EUROPAC

NHS
North East London
Cancer Alliance

European Registry of Hereditary Pancreatic Diseases (EUROPAC)

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 how they 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.

Who should be referred to EUROPAC?

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.
- 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

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**.

Patients can also check their eligibility and self-refer for the study using a simple online **Family History Checker**

Key Question for Patients

Ask patients whether they have a family history of pancreatic cancer.

Review responses as per the referral criteria on the next page.

Further Information & Resources

- North East London Cancer Alliance webpage
- EUROPAC Referral Form
- SSCA EUROPAC Toolkit
- SNOMED codes:
  - Family history of malignant neoplasm of pancreas is 429000004
  - Family history of disorder of the pancreas is 430685007

European Registry of Hereditary Pancreatic | Diseases (EUROPAC) - Referral Routes

Route	Individuals via this route	Eligibility criteria	Action
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).	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 referred to the EUROPAC team.
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 grand-parent or three or more relatives affected	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, 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.