



Family History Checker

Pancreatic Cancer UK Webinar
November 2024



Agenda

- 01** Introduction
- 02** Inherited risk for pancreatic cancer
- 03** How healthcare professionals can refer
- 04** Family History Checker
- 06** How Cancer Alliances can support

What is the campaign?

- Early detection saves lives. While most cases of pancreatic cancer do not run in families, we know that around 1 in 10 pancreatic cancers are inherited.
- Pancreatic Cancer UK, supported by NHS England, have launched a new campaign to increase awareness of the inherited risk of pancreatic cancer.
- The campaign aims to increase referrals of people with inherited risk of pancreatic cancer to a national study known as the European Registry of Hereditary Pancreatic Diseases (EUROPAC), so they can receive regular monitoring.
- Pancreatic Cancer UK have developed a new simple online **Family History Checker** which allows people to check their eligibility and self-refer to the EUROPAC study.

Who is eligible for referral to EUROPAC?

Familial pancreatic cancer eligibility

- Two or more relatives of first-degree kinship (sibling, parent and grandparent) affected by pancreatic cancer.
- Three or more relatives affected by pancreatic cancer (on the same side of the family i.e., maternal, or paternal).
- Carrier of a known genetic mutation, including BRCA1, BRCA2, PALB2, CDKN2A (p16), ATM, Lynch syndrome, and one family member affected by pancreatic cancer.
- Carrier of Peutz-Jeghers.

Hereditary pancreatitis eligibility

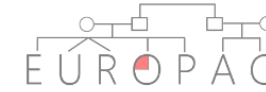
- Families with two or more relatives with idiopathic pancreatitis.
- Families with at least one case of pancreatitis and a confirmed causative mutation in the PRSS1 gene.

The registry criteria and does not determine eligibility for surveillance. A risk assessment is conducted as part of registration to determine eligibility for surveillance.

How can healthcare professionals refer?

1. Discuss the EUROPAC monitoring programme with patients who may have an inherited risk of pancreatic cancer and refer directly to EUROPAC through the regional navigators in your region.
2. Refer using the referral form and contact details for each regional navigator in England
3. Following a referral, the EUROPAC study team will contact the patient to undertake a full family history. A further risk assessment is then conducted as part of registration to determine eligibility for surveillance.

If you live in Scotland, Wales or Northern Ireland you can send referrals to Europac.Study@liverpoolft.nhs.uk.



The European Registry of Hereditary Pancreatic Diseases
 EUROPAC Office, 3rd Floor William Henry Duncan Building, 6 West Derby Street, University of Liverpool, L7 8TX
 Tel: +44 (0)151 795 1256 email: europac@liv.ac.uk www.europactrial.com

EUROPAC Referral Sheet			
Participant Details			
Participant Name		M/F	
NHS Number		Date of Birth	
Participant address		Post Code	
Participant Contact Number		Your Reference Number	
Referrer Details			
Referrer Name			
Date			
Referrer Email address			
Family History (Tick appropriate)			
2 or more First Degree Relatives with first degree kinship with pancreatic cancer (For example, parent and grandparent, parent and sibling, parent, and aunt/uncle etc.)			
3 or more cases of pancreatic cancer in the family			
1 or more cases of pancreatic cancer with an associated syndrome (BRCA1, BRAC2, ATM, PALB2, Lynch Syndrome/HPNCC, FAMMM/ Multiple Melanoma) Peutz-Jeghers Syndrome			
Two or more relatives with idiopathic pancreatitis			
Family history of pancreatitis and PRSS1 mutation			
Other:			
Is the patient aware that this is a study		Is patient happy to be contacted by the EUROPAC Team	
Referral Documents For genetics service only			
Family Pedigree	Yes	No	N/A
Lab Report	Yes	No	N/A
Confirmations of diagnosis	Yes	No	N/A

If you have any queries regarding eligibility, contact the EUROPAC Team via your Regional Navigator. The EUROPAC Study does take self-referrals, there is no referral sheet for this, patients simply contact the team.

