The European Registry of Hereditary Pancreatic Diseases
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EUROPAC Health Care Professional Information Sheet

Background

Around 10% of pancreatic cancer cases are linked to these inherited factors. These occur in families with a history of either pancreatic cancer or hereditary pancreatitis or who carry an at-risk genetic mutation predisposing to these conditions. NICE guidance (NG85) recommends surveillance for people with an inherited high-risk ideally to detect pancreatic cancer earlier.
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 we provide surveillance to individuals.
NHS England is working with EUROPAC to provide a route from the NHS into their national surveillance program run at NHS Trusts across the country for people who may be at high risk of pancreatic cancer.

What is EUROPAC?

The European Registry of Hereditary Pancreatic Diseases (EUROPAC) is in the first instance a registry for families with histories of Familial Pancreatic Cancer and Hereditary Pancreatitis. We register these individuals and collect their family history as well as samples for research purposes.

The EUROPAC study also runs surveillance programs for individuals who are deemed high-risk. Using the family history individuals provide we can assess their lifetime risk of developing pancreatic cancer. Surveillance is offered on a yearly basis, and we use a combination of CT, EUS, MRI and blood tests.

We are an open-ended study with no confirmed end date supported by The University of Liverpool, Pancreatic Cancer UK, NHS England, NIHR, and Cheshire and Merseyside Cancer Alliance.

What are the benefits of joining the EUROPAC study?

For those who join the registry, they will be contributing to research into pancreatic cancer. Individuals who join the registry will be able to provide blood and urine samples that will be used across several studies to better understand pancreatic cancer. As a part of registration, individuals will have a formal risk assessment for pancreatic cancer including the risk of their relatives. and may be offered surveillance.

Those who are eligible and wish to take part in our surveillance programme will be able to access a structured surveillance program tailored to them and their risk. Their risk will be reassessed on an annual basis including their family members. Individuals on the surveillance program will also have access to the EUROPAC team for any questions in relation to pancreatic cancer and their risk.

Who is eligible?

The EUROPAC study has two cohorts, familial pancreatic cancer, and Hereditary Pancreatitis.

Familial pancreatic cancer:

- 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 and one family member affected by pancreatic cancer. BRCA1, BRAC2, ATM, PALB2, Lynch Syndrome/HPNCC, FAMMM/ Multiple Melanoma
- Carrier of Peutz-Jeghers.

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

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

Potential routes from the NHS into the EUROPAC study

We have set out potential referral routes into EUROPAC, indicating where you may typically expect to find individuals who may be eligible for surveillance and the follow-up action. Anyone fitting the below criteria should be referred to the EUROPAC team for consideration, no matter what the route.

If you have any queries regarding eligibility, you can discuss this with your region's EUROPAC Surveillance Navigator.

Route	Likely individuals via this route	Eligibility criteria	Action
Pancreatic cancer MDT	Individuals newly diagnosed with pancreatic cancer and one relative affected by pancreatic cancer. NOTE: These individuals are for registration only and for relatives' consideration for surveillance.	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 Peutz–Jeghers syndrome Individuals with two first-degree relatives (over two generations) with pancreatic cancer with first-degree kinship, e.g., sibling, parent and grandparent or three or more relatives affected (on the same side of the family).	MDT should consider whether an individual 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. Discuss the study with the individual and refer onwards if they would like to consider joining the registry. If yes, fill out the referral form and send it to your regional navigator. If they would like to consider further or discuss with relatives, provide details of the EUROPAC website, noting they can also self-refer. At the first appointment, the navigators will advise on further communications and resources for wider family members.
Genetic services	Individuals newly testing positive with BRCA1, BRCA2, PALB2, CDKN2A (p16), ATM, Lynch Syndrome (mismatch repair gene [MLH1, MSH2, MSH6 or PMS2] mutations), PSSR1 or Peutz–Jeghers syndrome.	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 PRSS1 mutation and hereditary pancreatitis Peutz–Jeghers syndrome	Upon diagnosis of relevant genetic condition, ask relevant individuals about family history of pancreatic cancer or hereditary pancreatitis as appropriate. Consideration of referral to the EUROPAC study is already included in UKCGG guidance for those with BRCA1/2 and Lynch Syndrome, so this is aligned with current guidance. Discuss study with relevant individuals and refer onwards if individual would like to consider the study. If yes, fill out referral form and send to regional navigator. If they would like to consider further, provide details of EUROPAC website, noting they can also self-refer.
GPs	Individuals who are concerned about family history of pancreatic cancer or who use of the upcoming Pancreatic Cancer UK Eligibility Checker tool.	Individuals with two first-degree relatives with pancreatic cancer with first-degree kinship, e.g., parent and grandparent or three or more family relatives affected (on the same side of the family). Lynch Syndrome and at least one family member affected by pancreatic cancer.	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. If yes, fill out referral form and send to regional navigator. If they would like to consider further, provide details of EUROPAC website, noting they can self-refer. As per the NHS Genomic Test directory guidelines, individuals qualifying these criteria should be referred to your local genetics. This can be done alongside a referral to the EUROPAC team.

Self-referral to EUROPAC

We welcome self-referrals from individuals concerned about family history. Individuals can get in touch with EUROPAC through the 'contact us' section of the EUROPAC website, emailing europac@liv.ac.uk or calling +44 (0)151 795 1256.

Useful links

- EUROPAC website europactrial.com
- EUROPAC participant Information sheets for familial pancreatic cancer and hereditary pancreatitis https://www.europactrial.com/familial-pancreatic-cancer https://www.europactrial.com/hereditary-pancreatitis
- NICE guidance 85 (relevant sections for surveillance: 1.1.13 – 1.1.18) https://www.nice.org.uk/guidance/ng85