



THE FOLLOW-ON PARTICIPANT JOURNEY

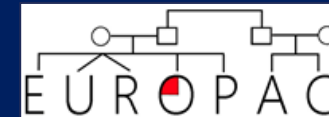
SUPPORTING PEOPLE
WITH AN INHERITED RISK
OF PANCREATIC CANCER

Annabelle Boughey
EUROPAC Operations Manager

Wednesday 27th November 2024

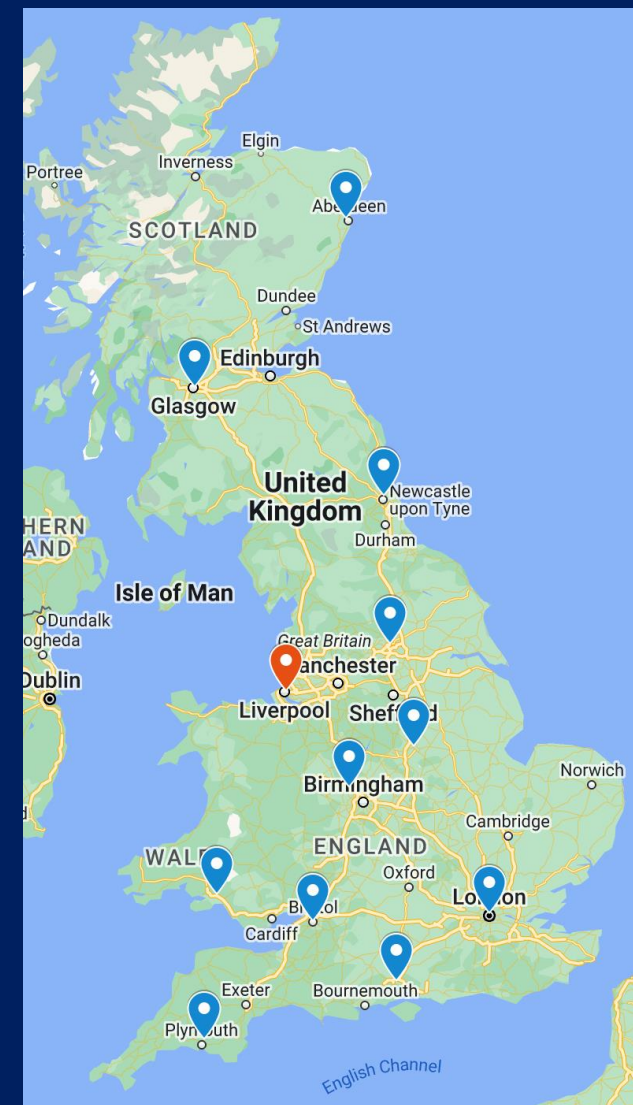
Institute of Systems,
Molecular and
Integrative Biology

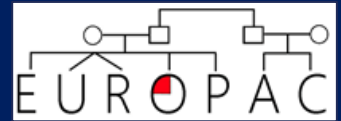




BACKGROUND

- **EUROPAC was set up in 1996 in response to the perception that pancreatic cancer was more common in some families than in the general population.**
- **We identified that some families had what is described as an “autosomal dominant predisposition”.**
- **EUROPAC set out to develop surveillance methods to identify pre-malignant lesions of the pancreas or pancreatic cancer at an early stage (T1/T2). We aim for early detection as opposed to early diagnosis so we can act on pre-malignant lesions rather than cancers. Upon detection of such a lesion prophylactic surgery is offered.**
- **We receive new referrals from all over the UK and now provide surveillance to over 700 participants a year who all have an increased lifetime risk of developing pancreatic cancer.**





**EUROPACS AIM IS TO PROVIDE
TARGETED AND TAILORED
PANCREATIC CANCER SURVEILLANCE**

REGISTRATION

PATHWAY

Referral

EUROPAC
Surveillance Navigator

Registration
documents

Added to the
database

MDT
meeting

Eligible for surveillance

Ineligible

Ineligible

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@liverpool.ac.uk www.europactrial.com

