

MAKING A DIFFERENCE

A PARLIAMENT MAGAZINE SPECIAL SUPPLEMENT
ON TACKLING PANCREATIC CANCER



A major challenge

The EU must take urgent action on pancreatic cancer, argue **Philippe de Backer, Françoise Grossetête, Philippe Juvin and Daciana Sârbu**

Pancreatic cancer represents a critical public health challenge for which the EU institutions, together with the member states, must take urgent measures.

Survival rates for all major cancers have improved markedly in the last 20 years, but pancreatic cancer represents a big exception. It is currently the fourth deadliest cancer in Europe. More than 95 per cent of patients affected by pancreatic cancer die from the disease and by 2020 it will be the second greatest cause of death from cancer, next to breast cancer.

Together we have decided to call on the EU institutions and the member states to reverse this death rate trend by improving national data collection systems in order to help researchers to better monitor the disease and find new treatments. Pancreatic cancer should become a research priority, particularly in flagship programmes such

as the innovative medicines initiative or Horizon 2020. Research can help bridge the knowledge gap and develop new treatments. Prevention and early diagnosis should also be encouraged and prioritised in national cancer plans and health awareness programmes, particularly as pancreatic tumours can be surgically removed if detected at an early stage.

While many risk factors are related to lifestyle, with tobacco use, obesity, and diabetes playing an important role, the genetic element of pancreatic cancer is also highly significant. Identifying all the genes responsible remains a challenge, but is essential in order to develop targeted screening programmes which could save lives. We need a more intense research effort into hereditary factors and a reduction of known risk factors such as smoking and obesity. We must complement this with increased training and education for Europe's healthcare professionals. These measures should be supported by the EU's health programme and would make a huge impact in the fight against this deadly disease.

Despite the urgent need for action, pancreatic cancer is one of the few cancers which fails to receive political attention and this must change. Pancreatic cancer needs to be prioritised in public health policies at both European and national level. Cancer does not stop at national borders and cancer patients from across Europe are facing similar problems. These difficulties can often be resolved, or at least be influenced, by decisions taken at EU level. There is much to be done.

Philippe de Backer, Françoise Grossetête, Philippe Juvin and Daciana Sârbu are MEP champions for the European parliament call to action on pancreatic cancer

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Warning signals

Pavel Poc says the lack of progress on reducing pancreatic cancer mortality is a serious concern

For Pavel Poc, the issue is clear; cancer must be high on the EU's health agenda, and, in particular, pancreatic cancer. A vice-chair of parliament's environment, public health and food safety committee, Poc pointed to the fact that "more than 1.3 million people will die because of cancer in the EU this year". The Czech MEP also underlined the need for specific action on pancreatic cancer as it "is the only cancer with growing mortality in both men and women" and it has the "highest mortality rates among major cancers". Poc, who put the question of how committed the European commission is to tackling this disease to commissioner-designate Vytenis Andriukaitis, says these numbers are "strong warning signals", adding that previous efforts to deal with the rising incidence of cancer had not succeeded. "It seems our best was not good enough," he says.

"It is a sad story that so many are dying of pancreatic cancer. This is due in part to the lack of diagnostic methods to identify the disease in its early stages. Also, pancreatic cancer generally causes only non-specific symptoms that could be indicators of many different problems within the gastrointestinal tract." These problems related to diagnosis combined with the fact that there are "only limited treatment options available" have led to the high mortality rates among pancreatic cancer sufferers, says Poc.

Despite responsibility for the organisation

and delivery of healthcare resting with the national governments, as set out in the treaties, Poc says there is a role for the European parliament and EU policy in improving outcomes for cancer patients. "The EU can help greatly," he says. "The European Union can work on the pooling of resources, facilitating of information sharing, as well as creating guidelines and expertise to tackle common challenges." As part of this, the S&D deputy said that the parliament will "develop the necessary political pressure on the commission and council to be active in this area".



"It is a sad story that so many are dying of pancreatic cancer. This is due in part to the lack of diagnostic methods to identify the disease in its early stages"

Regarding the efforts of the commission, Poc says, "The EU is keeping cancer on its agenda through the joint action for 2014-2017 called CanCon. This programme aims to reduce cancer incidence by 15 per

cent by 2020." Poc remains optimistic over the EU's combined efforts tackle cancer. "If there is strong support for this joint action from the new commission and in addition maybe an extra portion of pressure on the member states to exercise their competencies in the healthcare thoroughly, then I will be quite happy," he concludes.

