



# **Collaboration between PancreOs and the Joint Research Centre (JRC)– the European Network of Cancer Registries (ENCR)**

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**M. Dolores Chirlaque (European Network of Cancer Registries)**

**PancreOs Kick-off meeting**

**Madrid, 17 March 2016**

**Joint Research Centre**

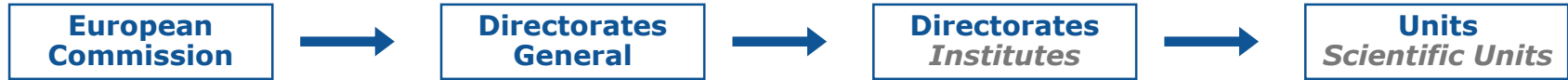
the European Commission's  
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**JRC Science Hub: [ec.europa.eu/jrc](http://ec.europa.eu/jrc)**

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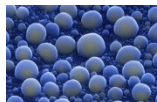
# The Joint Research Centre (JRC)



## Institute for Health and Consumer Protection (IHCP)



Genetically Modified Organisms



Nanotechnology



Public Health Policy Support



Food and Consumer Products



Chemical Assessment and Alternatives to Animal Testing

Nutrition and Health

Behavioral Research

Cancer and rare diseases

**Cancer Information**



# European Network of Cancer Registries (ENCR)

The network was established (1990) within the framework of the Europe Against Cancer Programme of the European Commission

- Objectives:**
- To promote collaboration between cancer registries
  - To define data collection standards
  - To provide training for cancer registry personnel
  - To disseminate information on cancer (incidence, mortality and survival) in the European Union and Europe



- The ENCR is governed by a Steering Committee
- ENCR is hosted by the European Commission's JRC
- ENCR is affiliated to the International Association of Cancer Registries (IACR)

<http://www.encr.eu/>

## Steering Committee

[Steering Committee Meeting Minutes](#)

### Elected members



**Professor Alexander Katalinic (Chairman)**  
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### Nominated members



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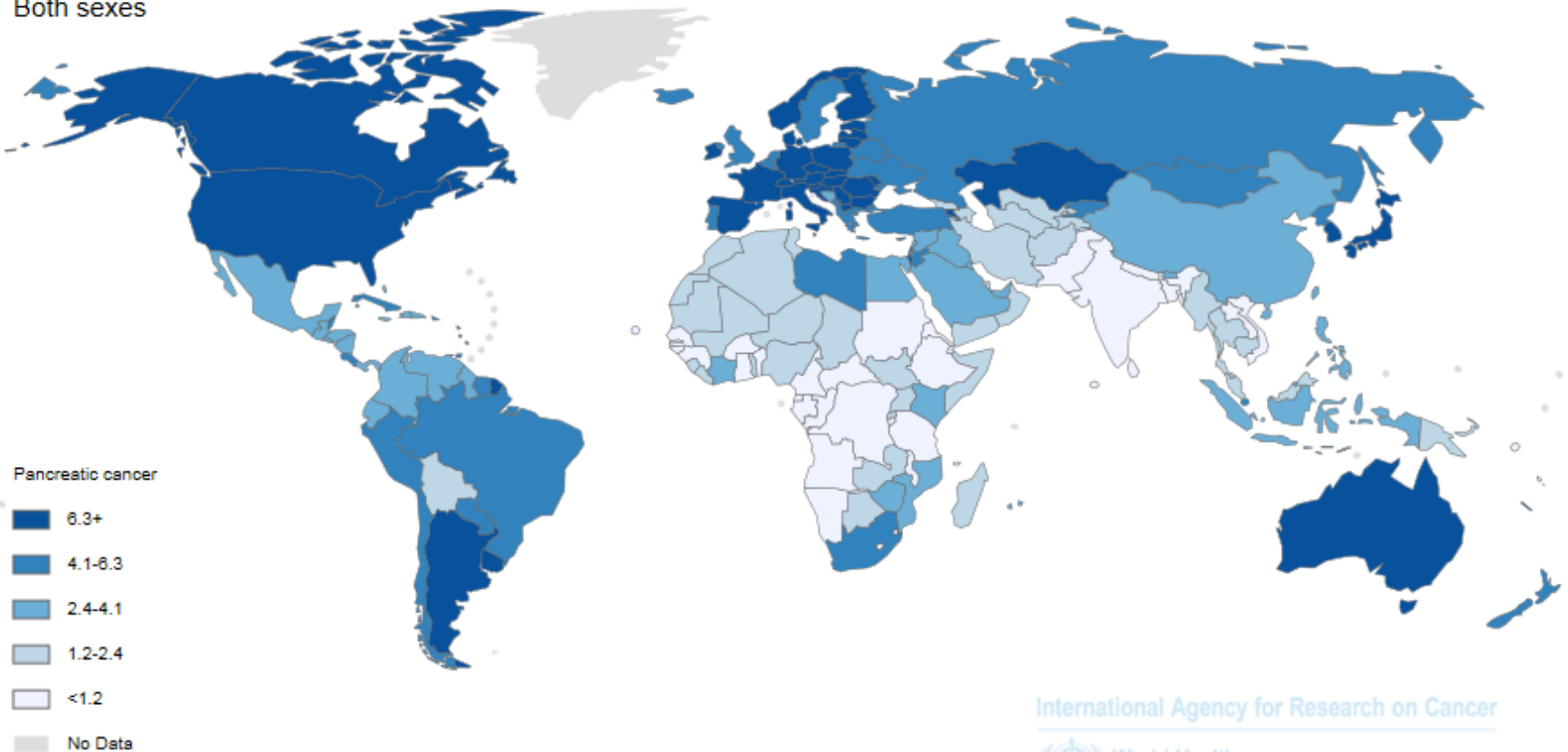