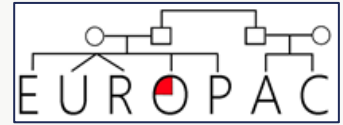
EUROPAC Referral Sheet

Participant Details			
Participant Name		SEX	
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, BRCA2, ATM, PALB2, Lynch Syndrome, HPS2CC, FAMMM, Multiple Melanoma) Peutz-Jeghers Syndrome			
Two or more relatives with idiopathic pancreaticitis			
Family history of pancreatitis and PDS1 mutation			
Other:			
Is the patient aware that this is a study?	Is patient happy to be contacted by the EUROPAC Team		
Referral Documents For assisting research only:			
Family Prodiges	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 EuropeStudy@liverpool.ac.uk

Page 1 of 1
IRAS ID: 248009
Version 2.0 Dated 08/09/2023

LIVERPOOL University of
Pancreatic Cancer UK



Referral Routes

Primary Care

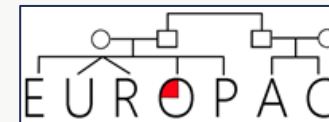
Secondary Care

Genetics

Self Referral

Pancreatic Cancer UK
Family History Checker

- We accept all kinds of referrals.
- The main referral route is the pancreatic cancer UK family history checker.
- The EUROPAC team triage all referrals and feed back to the referrer of ineligible referrals



REGISTRATION

PATHWAY

Referral

EUROPAC
Surveillance Navigator

Registration
documents

Added to the
database

MDT
meeting

Eligible for surveillance

Ineligible

Ineligible

The image shows three overlapping documents from the EUROPAC registry. The top document is the 'Participant Information Sheet' (Version 5.0 dated 12/01/2023), which includes background information and a consent form. The middle document is the 'EUROPAC Study Questionnaire of Familial Pancreatic Cancer', which asks for personal and medical history. The bottom document is the 'Consent form' for the EUROPAC registry of Familial Pancreatic Cancer, signed by Professor Christopher Halloran. The documents are branded with the EUROPAC logo and contact information for the Cancer Research Centre in Liverpool.

- All eligible referrals are sent a registration pack including a consent form to take part.
- We take a detailed family history as well as a previous medical history of the individual.
- We also take samples for research purposes.
- Individuals do not have to return their registration pack, participation is voluntary.

