DIGESTIVE CANCERS
EUROPE

Digestive Cancers Europe

Pancreatic Cancer: The Time To Act Is Now 2022

A white paper from the perspectives of patients with pancreatic cancer calling for urgent action in 10 key areas

About the white paper

This white paper has been developed by Digestive Cancers Europe (DiCE) after consultation with patients who have had pancreatic cancer, representatives of cancer patient organisations, and leading healthcare professionals working in pancreatic cancer.

The purpose of the paper is to highlight the key urgent unmet needs in pancreatic cancer from the patient perspective, ultimately with a view to improve patient care and outcomes in this very challenging disease.

About DiCE

Digestive Cancers Europe (DiCE) is the European umbrella organisation of a large group of national Members representing patients with digestive cancer – colorectal, gastric, liver, oesophageal, pancreatic and rare cancers. Our mission is to contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life.

You can find out more about DiCE on our website:
digestivecancers.eu

INTRODUCTION

Pancreatic Cancer: Why Are We Calling For Urgent Action?

Pancreatic cancer is a disease **requiring urgent attention from governments and policymakers.** Recently, both a position paper published by United European Gastroenterology and an editorial in The Lancet Gastroenterology Hepatology have declared that **pancreatic cancer is a state of emergency.**[1,2]

Pancreatic cancer has **the lowest survival rate of all common cancers,** with life expectancy at the time of diagnosis of around just five months.[3] Around 92% of patients die within five years of their diagnosis.[4] It is the fourth most common cause of cancer death in the EU, accounting for around 90,000 deaths in 2020.[5]

Where there has been progress in improving survival rates in most other cancers, there has been very little progress in pancreatic cancer.[6]

> "Pancreatic cancer is a 'siren' cancer – for us it is an emergency, the lights are flashing and the siren is sounding. We are fighting for survival. We need and demand improvements."
>
> **- Eva,** Pancreatic Cancer Patient, Sweden

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1. UEG Position Paper Pancreatic Cancer: a medical emergency. November 2020. Available at this link
2. The Lancet Gastroenterology Hepatology. Pancreatic cancer: a state of emergency? Lancet Gastroenterol Hepatol. 2021 Feb;6(2):81. doi: 10.1016/S2468-1253(20)30397-6. PMID: 33444531.
3. Ferlay J, *et al.* More deaths from pancreatic cancer than breast cancer in the EU by 2017. Acta Oncol. 2016 Sep-Oct;55 (9-10):1158-1160.
4. Minicozzi P, *et al.* Analysis of incidence, mortality and survival for pancreatic and biliary tract cancers across Europe, with assessment of influence of revised European age standardisation on estimates. Cancer Epidemiol. 2018 Aug;55:52-60. doi: 10.1016/j.canep.2018.04.011.
5. ECIS - European Cancer Information System. 2021. Available at this link
6. Guidelines in practice. Pancreatic cancer: GPs can help prognosis by identifying early signs. Available at this link

One of the major reasons why pancreatic cancer is associated with such poor outcomes is because it is usually diagnosed at a late stage: at least 85% of new diagnoses are not candidate for surgery and present a locally advance or metastatic disease.[7,8] **The survival rate is much higher when the cancer is found at an earlier stage and surgery is possible.**

In Europe, pancreatic cancer has a relatively high – and rising – incidence compared to other regions.[9] It is vital that governments and policy-makers provide adequate resources for the prevention, early diagnosis and management of pancreatic cancer to improve these trends in the near future. While the challenges in this area are great, these must also be seen as opportunities – **the potential impact of any improvements could be significant for patients.**

We are calling for action across 10 key areas to help improve awareness, prevention, diagnosis, treatment and proper management of patients with pancreatic cancer.

The time for action is now.

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7. Seigel RL, *et al.* Cancer Statistics 2021. CA Cancer J Clin. 2021;71:7–33
8. Mizrahi JD, *et al.* Pancreatic cancer. Lancet. 2020;395:2008–2020. doi: 10.1016/S0140-6736(20)30974-0.
9. Prades J, *et al.* Bratislava Statement: consensus recommendations for improving pancreatic cancer care. ESMO Open. 2020;5(6):e001051.