Pavel Poc is an ambassador for MEPs against cancer

Pancreatic cancer in numbers

- Pancreatic cancer is the seventh most prevalent cancer in Europe and accounts for 2.8% of cancers in men and 3.4 per cent in women.
- Pancreatic cancer is the fourth deadliest cancer, with more than 95 per cent of those affected dying from the disease.
- According to the European Cancer Observatory there are 103,773 people are currently living with pancreatic cancer in Europe.
- According to a Eurocare study, the overall one-year survival rate in Europe ranges from 11.5 per cent to 28.3 per cent.
- Patients continue to die soon after being diagnosed; research has shown that only 5.7 per cent of people diagnosed with pancreatic cancer in Europe are still alive five years after diagnosis. This means that for every 20 people diagnosed with pancreatic cancer, only one can expect to still be alive five years later.
- The high mortality rate of pancreatic cancer is due primarily to patients presenting with advanced metastatic disease, making the cancer inoperable.
- The pancreas is the only major cancer site for which no improvement in survival rates is predicted for both men and women; in fact, a slight increase in rates is anticipated. New treatment options that can change survival rates is needed.
- Although there have been advances in understanding the molecular make-up of pancreatic cancer, minimal progress has been made in effective treatment for patients that prolong survival

A better understanding

Francesco De Lorenzo says patients have a key role to play in the fight against pancreatic cancer

Firstly, I would like to mention that I have a personal commitment for fighting this type of cancer as my wife died of pancreatic cancer and I know the pain caused by this disease that acts like a time bomb. Pancreatic cancer is not well known and it is poorly understood, due to the fact that signs and symptoms of pancreatic cancer are very difficult to identify. Part of our work consists in educating decision makers about this condition.

Patients are the core and most valuable part of the healthcare team as they are the most affected by the success or failure of their treatment. We understand the disease better than anyone and we are the most determined to find a solution. Patients, carers and family can therefore communicate changes and observations that can make a real difference in their medical world.

However, due to the

high mortality of this disease, there are very few survivors able to advocate for pancreatic cancer patients: in the whole EU, there are currently only six patient organisations devoted to pancreatic cancer. Although these organisations provide very useful information tools to patients, there is still room for improvement, particularly through the

“Patients are the centre and most valuable part of the healthcare team as they are the most affected by the success or failure of their treatment”

support of general, national cancer patients' federations which should provide pancreatic cancer patients with all necessary information regarding treatment – particularly about the existence of innovative therapies.

The ECPC's role is therefore to promote actions enabling all pancreatic cancer patients in the EU to have access to early intervention, ongoing clinical trials and state-of-the-art treatment and care regardless of their nationality or economic status. Furthermore, ECPC has also matured extensive experience in advocating patients' position within the EU institutions and has established throughout the years a very strong network of collaborations. ECPC will effectively contribute in the future in changing EU norms to help optimise

pancreatic cancer prevention, detection, treatment and care throughout Europe, while making sure that the needs of patients are the ultimate priority.

ECPC is aware of the effort made by the EU to harmonise the way member states fight cancer, for example through the two joint actions on cancer EPAAC and CANCON. Through this joint action, the EU has the capacity to promote guidelines and early detection programmes at country level to detect pancreatic cancer at an early stage. Furthermore, the commission, in partnership with the WHO is working with member states to address some of the risk factors of pancreatic cancer such as tobacco, obesity or diabetes. The fourth edition of the European code against cancer is a great example of prevention measures and healthy living. However, the response and endorsement by Europeans need to be more ambitious. Unfortunately, lifestyle prevention policies are only part of the solution. Currently, invasive surgery is the only cure available. This type of treatment is very difficult to perform and requires a high degree of experience and knowledge, which is confined to the limited amount of excellence centres across Europe. Through the recently launched European reference networks, the EU can, in the future, maximise access to the best cancer centres in Europe to all patients needing state of the art treatment.

ECPC has collaborated in the organisation of the first international pancreatic cancer awareness day, which takes place on November 13. Together with several other organisations around the world, we have coordinated our efforts to raise global awareness on pancreatic cancer.