REGISTRATION

PATHWAY

Referral

Ineligible

EUROPAC Surveillance Navigator

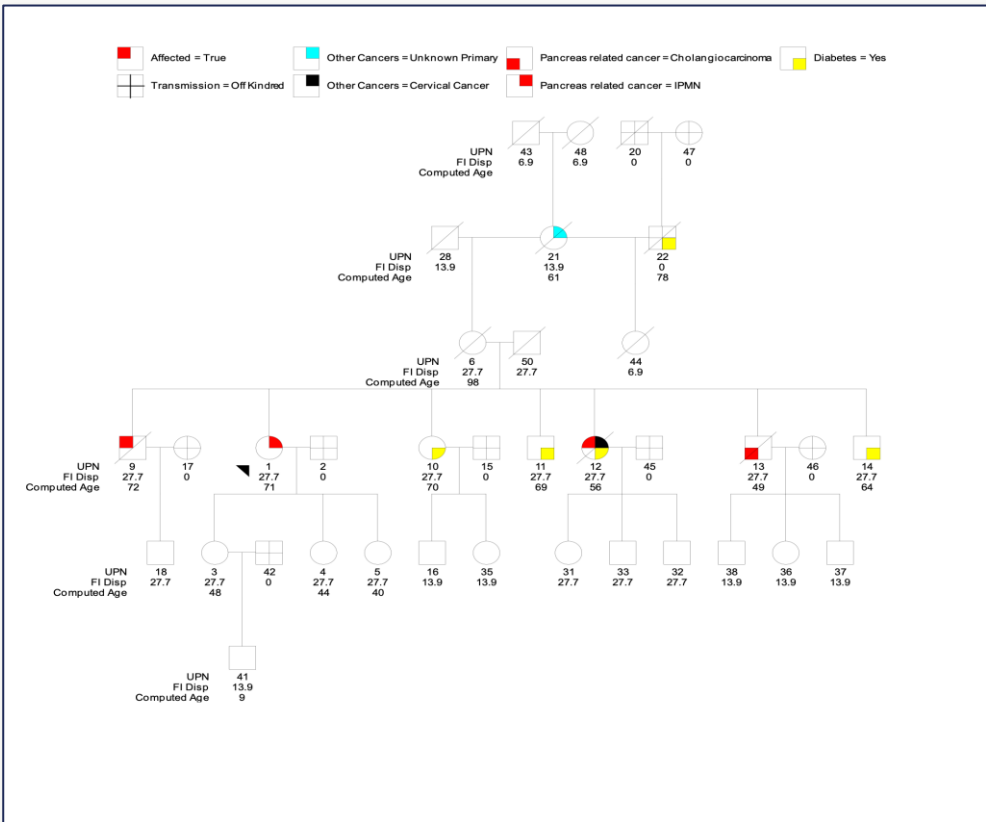
Registration documents

Added to the database

Ineligible

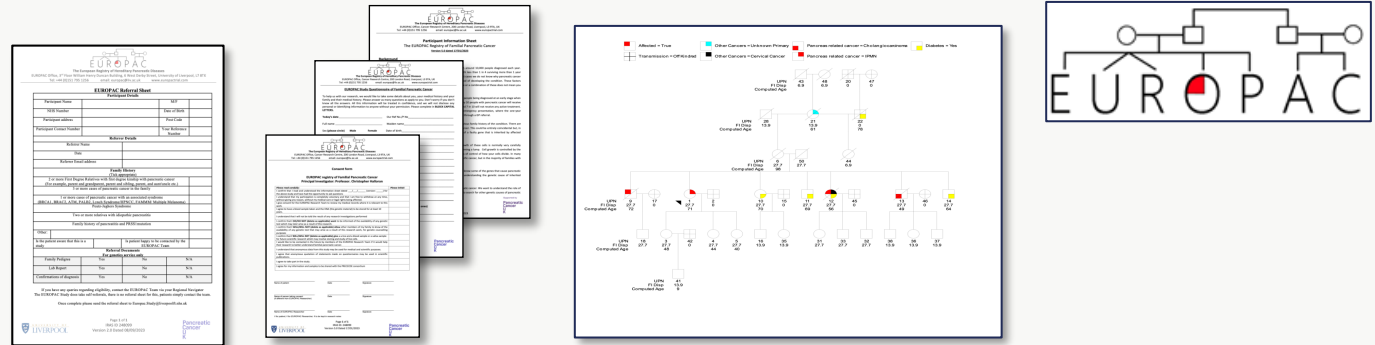
MDT meeting

Eligible for surveillance

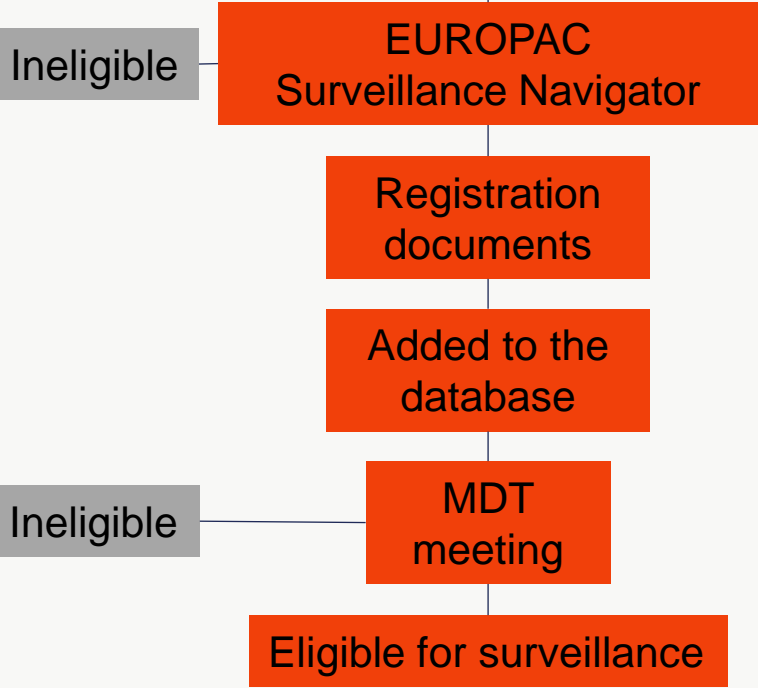


- Returned registration packs allow the navigator to build a family pedigree on our database (family tree).
- This allows us to determine a family's risk.
- The EUROPAC Team also confirm all cases of pancreatic cancer at this stage.