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# Pancreatic cancer: incidence

Incidence ASR

Both sexes



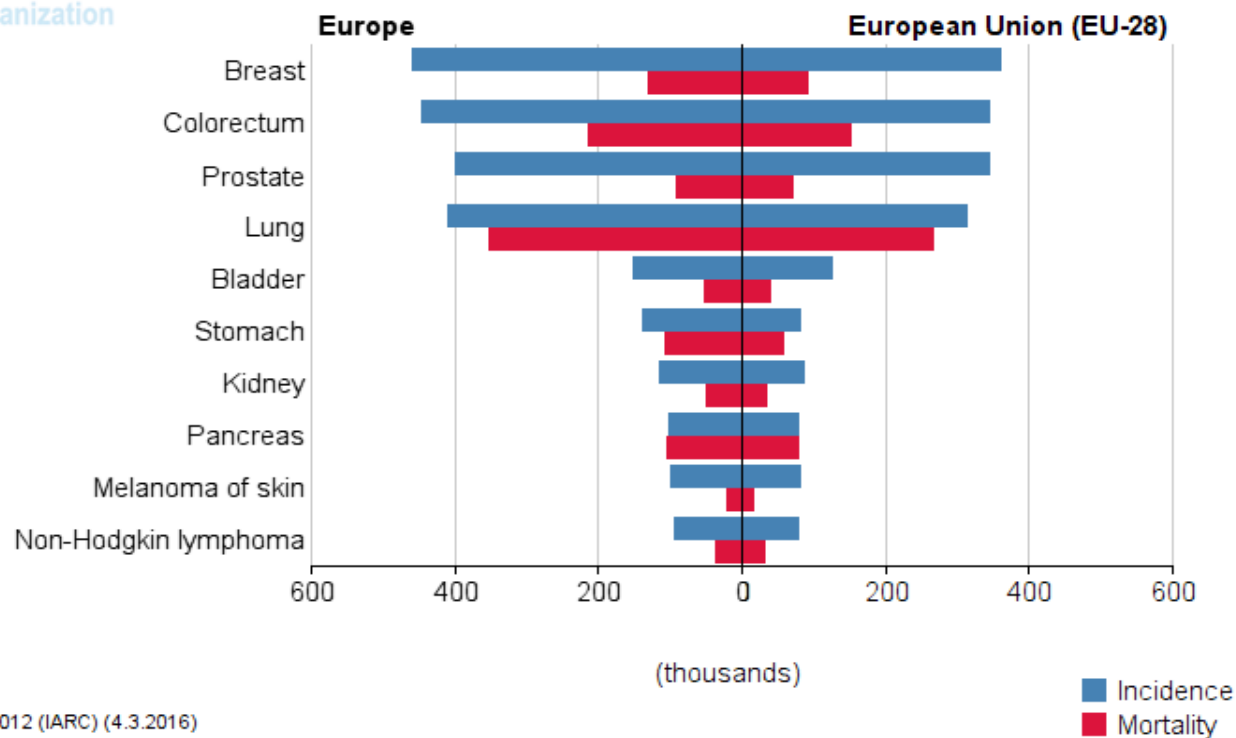
Source: GLOBOCAN 2012 (IARC)