We invite the readers of the Parliament Magazine to join the conversation online with the Twitter hashtag #WPCD and share their thoughts and their own or their loved ones' experience

Francesco De Lorenzo is president of the European Cancer Patient Coalition

Quality control

The European commission is firmly committed to the promotion and coordination of high quality cancer control, says Antoni Montserrat

Action against pancreatic cancer, says Antoni Montserrat, is a “field of activity which the European commission considers highly important”. “First of all we should recognise that the number of new cases of pancreatic cancer in the EU is increasing constantly, with more than 100,000 new cases already in 2012. This cancer is almost always fatal and is the fourth most common cause of death for cancer in the EU, all of which is evidence that we are facing a major health problem.”

Montserrat, who is a policy officer for cancer and rare disease in the commission, says that as far as health is concerned, “the powers of the EU stop at the doors of the hospital”. However, the commission has the capacity to involve itself in “all activities that are previous to the treatment”. “The commission has the possibility to coordinate actions in the field of prevention, in screening, in guidelines and in the coordination of national cancer plans. The commission has been very active with member states over the last three years in developing what we call a joint action with the European partnership for action against cancer (EPAAC). One of the objectives of EPAAC was to persuade member states to adopt national cancer action plans. At the moment, 25 of the EU28 have national cancer action plans in place, which I think is an excellent result.” The

commission has also had a hand in helping member states develop these national action plans, with Montserrat pointing to work on drafting “European guidelines for high quality national cancer control plans”.

For Montserrat, one of the only ways to lower the pancreatic cancer death rates is to “improve prevention measures”.

“There is not a particular scheme for pancreatic cancer, but there are general rules that every citizen should observe for preventing cancer which are very well summarised in the European code against cancer that was launched in October this year. For the most part, recommendations for prevention are similar to those of other cancers and relate to physical activity, smoking and diet. The code, however, constitutes an impressive tool at national level, regional level and citizens’ level across all the member states and is the result of cooperation between the commission and the international agency for research on cancer.”

An area of opportunity for EU level action on pancreatic cancer is through the Horizon 2020 research framework programme which has the “possibility to invest in research on how to prevent

pancreatic cancer”. Montserrat admits, however, that “the possibilities for being efficient in the prevention of pancreatic cancer are complicated”. “Research should be done and would be supported if the commission had good proposals in this field.”

“The possibilities for being efficient in the prevention of pancreatic cancer are complicated. Research should be done and would be supported if the commission had good proposals in this field”

Another means of lowering cancer death rates, says Montserrat, is the commission’s work on creating a “European guide on quality improvement in comprehensive cancer control”. “This is a new joint action called CanCon which was launched this year. This has the very

ambitious objective of adopting European guidelines on quality improvement on cancer which will give recommendations to member states in all the fields related to cancer control, including prevention, screening, treatment and rehabilitation, survival, palliative care, and comparable data collection.”

“These efforts in the areas of prevention and guidelines are what the commission can do at this moment in order to be really efficient in the coordination of member states in the field of cancer,” he concludes.

Antoni Montserrat is cancer and rare diseases policy officer for the European commission’s DG Sanco



Paradigm shift

Europe must 'kick off' a discussion on changing the pancreatic cancer landscape, says J-Matthias Löhr

Pancreatic cancer is a “medical emergency” and must be treated as such if the situation for patients is to be improved, says J-Matthias Löhr. As professor of gastroenterology and hepatology at Sweden's Karolinska Institutet, Löhr has direct experience in tackling what has been referred to as the world's ‘greatest oncological challenge’.

“This is a threefold problem,” he says, first underlining the difficulties surrounding the identification of the disease. “Pancreatic cancer suffers from a very late diagnosis. This is not something on the skin and there is no easy access to this organ. Often jaundice caused by a blocked bile duct is the first sign. Of those who are diagnosed with pancreatic cancer only 22 per cent qualify for surgery compared with 80 per cent for colorectal. For those who do undergo an operation they typically live for another 24 months, while the vast majority of sufferers have only six to eight months.”

The second problem highlighted by Löhr is the lack of money available for pancreatic cancer. “In childhood leukaemia there is lots of money for research, but in pancreatic cancer there is a lack of survivors to raise awareness and campaign for funding.” Pancreatic cancer needs an injection of funds in order to “develop new approaches that can help in earlier diagnosis”, he says.

