



Scientific Research Strategy

Delivering the decade of change

Saving lives through early diagnosis

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Our Vision

At Pancreatic Cancer Action we have a very clear vision. Our vision is that everyone survives pancreatic cancer.

Our mission is to improve survival rates of pancreatic cancer by ensuring more people are diagnosed early and that everyone has access to effective treatments, support, information and care.

In the UK, over 10,500 people are newly diagnosed with pancreatic cancer each year. Pancreatic cancer is the deadliest of all the common cancers. In England, only 25.4% of pancreatic cancer patients survive one year after diagnosis and only 7.3% of people survive five years after diagnosis. Pancreatic cancer is the 5th biggest cause of cancer death in the UK; however, it is set to become the 4th, overtaking breast cancer by 2026 as other cancers' survival rates continue to improve. That is why Pancreatic Cancer Action has set out a campaign to make the next ten years a decade of change. The survival rate beyond ten years is just 1% for pancreatic cancer, even if treatment is an option. To give context, the ten-year survival rate for breast cancer is 76%, prostate cancer is 78%, and bowel cancer is 53%.

Pancreatic cancer can be a difficult condition to diagnose. Symptoms of the disease can present as vague and therefore are often mistaken for other conditions which are more common. Misdiagnosis of pancreatic cancer can increase the time between visiting the doctor and getting the correct diagnosis. Patients who are misdiagnosed also have, on average, more visits to their GP and more diagnostic tests. This increases the risk of pancreatic cancer being diagnosed late.

Despite these clear and present challenges, the combined UK Government and voluntary sector investment into pancreatic cancer research is only 6.13% of the total cancer research funding.

In order to achieve our vision, we need innovative research. Our new research strategy sets out how we will put our words into action and help make our vision a reality. It demonstrates how we will both fund and support innovative research, to improve early diagnosis and develop effective treatments to improve pancreatic cancer outcomes.

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A history of investment

We have a proud history of investing in research focusing on the early diagnosis of pancreatic cancer. Our investments have enabled researchers to examine multiple new ways of looking at the disease. Even with a limited budget, research part or fully funded by Pancreatic Cancer Action has been important in the development of potential biomarkers to diagnose pancreatic cancer earlier, in some cases, before symptoms appear. Many of these studies have gone on to receive grants from other organisations to help the work move further.

In 2015, Pancreatic Cancer Action accepted submissions from researchers for its Early Diagnosis Challenge Award, a programme of work aiming to fund grants to research projects with a focus on early diagnosis of pancreatic cancer. Several projects have been funded using these grants with multiple papers published. Examples of these projects include:

Developing a urine test for pancreatic cancer

Pancreatic Cancer Action funded a project from Dr Tatiana Crnogorac-Jurcevic and her team studying potential biomarkers for pancreatic cancer in patient's urine. The project looks at urine as a sample that is easy to collect and avoids invasive testing. The team examined a series of proteins that may act as biomarkers, identifying patients who have pancreatic cancer via a simple test. Original results showed promise for some potential biomarkers when used with CA19-9, the most accurate biomarker currently in use. This research has now been expanded with a grant from Pancreatic Cancer Research Fund (PCRF) to test accuracy and reliability over a four-year study in patients.

Diabetes and pancreatic cancer

Studies originally funded by Pancreatic Cancer Action have resulted in a grant from Cancer Research UK to study the link between type 2 diabetes and pancreatic cancer. Dr Eithne Costello and her team at the University of Liverpool are conducting a study where patients will have blood tests to identify if their diabetes is type 2 or the rarer type 3c diabetes and if this is a result of pancreatic cancer. The test aims to identify biomarkers of type 3c diabetes and/or pancreatic cancer.

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In 2019, Pancreatic Cancer Action committed to further funding into early diagnosis with a focus on research that will benefit real-world patients as soon as possible. Pancreatic Cancer Action decided to fund and take part in research projects to better define the link between diabetes and pancreatic cancer. They included:

Retrospective case-control study

The first research project was produced in partnership with a University of Surrey research team led by Dr Agnieszka Lemanska. The aims of the study were to confirm the link between diabetes and pancreatic cancer and to examine the differences in diabetes management and primary care presentation between patients who go on to develop pancreatic cancer and those who do not. The project was a retrospective case-control study, interrogating the RCGP database to provide a large sample size of cases and controls. Multiple variables can be examined from demographics to diagnostics, number of presentations at primary care to disease management. The project involves examining the GP records of patients with diabetes who went on to develop pancreatic cancer and those who did not develop the disease. Records will be taken from the RCGP database where approximately 9.5 million patients' data are stored. This allows a large sample of patients to investigate.