# Pancreatic cancer: incidence and mortality

International Agency for Research on Cancer



Both sexes  
Numbers, all ages

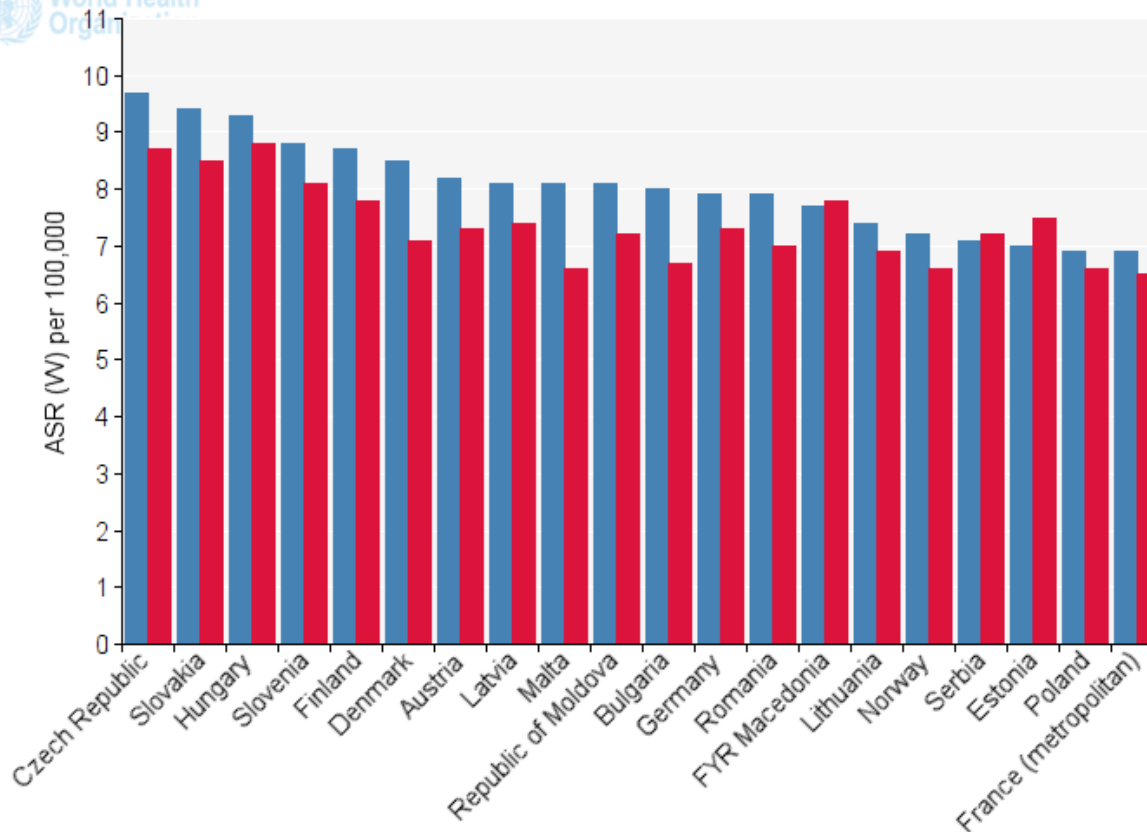


**103,000 cases in Europe**

**79,000 in the European Union**

# Pancreatic cancer: incidence and mortality

International Agency for Research on Cancer Pancreas: both sexes, all ages



■ Incidence  
■ Mortality

GLOBOCAN 2012 (IARC) (4.3.2016)

# Background

- ❑ Acknowledging the importance of the pancreatic cancer, the JRC considers that a joint collaboration between PancreOs and the European population-based cancer registries is essential to gain a better understanding of the disease and therefore, improve the care of the patients diagnosed with this cancer.
- ❑ A one day workshop was organised in Madrid (Spain), involving the main stakeholders in pancreatic cancer registration and research.



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## Workshop on Pancreatic cancer

Madrid, Spain • 5 October 2015

### Agenda

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## Workshop on Pancreatic cancer

Madrid, Spain • 5 October 2015

- 10:30–10:35 **Welcome, and aims of the workshop**  
Carmen Martos
- 10:35–10:50 **Overview of ENCR–JRC activities**  
M. Dolores Chirilaque and Carmen Martos
- 10:50–11:05 **Presentation of REDECAN**  
M. José Sánchez
- 11:05–11:20 **The EUPancreas COST Action and the MultiStakeholder Platform on Pancreas Cancer**  
Núria Malats
- 11:20–11:35 **PancrEos Project. Data collection: first results**  
Alfredo Carrato
- 11:35–11:50 – *Break*
- 11:50–13:30 **Discussion: Collaboration between REDECAN and PancrEos**
- 13:30–14:30 – *Lunch*
- 14:30–15:30 **Discussion: Planning a pilot study**
- 15:30–16:30 **Summary of the Workshop and conclusions**