The third issue relates to research in improving outcomes. “We need more specific research programmes on pancreatic cancer,” stresses Löhr. “At the moment it is the ‘big indicators’ which get the money, which is

shown by colorectal cancer receiving more grants than other types of cancer.” He highlights the technological improvements that are opening up possibilities for new treatments, saying, “Now that we can map the

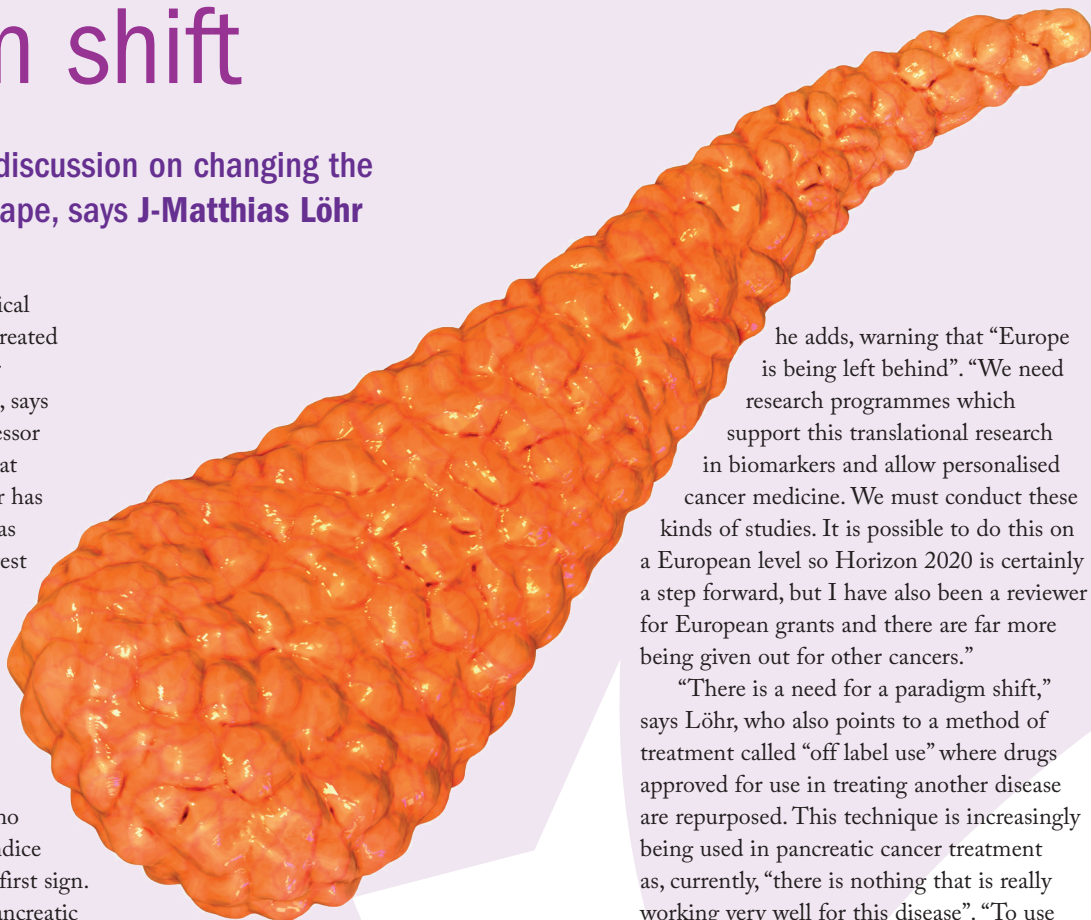
“We need more specific research programmes on pancreatic cancer”

whole genome of a person we must look into developing targeted therapies that work on a cancer's specific genes.” There must be more research into “tumour sequencing” if progress is to be made, says Löhr. “In the US the number of abstracts and studies that involve tumour profiling is increasing exponentially,”

he adds, warning that “Europe is being left behind”. “We need research programmes which support this translational research in biomarkers and allow personalised cancer medicine. We must conduct these kinds of studies. It is possible to do this on a European level so Horizon 2020 is certainly a step forward, but I have also been a reviewer for European grants and there are far more being given out for other cancers.”

“There is a need for a paradigm shift,” says Löhr, who also points to a method of treatment called “off label use” where drugs approved for use in treating another disease are repurposed. This technique is increasingly being used in pancreatic cancer treatment as, currently, “there is nothing that is really working very well for this disease”. “To use this technique on a patient by patient basis and maybe even try drugs which have not been taken for this particular tumour, this is something which people will have to get used to.” “Unfortunately,” he says, “health insurance providers are not allowed to pay out for this kind of therapy.” Löhr concludes by calling on EU policymakers to “kick off a discussion” on how to improve the situation for pancreatic cancer. “The European parliament or commission should,” he says, “actively pursue a discussion from the EU level on how to change the landscape for healthcare providers and how to make these kinds of drugs available for personalised cancer medicine.”

