



Event Report

Putting Pancreatic Cancer on the map – What we have and what we need

European Parliament, Brussels, October 10

Pancreatic Cancer Europe : shining the light on the neglected cancer

Pancreatic Cancer Europe is a European multi-stakeholder platform, gathering key experts from all over Europe, and dedicated to helping pancreatic cancer patients by putting forwards their needs and the inequalities of treatments they suffer from across Europe.

There is an **increasing gap** between the epidemiology of pancreatic cancer, with incidence and mortality rising for both sexes, and the level of policy consideration. This had led pancreatic cancer to be **considered a neglected cancer**. To counter this lack of prioritisation, **awareness and political visibility** are necessary. Pancreatic Cancer Europe has developed a large number of visual documents to be disseminated for all publics, in order to trigger **an evidence-based response** in policies.

Among this set of documents are the PCE Heatmap and the PCE inequality report. These documents are intended as **sources of information** on the status of pancreatic cancer care across Europe, offering the possibility to compare research, diagnosis, and public health plans in several European countries. The data they provide on pancreatic cancer is essential when it comes to making **an informed decision**.

Both of these documents were presented in the European Parliament on the 10th of October, in Brussels. To promote them and receive the support from key experts and decision-makers, with the support of the Digestive Health Groupe for the European Parliament, PCE and United European Gastroenterology (UEG) have put together this event hosted by Pavel Poc, MEP. The event led to fruitful discussions and allowed pancreatic cancer to receive a renewed attention by policy-makers.

**PUTTING PANCREATIC CANCER ON THE MAP
– WHAT WE HAVE AND WHAT WE NEED**

EUROPEAN PARLIAMENT, BRUSSELS

Introduction by Chair – *Pavel Poc, MEP (Czech Republic)*

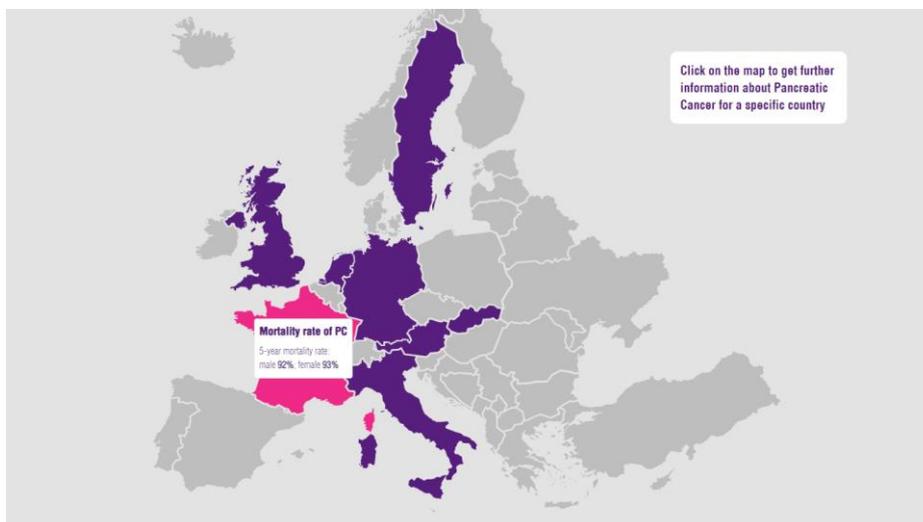
MEP Poc, who showed, over the last years, a constant support to the fight against pancreatic cancer, made the honour of opening the event. His presentation emphasised the terrible figures of pancreatic cancer : a low survival rate, **almost 90,000 EU citizens** affected each year, and only 2% of the overall cancer research funding across Europe.

MEP Poc then announced the upcoming release of a new report entitled “Pancreatic cancer across Europe; taking a stand against the continent’s deadliest disease” by UEG (United European Gastroenterology). His work in the past years with his colleagues in the EU Parliament as well as PCE and UEG, which has come to fruition so many times, will continue.

World Pancreatic Cancer Day in November will be yet another opportunity to outline the **urgency of the situation**. Until then and after, MEP Poc will pursue his objective of changing the numbers of this dreadful disease.

Presenting the PCE Heatmap – understanding the problem – *Dr Lydia Makaroff, European Cancer Patients Coalition*

Dr Lydia Makaroff, director of the European Cancer Patients Coalition (ECPC) presented the **Pancreatic Cancer Europe Heatmap** to the room. The objective of the heatmap is to show the inequalities between countries in Europe, by collecting health policy and public health data. The heatmap allows a better visualisation thanks to **comparative views of countries**, allowing for instance a quick access to epidemiology content.



