Position Paper for 2024 EU Elections





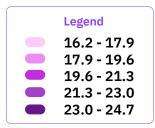
The facts

Pancreatic cancer is the only cancer whose incidence and mortality are on the rise in both sexes. It is also currently the 3rd leading cause of death by cancer in Europe (1).

We must act now to stop this trend.

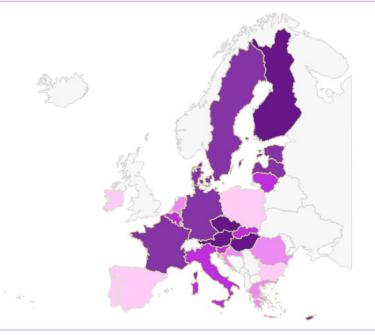
Estimates of cancer incidence in 2022, for all countries

EU27, Both sexes, Pancreas, All ages, 2022



Age standardised rate (European 2013) per 100,000

source: Elaborated by PCE on data from European Commission – European Cancer Information System, Cancer burden statistics and trends across Europe | ECIS (europa.eu)



Today, a diagnosis of pancreatic cancer is generally associated with a death sentence. as there are very few long-term survivors after diagnosis. Its usual late diagnosis is due to its aggressive biology and various challenges and limitations: the lack of awareness of its specific symptoms; the difficulty of accessing the organ; the lack of a definition of the high-risk populations; the lack of a specific screening program; the lack of a European health policy that surgery should only be performed in experienced centres; the lack of new active drugs; the lack of sufficient investment in pancreatic cancer research; and the lack of coordination among European countries to fight the disease together and to regard it as the health emergency that it is.

Earlier diagnosis could help reduce the mortality of the disease. Survival rates could be increased through better health policy organisation, by improving knowledge of the disease behaviour and, as a result, increasing the feasibility of early diagnosis, and by identifying new targets and strategies for a more successful therapy.

We call to action those who wish to contribute to a better quality of life for patients and survivors. We aim to ensure that policymakers do not forget pancreatic cancer so that appropriate policies can be implemented to beat the disease.

This document identifies key action points to be put into practice within the next 5-year mandate of the new Parliament.

Our position

Awareness and diagnosis

The current challenges

Lack of awareness: This is one of the biggest obstacles to acting against pancreatic cancer, which is often referred to as a "neglected cancer". The main symptoms and early signs of pancreatic cancer are underestimated among the general population and the medical community.

Late detection: The rise in incidence rates indicates the need for early detection strategies. There is a lack of effective screening programs addressed to the general population and different target groups, as well as uncertainty regarding novel diagnostic tools.

The goals to achieve

- To disseminate appropriate and accessible information among the general public, to raise awareness of the importance of early detection and the resulting possible increase of survival rates.
- To define the high-risk populations.
- To develop a highly sensitive, specific, and cost-effective screening program.
- To increase routine screening and surveillance, to improve early detection.
- To better understand the disease and to deepen the knowledge of the potential risk factors.
- To clearly explain the rising incidence and its dramatic projections for the future (2) and to implement primary prevention programs.

National support

The current challenges

Differences in the pancreatic cancer scenarios: This refers to the incidence and the survival rates of pancreatic cancer in the different European Countries.

Inequalities from one country to another: There are unequal approaches to prevention, screening, diagnostics, and treatment among the European Countries. Cancer care is not standardised across Europe, and Countries have different investment policies, sometimes not focussed specifically on pancreatic cancer.

The goals to achieve

- To boost epidemiological research at the national level for a better understanding of each Country's unmet needs.
- To support Countries in improving quality approaches to the different aspects of pancreatic cancer prevention, diagnosis, and treatment.

Estimates incidence by country - comparison with EU-27

	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czechia	Denmark	EU-27	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden
Number of cases	2.159	2.338	1.280	801	169	2.479	1.354	100.152	302	1.497	15.895	21.869	2.305	2.419	694	15.710	454	605	95	107	3.490	5.881	2.158	3.389	1.008	458	8.823	2.41
Crude rate	24	20,1	18,7	20,7	18,7	23,6	23,1	22,4	22,7	27	23,4	26,3	22	25	13,7	26,6	24,2	21,6	14,7	20,5	19,8	15,6	20,8	17,8	18,5	21,7	18,6	23,1
ASR (European 2013)	23,2	19,6	17,3	18,4	22,3	23,1	22,5	20,5	21,7	23,6	22	22,4	18,8	24,7	17,3	21,1	22,4	20,2	18,2	21,7	19,2	16,2	17,1	18,1	20,9	20,2	17,4	22,6
ASR (European 1976)	14,4	11,7	11,2	11,4	13,1	14,5	13,3	12,7	13,2	14	13,8	13,6	11,8	15,6	10,5	12,6	14	12,5	10,5	13,1	12,2	10,3	10,2	11,9	13,2	12,6	11,3	14
ASR (world)	9,5	7,6	7,5	7,5	8,5	9,6	8,5	8,4	8,6	9	9,2	8,8	7,8	10,4	6,9	8,2	9,2	8,2	6,6	8,6	8,2	6,9	6,6	8	8,8	8,4	7,6	9,2
Cumulative risk	2,8	2,6	2,1	2,3	3	2,8	3	2,6	2,7	3	2,7	2,8	2,3	3	2,2	2,7	2,8	2,6	2,5	2,8	2,3	2	2,2	2,1	2,5	2,5	2,1	2,8

EU27, Both sexes, Pancreas, All ages, 2022

source: Elaborated by PCE on data from European Commission - European Cancer Information System, Cancer burden statistics and trends across Europe | ECIS (europa.eu)

Registries

The current challenges

Lack of organised data collection on pancreatic cancer: This lack results in a suboptimal understanding of the disease and the poor development of efficacious diagnosis strategies and personalised treatments. The availability of data for researchers is, and always has been, a vital component of oncological research.

