

Frequently Asked Questions

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Inherited risk of pancreatic cancer

What proportion of pancreatic cancers are inherited?

Around **1 in 10 pancreatic cancers are inherited**. This includes people who have a family history of pancreatic cancer, people with hereditary pancreatitis or rare genetic conditions such as Lynch syndrome or Peutz-Jeghers. NICE NG85 guidelines state that people with an inherited pancreatic cancer risk should be monitored so that any changes to their pancreas can be detected at an early stage.

Does pancreatic cancer run in families? Can pancreatic cancer be inherited?

Most cases of pancreatic cancer are not inherited. However, around 1 in 10 cases of pancreatic cancer run in families. This includes people who have a family history of pancreatic cancer, people with hereditary pancreatitis or rare genetic conditions such as Lynch syndrome or Peutz-Jeghers.

Having a family history of pancreatic cancer does not mean an individual will definitely get pancreatic cancer. It is possible for families to have several cases of pancreatic cancer just by chance. But the more cases there are in a family, the more likely it is that pancreatic cancer runs in the family.

Who should be referred for pancreatic cancer surveillance?

NICE NG85 guidelines state that people with an inherited pancreatic cancer risk should be monitored so that any changes to their pancreas can be detected at an early stage. A national study called EUROPAC is available to assess people who have an inherited risk of pancreatic cancer. Healthcare professionals can refer anyone they believe to be at risk directly to EUROPAC for assessment and surveillance.

People with familial pancreatic cancer and hereditary pancreatitis are among those eligible to take part in EUROPAC study .

Familial pancreatic cancer eligibility includes any one of the below:

- Two or more relatives of first-degree kinship (e.g., 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 includes any one of the below:

- 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

Please note that the EUROPAC registry criteria does not determine eligibility for surveillance. A further risk assessment is conducted as part of registration to determine eligibility for surveillance.

The EUROPAC study

What is the EUROPAC study?

The European Registry of Hereditary Pancreatic Diseases (EUROPAC) is a registry for families with a history of familial pancreatic cancer and hereditary pancreatitis. EUROPAC collects data on family histories and samples for research.

EUROPAC also assesses an individual's lifetime risk of developing pancreatic cancer based on their family history and offers surveillance programmes for people who are at higher risk.

You can read more about the [EUROPAC study](#).

How should healthcare professionals refer patients to EUROPAC?

NHS England is supporting the national roll out of pancreatic cancer surveillance through investment into regional navigators who will support and facilitate the enrolment of people onto the EUROPAC study. These specialised professionals are dedicated to supporting individuals from the point of registration through to their ongoing surveillance.

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 them directly to EUROPAC through the regional navigators in your region. The referral form and contact details for each regional navigator in England can be found [here](#). If you live in Scotland, Wales or Northern Ireland or you are not sure who to contact, please send the referral to europac@liverpool.ac.uk.

The referral to EUROPAC does not replace existing pathways for urgent referrals if a GP suspects a patient has symptoms of pancreatic cancer.

What happens following referral to EUROPAC?

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. EUROPAC typically aims to contact people within 10 days (about 1 and a half weeks). However, response times might be longer due to the campaign just being launched and the potential for a higher volume of inquiries.

For people who are not considered to be at a higher lifetime risk of developing pancreatic cancer, the EUROPAC team will write to them to let them know this and reassure them that there is no reason to be concerned by their family history. Details on an individual and their family will be kept on the EUROPAC database and patients should contact EUROPAC again if there are any new developments in their family. At this point, they will determine whether this has any significant impact on their lifetime risk of developing pancreatic cancer.

People who are identified as having a higher lifetime risk of pancreatic cancer, will be offered the chance to take part in a surveillance programme with a structured, personalised surveillance plan. Surveillance is offered on an annual basis and uses a combination of investigations and blood tests (including CT, EUS, MRI and blood tests). Individuals on the surveillance programme will be able to contact the EUROPAC team with any questions in relation to pancreatic cancer and their risk.

Full patient information on what is involved in the EUROPAC registry and the EUROPAC screening programme can be found [here](#).