Once complete please send the referral sheet to your area's navigator or Europac.Study@liverpoolft.nhs.uk

Potential routes to refer patients

Pancreatic cancer MDT

- MDT should consider whether an individual with pancreatic cancer or relatives maybe is eligible for registration during MDT discussion
- Individuals with pancreatic cancer are eligible for the registry only. Relatives of patients may be eligible for both registration and surveillance.

Genetic services

- Upon diagnosis of relevant genetic condition, ask relevant individuals about family history of pancreatic cancer or hereditary pancreatitis as appropriate.

GPs

- GP to discuss concerns and family history of pancreatic cancer.
- Discuss study with relevant individuals and refer onwards if individual would like to consider the study.

Inherited risk campaign

- 1 Development of an **online interactive self-referral tool** to identify and signpost eligible people to the EUROPAC surveillance programme
- 2 Development and **delivery of a national campaign to maximise awareness** of inherited risk and the availability of the surveillance programme among:
 - o Pancreatic Cancer UK existing patient and supporter audience
 - o Healthcare professionals, current patients and health bodies

This will in turn:

- Increase the number of people enrolled onto the EUROPAC registry
- Increase the number of people enrolled onto active surveillance for pancreatic cancer
- Shift the stage at diagnosis for pancreatic cancer and support the NHS England 75% early diagnosis ambition

Family History Checker

What does the platform look like?

While most cases of pancreatic cancer do not run in families, some can be inherited.

Find out if you and your family may be at higher risk of developing pancreatic cancer. You may be able to take part in a study which monitors people for pancreatic cancer.

Just answer a few quick questions to check your family risk today.

This is not a formal risk assessment and if you would like more information please visit the [family history section on our website](#).

Check my risk

13:01

We will ask you about blood relatives on the same side of your family. By this we mean relatives who are directly related to you and each other by birth. They should be **either** on your mother's side of the family, **or** your father's side of the family – not people on both sides. For example, your mother, your mother's parents, and your children.

We don't mean people who are part of your wider family but not directly related to you, like your step-father, or sister's partner.

Including yourself, how many relatives with pancreatic cancer have you had on the same side of the family?

More than one

13:01



13:01

People can self-refer to EUROPAC

Family History Checker



13:01

But based on the answers you provided, you and your family may be able to take part in a research study looking at the inherited risk of pancreatic cancer.

This is called the EUROPAC study. If you're eligible to take part, you may be able to have regular monitoring. This aims to spot any changes to your pancreas at an early stage.

So what next?

13:02

The EUROPAC study team take a detailed family history. They will then use that to work out your level of risk.

The EUROPAC team will discuss your risk with you in detail and whether you would benefit from monitoring. For many people, regular monitoring is not needed, as the level of risk is low.

There is not an age limit for the EUROPAC study, but in most cases screening starts from the age of 40.

If you fill out your contact details, we will share them with the EUROPAC study team. They will contact you by email with more information within **10 days**. We will also send you an email with the information we have given you today and links to other helpful resources.



13:02

Yes, please

13:04

What's your first name?

Type here...



13:04

Follow up information and support email – referral

Test: Your Family History Checker results



○ Pancreatic Cancer UK <donotreply@email.pancreaticcancer.org.uk>

Today at 15:27

To: ● Peter de Rosa



Your Family History Checker results

Dear Peter,

Thank you for completing our Family History Checker. [This email explains family history of pancreatic cancer, and what will happen next.](#)

Based on your answers in the Family History Checker, [you and your family may be able to take part in a study looking at the inherited risk of pancreatic cancer.](#) This is called the EUROPAC study. As part of this, you and your family may be able to have regular monitoring. This aims to spot any changes to the pancreas at an early stage.

[Find out more about EUROPAC](#)

[Why might my family and I have a higher risk of pancreatic cancer?](#)

What happens next?

The EUROPAC study team should contact you by email with more information about the study within 10 working days.

If you decide to sign up to the study, the EUROPAC team will take a detailed family history. They will use this to work out your and your family's exact risk. [They will discuss the risk with you in detail and whether you and your family would benefit from monitoring.](#) This process can take a few months. For many people, regular monitoring is not needed.

