

# PancreOs Registry

## Pancreatic Cancer Overall Survival EUROPE

### Kick-off meeting

### CNIO, March 17<sup>th</sup>, 2016

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**PANCREATIC CANCER EUROPE**  
The European Multi-Stakeholder Platform on Pancreatic Cancer

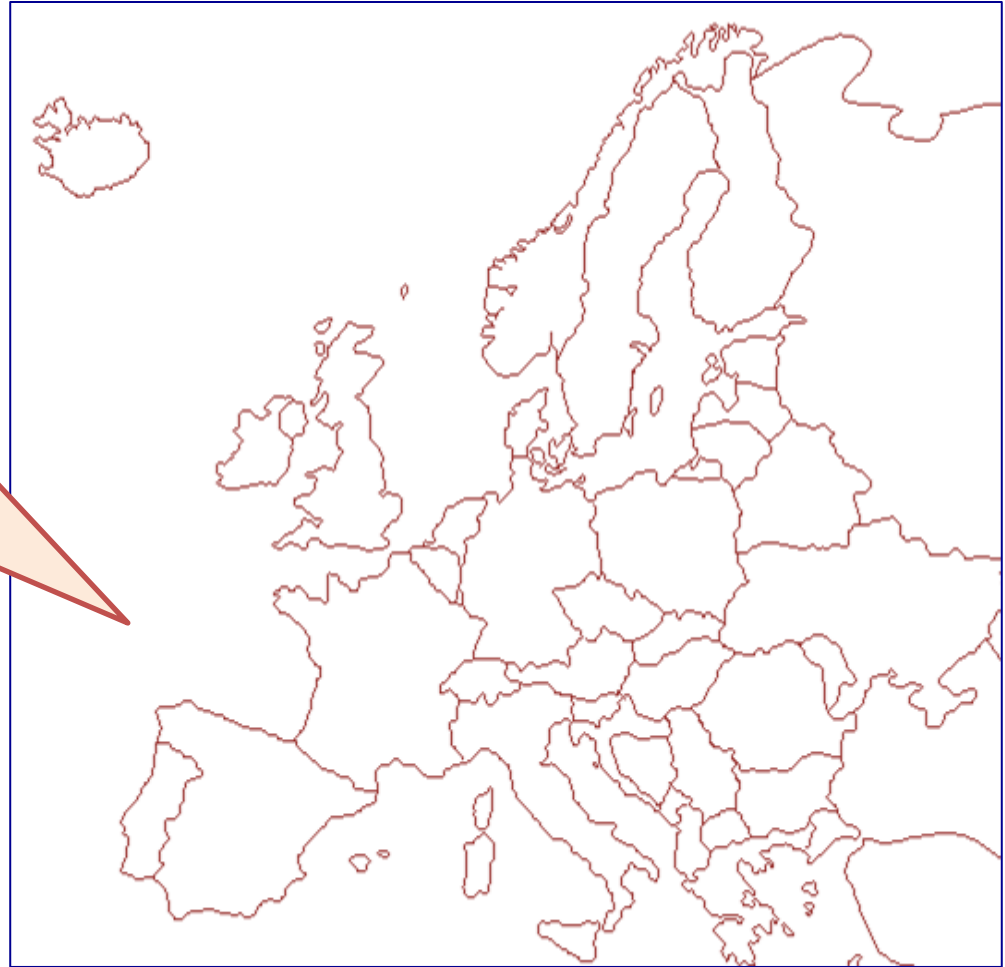


**cost**  
EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY



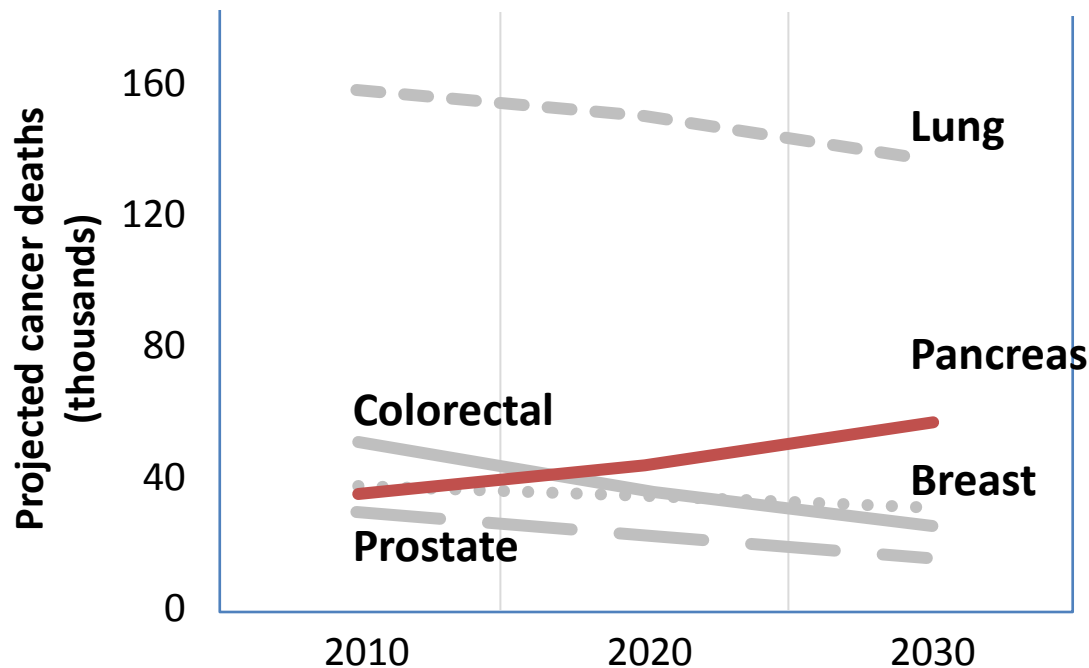
# Around 100 000 people each year in Europe die with a diagnosis of pancreatic cancer in less than 1 year