The EUROPAC study (continued)

Will all patients referred to EUROPAC be offered active surveillance?

No. 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.

For people who are not considered to be at a higher lifetime risk of developing pancreatic cancer, the EUROPAC team will write to them to let them know this and reassure them that there is no reason to be concerned by their family history. Details on an individual and their family will be kept on the EUROPAC database and patients should contact EUROPAC again if there are any new developments in their family. At which point they will determine whether this has any significant impact on their lifetime risk of developing pancreatic cancer.

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What is the eligibility criteria for active surveillance?

Following referral, the EUROPAC team will contact the patient to undertake a full family history. A further risk assessment is then conducted as part of the registration to determine eligibility for surveillance. Each week, their team reviews the information in a meeting to assess people's individual risk of developing pancreatic cancer.

Who will carry the surveillance of those eligible?

Everyone who is eligible for active surveillance and offered the opportunity to take part in the screening will be seen in the EUROPAC clinic at the Royal Liverpool Hospital or offered a telephone appointment. At this appointment, they will discuss personal and family history again and talk through the rationale and process of screening.

EUROPAC work with several collaborators across the UK who can facilitate local screening. If appropriate, patients can be referred to a local screening centre who will offer you an appointment to meet them before screening.

What is the age limit for active surveillance?

People at any age can join the EUROPAC registry – which is the national database of people with a family history of pancreatic cancer and hereditary pancreatitis. Individuals under the age of 18 will require a parent or guardian as part of the registration process.

There is not an age limit for the active surveillance. However, in most cases active surveillance would only start from the age of 40.

What existing guidelines or evidence is there that suggests that this should be implemented?

[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.

Pancreatic Cancer UK Family History Checker

What is the Family History Checker?

The [Family History Checker](#) is a new online platform that asks people three quick questions about their family history of pancreatic cancer and genetic conditions.

This allows people and their families affected by pancreatic cancer to self-assess if they may have an inherited pancreatic cancer risk and if they may benefit from taking part in a study looking at the inherited risk of pancreatic cancer.

If the Family History Checker shows that a person or family may have an inherited risk of pancreatic cancer, the individual can then self-refer onto a study looking at the inherited risk of pancreatic cancer. This is known as the EUROPAC study. Following this self-referral, the EUROPAC study team will contact the individual to undertake a full family history and risk assessment to confirm if the individual has an inherited risk for pancreatic cancer.

Based on this family history and risk assessment, the EUROPAC clinical team will determine if a person has inherited pancreatic cancer risk and if they would benefit from regular monitoring to spot any changes to their pancreas at an early stage

What eligibility criteria does the Family History Checker use for self referral?

We have worked closely with the EUROPAC team to agree which people can self-refer to the EUROPAC study. The Family History Checker allows the following people to self-refer to EUROPAC.

- Families with more than one family member with pancreatic cancer on the same side of the family
- Families with specific genetic condition in the family
- Families with hereditary pancreatitis

Does the Family History Checker assess patients' risk for pancreatic cancer?

No. The Family History Checker does not attempt to assess an individual's specific risk for developing pancreatic cancer or determine if a person needs to have regular monitoring. The Family History Checker aims to identify people and families who may have inherited pancreatic cancer risk and may benefit from taking part in a study looking at the inherited risk of pancreatic cancer.

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Does the Family History Checker cover symptoms for pancreatic cancer?

No. The Family History Checker does not cover the signs or symptoms of pancreatic cancer. The Family History Checker does not predict an individual's current risk of having or developing pancreatic cancer right now.

Remember the symptoms for pancreatic cancer are:

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

The referral to EUROPAC does not replace existing pathways for urgent referrals if a GP suspects a patient has symptoms of pancreatic cancer.

Pancreatic Cancer UK Family History Checker (continued)

Will this cause anxiety in patients and families affected by pancreatic cancer?

We understand that learning about inherited risk for pancreatic cancer can be unsettling and uncertain for patients and families affected by pancreatic cancer.