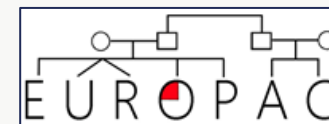
REGISTRATION PATHWAY



Referral

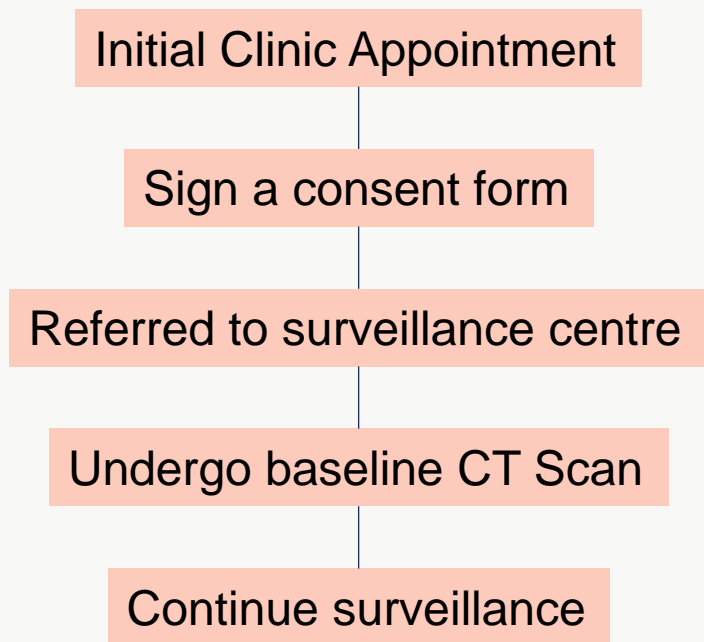


- All the above information is then collated by the team and brought to the EUROPAC MDT.
- This meeting involves both the clinical study lead and the scientific study lead. Relevant principal investigators also join from across the country.
- The whole family is discussed as well as each individual risk.
- A surveillance outcome is decided, and the team will feed this information back to the individual.



- Surveillance is started from the age of 40 unless the family member affected by pancreatic cancer is younger than 50.
- Peutz-Jeghers Surveillance is started at the age of 20.
- All surveillance investigations are optional, and participants can take part in as many or as little as they wish.

SURVEILLANCE PATHWAY



Surveillance for Familial Pancreatic Cancer Individuals

Surveillance Intensity		EUS Frequency	MRI Frequency
STANDARD	Germline mutation <u>or</u> risk score >30	Every 1 Year	Every 3 Years
ENHANCED	Germline mutation <u>and/or</u> risk score >60	eMRI and EUS every year	

Surveillance for Hereditary Pancreatitis Individuals

Surveillance Intensity		CT Frequency	MRI Frequency
STANDARD	No Diabetes No Smoking No ethanol	Every 2 years	-
ENHANCED	Diabetes <u>or</u> Smoking <u>or</u> Ethanol	Alternate 2 years	