J-Matthias Löhr is professor of gastroenterology and hepatology and senior consultant at the Karolinska Institutet



Raising awareness

Improving patients' understanding of pancreatic cancer is crucial to assisting the fight against this deadly disease, says Ali Stunt

Given the incredibly low survival rate for pancreatic cancer patients, Ali Stunt is lucky to be here at all. The founder and chief executive of Pancreatic Cancer Action – a national UK charity aiming to improve survival through early diagnosis – Stunt says that her beating of this disease was down to “persistence and circumstance”. “I had pain and I would continually go to see my doctor, or go to emergency rooms, and this continued pressure resulted in me receiving a diagnosis. Had it been discovered just a month later I might not have survived.”

Most common symptoms of pancreatic cancer

- **Abdominal pain:** Pain is a symptom in about 70 per cent of pancreatic cancer cases. This often begins as general discomfort or pain in the abdomen which can spread to the back.
- **Jaundice:** Jaundice occurs in about half of pancreatic cancer cases. Common indicators of jaundice are a yellowing of the skin and the whites of the eyes.
- **Weight loss:** Loss of a lot of weight can be a sign that something is wrong. People may also experience a loss of appetite or changes in what they feel like eating.

Stunt's experience highlights the main problems facing pancreatic cancer patients, which she says is that “they are being diagnosed too late”. “There is a problem with medical education,” she says, pointing to the fact that “over 70 per cent of the UK population don't know where the pancreas is located in the body and 50 per cent of patients have never heard of pancreatic cancer before their diagnosis”.

As is clear by the low survival rate for pancreatic cancer patients, raising awareness is crucial to improving outcomes for this disease. “Across Europe there is a lack of individual patient support for pancreatic cancer,” she says, highlighting advocacy as a “really big problem”. However, Stunt praises the efforts of the World Pancreatic Cancer Day campaign, which, she says, “shows that there is a community and allows us to find some focus”. Stunt also underlines the need for a “huge injection of funds” if pancreatic cancer outcomes are to improve. “Pancreatic cancer has been chronically underfunded for decades and there is a serious lack of resources. In the UK the amounts are pitiful, with pancreatic cancer accounting for around one per cent of overall spending on cancer.

“Across Europe there is a lack of individual patient support for pancreatic cancer”

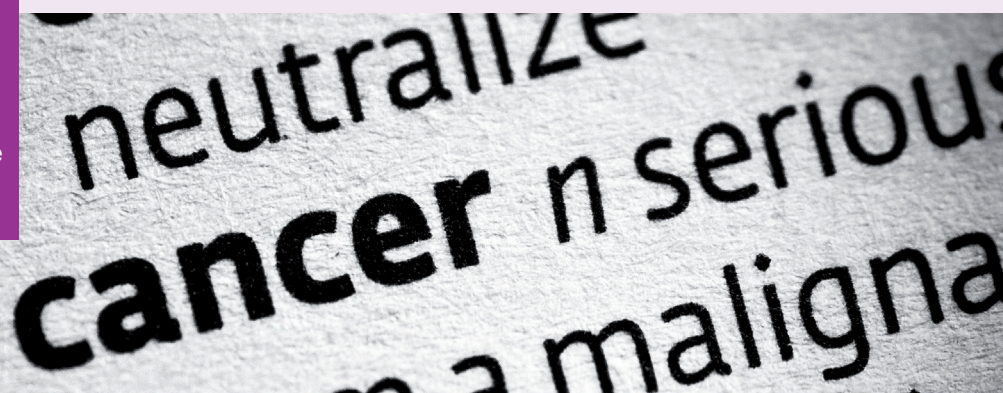
The spend is not proportional to the effects of the disease, but again this brings us back to the awareness issue,” she stresses.