Through the development process, we have ensured that the Family History Checker and wider campaign strikes a balance between raising awareness of inherited risk and providing reassurance and support for people and families affected by pancreatic cancer. We have undertaken extensive testing with people affected by pancreatic cancer on the approach, messaging and user experience and feasibility of the Family History Checker.

It is important to remember that most cases of pancreatic cancer are not inherited. Therefore, most people who use the Family History Checker will be informed that they do not have an inherited pancreatic cancer risk and would not benefit from taking part in a study looking at the inherited risk of pancreatic cancer. For these people, our aim is to provide reassurance that they do not have an inherited pancreatic cancer risk.

How was the Family History Checker developed and who was involved?

We have undertaken extensive testing with people affected by pancreatic cancer and healthcare professionals. This has involved focus groups with people who have a lived experience of pancreatic cancer and healthcare professionals on the approach and messaging. It has also included extensive input from the EUROPAC clinical team to determine who can self-refer to the EUROPAC study.

We have also undertaken user testing with people and families affected by pancreatic cancer on the user experience, acceptability, and feasibility of the Family History Checker.

How long will it take for EUROPAC to respond?

EUROPAC is working hard to reach everyone as quickly as possible. EUROPAC typically aims to contact people within 10 days (about 1 and a half weeks) of receiving a self-referral from the Family History Checker. However, response times might be longer due to the campaign just being launched and the potential for a higher volume of inquiries.

Unfortunately, Pancreatic Cancer UK cannot answer questions about individual cases or the processing of patient details once the referral to the EUROPAC team has happened.

Pancreatic Cancer UK, NHS England and EUROPAC will work together to continue to monitor waiting times.

Where should I refer a patient if they contact me asking about the Family History Checker or EUROPAC?

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.

The referral form and contact details for each regional navigator in England can be found [here](#). If you live in Scotland, Wales or Northern Ireland or you are not sure who to contact, please send the referral to europac@liverpool.ac.uk.

Where can I find out more information about the Family History Checker and EUROPAC?

You can visit our healthcare professional [inherited risk resources hub](#) for more information about the EUROPAC study, who is eligible, how to refer patients, and for patient resources.

Pancreatic Cancer UK campaign on inherited risk

What is the purpose of the campaign on pancreatic cancer inherited risk?

Pancreatic Cancer UK are working together with EUROPAC, supported by NHS England to deliver a national campaign to maximise awareness of the inherited risk of pancreatic cancer and the availability of the EUROPAC surveillance programme. The campaign also aims to help people assess if they may have an inherited pancreatic risk through the Family History Checker, and for them to see whether they would benefit from having a full assessment with the EUROPAC clinical team.

This campaign will initially be targeted at our supporters and people who currently use our services, as well as healthcare professionals.

How long will this campaign last?

The campaign will launch on the 11th September and run until the 10th March 2025.

Are the NHS involved in this campaign?

We have been supported by NHS England to deliver the Family History Checker and the national campaign to raise awareness of the inherited risk of pancreatic cancer and the availability of the EUROPAC surveillance programme.

Will this campaign increase demand on primary care?

If the Family History Checker shows that a person or family may have an inherited risk of pancreatic cancer, the individual can then self-refer onto a study looking at the inherited risk of pancreatic cancer. This is known as the EUROPAC study.

The Family History Checker will not signpost people to primary care or other parts of the health system.

How can healthcare professionals support the campaign?

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 them directly to EUROPAC through the regional navigators in your region. The referral form and contact details for each regional navigator in England can be found [here](#). If you live in Scotland, Wales or Northern Ireland or you are not sure who to contact, please send the referral to europac@liverpool.ac.uk.

Your patients can also check their eligibility and self-refer onto the EUROPAC study using our simple online **[Family History Checker](#)**.

Healthcare professionals can also share and promote the wider campaign assets and materials to raise awareness of the inherited risk of pancreatic cancer and the EUROPAC surveillance programme. You can visit our healthcare professional [inherited risk resources hub](#) for more information about the EUROPAC study, who is eligible, how to refer patients, and for patient resources.