PancreOS Project

A network of registries on pancreatic cancer in Europe

PancreOS PROJECT REPORT

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Raquel Benítez Dorta

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Pancreatic Cancer Europe ASBL – Registration number: 656.553.804
Headquarters: Square Ambiorix 10 – 1000 Brussels (BELGIUM)
Email: contact@pancreaticcancereurope.eu
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PANCREOS 6-MONTH PROGRESS REPORT

Over the last six months, PancreOS has consolidated its role as a feasible and impactful European network of pancreatic cancer registries. Building on the initial phase, the project has strengthened engagement with participating registries, expanded visibility at key European meetings, and generated the first aggregated insights into real-world pancreatic cancer diagnostics, treatment, and outcomes across Europe.

Eleven registries are currently contributing data, with additional registries engaged and onboarding in progress. Early analyses confirm substantial heterogeneity in diagnostic pathways, staging practices, treatment approaches, and survival reporting. These findings reinforce the urgent need for standardized data collection and coordinated registry collaboration.

The next phase will focus on expanding participation, refining variables, and demonstrating PancreOS' ability to answer clinically, scientifically, and policy-relevant questions, in alignment with European initiatives such as the European Health Data Space (EHDS).

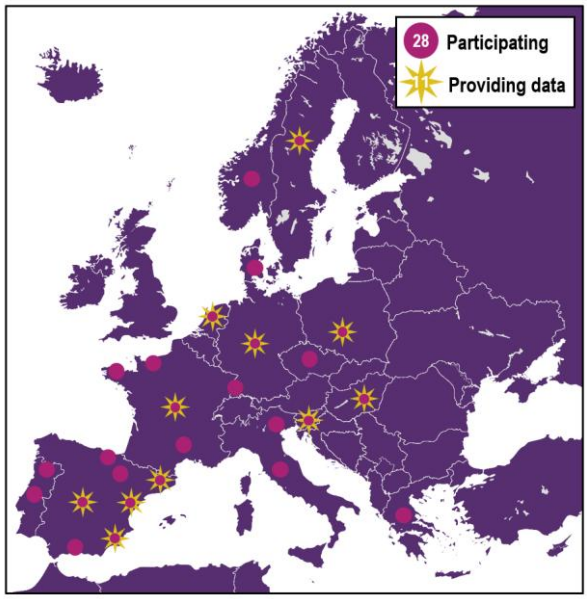

***Figure 1**. Map showing the geographical distribution of the PancreOS registries.*

DATA COLLECTION AND INITIAL AGGREGATED RESULTS

PancreOS continues to collect summarized, pathology-confirmed data on PDAC and adenocarcinoma non-otherwise specified (NOS) via the software platform, Research Electronic Data Capture (REDCap), using standardized REDCap questionnaires to ensure structured, harmonized, and high-quality data entry (Annex I). Currently, out of the **28 registries** that have already expressed their interest in the project, 11 of them have provided data (Figure 1, Annex II).

Early analyses reveal substantial variability across registries. Diagnostic practices differ notably, with wide variation in imaging modalities and tumour sampling methods. Tumour characteristics also show inconsistency, including differences in how tumour location, grade, and staging systems are reported. Treatment approaches vary markedly between registries, reflecting diverse clinical practices and available resources. Reported three-year survival ranges from 6% to 25%, a spread that likely reflects both true clinical differences and significant heterogeneity in cancer's stage, follow-up and reporting.

A key lesson emerging from this work is that differences in data-recording methodologies greatly influence comparability—especially when assessing survival outcomes.

LESSONS LEARNED SO FAR

What works

Several insights have emerged from the PancreOS collaboration to date. One clear strength of the initiative is the use of a summarized dataset, which makes it possible for registries with very different infrastructures to participate meaningfully, overcoming the GDPR constraints. Regular meetings have also proved highly effective, helping to build trust, maintain transparency, and support ongoing engagement across the network.

What needs improvement

At the same time, important areas for improvement have been identified. Standardizing core variables, particularly those related to diagnosis, tumour characteristics, staging, and treatment, is essential to enhance comparability. A clearer distinction between incident and prevalent cases is also needed, as this has direct implications for interpreting survival and outcome measures. In addition, a more detailed understanding of which registries routinely capture comorbidities, such as diabetes, would strengthen the broader analytical potential of the dataset.