What is Pancreatic Cancer

Pancreatic cancer is a cancer that forms in the pancreas. The pancreas is an essential organ in the body, located below the stomach, which is important for digesting food and managing use of sugar for energy after digestion. **There are several types of pancreatic cancer, including pancreatic cancer ductal adenocarcinoma (PDAC), pancreatic neuroendocrine tumours (pNETs) and pancreatic neuroendocrine carcinomas (pNECs).**

The vast majority (around 93%) of pancreatic cancers arise from the exocrine parts of the pancreas (which aid digestion).[10] Within this category, most tumours are 'adenocarcinomas', which means a cancer which originated in glandular cells. This form of cancer is often known as pancreatic cancer ductal adenocarcinoma (PDAC).

For the purpose of this white paper, we will focus on PDAC as it is the most prevalent form and also extremely aggressive. When we refer to 'pancreatic cancer' in this document, we are referring to PDAC.

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10. Pancan, 2021. Pancreatic Cancer Action Network. Available at this *link*
11. ACS 2021. Pancreatic Cancer Risk Factors. Available at this *link*
12. Li D, Diabetes and pancreatic cancer. Mol Carcinog. 2012;51(1):64-74. doi:10.1002/mc.20771
13. NICE 2020. Pancreatitis NICE guideline [NG104]Published: 05 September 2018 Last updated: 16 December 2020. Available at this link.
14. CRUK, 2021. Pancreatic Cancer. Risks and causes. Available at this *link*
15. John Hopkins, 2021. About familial pancreatic cancer. Available at this *link*

What Causes Pancreatic Cancer?

Factors that may increase the risk of pancreatic cancer include:

Smoking

Smoking increases risk of all types of cancer. About 25% of pancreatic cancers are thought to be caused by cigarette smoking.[11]

Obesity

Obese people (body mass index [BMI] of 30 or more) are about 20% more likely to develop pancreatic cancer.[11]

Type-2 diabetes mellitus

Long-term type 2 diabetes mellitus is associated with a 1.5 to 2.0-fold increase in the risk of pancreatic cancer.[12]

Chronic pancreatitis

It is the inflammation of the pancreas. It is typically a painful pancreatic disease, which significantly increases the risk of pancreatic cancer.[13]

Heavy alcohol consumption

Around 7 out of 10 cases of chronic pancreatitis are due to long term heavy drinking.[14]

Family history of cancer, particularly pancreatic cancer

About 5-10% of pancreatic cancer patients have another close relative who has also developed pancreatic cancer. Individuals with a family history of pancreatic cancer are more likely to have an inherited mutation in a gene that increases their risk of developing pancreatic cancer.[15]

Blood type other than type O

Studies have shown that the risk of pancreatic cancer is lowest among individuals with blood type O.[16]

Asthma and nasal allergies have been associated with a reduced risk of pancreatic cancer.[17]

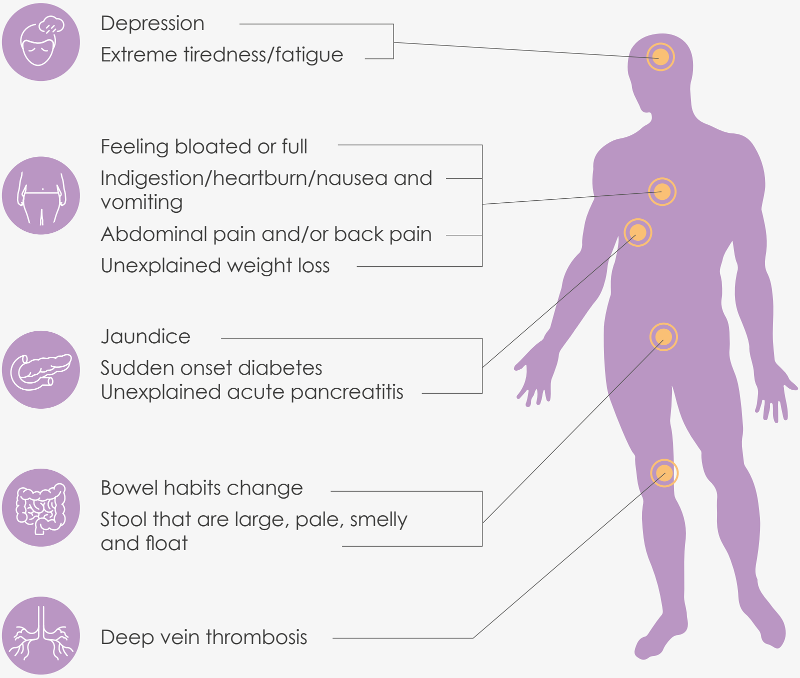
16. Wolpin BM, *et al.* ABO blood group and the risk of pancreatic cancer. Journal of the National Cancer Institute. 2009; 101:424-431