If you don't hear back from the EUROPAC study team within 10 days or would like more information, you can find their contact details on the [EUROPAC website](#). Unfortunately, we can't answer questions about how EUROPAC are processing your details.

If you still have any questions or worries about pancreatic cancer, you can contact us on our free Support Line. We are all specialist nurses, and are experts in pancreatic cancer. Although we won't have any information about your assessment with EUROPAC, we can provide support if you are concerned. Call us on [0808 801 0707](tel:08088010707) or [email us](#).

Warm wishes,



Nicci, Jeni, Rachel, Lisa, & Lynne
Pancreatic Cancer UK Specialist Nurses
nurse@pancreaticcancer.org.uk

Follow up information and support email – no referral

Test: Your Family History Checker results



Pancreatic Cancer UK <donotreply@email.pancreaticcancer.org.uk>

Today at 15:25

To: Peter de Rosa

[Find out more about the symptoms](#)

[View in browser](#)



Thank you for using our Family History Checker

Dear Peter,

Thank you for completing our Family History Checker.

Based on your answers, **you and your family do not have any of the main risk factors for inherited pancreatic cancer**. This means you and your family would not benefit from monitoring for pancreatic cancer.

This is because you told us that you:

- do not have more than one family member with pancreatic cancer on the same side of the family
- don't have a genetic condition that increases the risk of pancreatic cancer in the family
- do not have hereditary pancreatitis in the family.

People who have a risk of inherited pancreatic cancer would usually have one or more of these.

[Find out more](#)

Know the symptoms of pancreatic cancer

Remember you can still get pancreatic cancer, even if you don't have a family history. **Over 10,000 people are diagnosed a year in the UK**. Only around 1 in 10 pancreatic cancers run in families, and **most cases of pancreatic cancer are not inherited**. So make sure you know the symptoms.



Symptoms include:

- indigestion
- tummy and back pain
- changes to your poo
- unexplained weight loss
- loss of appetite
- jaundice (yellow skin or eyes and itchy skin).

How can healthcare professionals support the campaign?

1. Discuss the EUROPAC monitoring programme with patients who may have an inherited risk of pancreatic cancer and refer directly to EUROPAC through the regional navigators in your region.
2. You can also **visit Pancreatic Cancer UK's inherited risk resources hub** for more information about the campaign and to order patient and healthcare professional resources.
3. Promote and share the **Family History Checker** and download campaign resources to raise awareness among healthcare professionals and local populations.
4. Your patients can also check their eligibility and self-refer for the study using a simple **online Family History Checker**

Healthcare professional resources

Pancreatic Cancer UK Inherited Risk Resources Hub

- Healthcare professionals can visit the [Pancreatic Cancer UK Inherited Risk Resources Hub](#) for more information about the campaign and to order patient and healthcare professional resources.

Health professional information sheet

- Healthcare professionals can [download the healthcare professional information sheet which](#) has further information about the EUROPAC study and how to refer patients.



Pancreatic cancer inherited risk fact sheet

Pancreatic Cancer UK and EUROPAC are working together, supported by NHS England, to widen the roll out of pancreatic cancer surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis across England. As a healthcare professional, you have a central role in supporting this by referring patients who may have an inherited risk of pancreatic cancer to the national study – known as The European Registry of Hereditary Pancreatic Diseases (EUROPAC).

Pancreatic cancer has the lowest survival of all common cancers. **Over half of people diagnosed die within 3 months.** Early detection of pancreatic cancer, for example by identifying and monitoring people who are most at risk, could save thousands of lives every year.

Together we can detect early and save lives.

Surveillance is available to patients at higher risk

Around 1 in 10 pancreatic cancers are inherited.

NICE NG85 guidelines state that people with inherited pancreatic cancer risk should be monitored so that any changes to their pancreas can be detected at an early stage. The surveillance of people with an inherited risk of pancreatic cancer is available through the national study – known as The European Registry of Hereditary Pancreatic Diseases (EUROPAC).

How can I refer my patients?