The study will compare the records of patients to find any differences in their demographics such as BMI and age. Comparisons can also be made in patients' journeys, both in the control and development of their diabetes, and other symptoms presented at GP appointments.

At the time of writing, we are awaiting the final publication of the paper. If successful, the project may identify a pattern of symptoms or patient profile that identifies those with early-stage pancreatic cancer. This would have implications for early diagnosis as diabetes can present in patients' months or years before a pancreatic cancer diagnosis and in many cases before other, established symptoms present.

Other projects had been agreed upon and funding allocated such as a **Prospective cohort study** in partnership with Bromley CCG and the Southeast Cancer Alliance. Patients with type two diabetes without weight gain were to be invited to take part in pancreatic cancer screening. This will consist of an experimental blood test offered via Immunovia who are looking to confirm blood-borne biomarkers of pancreatic cancer. This will be accompanied by a CT scan for pancreatic cancer. The aim of the study was to test the efficacy and effectiveness of the blood test and identify patient groups who would benefit from early referral for possible pancreatic cancer. However, due to the impact of the Covid-19 pandemic, this research project has been postponed.

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Clinical Nurse Specialists

Since August 2018, Pancreatic Cancer Scotland and now Pancreatic Cancer Action has been fully funding an innovative new role; a Clinical Nurse Specialist within the West of Scotland Cancer Network. The role provides an additional resource, helping support patients' and families' understanding of clinical trials and has contributed to enhanced participation and recruitment of patients to clinical trials, including the Precision-Panc study. The success of this role demonstrates how a collaborative approach with the third sector, healthcare professionals and research programmes can make a real difference. Recruitment to clinical trials for pancreatic cancer has been an ongoing struggle due to the poor survival rate. A clinical nurse specialist is a key tool to improve both patient care and support research opportunities.

A New Focus

The Covid-19 pandemic has had a dramatic impact on research around the world. Due to public concern about COVID-19, fears about burdening the NHS and reluctance from GPs to refer, fewer people received the support they needed. Fewer people going to their GP led to both delayed and missed pancreatic cancer diagnoses as well as delays in treatment, resulting in later-stage presentation and missed opportunities for treatment. Those who did not present during the height of the pandemic are starting to come forward, as well as those who would typically present at this time meaning there is significant additional pressure on the demand for diagnostic and treatment capacity.

We are rightly proud of our history of investing in pancreatic cancer research. This research has led to huge developments in our understanding of pancreatic cancer, but we know that we need to do more if we're going to achieve our vision and deliver the decade of change.

Pancreatic cancer is the UK's fifth biggest cancer killer (behind lung, bowel, breast, and prostate cancers) and has the lowest survival rate of any of the top 20 most common cancers. Diagnostics and treatments continue to improve for other cancers whilst pancreatic cancer is left behind and has an incidence-to-mortality ratio of almost one. The disease could become the UK's second-biggest cancer killer in just ten years' time.

Pancreatic cancer research funding has increased nationally in recent years as the scale of the potential problem of the disease becomes clear due to campaigning by organisations such as Pancreatic Cancer Action.

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Despite an increase in pancreatic cancer funding, there is still a low output in terms of clinical trials and published studies. A 2018 review found that only 1.8% of European cancer research papers were on pancreatic cancer. The paper concludes that pancreatic cancer is one of three cancer-specific sites where research funding needs to increase, and measures need to be taken to ensure research is focused on early diagnosis and screening.

Pancreatic Cancer Action focuses on early diagnosis in everything we do. Currently, there is no population-level screening for pancreatic cancer or any simple diagnostic test for use in primary care. Research funding is one of the core pillars of the charity's vision. Early diagnosis research is vital in developing simple diagnostics and effective screening for pancreatic cancer.

Following the Covid-19 pandemic, a new focus is needed to drive investment in pancreatic cancer research. Pancreatic Cancer Action has a key role in providing seed funding to projects that have the potential to improve outcomes for patients. These projects may not have taken place otherwise without Pancreatic Cancer Action.