17. Gomez-Rubio P, *et al.* PanGenEU Study Investigators. Reduced risk of pancreatic cancer associated with asthma and nasal allergies. Gut. 2017 Feb;66(2):314-322. doi: 10.1136/gutjnl-2015-310442. Epub 2015 Dec 1. PMID: 26628509

What Are The Signs And Symptoms Of Pancreatic Cancer?

One of the biggest challenges with diagnosing pancreatic cancer at an early stage is **that signs and symptoms of pancreatic cancer often don't occur until the disease is advanced** [18] and when symptoms do appear, they may be easily confused with those of other illnesses. It is therefore vital that the general public and general practitioners (who act as a gateway to diagnosis and care) are aware of the common symptoms.

The key warning signs of pancreatic cancer are [19]:



- Depression
- Extreme tiredness/fatigue

- Feeling bloated or full
- Indigestion/heartburn/nausea and vomiting
- Abdominal pain and/or back pain
- Unexplained weight loss

- Jaundice
- Sudden onset diabetes
- Unexplained acute pancreatitis

- Bowel habits change
- Stool that are large, pale, smelly and float

- Deep vein thrombosis

18. Mayo Clinic. Pancreatic Cancer. Available at this *link*
19. Pancreatic Cancer Europe. 2016. The 10 warning signs of pancreatic cancer. Available at this *link*

Call to Action

Pancreatic cancer represents an urgent unmet need in Europe, which is often overlooked. The appalling patient outcomes associated with this disease speak for themselves. Not enough progress has been made in the last decades. The patient voice largely goes unheard in this area. This is why we have positioned this white paper from the perspective of patients and it has been developed in close consultations with patients from across Europe. It is time their voices are heard.

We are proposing core recommendations across 10 key areas as follows:

1. **AWARENESS:**
   Raise awareness of pancreatic cancer and potential ‘red flags’ to drive earlier diagnosis
2. **SCREENING:**
   Screen high-risk populations and accelerate referral times
3. **INFORMATION:**
   Ensure patient information is clear, timely and contains hope
4. **CENTRES OF EXCELLENCE:**
   Ensure that patients are only treated in high-volume pancreatic cancer centres
5. **HEALTHCARE PROFESSIONAL RELATIONSHIP:**
   Ensure continuity of care for patients, supported by amulti–disciplinary team (MDT)
6. **TREATMENT:**
   Ensure patients can proactively participate in their own care
7. **SUPPORT:**
   Ensure patients have access to essential psychological, nutritional and pain relief support as needed
8. **PATIENT ORGANISATIONS:**
   Create environment for national patient organisations to flourish, including via proper funding
9. **RESEARCH:**
   Increase levels of research and funding for pancreatic cancer
10. **DATA AVAILABILITY:**
    Practice good data collection and sharing. More information on each of these areas can be found on the following pages. We are calling for action across all 10 key areas to help improveawareness, prevention, diagnosis, treatment and management of patients with pancreatic cancer.

10 Key Areas Of Action In Pancreatic Cancer

1 Awareness: Raise awareness of pancreatic cancer and 'red flags' to drive earlier diagnosis

Despite being one of the leading causes of cancer death, there is "a startling lack of awareness" of pancreatic cancer.[2]

This must be urgently addressed because late-stage diagnosis is a major reason for the appalling mortality rate in pancreatic cancer. The survival rate is much higher when the cancer is found at an earlier stage. Because the signs and symptoms of pancreatic cancer are easy to confuse with those of other illnesses, it is vital that the general public and general practitioners (who act as a gateway to diagnosis and care) are aware of the common symptoms, so that a diagnosiscan be made as early as possible.