As a healthcare professional, you should discuss the surveillance programme with patients who may have an inherited risk of pancreatic cancer and you can refer patients directly to EUROPAC through the regional navigators in your region.

You can find more information about the EUROPAC study, who is eligible and how to refer patients on our inherited risk resources hub:

pancreaticcancer.org.uk/inherited-risk-hub

Order printed campaign resources

Healthcare professionals can order a pack of resources to help raise awareness of the inherited risk of pancreatic cancer.


The pack contains:

- 2 A4 Family History Checker posters
- 10 A6 Family History Checker postcards
- 1 A4 Health professional information sheet

The pack of resources is available to order from the Pancreatic Cancer UK [website](https://www.pancreaticcancer.org.uk).

You can also download and print the following resources:

- [Family History Checker poster](#)
- [Health professional information sheet](#)





Is pancreatic cancer in your family?

Most cases of pancreatic cancer do not run in families. However, if more than one person in your family has been diagnosed with pancreatic cancer, you could be at higher risk. And we're here to support you. Detecting pancreatic cancer early could save your, or a loved one's, life.

Answer three quick questions to check your risk today. Scan the QR code or visit:

pancreaticcancer.org.uk/checker



Is pancreatic cancer in your family?

Most cases of pancreatic cancer do not run in families. However, if more than one member of your family has been diagnosed with pancreatic cancer, you could be at higher risk.

Social media campaign assets

Promote and share Pancreatic Cancer UK's Family History Checker on social media to raise awareness among healthcare professionals and local populations.

www.pancreaticcancer.org.uk/information/family-history-checker/

Social media assets:

Instagram, Facebook or LinkedIn

- [Download](#) Family History Checker asset (Option 1)
- [Download](#) Family History Checker asset (Option 2)

X

- [Download](#) Family History Checker asset (Option 1)
- [Download](#) Family History Checker asset (Option 2)

[Pancreatic Cancer UK's Family History Checker \(youtube.com\)](https://www.youtube.com/watch?v=...)

P Pancreatic
CANCER UK

Is pancreatic cancer in your family?

Answer three quick questions to check your risk today

pancreaticcancer.org.uk/history-checker

P Pancreatic
CANCER UK

1 IN 10 cases of pancreatic cancer run in families

pancreaticcancer.org.uk/history-checker

Example posts for social media

Facebook, Instagram or LinkedIn

Pancreatic cancer has the lowest survival of any common cancer. Detecting this devastating disease early could save your, or a loved one's, life. Most cases of pancreatic cancer do not run in families, however if more than one member of your family has been diagnosed with the disease, you could be at higher risk.

Pancreatic Cancer UK have launched a new Family History Checker, supported by NHS England, which allows you to check your family risk by answering three quick questions.

Find out if you and your family may benefit from regular monitoring which could save your life <https://bit.ly/3MB6ALh>
#PCUKHistoryChecker

X

1 in 10 cases of #PancreaticCancer run in families. @PancreaticCanUK's Family History Checker can help identify people with a family history of pancreatic cancer who may benefit from regular monitoring that could save their lives <https://bit.ly/3MB6ALh> #PCUKHistoryChecker



The graphic is a vertical rectangle with a purple background. At the top left is the Pancreatic Cancer UK logo. The main text is in a large, bold, orange font. Below the text is a white icon of a family tree with a heart in the center. At the bottom is the website URL in white text.

Pancreatic
CANCER UK

Is pancreatic cancer in your family?

Answer three quick questions to check your risk today



pancreaticcancer.org.uk/history-checker

How can Cancer Alliances support the campaign?

1. Continue to work to set up and support referrals into EUROPAC via regional navigators, as requested by NHS England.
2. Promote and share the [Family History Checker](#) and download campaign resources to raise awareness among healthcare professionals and local populations.
3. Share the [Pancreatic Cancer UK Inherited Risk Resources Hub](#) via healthcare professional channels and networks.

Pancreatic Cancer UK are keen to explore new ways to promote the campaign, including improving reach to diverse communities, setting up automatic GP text services or promoting case studies in local media.

THANK YOU



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CANCER UK