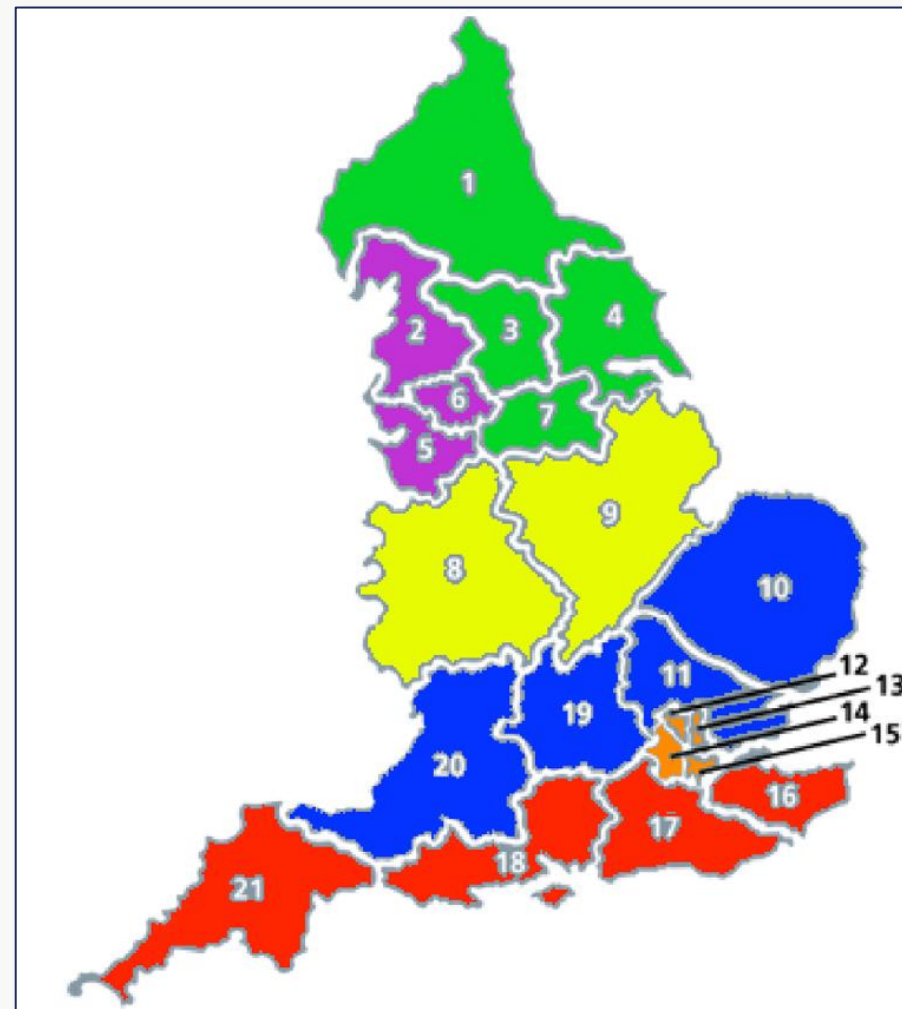
A baseline CT scan is performed in the first year; to check the individual does not already have cancer and to be used to refer to over the time the individual is under surveillance.

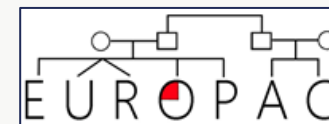
NAVIGATOR

THE ROLE

The EUROPAC Surveillance Navigators work closely with their nominated cancer alliances to increase awareness of EUROPAC and subsequently referrals into the program.

They are responsible for the management of individuals from the EUROPAC registration process through to the point of Surveillance, using specialist access to both the EUROPAC database and NHS systems to navigate and streamline the surveillance experience.





EUROPAC

NAVIGATORS

Liam Royle

Northern Cancer Alliance
West Yorkshire and Harrogate
Cancer Alliance
Humber, Coast and Vale Cancer
Alliance
South Yorkshire and Bassetlaw
Cancer Alliance

Kayleigh Jevons

Lancashire and South Cumbria
Cancer Alliance
Cheshire and Merseyside Cancer
Alliance
Greater Manchester Cancer
Alliance

Isobel Quinn

West Midlands Cancer Alliance
East Midlands Cancer Alliance

Eleri Hughes

East of England Cancer Alliance
Thames Valley Cancer Alliance
Somerset, Wiltshire, Avon and
Gloucestershire Cancer Alliance

Beata Gubacsi

Kent and Medway Cancer Alliance
Surrey and Sussex Cancer Alliance
Wessex Cancer Alliance
Peninsula Cancer Alliance

Emma Crowe

North Central London Cancer
Alliance
North East London Cancer Alliance
RM Partners
South East London Cancer Alliance



THANK YOU

We are the projects
that make headlines
And people that
make history

We are the original redbrick



CONTACT

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