The goals to achieve

- To establish a prospective European network of registries and biobanks for pancreatic cancer that would collect standardised and comprehensive data on patients, their treatments, and outcomes. Such registries make it possible to see areas for improvement, help identify patterns and trends in patient management and treatment response and can provide valuable insights for research. In addition, federated biobanks gathering several types of sequential biological samples from pancreatic cancer patients obtained through standardised protocols are crucial to support research.
- To create shared guidelines for the collection of data and samples in order to guide researchers towards a common goal.

Research

The current challenges

Research on pancreatic cancer has received minimal funds from European funding bodies (3): This leads to limited possibilities to deepen the research efforts and to limited collaboration among the relevant stakeholders.

There is no clear identification of centres of excellence in Europe for both pancreatic cancer patient care and research: Therefore, the current research efforts are less efficient and effective, and the patients cannot receive the best benefit from them.

The goals to achieve

- To underline the importance of advocacy and collaboration with policymakers, funding agencies, and philanthropic organisations to secure more resources for studying and combating pancreatic cancer.
- To increase the funding of specific research strands relevant to pancreatic cancer.
- To establish specialised institutions with expertise in diagnosing and treating pancreatic
 cancer. By centralising care and enhancing research in these centres, it would be possible
 to coordinate clinical drug trials more efficiently, ensuring that patients have access
 to cutting-edge treatments and allowing researchers to collaborate more effectively.

Treatments

The current challenges

The heavy burden of the disease (2): The pancreatic cancer community struggles with many objective facts. Among the main ones there are the following:

- Pre-neoplastic lesions are difficult to detect and classify in their malignant potential.
- In some countries, there's a shortage of expert endoscopy centres that can perform advanced procedures for proper tissue sampling in pancreatic cancer.
- Surgery is still performed in centres with low caseloads, which is associated with enhanced risk of residual disease and higher morbidity and mortality rates.
- A considerable fraction of patients with advanced stages of pancreatic cancer across European countries do not receive any chemotherapy that can improve their quality of life and survival.
- All novel treatments that have shown tremendous benefit in other tumours, such as immunotherapy and targeted therapies, have so far failed in pancreatic cancer.
- Palliative care is frequently underprovided across Europe.

The goals to achieve

- To strengthen the collaboration among the members of the European pancreatic cancer biomedical community.
- To facilitate access to clinical trials for patients, providing them with easy-to-obtain full information and support for their stay and journey.
- To ensure equal access to treatments and palliative care all throughout Europe.

The action points to be put into practice

- Accessible, updated and understandable information on the importance of early detection, addressed to the general public, disseminated by the European pancreatic cancer community.
- Collaborative efforts to implement effective screening programs, identify high-risk populations, and explore novel diagnostic tools.
- Improved national research efforts in each European Country, to provide better pancreatic cancer prevention, diagnosis and treatments.
- Development of common European guidelines for data and sample collection.
- 5) Availability of specific European funding strands for pancreatic cancer research.
- 6) High-profile centres open to the pancreatic cancer community.
- 7) Clear and accessible information on clinical trials.

The signatories



Pancreatic Cancer Europe (PCE) is a European multi-stakeholder platform which aims at bringing together patient communities and experts from all over Europe Read more: www.pancreaticcancereurope.eu



Cancer Patients Europe is a European non-profit organisation representing and empowering the voices of cancer patients and survivors, advocating for their needs and rights at every stage of their journey.

Read more: www.cancerpatientseurope.org



Digestive Cancer Europe is a European non-profit umbrella organisation uniting patient organisations and collaborating with stakeholders dedicated to digestive cancers.

Read more: www.digestivecancers.eu



European Pancreatic Club is a non-profit, international scientific organisation dedicated to the study of the pancreas, created as the world's first scientific society specifically dedicated to this.

Read more: www.europeanpancreaticclub.org



United European Gastroenterology is a leading non-profit organisation for excellence in digestive health in Europe and beyond. It improves the prevention and care of digestive diseases in Europe through providing top-tier education, supporting research, and advancing clinical standards.

Read more: www.ueg.eu

Notes and resources

1) M. Dalmartello, C. La Vecchia, P. Bertuccio, P. Boffetta, F. Levi, E. Negri & M. Malvezzi, European cancer mortality predictions for the year 2022 with focus on ovarian cancer, ESMO Annals of Oncology, March 2022, European cancer mortality predictions for the year 2 with focus on ovarian cancer - PubMed (nih.gov)

2) The Neglected Heavy Burden: Pancreatic & Gastric Cancers, Policy asks. A UEG, PCE and DiCE initiative, November 2022, 8208974663db80265e9bfe7b222dcb18.pdf (ueg.eu)

3) UEG position paper on pancreatic cancer. Bringing pancreatic cancer to the 21st century: Prevent, detect, and treat the disease earlier and better, 2021, UEG position paper on pancreatic cancer. Bringing pancreatic cancer to the 21st century: Prevent, detect, and treat the disease earlier and better - PubMed (nih.gov)