> "Pancreatic cancer is a 'siren' cancer – for us it is an emergency, the lights are flashing and the siren is sounding. We are fighting for survival. We need and demand improvements."
>
> - **Eva,** Pancreatic Cancer Patient, Sweden

Information and training should be made available for primary care practitioners to spot early 'red flag' signs and symptoms in their patients. A red-flag symptom can be defined as one that might alarm the patient and indicate the presence of pancreatic cancer, and may include symptoms of dysphagia, loss of appetite, weight loss, abdominal or back pain, or abdominal distension.[20] Diabetes mellitus is a presenting feature in up to 10% of cases, so primary care physicians should be clinically suspicious when treating patients with new-onset diabetes.[21] It is also important **that the general public is made aware that symptoms such as these necessitate a visit to the doctor.**

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2. The Lancet Gastroenterology Hepatology. Pancreatic cancer: a state of emergency? Lancet Gastroenterol Hepatol. 2021 Feb;6(2):81. doi: 10.1016/S2468-1253(20)30397-6. PMID: 33444531.
20. Hippisley-Cox J, *et al.* Identifying patients with suspected pancreatic cancer in primary care: derivation and validation of an algorithm. Br J Gen Pract. 2012;62(594):e38-e45. doi:10.3399/bjgp12X616355
21. Raimondi S, *et al.* Nat Rev Gastroenterol Hepatol 2009; 6(12): 699-708.

2 Screening: Screen high-risk populations and accelerate referral times

Given the low 5-year survival rates associated with pancreatic cancer and the need for earlier diagnosis, **there may be great potential in defining populations at risk who could benefit from a protocolised screening program.**[22]

> "It's really important that primary care professionals and also the general public are aware of the symptoms. I'd never heard of pancreatic cancer before my own diagnosis. I assumed everyone had surgery for pancreatic cancer until I found out actually it's only one in five of us at the most who are able to have that."
>
> **– Ali,** Pancreatic Cancer Patient, UK

Unfortunately, there is currently a lack of effective screening tests, and defining high-risk populations has proven to be very challenging.[22] A recent UEG position paper on pancreatic cancer calls for more multi-national large-scale studies to elucidate the impact of various factors, including lifestyle habits, diets and dietary constituents, microbiota and others.[22]

Some of the key warning signs of pancreatic cancer are unexplained weight loss, changed bowel habits (diarrhoea, steatorrhoea), nausea, jaundice, abdominal pain, mid-back pain, new onset of diabetes not associated with weight gain (especially in case of pain) and deep vein thrombosis.[19] There is also research that suggests an increased vulnerability to depression in the early stages of pancreatic cancer.[23] For now, **a specific screening program is proposed to individuals with a strong family history of pancreatic cancer and/or genetic susceptibility of developing the condition,** among them individuals with suspected familial pancreatic cancer (FPC).[22]

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19. Pancreatic Cancer Europe. 2016. The 10 warning signs of pancreatic cancer. Available at this link

22. Michl P, *et al.* UEG position paper on pancreatic cancer. Bringing pancreatic cancer to the 21st century: Prevendetect, and treat the disease earlier and better. United European Gastroenterol J. 2021 Aug 25;9(7):860–71. doi: 10.1002/ueg2.12123. Epub ahead of print. PMID: 34431604; PMCID: PMC8435257.

23. Sebti J, *et al.* (2015). Prodromal depression in pancreatic cancer: Retrospective evaluation on ten patients. Palliative and Supportive Care, 13(3), 801-807.

It is thought that up to 10% of pancreatic cancer cases are linked to genetic conditions.[24] Genetic screening is currently available and certain genetic mutations and risk factors have been detected. Individuals with mutations in the BRCA2, PALB2, p16, STK11, ATM, PRSS1, and HNPCC genes are associated with significantly increased risk for pancreatic cancer and need to be screened.[25]

There are treatments available that are more effective for patients with certain gene mutations. Patients with germline BRCA1/2 mutations may benefit from platinum-based chemotherapies or treatment with a PARP inhibitor.[26] **All patients should have the right to be tested for relevant mutations.** This is a fast-moving space. As such, genomic sequencing should be offered as standard for those with suspected pancreatic cancer to provide the best possible insight to tumour biology and current and future targeted treatments.

In addition, there is great potential for faster and more joined up referrals and earlier onset of treatment. One study showed that 40% of pancreatic cancer patients visit their primary care practitioner three times or more before being referred to hospital for investigation.[27]

There is a great need to accelerate referral times to ensure patients have the best possible opportunity for effective treatment, including surgical resection. The pathway from diagnosis to treatment is more complex in pancreatic cancer than most other diseases and it involves multiple clinical investigations and tests from different specialists and hospitals. This is why referral to a high-volume specialised centre under the management of a MDT to determine the best treatment plan for each individual is so essential (see point 4).

