

Euro Pancreatic Cancer Index 2014 Summary

The Euro Pancreatic Cancer Index 2014 is the first Index of its kind. It reflects pancreatic cancer healthcare provision in 30 countries (28 EU member states, Norway and Switzerland) and provides a quick orientation into the matter. The approach taken: how do countries take care of pancreatic cancer patients? What do pancreatic cancer patients receive in terms of healthcare provision? This Index provides an evaluation of the situation in 6 main sub-disciplines important for pancreatic cancer patients and also carers. It looks into Patient rights, information and accessibility issues for pancreatic cancer patients, Prevention, Outcomes, Diagnostics, Treatment and pharmaceuticals and Palliative care by benchmarking countries.



This Index provides 900 scores to 30 indicators x 30 countries. The sub-disciplines and indicators were carefully identified with the valuable expertise of pancreatic cancer specialists. Needless to say, more needs to be done in all areas and most countries can look up to the Netherlands (the winner of the EPCI 2014), closely followed by Denmark, France, Ireland and the UK. The most critical observation is the Outcomes sub-discipline where much of the information hardly exists in the public domain.

On the basis of the information obtained, pancreatic cancer is the only major cancer where survival rates are not improving and action needs to reverse this trend. Improvement will not happen spontaneously, but it can happen. Twenty years ago, most believed HIV/AIDS would remain a death sentence. This Index shows that governments need to invest to make a difference in data collection and provide information to the public and even more so, support patients with pancreatic cancer and improve integrated care and ensure a speedy pathway of treatment: from diagnosis to treatment to outcomes. There may be a need to establish centres of excellence given the incidence rate and combine efforts throughout the EU, Norway and Switzerland for an improved and earlier detection of diagnosis and treatment. Pancreatic cancer patients should not be immediately considered as palliative patients. Speed of care is vital for survival!

EPCI main conclusions:

- Pancreatic cancer, although being fairly rare, has today overtaken stomach cancer to become the fourth largest cancer cause of death in the EU, with currently close to 100 000 deaths per year.
- The low survival rate seems to have created a sense of hopelessness, even among medical professionals. The way forward must be to build on the relative differences of >100 % in national survival rates (from less than 3 % to 7 – 8 %).
- Pancreatic cancer patients are in a particularly vulnerable situation, as the nature of the disease makes it very difficult to form patient organisations/support groups, particularly in countries with less than ~40 million people (= all of the 30 countries except 6).
- It would seem that the low survival rates of pancreatic cancer – largely due to late diagnosis of the disease – have de-motivated registry holders from monitoring progress of pancreatic cancer care.
- There might be a risk for complacency as a result of palliative care being well established, thus blurring the focus on curative treatment.

What to do – best practice:

- Early detection: educate primary care physicians to recognize and act on the *combination* of vague symptoms of Pancreatic Cancer.
- Because of the relative rarity of pancreatic cancer, surgery for the disease should be concentrated to specialist centres, information about and *rapid* access to such centres should be a high priority.
- Collect and report pancreatic cancer data to national cancer registries and make this information layman-friendly and readily available.
- Better manage survival rates by taking actions in narrowing the gaps in pancreatic cancer care provision.
- Measure pancreatic care provision in the same way as any other more common cancer.
- Encourage governments to invest in pancreatic cancer research especially in the field of early diagnostics.
- Improve integrated care for pancreatic cancer patients by ensuring rapid referral for specialist treatment as speed is vital for survival.