

Pancreatic Cancer UK

**Taking it
on together**

Contents

1	Executive summary	5
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2	Introduction	12
	How we developed this strategy	14
	Who we are	16

3	We've made a difference	20
	Support and information services	21
	Research	24
	Policy and campaigning	25
	Fundraising	28

4	The next ten years: Transforming pancreatic cancer	30
	The next five years: How we will get there	33

5	Taking it on together	44
	Fundraise for us	47
	Support us	47
	Remember us	49
	Join us	49

1

Executive summary

Pancreatic cancer needs a strong community of patients, carers, health professionals, researchers and influencers to take it on together.

We have proven over the past three years that we can achieve what was once thought impossible; the first ever national pancreatic cancer clinical guidelines; a doubling of UK research investment to £10million; the start of a culture change in treatment and care for pancreatic cancer patients.

We have grown the pancreatic cancer community, and broken through our fundraising targets — raising well over £4million for the last two years running.

Today, five year survival rates in the UK are at around 5%. In light of no change in survival for decades, recent years have seen slow but significant progress. Each year, there are now 180 more pancreatic cancer patients surviving more than five years. That's almost 1,000 people living considerably longer since 2011.

Things are changing

Now, we want no less than to transform the future for everyone with pancreatic cancer and our five year strategy sets out how we will lead the way to that transformation.

- We will campaign and fundraise for a game changing annual UK pancreatic cancer research funding pot of £25million by 2022. This will include a significant investment of £10million from Pancreatic Cancer UK over the next five years. We remain committed to doubling the five year survival rates and believe that this level of research will begin to transform the diagnosis and treatment of the disease.

- We will define a gold standard of treatment and care for everyone diagnosed with pancreatic cancer, and work tirelessly with others to make that standard a reality. This continues our commitment to change the pancreatic cancer patient's NHS experience from one of the worst to one of the best.

In addition, we will:

- Be there for everyone diagnosed and their families by investing a further £5 million over five years in new and improved information and services. This will include doubling the use of our flagship national service, the Pancreatic Cancer UK Support Line.
- Work with researchers, policy-makers, NHS partners and industry to launch a pioneering campaign aimed at transforming access to treatments.
- Expand and support a pancreatic cancer community with a stronger, louder voice, and collaborate with others facing similar challenges in cancers of unmet need.
- Increase our funds raised year on year to make it all happen, aiming to raise £10 million a year by 2022.

We can't do this alone. We have always been at the heart of a determined community of people who share our ambitions.

But we need more; more influence, more research, more reach, more funds and more support. Join us to take on pancreatic cancer. It will be tough, but we are ready. And we won't stop until we transform the future for pancreatic cancer patients.

**Pancreatic
cancer
is tough.**

**Tough to
diagnose.**

**Tough
to treat.**

**Tough
to survive.**

**And it'll
be tough
to change
that.**

**But we're
ready.**

2

Introduction

When I joined Pancreatic Cancer UK in 2010 I was appalled by the lack of progress that had been achieved for patients and carers affected by this deadly disease. I wasn't alone. Five year survival rates were less than 3% - something that hadn't changed for nearly forty years. UK investment in research was less than 1% of the total cancer research spend. Patients and carers were reporting the worst NHS experience of almost any cancer patient group.

We knew this wasn't good enough, and along with a small but committed pancreatic cancer community, we set out to lead the change. We all knew it would be tough, but we faced the challenge head on.

Our Pancreatic Cancer UK 2013-2016 strategy focused on hope and on working with and supporting the efforts of the whole community. Hope is a huge word, and a word we don't take lightly. Hope for everyone involved in pancreatic cancer means finding the breakthroughs, however small, to make a difference to everyone affected by the disease.

Since 2013 we have seen important steps in the right direction. Survival rates have begun to improve for the first time in decades, investment into pancreatic cancer research has significantly increased, some positive inroads have been made towards improved patient experience and there is much greater public and political awareness of the need to tackle this disease.

I am proud of Pancreatic Cancer UK's contribution to these achievements.

Yet, there can be no doubt that despite this progress, pancreatic cancer remains one of the toughest cancers to diagnose and treat.

This new strategy is about where we go from here. We won't accept the status quo, and we will always demand better. We will continue to be there to support everyone living with a diagnosis of pancreatic cancer. We will empower patients and their families to get the best treatment and care to live as well as they can, for as long as they can.

We have a goal that in 2026 – ten years from now – the future for people with pancreatic cancer will be transformed, if we take on this challenge together.

