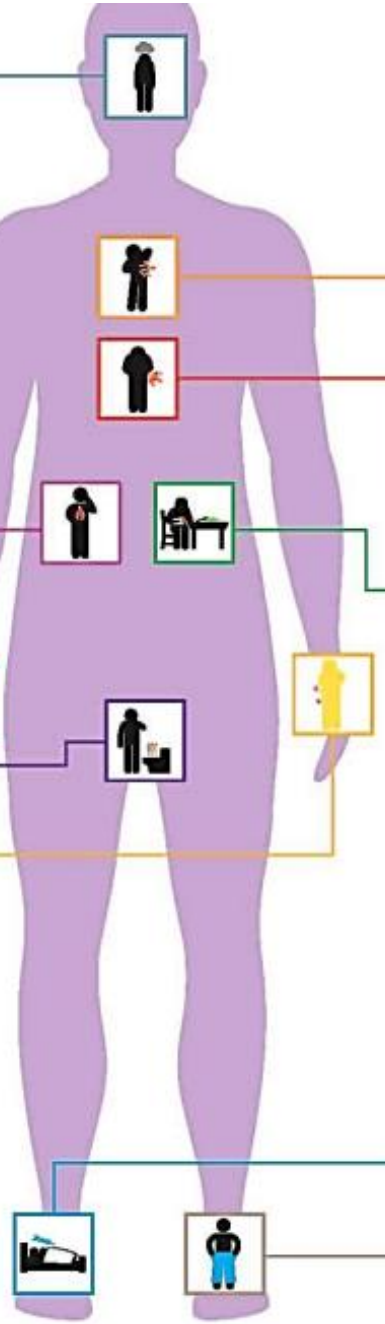
There is no standard diagnostic tool or established early detection method for pancreatic cancer.

[Why is pancreatic cancer diagnosed late]
[Early diagnosis challenge]
[Early Detection - Pancreatic Cancer Action Network]

Signs & Symptoms

of pancreatic cancer

pancreatic cancer action



Low mood or depression Continued feeling of sadness

Indigestion Not responding to medication

Diabetes New onset type 2

Pale and smelly stools That don't flush easily

Jaundice Yellowing of the skin and whites of the eyes, &/or very itchy skin

Mid-back pain or discomfort

Upper abdominal pain or discomfort

Pain on eating or loss of appetite

Fatigue Persistent feeling of tiredness or exhaustion

Unexplained weight loss Without trying

Common Misdiagnosis

- Gallstones
- Gastritis
- Irritable Bowel Syndrome
- Gastroenteritis
- Indigestion
- Liver disease
- Muscular pain and Diverticulitis

Saving lives through early diagnosis

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.

Risk factor and causes

Risk factors fact sheet

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 pancreatic cancer if they are aged 40 and over and have jaundice.

Additional Resource

- NICE NG12 guidelines
- Fact sheet – Explaining the NICE guidelines for diagnosing and managing pancreatic cancer
- Diabetes resources for health professionals
- Managing diabetes if you have pancreatic cancer
- Protocol research
- Pancreatic cancer could be diagnosed up to 3 years earlier

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.

QCancer calculator and guidance

Know your codes…

Family History of Pancreatic cancer: SNOMED concept ID 429000004
This code is now available on EMIS