What this confirms

Overall, the experience so far confirms that building a coordinated European pancreatic cancer registry network is not only feasible but also fundamentally important for generating comparable, high-quality data across countries.

VISIBILITY AND OUTREACH EFFORTS

The PancreOS project has been actively disseminated at key scientific and stakeholder events. It was presented as a poster at the following conferences:

- GRELL-ENCR 2025, held in Porto from May 27–30
- DISCERN Project 2025 General Assembly, on June 5
- EPC 2025, held in Düsseldorf from July 2–5

Additionally, the PancreOS project meeting took place on June 12 2025, providing an opportunity to review progress and define and agree next steps.

PANCREOS FUTURE DIRECTIONS

Over the next six months, PancreOS will shift from demonstrating feasibility to generating tangible impact. A key priority will be expanding the number of registries actively contributing data, ensuring broader representation and improving analytical power. Refinement of core variables, including age-group definitions, biobank-related fields, and differentiation between incident and prevalent cases, will enhance comparability and prepare the dataset for more advanced analyses.

Building on the initial insights, the team will undertake pilot analyses addressing two to three priority research questions, allowing the network to showcase the real value of harmonized European pancreatic cancer data. At the same time, PancreOS will transparently document data gaps and sources of heterogeneity, supporting both technical improvements and clear communication with stakeholders. Preparatory work will also begin on governance principles for research access, laying the groundwork for a future federated research infrastructure.

Success in this next phase will be measured by:

- Growth and retention of actively contributing registries
- Completion of the planned pilot analyses
- Use of PancreOS by researchers and stakeholders beyond

CONCLUSION

In the past six months, PancreOS has identified several key actions required to improve data quality, comparability, and impact. In addition, the project has begun to make the transition away from the proof-of-concept stage and into the important phase of data analysis. demonstrating capacity to generate data that provide meaningful real-world insights.

ANNEX I: PANCREOS ICD-3-O

In order to ensure that any project is feasible and sustained over time, its goals should be broken down into small steps. Therefore, to achieve the main objective of PancreOS, data collection will be carried out in different phases. For the design of each of these phases, PancreOS will consult with the participating registries.

PancreOS collects the summarised data for each registry by using the REDCap web application, which allows the creation of surveys to collect the summarised data.

During Phase I, PancreOS will request, from each registry, the total number of histologically confirmed Pancreatic ductal adenocarcinoma (PDAC), Adenocarcinoma non-otherwise specified, Not confirmed pancreatic cancer (PC), and other confirmed PC (see below). In this first step of data collection, PancreOS is focused only on PDAC and NOS, and collecting information about the general population description, the diagnosis procedures, treatment, tumour characteristics, and survival.

The different PC cancer groups collected by PancreOS are defined based on the ICD-3-O WHO classification as follows (Figure 1):

1 Pancreatic ductal adenocarcinoma (PDAC)

- Pancreatic Ductal Adenocarcinoma - 8500/3
- Adenosquamous carcinoma - 8560/3
- Mucinous adenocarcinoma - 8480/3
- Signet ring cell carcinoma - 8490/3
- Medullary adenocarcinoma - 8510/3
- Undifferentiated carcinoma - 8020/3
- Carcinoma with osteoclast-like giant cells - 8035/3

2. Adenocarcinoma non-otherwise specified – 8140

3. Not confirmed PC

4. Other Confirmed PC

- Acinar cell carcinoma - 8550/3
- Acinar cell cystadenocarcinoma - 8551/3
- Intraductal papillary mucinous neoplasm with an associated invasive carcinoma - 8453/3
- Mixed acinar-ductal carcinoma - 8552/3
- Mixed acinar-neuroendocrine carcinoma - 8154/3
- Mixed acinar-neuroendocrine-ductal carcinoma - 8154/3
- Mucinous cystic neoplasm with an associated invasive carcinoma - 8470/3

- Pancreatoblastoma - 8971/3
- Serous cystadenocarcinoma - 8441/3
- Solid-pseudopapillary carcinoma - 8452/3