As a means of improving the situation, Stunt issues a call for MEPs and EU policymakers to join the fight against pancreatic cancer by “helping us raise levels of awareness and spreading public health symptoms messages”. She points to the “disparities in survival rates between different countries” as an area where efforts on the European level could be beneficial. “One year survival rates in Bulgaria are as low as 16 per

cent, while other countries have rates as high as 40 per cent. We need to find a way of determining why there are these inequalities in survival rates between countries,” she says. “We must look at the provision

of healthcare across Europe and I would love to see some kind of benchmarking exercise so we can see why it is that some member states are doing much better with one year survival than others. Maybe we can look at benchmarking for pancreatic cancer to take the best performers in Europe and make sure that what they are doing is replicated across the rest of the continent. This might allow us to actually bring up survival rates for patients across the whole of the European Union,” she concludes.

Ali Stunt is founder and chief executive of Pancreatic Cancer Action



A call to action

Giving a voice to pancreatic cancer

Pancreatic cancer is currently a death sentence

Today, a diagnosis of pancreatic cancer is generally associated with a death sentence and few patients are alive one year after diagnosis. The median survival for a person diagnosed with metastatic pancreatic cancer is three months. Worryingly, as the incidence of pancreatic cancer increases with age, it is expected to become even more prevalent in the coming decades as the European population ages. Consequently, by 2020, pancreatic cancer will be the second-greatest cause of death from cancer after breast cancer. While its incidence continues to increase, in the last 20 years there have been very few advances in treatment, making pancreatic cancer a largely neglected disease. There is an urgent need to provide solutions for patients with pancreatic cancer, a deadly disease that leaves patients, their families and healthcare professionals with very little hope.

A variety of factors contributes to increasing mortality rates

Most European countries do not use cancer registries to collect outcome data on the treatment of pancreatic cancer patients. This lack of data collection therefore hampers physicians and researchers' efforts to better understand the disease. It also results in a lack of shared experience amongst scientists, something that has been shown to improve diagnosis and the effectiveness of treatment in other cancers. The increasing mortality rates relate to late diagnosis, generally after the cancer has spread to other organs, which elicits a reaction of resignation and hopelessness in healthcare professionals, explaining why the general course of action is palliation rather than treatment. Furthermore, the high and sudden death rates of people with pancreatic cancer mean that only very few survivors are able to share their experience, which also explains the lack of patients' organisations devoted to pancreatic cancer. Without a strong unified voice, the fight against pancreatic cancer is failing to receive the attention it deserves.

Paving the way for improved care and increased hope

Since 1980, there has been a significant improvement in the death rates of the most prevalent cancers in the European Union, such as breast, cervical, colorectal and lung cancer. Political leadership has proven vital in helping society tackle cancer. European initiatives aiming to address the burden of cancer have significantly influenced policies, awareness programmes and improvement of patient care across Member States. It is proven that a strong, holistic, political commitment to act can have tremendous impact on health issues. It is therefore now time to devote attention to pancreatic cancer, the only cancer where survival rates are declining in both sexes. The European Union has a fundamental role to play in the fight against pancreatic cancer: it is time for EU institutions, Members of the European Parliament and national ministries to support European citizens affected by pancreatic cancer, and trigger real change in research, treatment and care.



We call on European institutions and EU Member States to take immediate action to reverse pancreatic cancer death rates trend by:

- 1. Ensuring pancreatic cancer is included in key European initiatives aiming at fighting cancer, such as the Member States-led 2014-2017 Cancer Control Joint Action (CANCON), the Expert Group on Cancer Control and the EU Network for Cancer Registries hosted by the Joint Research Centre, in view of :**
 - Increasing research to better understand the mechanisms and basic biology of pancreatic cancer;
 - Improving systematic data collection through setting up and maintaining disease registries to increase knowledge of the disease and inform treatment decisions;
 - Identifying appropriate tools and methods to promote earlier diagnosis to provide patients with timely and appropriate care, and therefore improved health outcomes;
 - Providing widespread education programmes to reduce the time from diagnosis to treatment and increase prevention initiatives;
 - Improving the standard of care from purely palliation to active treatment where appropriate.
- 2. Ensuring that Member States include pancreatic cancer in their national cancer plans and in their health awareness programmes**
- 3. Encouraging the creation of a European pancreatic cancer multi-stakeholder platform, including patient representatives, academia, clinicians, policy-makers and industry with an interest in pancreatic cancer:**
 - To help maximise European policy initiatives in view of the dramatic rise in pancreatic cancer mortality rates across Europe;
 - To increase awareness at European and national levels around the need to significantly improve the standard of care for patients with pancreatic cancer.

**Philippe de Backer, Françoise Grossetête,
Philippe Juvin and Daciana Sărbu**