This strategy outlines how we will work towards this over the next five years. It won't be easy, but nothing about pancreatic cancer is easy.

We can't do it alone. We hope you'll join us.



A black ink handwritten signature, appearing to read 'Alex Ford', written in a cursive style.

Alex Ford
CEO, Pancreatic Cancer UK

How we developed this strategy

Pancreatic Cancer UK sits at the heart of a community of people with personal and professional experience of pancreatic cancer. We would not be able to do this without them. To help us to define our vision and objectives for the future, we listened to their views, hopes and ambitions.

We would like to thank all the patients and carers who participated in one-to-one interviews and workshop events, including our own Patient and Carer Advisory Board. Their experiences are the reason we continue to fight.

We have a strong and valued relationship with health professionals across the UK. Surgeons, oncologists, nurses, dieticians, gastroenterologists and palliative care specialists talked to us at a series of round-table discussions. Our Study Days and pilot programme continue to bring us into contact with their vital work, and ensure that our objectives meet their needs.

The National Clinical Cancer Director for NHS England, as well as industry stakeholders working in the pharmaceutical and private healthcare arenas took time to share their important perspectives and insights with us.

Thanks too must go to the members of our Scientific Advisory Board, Medical Advisory Board and Development Fund Board who were involved in the strategy development and, of course, our own Trustees who contributed throughout the process.

We are proud to be part of a growing community of people taking on pancreatic cancer. We couldn't do this without you all.



Sarah Roberts

Sarah Roberts

Chair, Pancreatic Cancer UK

Who we are

Our vision

Everyone with pancreatic cancer survives to live long and well.

Our mission

We lead the fight against pancreatic cancer.

Our values

Compassion, integrity, enterprise, passion.

Why we exist

Pancreatic Cancer UK is fighting to make a difference. We're taking on pancreatic cancer together: by supporting those affected by the disease, investing in research, lobbying for greater recognition of pancreatic cancer, and being there for everyone involved in the fight. For too long this disease has been sidelined. We want to make sure that everyone touched by it gets the support and information they need.

We're here for everything you need to know about pancreatic cancer.



3



We've made a difference

We called our 2013 – 2016 strategy a Strategy for Hope. People questioned where the hope was in a disease sidelined, ignored and underfunded for too long.

But we developed this by listening to our community, who all said that hope, in even the smallest things, was essential to taking on the disease.

Our Strategy for Hope was a rally call with an ambitious vision:

- Double pancreatic cancer five year survival rates.
- Move the NHS experience of pancreatic cancer patients from being one of the worst to one of the best.

We are cautiously encouraged by progress since then.

Today, five year survival rates in the UK are at around 5%. In light of no change in survival for decades, recent years have seen slow but significant progress. Each year, there are now 180 more pancreatic cancer patients surviving more than five years.

There's been a fall of 5% in emergency admissions for pancreatic cancer, and we know from the National Cancer Patient Experience Surveys (England) that pancreatic cancer patients have reported some improved experience. It's a step in the right direction, but we need to keep fighting for more.

We are delighted that through our efforts, and others investing in research, there has been a significant increase in UK research spend. National Cancer Research Institute partner spending was £7 million in 2014. Add in our own and other pancreatic cancer charity investment, and that's almost £10 million spent on UK research.

We may not yet have found the breakthrough that will beat pancreatic cancer, but this progress gives us huge hope. We won't give up.

Breaking it down: how we've made a difference

In three years, our organisation has made exciting progress. We have grown, developed new services and pioneered new thinking in pancreatic cancer.

Support and Information Services

What we said

Develop our national and local services for patients and their families/carers.

Deliver local training courses for health professionals, and build an active network.

Ensure that everyone affected by pancreatic cancer has access to high quality support and information.

What we did

A team of specialist nurses and community engagement experts are directly reaching people to help them cope better with their symptoms, treatment and side effects. Our Support Line is helping 10% of all those diagnosed, and their carers with information and support in diet, treatment options and wellbeing.

Over 800 health professionals have engaged with our professional services, from Study Days to our panels and Advisory Boards. We ensure the latest information on the treatment and care of people with pancreatic cancer is shared among the professional community.

10 new patient and carer support groups have been established across the UK directly supported by us.

Over 25,000 publications have been ordered by health professionals for their patients, and there have been over 11,000 downloads of materials from our website.

We are providing the most comprehensive package of specialist support and information on pancreatic cancer in the UK.



“Pancreatic Cancer UK’s nurses were with me and my partner almost right throughout our journey with pancreatic cancer. I cannot imagine how different things would have been without their invaluable support, advice and encouragement.”

