# 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**

Pancreatic CANCER UK

## Who is eligible for surveillance?

Someone with more than one family member diagnosed with pancreatic cancer could be at higher risk. People with hereditary pancreatitis or rare genetic conditions such as Lynch syndrome or Peutz-Jeghers can also be at risk.

People with familial pancreatic cancer and hereditary pancreatitis are among those eligible to take part in the EUROPAC registry. The registry is a national database of people with a family history of pancreatic cancer and hereditary pancreatitis, which supports several research studies to better understand pancreatic cancer. Upon registration to the registry, a further risk assessment is conducted to determine which people are at higher risk and will be offered surveillance.

### 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.

## What happens following referral?

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.

People who are identified as being at higher lifetime risk of pancreatic cancer, will be offered 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 also be able to contact the EUROPAC team for any questions in relation to pancreatic cancer and their risk.

## Pancreatic Cancer UK Family History Checker

Your patients can also check their eligibility and self-refer to the EUROPAC study using our simple online Family History Checker on the QR code below. This has been created by Pancreatic Cancer UK and EUROPAC, supported by NHS England.

For more information about the EUROPAC study and for patient resources, you can visit our healthcare professional **inherited risk resources hub** on the link below:

**pancreaticcancer.org.uk/inherited-risk-hub**

**Scan the QR code or visit: pancreaticcancer.org.uk/hp-checker**