> "If I was in that small percentage, I would absolutely want to have that treatment. But people will be walking around with the disease that actually don't know that they could respond because they've not been tested."
>
> **– Ali,** Pancreatic Cancer Patient, UK

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[24] Salvatore T, (2015). Pancreatic cancer and diabetes: A two-way relationship in the perspective of diabetologist. International Journal of Surgery. 21 (1), 72-77.

[25] Chang Wu, *et al.* Pancreatic cancer screening in different risk individuals with family history of pancreatic cancer-a prospective cohort study in Taiwan. Am J Cancer Res. 2017;7(2):357–69.

[26] Idachaba S, *et al.* A Review of Pancreatic Cancer: Epidemiology, Genetics, Screening, and Management. Open Access Maced J Med Sci. 2019;7(4):663-671. Published 2019 Feb 14. doi:10.3889/oamjms.2019.104

[27] National Cancer patient Survey, 2010, Department of Health

3 Information: Ensure patient information is clear, timely and contains hope

One of the key principles of the European Cancer Patient's Bill of Rights is the right of every European citizen to receive the most accurate information and to be proactively involved in his/her care.[28]

The amount and type of information provided to patients with pancreatic cancer is key.

In terms of the amount, patients say they are often overwhelmed by information, which can be difficult to process. Often a lot of information is not relevant to a patient's individual situation. Sometimes, information is difficult to understand. **Information should be clear and timely, providing the right information at the right time.** This should also be made available to carers and loved ones.

With a type of cancer with such a poor prognosis as pancreatic cancer, it is also important that the tone of information is well balanced. A lot of publicly available information on pancreatic cancer is very bleak for newly diagnosed patients (and their loved ones) to read. Many cancer patients (and healthcare professionals) talk about the value of hope. Indeed, data suggest that hope is an important resource for oncology patients that impacts their quality of life and has been found to mediate the relationship between psychological distress and health status.[29] It is important to offer this hope in the context of the facts. **Even if the chances of survival are small, knowing that there is a chance is hugely important for many patients at the start of their journey.**

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[28] Lawler M, *et al.* The European Cancer Patient's Bill of Rights, update and implementation 2016. ESMO Open. 2017;1(6):e000127.

[29] Rustøen, *et al.* PhD; Miaskowski, Christine PhD, RN, FAAN The Importance of Hope as a Mediator of Psychological Distress and Life Satisfaction in a Community Sample of Cancer Patients, Cancer Nursing: July 2010 - Volume 33 - Issue 4 - p 258-267

④ Centres of Excellence: Ensure that patients are only treated in high-volume specialist centres

Diagnosis and management of pancreatic cancer is more complex that most other diseases and it involves multiple clinical investigations and tests from different specialists. This is why referral to a high-volume specialised centre under the management of an MDT to determine the best treatment plan for each individual is so essential. The Organisation of European Cancer Institute (OECI) published 100 European core quality standards for cancer care and research centres, which helps to define quality standards for cancer care, treatment, and research in Europe, with a focus on cancer hospitals, centres, and networks.[30]

High-volume specialised centres are associated with reduced post-surgery mortality and better median survival.[31]

The use of centralised specialist centres for advanced pancreatic cancer management results in prompt, safe and higher use of chemotherapy or participation in clinical trials, when compared with devolved care, associated with a modest survival benefit.[32]

The recent Bratislava consensus statement concluded that **substantial improvements can be achieved in patient outcomes by centralising pancreatic cancer care around state-of-the-art reference centres,** staffed by expert multidisciplinary teams capable of providing high-quality care.[9] In addition, there have been calls for consensus around defining quality standards for cancer care, treatment, and research in Europe, with a focus on cancer hospitals, centres, and networks. Specialist centres in pancreatic cancer produces a net benefit for both patients (better outcomes) and healthcare systems (more efficient use of resources).

Every patient should have the right to be treated at a specialist centre to provide the best opportunity for a positive outcome. Health ministers of every country should ensure expert centres have been identified in the country based on their proven expertise.