The Pancreatic Cancer Europe heatmap

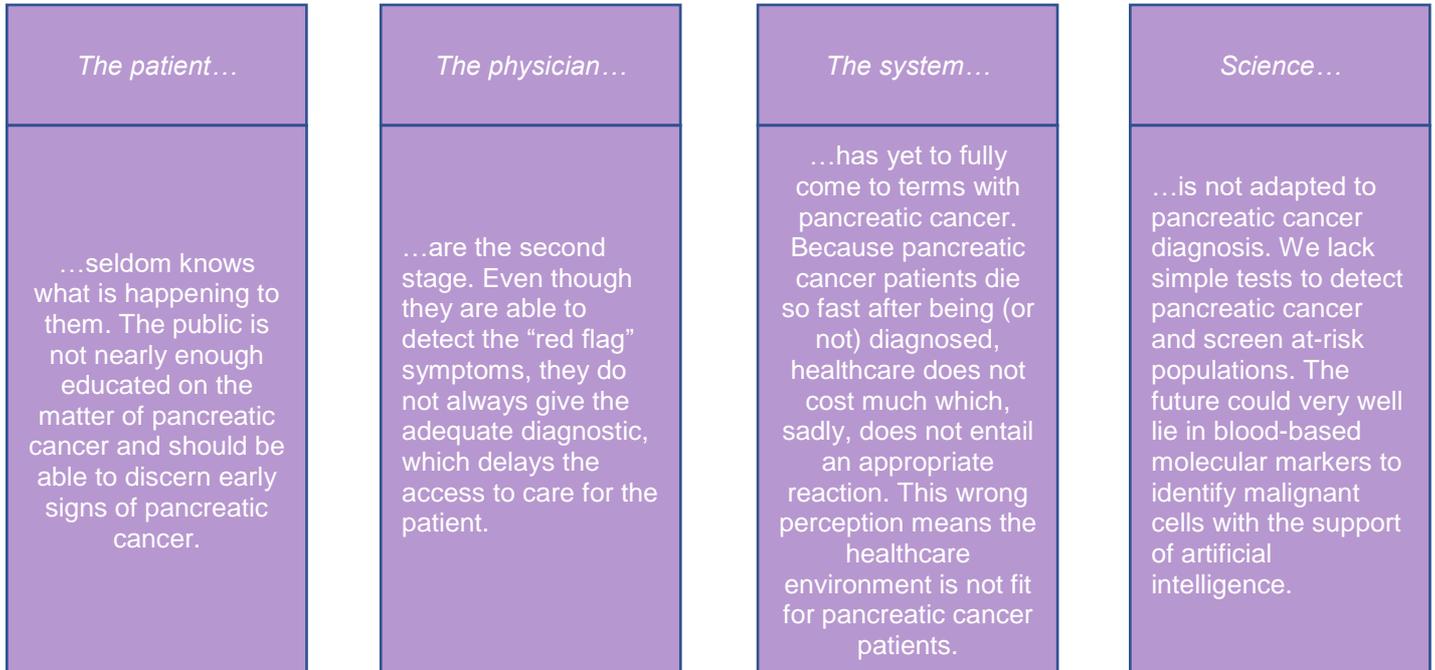
In order to provide a comprehensive view of the situation of pancreatic cancer consideration in European countries, seven criteria have been selected : awareness, cancer plan, diagnosis, registries, research, treatments and public health data.

The heatmap already features **eight countries**. Pancreatic Cancer Europe plans on expanding it to provide more information and allow for a better comparison between a large number of European countries.

Addressing barriers in diagnostics – *Professor Matthias Löhr, United European Gastroenterology*

One of the main reasons for the high mortality rate of pancreatic cancer is that **diagnostic is often late**, due to a variety of factors. Prof Matthias Löhr, one of the founding members of PCE and professor of gastroenterology at the Karolinska Institutet, a former PCE Board member and a

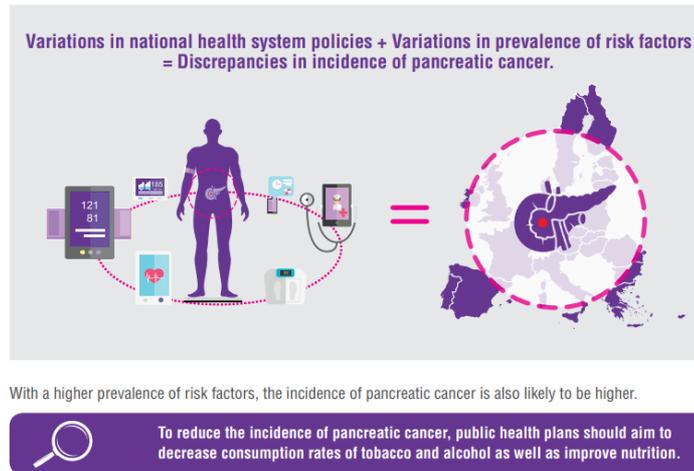
member of the Public Affairs Committee in UEG, elaborated on these factors, considering there are **four levels constrained by barriers** to diagnosis:



Pancreatic Cancer policy – what we have and what we need : presenting the inequality report–
Ali Stunt, Pancreatic Cancer Action and 2018/19 Chair of Pancreatic Cancer Europe

Ali Stunt, Chair of Pancreatic Cancer Europe for 2018 / 2019, founder and chief executive of Pancreatic Cancer Action, is a **survivor of pancreatic cancer herself**. As such, she has intimate knowledge of what it takes to win over pancreatic cancer and is a fierce advocate of pancreatic cancer patients. She outlined, in her presentation, the discrepancies that exist in Europe, using the last document PCE produced : the **inequality report**.