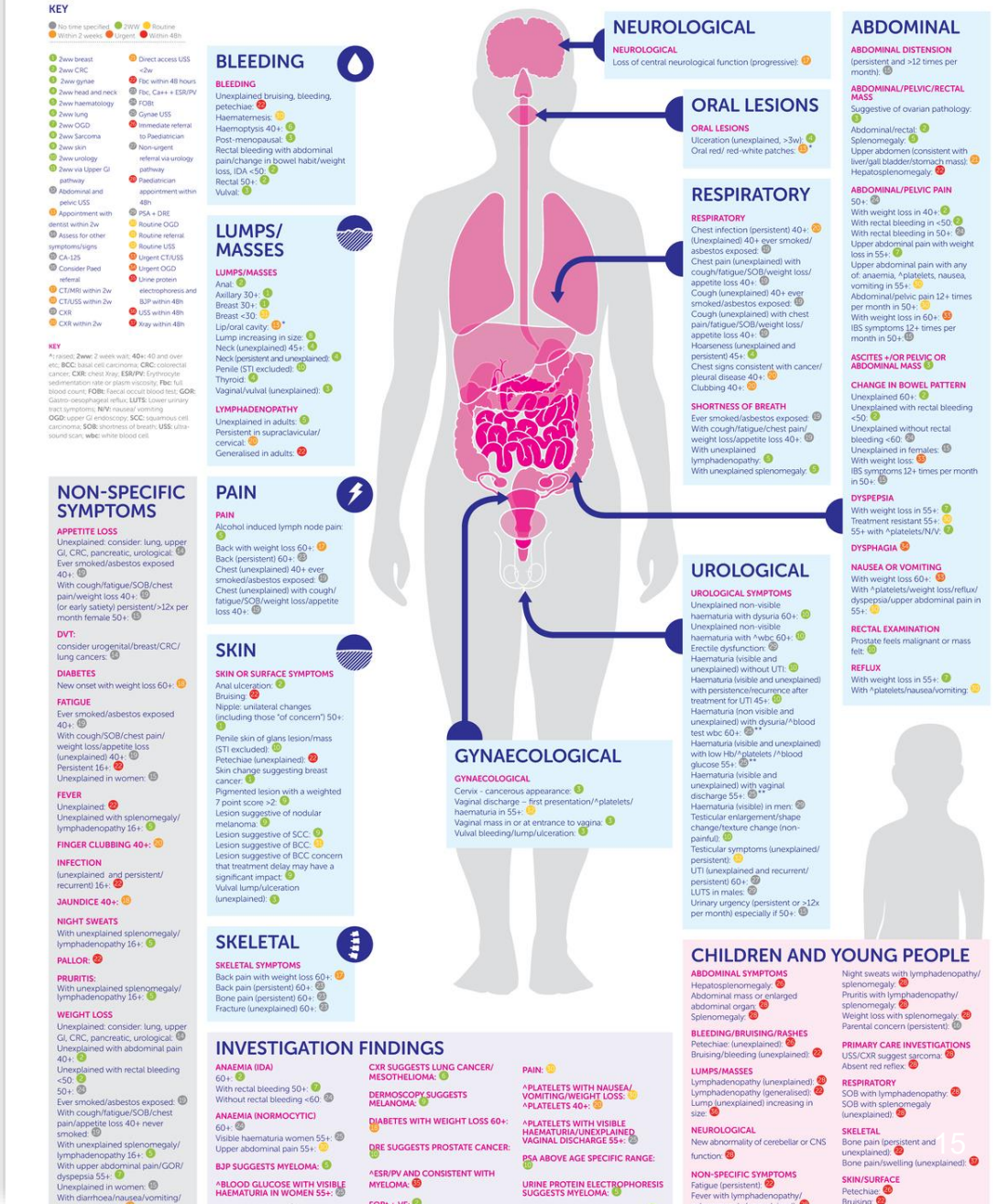
Cancer Research UK Symptom Reference Guide

This symptoms 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

[Order a free copy](#)
[Guideline Summary](#)



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 not aware of their risk or involved in any surveillance.

Image credit: https://arielmedicine.com/patients-

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.

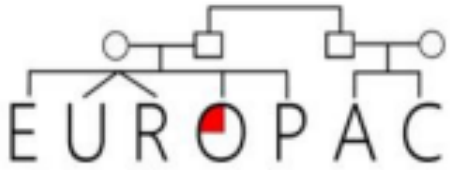
As early diagnosis plays such an important role in **NICE guidance NG85** Pancreatic cancer in adults; diagnosis and management recommends surveillance for people with an inherited high-risk, to detect pancreatic cancer earlier.

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

Pancreatic Cancer Surveillance – NG85

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.

Read more from NICE guidance NG85 Pancreatic cancer in adults: diagnosis and management

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 West Midlands is Isobel Quinn

Isobel can be contacted for queries and referral as below:

Isobel.Quinn2@rlbuht.nhs.uk

0151 794 0712

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

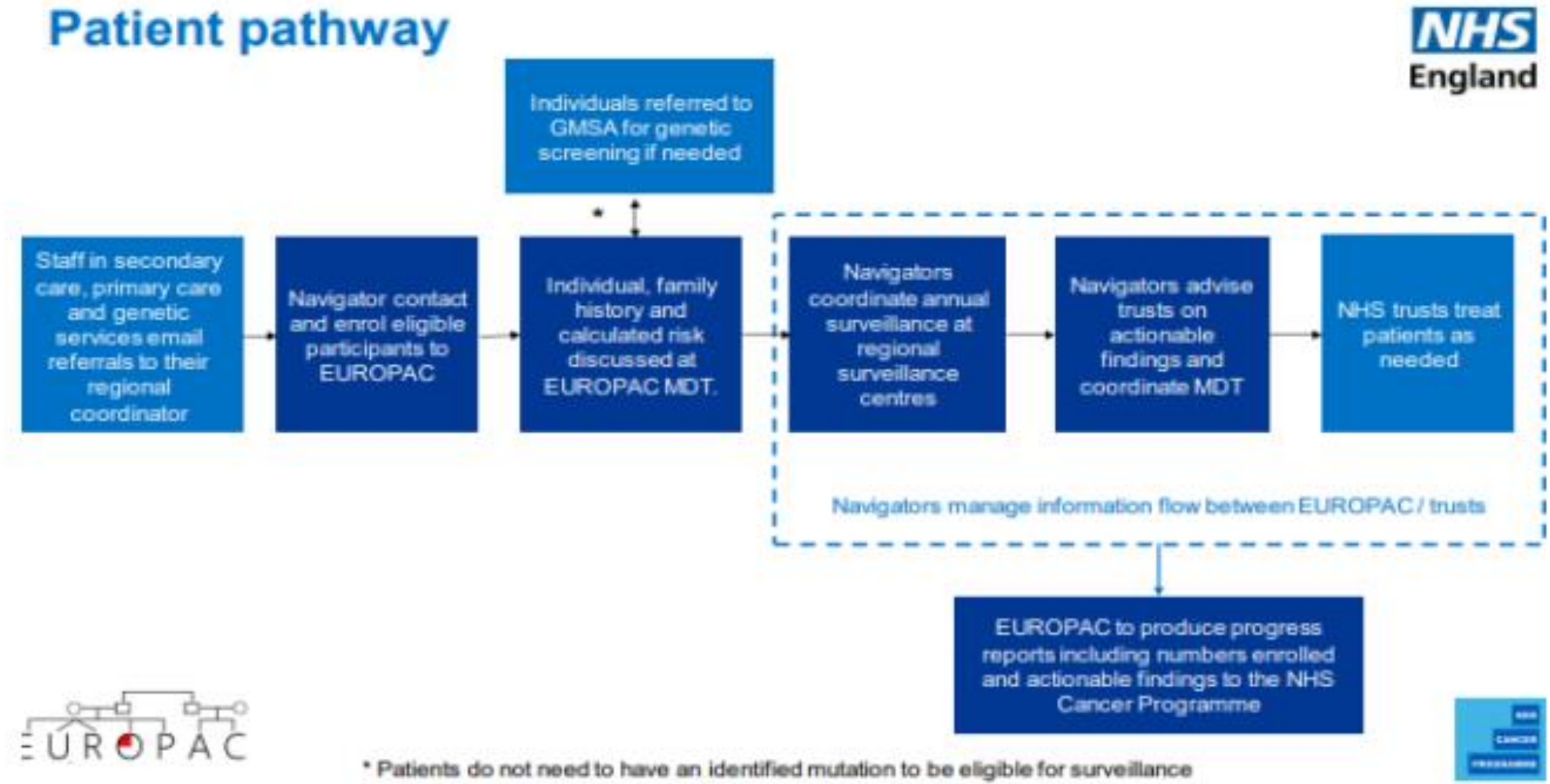
Genetic services

- 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)