If treatment or a certain procedure is not available in a patient's home country, they should have the opportunity for care in another European country thanks to the cross border healthcare directive.

However, the volume of patient mobility within the European Union remains relatively low as people are frequently unwilling to travel to other countries for care. In addition, the directive asks patients to pay for their treatment, and then get reimbursed, which is prohibitive for many patients as cancer care is often very expensive. Nonetheless, the option for cross-border care should be one that patients are made aware of.

> "I think we need to make patients aware that if they're willing to travel, then they have a right to treatment anywhere in Europe."
>
> – **Ali,** Pancreatic Cancer Patient, UK

European Reference Networks (ERNs) are networks of expert reference centres for rare medical conditions, bringing together healthcare professionals with documented expertise across all countries in Europe. While this model is currently for rare diseases only, it could offer a model for cross-border best practice sharing for other diseases, including pancreatic cancer.

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9. Prades J, *et al.* Bratislava Statement: consensus recommendations for improving pancreatic cancer care. ESMO Open. 2020;5(6):e001051.

30. Oberst S, *et al.* 100 European core quality standards for cancer care and research centres. Lancet Oncol. 2020 Aug;21(8):1009-1011.

31. Gooiker G. A, *et al.* Impact of centralization of pancreatic cancer surgery on resection rates and survival. British Journal of Surgery 101, 1000-1005, doi:10.1002/bjs.9468 (2014).

32. Faluyi O, *et al.* Advanced pancreatic adenocarcinoma outcomes with transition from devolved to centralised care in a regional Cancer Centre. Br J Cancer 116, 424–431 (2017).

5 Healthcare Professional Relationship: Ensure continuity of care for patients supported by MDT

The doctor-patient relationship is extremely important. Trust, knowledge, regard, and loyalty are the four elements that form the doctor-patient-carers relationship, and the nature of this relationship has an impact on patient outcome.[33]

Every patient has the right to have their diagnosis provided to them in an accurate and compassionate manner, by a specialist/experienced clinician [28], and for their ongoing care to continue in the same way. The European Cancer Patient's Bill of Rights highlights the right to a nominated member of the treatment team who can answer patient concerns and who can coordinate care on a patient's behalf when necessary.

> "It can be difficult changing doctors so often. It would be helpful to have the continuity of care of having one key doctor throughout, who takes your hand at the beginning and comes with you through the whole journey."
>
> **– Eva,** Pancreatic Cancer Patient, Sweden

Pancreatic cancer is a complex disease requiring a multitude of different healthcare professionals, so the single point of contact is not always a reality.

However, for patients, having **continuity of care** – in terms of a patient repeatedly seeing the same doctor and forming a therapeutic relationship – has been described as an essential feature of general practice.[34]

Relationship continuity is highly valued by both patients and clinicians, and it leads to more satisfied patients and staff, reduced costs and better health outcomes.[34] Behind that single point of contact should be appropriately multidisciplinary specialised care to ensure best possible outcomes.

Every patient should also have the opportunity to have a second opinion. In addition, if patients are unhappy with the care they are receiving, every patient should have the right and the possibility of changing their doctor accordingly.

> "The relationship you have with your doctor is really crucial, but it's hard to find someone you fully connect with and fully trust."
>
> **– Patrycja,** Pancreatic Cancer Patient, Poland

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28. Lawler M, *et al.* The European Cancer Patient's Bill of Rights, update and implementation 2016. ESMO Open. 2017;1(6):e000127.
33. Chipidza FE, *et al.* Impact of the Doctor-Patient Relationship. Prim Care Companion CNS Disord. 2015;17(5):10.4088/PCC.15f01840. Published 2015 Oct 22. doi:10.4088/PCC.15f01840
34. The King's Fund. Continuity of care and the patient experience. Available at this link

6 Treatment: Ensure patients can proactively participate in their own care

Patients should have the right to access, if they so choose, all information regarding their state of health and to proactively participate in decision making regarding their treatment.[28]

Unfortunately, effective treatment options for pancreatic cancer are limited. Surgery is the only potential curative treatment for the disease, but just 20% of patients – at most – are candidates for this approach.[9]

Furthermore, health services must place a clear emphasis on reducing delay in starting surgical treatment as commonly reported by patients.