Strategic Principles

Pancreatic Cancer Action is committed to funding excellent quality scientific research that will improve early diagnosis and ensure that more people survive the disease. As a result, future research funding decisions will be guided by the following strategic principles:

1. **Driving innovation.** Our research will seek new opportunities to drive innovations by providing seed funding to get them off the ground
2. **Partnership working.** We will actively seek to work with industry, charities and funders who share common goals to fund larger projects
3. **Early diagnosis.** Our research will focus on early diagnosis and improving the survival of our patients.
4. **Nursing.** Where appropriate we will develop opportunities to expand the number of Clinical Nurse Specialists we fund.
5. **Patient voices.** We will put patients at the heart of research and involve them in decisions relating to funding projects.

The strategic principles governing funding decisions will be administered by the scientific committee of Pancreatic Cancer Action.

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Priorities for the Decade of Change

The 2020s are to be the decade of change for pancreatic cancer. We want to see a radical improvement in survival rates. As a result, we have set three priorities for a new focus of research and investment to deliver the Decade of Change.

Improving early diagnosis.

Early diagnosis of pancreatic cancer is vital for the simple reason that if it can be diagnosed and treated at an early stage before the tumour has spread or grown too large, then survival rates for patients are significantly better. Public awareness of pancreatic cancer is very low with half of all patients having not heard of the disease before their own diagnosis. One reason for the poor outlook for pancreatic cancer in the UK is that it is often diagnosed late. By the time someone has symptoms, goes to their doctor, and is diagnosed, the cancer is very often quite advanced. Only around 10 in 100 people (around 10%) can have surgery to remove pancreatic cancer due to the late stage it is diagnosed. We need to understand more about potential biomarkers, gene mutations, predispositions, screening, and the drivers of pancreatic cancer so we can catch the disease early and save lives.

Pump priming research

The National Institute for Health Research reports that pump priming for underfunded research areas such as pancreatic cancer leads to larger grants for these research projects. Also referred to as seed funding, these grants will be allocated to projects and proposals that may otherwise struggle to gain funding. This type of grant helps to invigorate research and often leads to continuing funding from much larger providers. Recognising the limited budget available to Pancreatic Cancer Action, pump priming projects allows us to support innovation and multiply our impact from an initial investment.

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Expanding the number of pancreatic clinical nurse specialists.

In the fight against pancreatic cancer, clinical trials often provide the best treatment options, and they give patients early access to cutting-edge treatments that can lead to progress in research, improved treatment options and better outcomes. Clinical trials are research studies that investigate new treatments or new combinations of treatments. Pancreatic cancer clinical trials are necessary to determine whether new treatments developed in the laboratory are beneficial to people living with pancreatic cancer. Data is then reviewed and analysed from successful clinical trials to determine whether an experimental treatment should be approved for a specific disease or disorder, such as pancreatic cancer.

There are significant challenges with recruitment to clinical trials for pancreatic cancer due to the late stage of the disease being diagnosed and the low survival rate.

As a charity, we fund Pancreatic clinical nurse specialists, who provide extra resources to help support patients and families understanding of clinical trials and to support a hospital's pancreatic team.

Potential future areas for nursing posts where they can support recruitment to clinical trials are rapid diagnostic centres (RDCs) where a PCA salaried nurse could also optimise the patient pathway for pancreatic cancer and support patients suspected of the disease. If the opportunity presented itself, this nurse may be able to conduct clinical research on areas of delay and where the pancreatic cancer pathway could be improved within RDCs.

How will we know if we've been successful?

The Covid-19 pandemic has had a big impact on all medical research charities, including Pancreatic Cancer Action. Despite the financial impact of Covid-19, our vision of a day that everyone survives pancreatic cancer, and the decade of change is undiminished. We commit to allocating a dedicated budget for research for each financial year throughout the decade of change. We will monitor and measure our impact and expect to see things such as:

- Discoveries leading to changes in survival rates of people diagnosed with pancreatic cancer.
- Discoveries leading to new treatments being introduced.
- Discoveries enabling us to better predict/understand biomarkers.
- Pump-primed projects receiving continuing funding.
- Greater and better use of data.
- Increased clinical trial participation.
- Patient and public involvement in pancreatic cancer research.
- New investment into pancreatic cancer research.

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