The inequality report is an analysis of **the differences in access to care** for pancreatic cancer patients. Scrutinising epidemiology statistics as well as exposure to environmental factors, looking into public funding for research and frequency in European cancer plans, the report intends to decompose the problem of inequalities and **present recommendations** to address this situation.



A preview of the inequality report, presented on the 10th of October

Ali Stunt also mentioned the importance of **organised data collection**. **PancreOS**, an initiative led by Prof Alfredo Carrato, Professor of Medical Oncology at the Institution Ramon y Cajal University Hospital, in Madrid and Board member of PCE, will federate thirteen countries in a single registry project.

Pancreatic Cancer threat – do we have a chance for the future? – Miroslav Ryska, Charles University & Central Military Hospital, Prague

Prof. Miroslav Ryska, from the Charles University and Central Military Hospital in Prague presented population data on the incidence and prevalence of pancreatic cancer in Czech republic as well as trends of epidemiology of malignant tumours, with a special focus on pancreatic cancer.

“Pancreatic Cancer is the most aggressive and devastating solid tumor, with the worst mortality.”

Miroslav Ryska

Patients with pancreatic cancer are treated mostly when they are at an advanced stage of the disease : resection can only be provided in only about **15-20% of cases**.

To address pancreatic cancer, one of the greatest oncological challenges of this century, **early diagnosis is set to be the best answer**. The main role falls to general practitioners, but surgery can also be improved : management and treatment of patients with pancreatic cancer should respect clinical practice guidelines.

Finally, the follow-up with patients should be done more rigorously, to detect recurrence of cancer early in case it reappears.

Showcasing best practices : the French situation – *Mariella de Bausset, Secretary General of the Foundation A.R.CA.D*

Mariella de Bausset and the Foundation A.R.CA.D, founded by Professor Aimery de Gramont, have accomplished many feats in France for pancreatic cancer. Most notably, the Foundation has launched **an ambitious strategy** to discuss pancreatic cancer at every level : with national decision-makers, regional decision-makers, health professionals and the general public. Among other actions, the Foundation has initiated **a series of roundtables in French regions** with high incidence rates to advocate for pancreatic cancer.

The Foundation also sponsored a study to identify loopholes in pancreatic cancer patient's management. The **“Urgence Pancréas”** protocol was launched as a result and aims to accelerate diagnosis and intensive care (within 14 days).

Advocating for a diagnosis programme in Eastern Europe – *MEP Marian-Jean Marinescu (Romania)*



An EU targeted policy begins its journey here, in the European Parliament

MEP Marinescu is an engineer. In his country, Romania, pancreatic cancer is the 6th on the list of the most lethal cancers. Pancreatic cancer incidence and mortality are increasing for all sexes.

MEP Marinescu stated that there is a clear need for an **EU targeted policy**, which will provide research funding to find efficient early diagnosis methods and more efficient treatments. The Horizon 2020 programme might represent an opportunity to pilot a research project, said MEP Marinescu, as he reminded the room that he was **ready to participate to any concrete projects** putting forward the cause of pancreatic cancer.

Open floor discussion and closing

Participants also outlined the **central role of fundamental research** and public funding in pancreatic cancer research. They warned about the current status of research, with a majority of drugs in development outside of Europe, and about the consequent risk of expensive drugs in the coming



years. There are many barriers today that prevent young researchers from dedicating themselves to pancreatic cancer. For instance, a pancreatic surgeon present at the event, went to Canada to do his research thesis because he did not find enough support in Belgium.

“Diagnosis length remains one of the vital challenges all stakeholders need to address and improve. Fundamental research is key in understanding how pancreatic cancer appears.”

MEP Lieve Wierinck (Belgium)

The participants and the speakers finally concluded that **awareness will need to be the centre of any action** undertaken to fight pancreatic cancer. Only when the general public, physicians, policy-makers and industrials are aware of the dramatic situation of pancreatic cancer will we have policies matching the lethality of the **silent killer**.

Contact & Additional information

- If you are interested in the PCE Heatmap, you can access it [here](#).
- The PCE Inequality report is accessible [here](#).
- PCE is always looking to open its doors to new members to support its cause. If you wish to join the fight, you can email us at actionpancreaticcancer@outlook.com.

PCE is registered in the European Transparency Register by the number: 791220833072-74.

List of participants

Name	Organisation
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