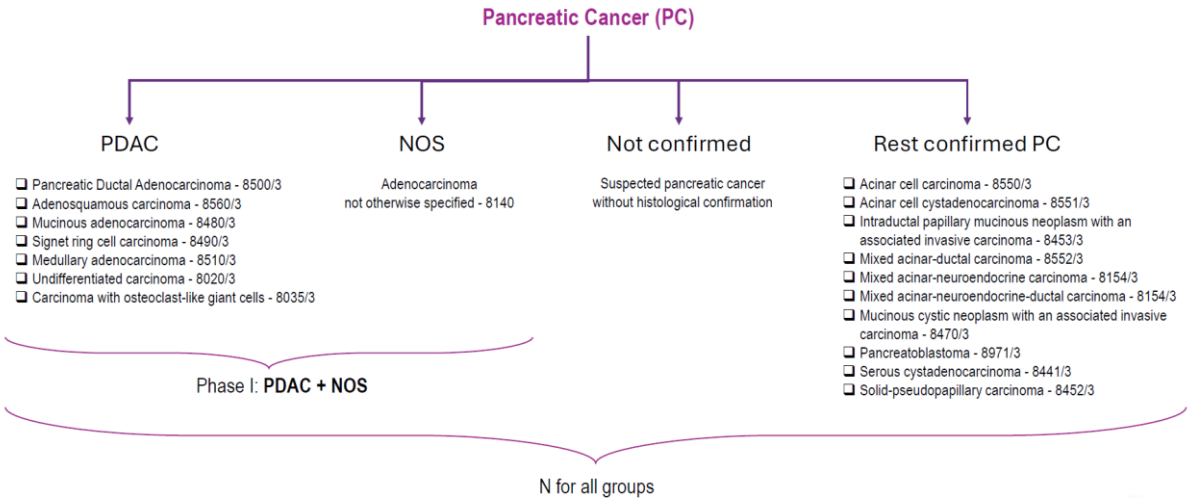

Figure 1. *Schema summarising PancreOS PC collection groups.*

ANNEX II: PANCREOS PARTICIPANTS LIST

As of 31 December 2025, 28 registries have already expressed their interest in participating in PancreOS. Out of them, 11 are already providing data. Below is the list of the registries engaged with the PancreOS initiative.

Registries that are already providing the data are highlighted in bold:

1. Azores Cancer Registry, Azores Archipelago (Portugal)
2. **Girona Cancer Registry, Girona province (Spain)**
3. **Cancer Registry of Baden-Württemberg, Baden-Württemberg (Germany)**
4. The Italian Rare Pancreatic Exocrine Cancer Initiative, Italy
5. Veneto Tumour Registry, Veneto Region (Italy)
6. Norwegian Pancreatic Cancer Registry, Norway
7. Registres des Tumeurs Digestives du Finistere, Finistary (France)
8. Basque Country Cancer Registry, Basque Country (Spain)
9. Registo Oncológico Regional do Norte (RORENO), North Region of Portugal
10. StuDoQ|Pancreatic surgery, Germany
11. **BACAP, France**
12. **Registro de Tumores de Castellón, Castellón (Spain)**
13. Registre des tumeurs digestives du Calvados, Calvados (France)
14. Granada Cancer Registry, Granada (Spain)
15. **Slovenian Cancer Registry, Slovenia**
16. **Swedish National Registry for periampullary and pancreatic cancer, Sweden**
17. Navarra Cancer Registry, Navarra (Spain)
18. Granada Cancer Registry, Granada (Spain)
19. **Pancreas solid tumour and pancreatic cancer registry, Hungary**
20. Dansk Pancreas Cancer Database, Denmark
21. **Netherlands Cancer Registry (NCR), The Netherlands**
22. Luz Saúde, Portugal
23. Masaryk Memorial Cancer Register, Czech Republic
24. Registre des tumeurs de l'Hérault, Hérault (France)
25. **Registro de Cáncer de la Región de Murcia, Murcia (Spain)**
26. Pancreas sample, Greece
27. **Biobank Narodowego Instytutu Onkologii, Gliwice (Poland)**
28. **TTD - Grupo de Tratamiento de los Tumores Digestivos (Spain)**