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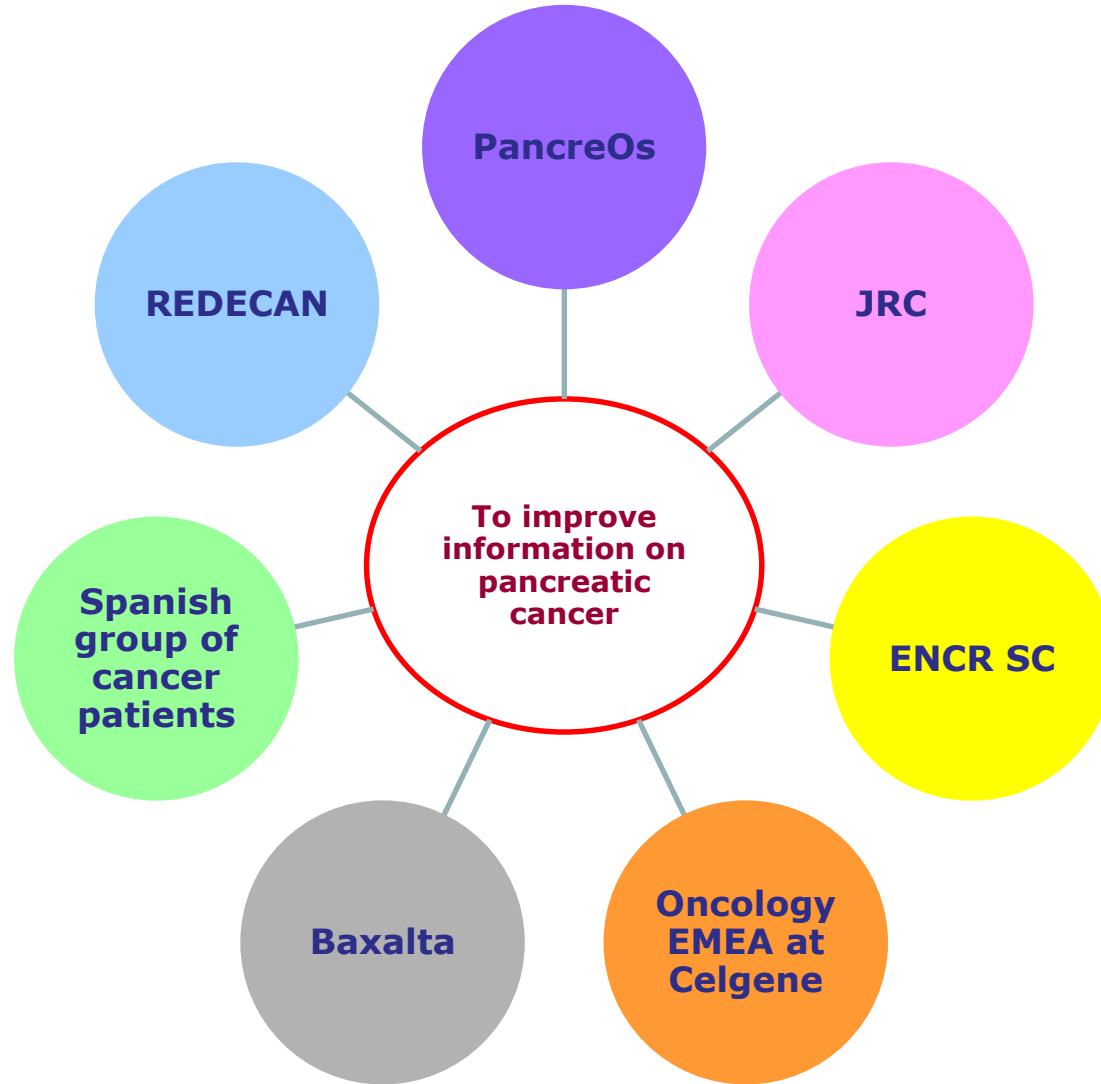
# Aims

- ❑ To explore the interest of collaboration between the Spanish Network of Cancer Registries (REDECAN), PancreOs, the ENCR and the JRC.
- ❑ To discuss the feasibility of carrying out an exploratory pilot study in selected areas covered by a population-based cancer registry.



To increase the availability of information on pancreatic cancer collected by the population-based cancer registries by adding detailed clinical data and to provide PancreOs with valid information to generalise research findings.

# Participants



# Collaboration between REDECAN and PancreOs

## PancreOs

- ❑ Data collection: hospital-based at Medical Oncology Services  
detailed data related to diagnosis and treatment  
Prospectively.
- ❑ Disadvantages: case selection bias  
incidence, prevalence and population-based survival cannot be  
computed.