**103 845 patients**  
affected by pancreatic  
cancer in Europe<sup>23</sup>



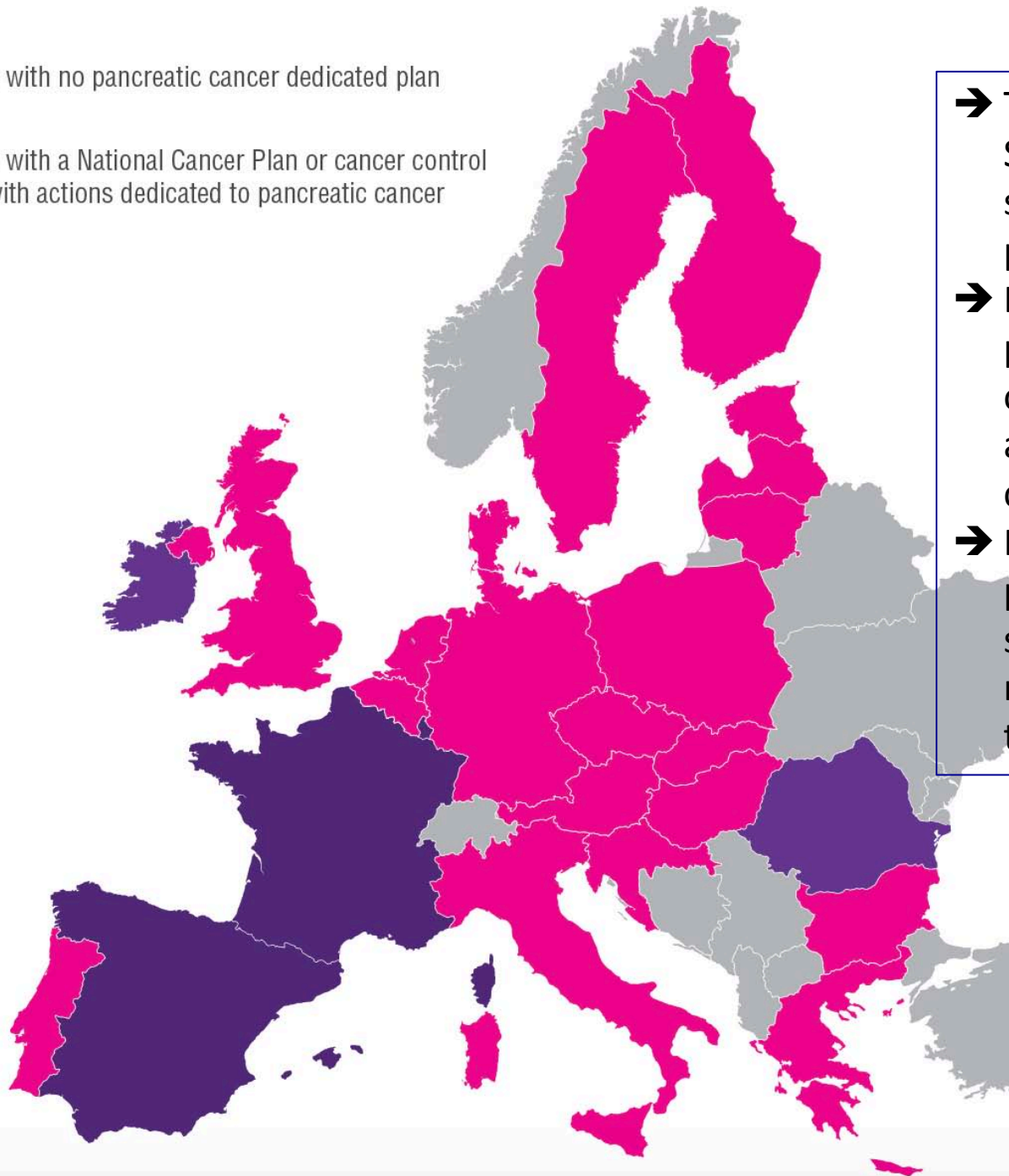
# Pancreatic cancer will be responsible for more deaths than breast or CRC cancer by 2030