EUROPAC Patient Pathway



EUROPAC Referral Resources

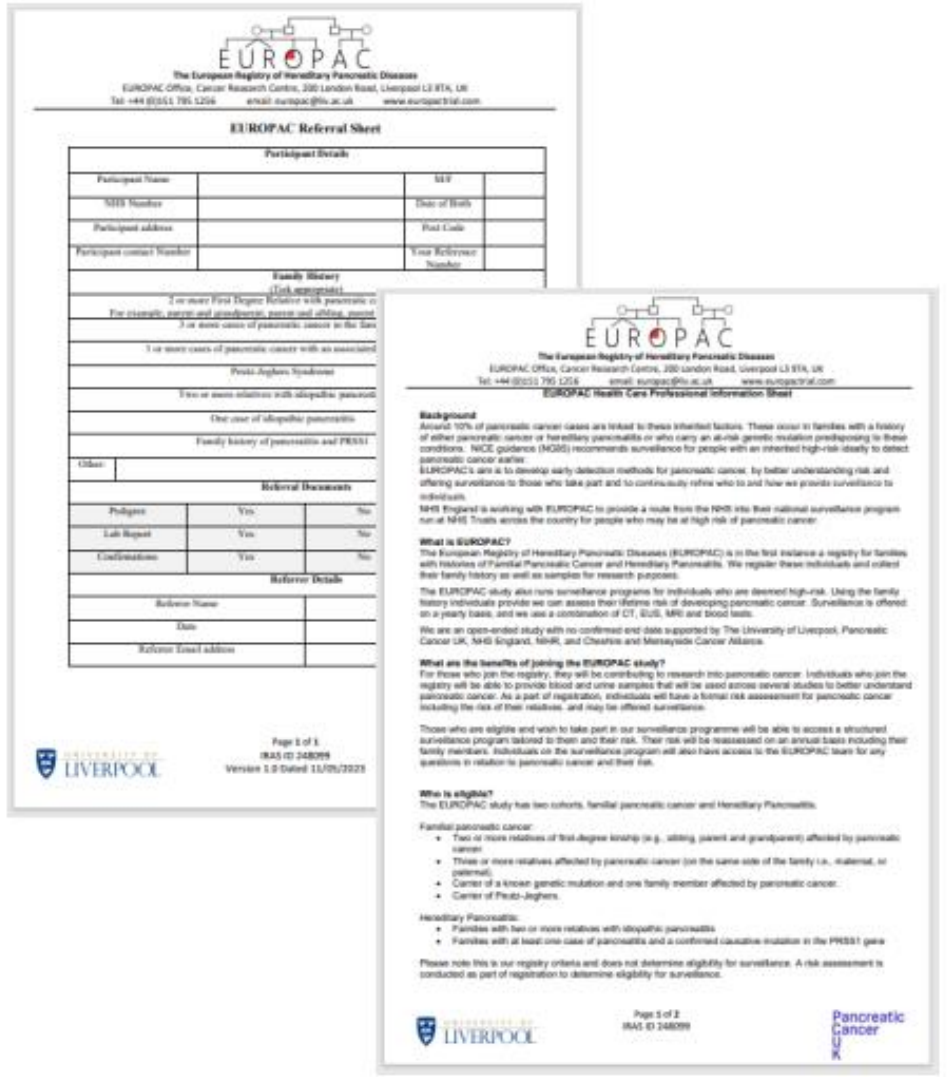
EUROPAC have developed a referral form and information sheet
For healthcare professionals to refer patient to the registry.

Download here:
[Information sheet]
[Referral form]

EUROPAC website
[Https://www.europactrial.com]

EUROPACE participant information sheets for
familial pancreatic cancer and hereditary pancreatitis below:

[EUROPAC Familial Pancreatic Cancer]
[EUROPAC Hereditary Pancreatitis]



Further Resources

Source	Resource
Pancreatic CANCER UK	Symptoms z-card Free resources Fact Sheet – Explaining the NICE guidelines for diagnosing and managing pancreatic cancer Risk Factors Diabetes resources for health professionals Diabetes and pancreatic cancer presentation Early diagnosis challenge
CANCER RESEARCH UK	Statistics Cancer symptoms poster

Further Resources

Source	Resource
UNIVERSITY OF LIVERPOOL	research
pancreatic cancer action	Order free awareness material Living with pancreatic cancer/Type 3C diabetes Resources for Healthcare Professionals Pancreatic Cancer Facts Why is pancreatic cancer diagnosed late?
NICE National Institute for Health and Care Excellence	NICE NG12 Guidance

Further Resources

Source	Resource
NIH National Library of Medicine National Center for Biotechnology Information	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 Could diagnosis be upt o 3 years earlier
PANCREATIC CANCER ACTION NETWORK	Pancreatic cancer risk factors Diabetes and Pancreatic Cancer – Diet and Nutrition Early detection information and research

Further Resources

Source	Resource
QCancer®	Qcancer Calculator and guidsnce
MACMILLAN CANCER SUPPORT	Primary Care Top 10 Tips

Training

Source	Resource
GatewayC	Pancreatic Cancer – GatewayC Pancreatic cancer: tips to aid early recognition and referral - GatewayC
Pancreatic CANCER UK	Resources for GPs - Pancreatic Cancer UK
RCGP	Summary of Pancreatic Cancer: Early Diagnosis in General Practice | RCGP Learning