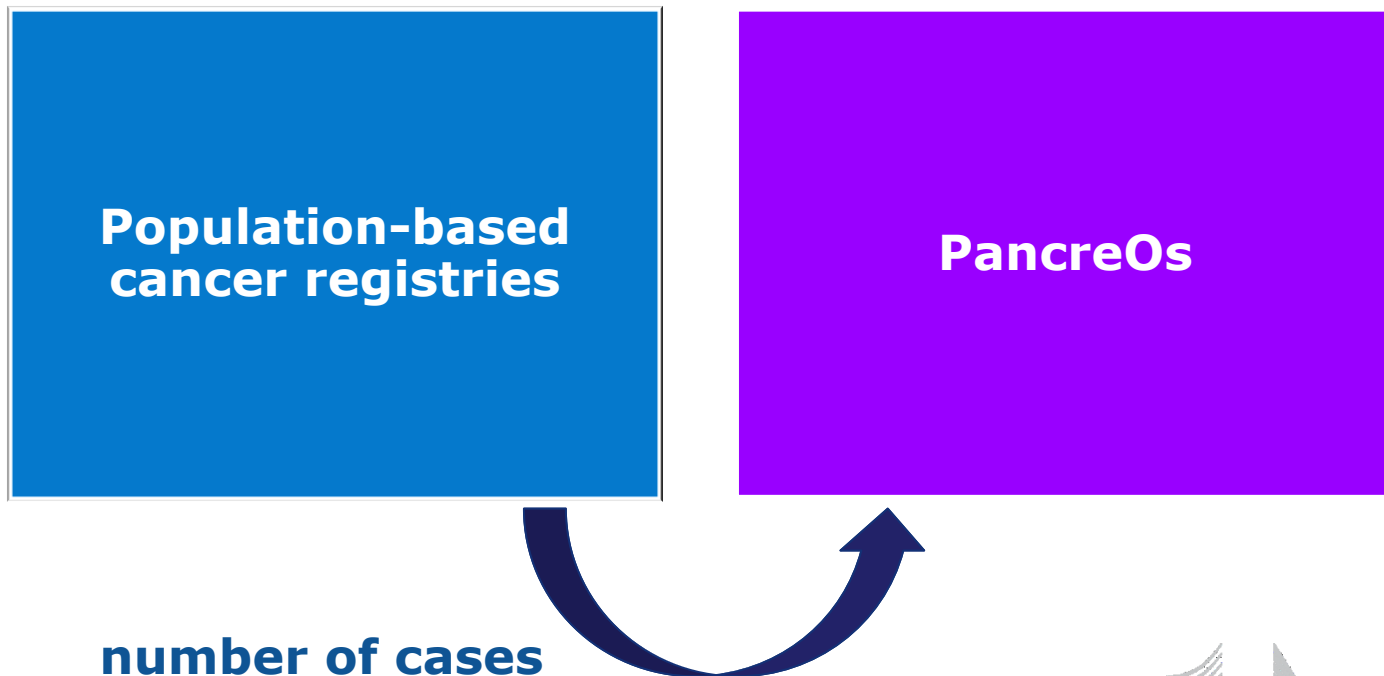
## Population-based cancer registries

- ❑ Data collection: all new cases of cancer occurring in a well-defined population  
incidence, prevalence and population-based survival can be  
computed.
- ❑ Disadvantages: not up – to - date  
information collected routinely concerning diagnosis and  
treatment are limited → High resolution studies.

# Collaboration between REDECAN and PancreOs

All participants agreed to join efforts to improve information on pancreatic cancer. Two scenarios for collaboration were proposed:

- ❑ "Minimum" collaboration → CRs provide to PancreOs the number of pancreatic cancer cases (e.g. distributed by sex and age) for the study period when the data are available to the CR.