When surgery is not an option, chemotherapy can increase life expectancy and quality of life of people living with pancreatic cancer.[35] However, not all patients have it. Increasing the number of people receiving treatment will give people diagnosed with pancreatic cancer a chance to survive longer. In all cases, patients diagnosed with advanced disease must receive immediate supportive care for mitigate or control their symptoms.

> “They were not at all willing to give me FOLFIRINOX in the beginning. It was only because I was so determined that they gave it. Of course it was tough, but it had the desired effect as the tumour shrank and it stabilised, which meant I could have an operation.”
>
> **– Eva,** Pancreatic Cancer Patient, Sweden

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28. Lawler M, *et al.* The European Cancer Patient’s Bill of Rights, update and implementation 2016. ESMO Open. 2017;1(6):e000127.
9. Prades J, *et al.* Bratislava Statement: consensus recommendations for improving pancreatic cancer care. ESMO Open. 2020;5(6):e001051.
35. Shaikh J, Is Chemo worth it for pancreatic cancer? Medicinenet. 2021. Available at this *link*

Patients diagnosed with pancreatic cancer should have all realistic options open to them – which may include surgery, chemotherapy and/or participating in clinical trials.

Clinical trials may represent the best possible treatment option for patients, but too many patients are never informed about the possibility of participating in them. **Patients should have access to up-to-date information on clinical trials** via a public domain and through their clinicians and request their participation in clinical trials if they meet the inclusion criteria.

> "They were not at all willing to give me FOLFIRINOX in the beginning. It was only because I was so determined that they gave it.
>
> Of course it was tough, but it had the desired effect as the tumour shrank and it stabilised, which meant I could have an operation."
>
> **– Eva,** Pancreatic Cancer Patient, Sweden

It is also important to ensure patients are constantly assessed by the MDT/ tumour board as the situation can change very quickly. Ideally, restaging should be undertaken every 2-3 months and the results again discussed in an MDT meeting.

7 Support: Ensure patients have access to essential psychological, nutritional and pain relief support as needed

Pancreatic cancer and its treatment can lead to a range of other physical and psychological problems for which patients need – but don't always receive – support.

In a systematic review of the burden of pancreatic cancer in Europe, including on health-related quality of life (HRQoL), patients with pancreatic cancer had significantly lower scores on validated HRQoL scales than the general population, with the most significant symptoms being pain, appetite loss and insomnia. Patients with pancreatic cancer experienced depression and anxiety.[36]

People with pancreatic cancer have high levels of anxiety and depression and reduced quality of life.[37]

Depression is also relatively common in relatives or carers. One study showed that caregivers more frequently than patients described feeling heartbroken or devastated at diagnosis.[37] Cancer patients with depression have 39% higher risk of mortality, higher healthcare utilisation, and higher healthcare expenditure than patients who do not have depression [38] – pointing to the need for appropriate psychological support.

Psychological support should be made available for all patients and carers. However, a global report revealed that a third (34%) of those patients who said they needed psychological support reported it was 'not available'.[39]

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37. Janda M, *et al.* Anxiety,depression and quality of life in people with pancreatic cancer and their carers. VL.Pancreatology. 2017 Mar-Apr;17(2):321-327. doi: 10.1016/j.pan.2017.01.008. Epub 2017 Jan 20.PMID: 28153446
38. Smith HR. Depression in cancer patients: Pathogenesis, implications and treatment (Review). Oncol Lett. 2015;9(4):1509-1514. doi:10.3892/ol.2015.2944
39. All.Can. Patient insights on cancer care: opportunities for improving efficiency Findings from the international All. Can patient survey. 2019. Available at this *link*

More than 80% of patients suffer from significant weight loss at diagnosis and over time develop severe cachexia (a condition that causes extreme weight loss and muscle wasting). Early nutritional support is therefore essential.[40] However, there is a huge unmet need to integrate nutritional therapy as a crucial part of the multimodal care process in patients with pancreatic cancer.[41]

> "I was in awful pain. I remember one of the nurses saying to me that in this day and age, nobody should be in pain because we've got the drugs to treat it. But there just seems to be a lack of will or lack of thinking."
>
> **– Ali,** Pancreatic Cancer Patient, UK

Pain in the abdomen (belly) or back is common in pancreatic cancer. Some patients experience excruciating pain. With the pain relief available today, there is absolutely no reason why any patient should consistently be in pain, but it is too often still the case. Research into alternative methods of pain relief, such as medicinal cannabis, should be supported.