US mortality rates of pancreatic cancer compared with other diseases<sup>25</sup>



25. Pancreatic Cancer action network. 2012. The alarming rise of pancreatic cancer deaths in the United States: Why we need to stem the tide today. Based on Rahib et al, Cancer Res 2014

- Countries with no pancreatic cancer dedicated plan
- Countries with a National Cancer Plan or cancer control policies with actions dedicated to pancreatic cancer



- There is no Member State with a national strategy dedicated to pancreatic cancer.
- In cancer control plans, specific actions on pancreatic cancer are included in only 5 countries.
- In 7 countries, pancreatic cancer is simply mentioned, mostly in mortality trends.



# PANCREATIC CANCER EUROPE

The European Multi-Stakeholder Platform on Pancreatic Cancer

- Pancreatic Cancer Europe is a European multi-stakeholder platform which aims at bringing together experts from all over Europe including academics, physicians, politicians, patient groups, journalists and industry with a common interest and willingness to improve care for patients with pancreatic cancer.
- Initiated by 4 MEPs from 3 different Member States and 3 different political groups, launched in July 2014 & co-signed by 32 additional MEPs
- On the last World Pancreatic Cancer Day, the European Multi-Stakeholder Platform on Pancreatic Cancer held its third face-to-face meeting in the European Parliament, in Brussels





# PANCREATIC CANCER EUROPE

The European Multi-Stakeholder Platform on Pancreatic Cancer

A strong need for public policy support: no plans dedicated to pancreatic cancer today in the European Union.

- Key actions: Awareness, Diagnosis, Registries, ECPC

## Implementing efficient data collection and pancreatic cancer registries

- Improve data collection on diagnosis, treatment and outcome of pancreatic cancer patients, supporting physicians and researchers' efforts to better understand the disease.
- Leverage EU-wide initiatives, such as the European Network of Cancer Registries, to support the development of national registries.



# Objectives of PancreOS Europe

- The main objective of the Registries work stream is to **fill the gap of the lack of organized data collection in pancreatic cancer**, which would lead to a better understanding of the disease and development of more efficacious diagnosis strategies and personalized treatments:
  - Improve information on pancreatic cancer
  - Ensure appropriate sustainable collection of clinical data, comparability issues, exchange of data and information within and between European countries
  - **Build a common European infrastructure for standardized information exchange in pancreatic cancer care**



# Advantages of PancreOS Europe

- The main outcome of the PancreOS project will be a **permanent and sustainable online standardised exchange of data**, through the use of a common dataset, to produce global indicators on patient's characteristics and the clinical management of pancreatic cancer in Europe, to identify different groups of patients and areas of improvement
- The main advantage of starting PancreOs Europe in several European centres at the same time is that **the methodology (data collection, software use, data analysis and ethics) will ensure direct comparability.**





# Developing PancreOS registries across Europe

- The Spanish Cooperative Group on Digestive Tract Tumors (TTD ) has finished a **pilot registry** called PancreOS Spain. This project has **collected a comprehensive set of prospective data** from pancreatic cancer patients **at any stage of the disease**.
- The pilot project led in Spain can be a good example of what can be done at EU level for pancreatic cancer registries.
- The European Multi-Stakeholder Platform will help **endorsing and expanding the registry** to more countries all across Europe.



# PancreOS Data base. Variable listing

<ul style="list-style-type: none"><li>■ Inclusion Criteria</li></ul>	<ul style="list-style-type: none"><li>■ Therapeutic strategy</li></ul>
<ul style="list-style-type: none"><li>■ Socio-demographic data</li></ul>	<ul style="list-style-type: none"><li>■ Chemotherapy</li></ul>
<ul style="list-style-type: none"><li>■ Clinical history<ul style="list-style-type: none"><li>■ Cancer in the family</li></ul></li></ul>	<ul style="list-style-type: none"><li>■ Radiation therapy</li><li>■ Surgery</li></ul>
<ul style="list-style-type: none"><li>■ Prior medical history</li></ul>	<ul style="list-style-type: none"><li>■ Patient Status &amp; Outcome</li></ul>
<ul style="list-style-type: none"><li>■ Pancreatic cancer history</li></ul>	
<ul style="list-style-type: none"><li>■ Diagnostic procedure</li></ul>	<div style="border: 1px solid black; padding: 5px; text-align: center;">ORACLE RDC Onsite</div>
<ul style="list-style-type: none"><li>■ Tumor stage</li></ul>	