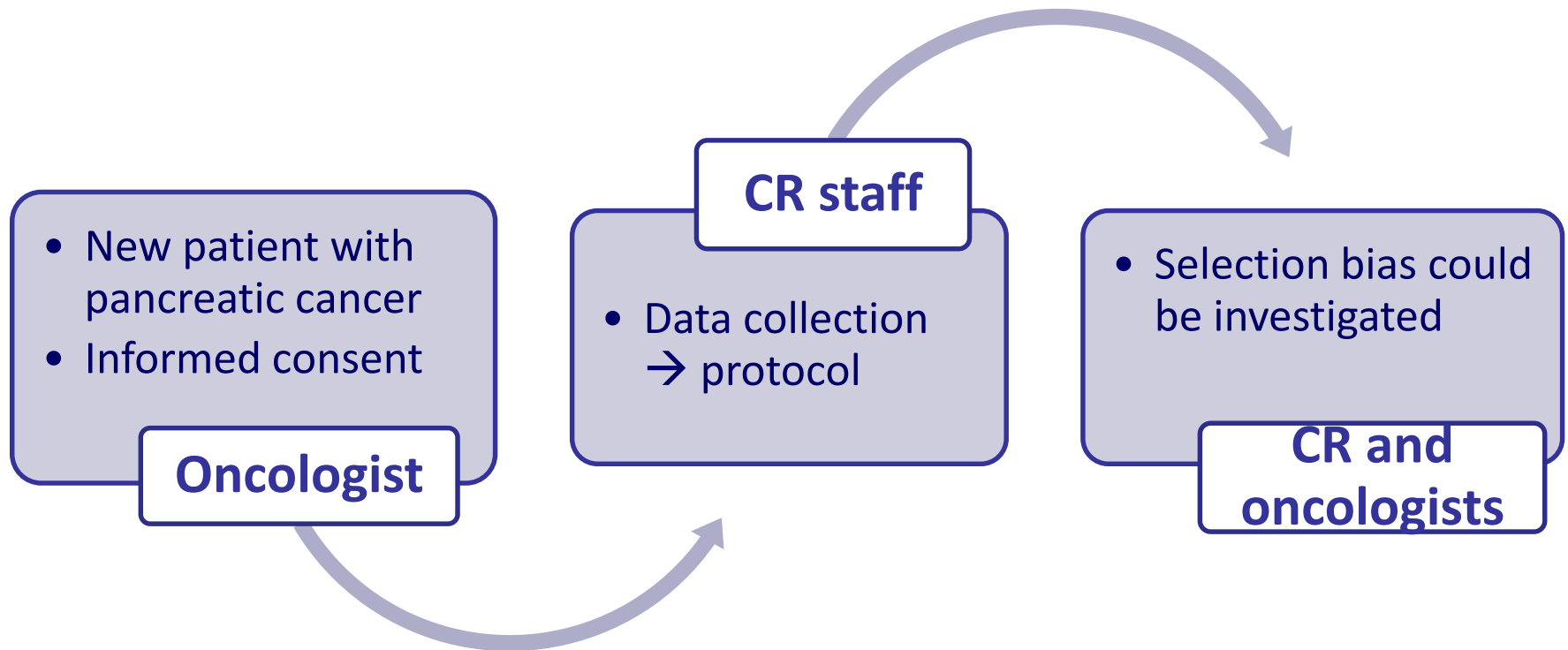
# Collaboration between REDECAN and PancreOs

## ❑ Towards "maximum" collaboration:

Oncologists, participating in PancreOs, would become an information source for the CR operating in their area.

1. When a new patient with pancreatic cancer is identified by the oncologists and having the informed consent → report the case to the CR → CR staff collect the information, according to a data collection protocol.
2. When the CR has collected the information on all cases that have occurred in the study period, the selection bias will be investigated → depending on the results, a retrospective data collection could be carried out by the CR to complete information about cases not included previously in PancreOs.

# Collaboration between REDECAN and PancreOs

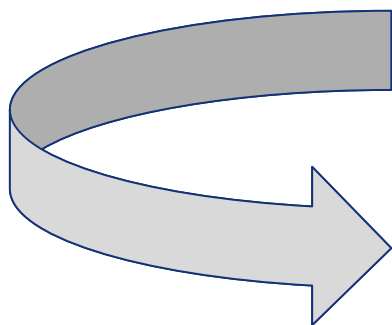


This proposal could be a sustainable data collection strategy.  
The study could be extended to other European geographical areas.

# Collaboration between REDECAN and PancreOs



The CR provides the IT platform for the oncologists to enter the clinical information



When the CR has collected information on all cases that have occurred during the study period, the selection bias will be investigated

# Conclusions

The participants agreed that the collaboration between population-based cancer registries and clinicians, participating in PancreOs, is essential to improve the available information on pancreatic cancer and therefore, improve the diagnosis and treatment of patients diagnosed with this disease.

The workshop discussions provided useful input for future work and collaboration between PancreOs and population-based cancer registries.

# Conclusions

Next steps:

- ❑ To prepare a data collection protocol based on the results of the pilot study carried out in Spain and the existing data collection protocols on pancreatic cancer
- ❑ Systematic review: clinical guidelines

# Thank you and stay in touch



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