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40. Gärtner S, *et al.* Nutrition in Pancreatic Cancer: A Review. Gastrointest Tumors. 2016;2(4):195-202. doi:10.1159/000442873

41. Carrato A, *et al.* Clinical nutrition as part of the treatment pathway of pancreatic cancer patients: an expert consensus. Clin Transl Oncol (2021). Available at this *link*

8 Patient Organisations: Create environment for national patient organisations to flourish, including via proper funding

Patient organisations and advocacy groups play a significant role in cancer, from raising awareness of a condition, providing guidance and advice to patients throughout their treatment journey, to acting as an advocate and champion for patients to ensure their voice is heard. However, in part due to the high mortality of pancreatic cancer and thus the lack of survivors, there are only six pancreatic cancer patient organisations in Europe.[42] Lack of funding and support is also a major issue.

It is essential that national patient organisations are given all the support required to start and to flourish and to play an active role in patient care. This may include providing information for patients, raising awareness of the condition among primary healthcare professionals and the general public, provision of counselling or listening services, legal and financial support, and advocating for patients at the policy level.

> "Some countries just culturally are not used to having patient advocacy groups. So there isn't always that support for people to go to."
>
> **– Ali,** Pancreatic Cancer Patient, UK

To be able to flourish, **governments should provide funding for patient organisations to ensure continuity and development, and optimal support for patients.** Currently, patient organisations are the only stakeholders expected to work pro bono and invest their own time and finances. To ensure stable and functioning organisations, with time available to engage in advocacy and promote the changes needed, this must change.

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[42] ECPC. Pancreatic Cancer. Available at this *link*

9 Research: Increase levels of research and funding for pancreatic cancer

There are still many unanswered questions about the biology and aetiology of pancreatic cancer; in particular, the discovery of biomarkers that will aid earlier detection of pancreatic cancer is imperative, as is a more precise definition/understanding of "high-risk populations".

Unfortunately, pancreatic cancer is a "neglected cancer", which lacks high-visibility research efforts to improve care.[9]

The Bratislava consensus statement stated the need to establish a research agenda for neglected cancers at the European level, using pancreatic cancer as the archetype. In particular, research should be prioritised on prevention, risk prediction, early detection and diagnosis, and rapid referral for treatment.[9]

There is a need to encourage international exchanges on the management of pancreatic cancer in order to improve our knowledge of the disease. "Research programmes should be developed and carried through in collaboration with national and international partners, patient organisations, and other public and private partners with a special interest in pancreatic cancer".[9]

Funding for pancreatic cancer research has lagged behind other cancers in many countries, and in Europe has received less than 2% of all cancer research funding. This needs to be urgently addressed to increase the possibility of progress.

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9. Prades J, *et al.* Bratislava Statement: consensus recommendations for improving pancreatic cancer care. ESMO Open. 2020;5(6):e001051.

10 Data Availability: Practice good data collection and sharing

Good cancer data collection and sharing, predominantly via national cancer registries, can be used for cancer control and epidemiological research, public health programme planning, and patient care improvement. Ultimately, all of these activities reduce the burden of cancer.[43]

However, **cancer registration practice, coverage and quality are highly unequal across Europe.[44]**

Consequently, basic epidemiological data on incidence, mortality and survival are not uniformly available for all countries.

Only a few countries have established clinical registries capable of benchmarking pancreatic cancer care and there is little historical pan-European cooperation on establishing comparable indicators. There are recent initiatives that are aiming to fill this gap from Pancreatic Cancer Europe and EURECCA (European Registration of Cancer Care).[45]

Collection of data is also vital for identifying gaps within and between countries in patient diagnosis and treatment.

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44. Forsea A.M, 2016. Cancer registries in Europe – going forward is the only option. Ecancermedicalscience 10, 641.
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Conclusions

There is no common cancer with so many areas of urgent unmet needs as pancreatic cancer.

The appalling patient outcomes associated with this disease speak for themselves. Not enough progress has been made in recent years.

The patient voice largely goes unheard in this area. It is time to be heard.

We are calling for governments and policymakers to act now across all 10 key areas highlighted in this report to help improve awareness, diagnosis, treatment and management of patients with pancreatic cancer.

The time to act is now

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