Cath Armstrong
Patient and Carer Advisory Board

“Pancreatic Cancer UK has been fundamental in funding some of our research. I’m confident that more funding in pancreatic cancer research now will lead to saving lives.”

Steve Pereira

Professor of Hepatology & Gastroenterology
at University College London



Research

What we said

Increase our research funding year on year, including investment in more Future Research Leaders.

Continue to campaign to bring overall investment in research in the UK to at least £10million.

What we did

Invested almost £3million in the most innovative and cutting edge research.

Worked in partnership with Cancer Research UK who recently announced a substantial increase in their investment into pancreatic cancer.

Saw UK investment climb towards £10million, a major milestone in the fight against pancreatic cancer.

Funded 41 active research projects in the UK.

Policy and campaigning

What we said

Campaign to increase the political profile of pancreatic cancer across the four nations.

What we did

Secured a commitment from the National Institute for Health and Care Excellence to produce clinical guidelines on pancreatic cancer.

Influenced a number of other significant policy changes including a dedicated section on pancreatic cancer in the referral guidelines for suspected cancer in England and Scotland.

Work with all governments to make pancreatic cancer a government priority.

Supported the influential Westminster All-Party Parliamentary Group (APPG) in developing key reports.

Find solutions to the challenges laid out in our Study for Survival report (2011).

Evidenced the need for increased research spend and set out the case for a UK pancreatic cancer research strategy.

Create a movement for change within the pancreatic cancer community.

Established an expert Patient and Carer Advisory Board, and ensured that there is patient and carer representation on our Scientific Advisory Board.

Our 'Two More Months' campaign worked to make Abraxane available on the NHS. Abraxane is now only available in Scotland and Wales and not in the rest of the UK, but we won't give up fighting for better access to treatment.

“Pancreatic Cancer UK has given me the opportunity to help others through my involvement with them. I now feel I have my ‘identity’ back after my diagnosis.”

Karen Stead

Patient and Carer Advisory Board





Fundraising

What we said

Increase fundraising income to £2 million.

What we did

Projected annual income for 2015/2016 will be £4.5 million, significantly beating our target.

Diversify income to include more funds raised from corporates, trusts, legacies and regular giving.

Successfully diversified our income, with an average of 41% of our income from corporates, legacies and trusts over the last three years.

“Supporting Pancreatic Cancer UK this past two years has been absolutely fantastic. We have received first class support from the fundraising team, which has resulted in our most successful charity partnership to date.”

Martin Meech

Group Director and CEO
Travis Perkins (Properties) Ltd

4

The next ten years: Transforming pancreatic cancer

We asked all of those who contributed to this strategy one question: what needs to change in the next ten years?

The message was clear and simple.

We need to fix everything about pancreatic cancer. Nothing less than transformation will do. We cannot let this disease be marginalised any longer. It needs specialised and focused attention.

We want to lead this fight and effect real and lasting change for everyone touched by this tough disease.

Yes, there has been progress. Some significant progress, such as in research funding and clinical guidelines. And huge organisational success in growing our funding well beyond our targets. But we are still waiting for that breakthrough, that big change.

Making progress means continuing to fight on all fronts.

Our strategic objectives are a combination of **cause** objectives (alongside our partners and stakeholders, transforming the future for everyone with pancreatic cancer), and our own **delivery** objectives, which will allow us to be effective in our mission.

We must continue to develop research that leads to clinical advances and early diagnosis. We must transform the culture around pancreatic cancer from defeatism to optimism and tireless determination. We must dramatically transform the patient and carer experience of pancreatic cancer.

Everyone affected by pancreatic cancer knows that there is much, much more that can be done to help people live as well as they can, for as long as they can.

It seems like a huge task, but we are ready. There is much we can do to change things in the short-term; by empowering, supporting and leading.

2026

By 2026, we want to
transform the future for
pancreatic cancer patients.

We cannot do this alone.
We need to take it on together.



The next five years: How we will get there

Strategic objective 1:

Significantly grow our specialist support and information services for patients, families and friends.

Each year, our national services (our unique Support Line and online community) reach 10% of the 8,800 people diagnosed with pancreatic cancer. Thousands more come to us through our website. We work hard to promote our services, yet there are still too many people who are not aware of the direct support we offer, or able to access it.

We have committed to invest a further £5 million to improve our reach across the UK over the next five years.

We want to be in every region and all four nations, available for every patient and carer. We can do that by rolling out our national and local services.

But we can't do this alone. We need to build new partnerships with health professionals who are in daily contact with patients.

How will we do this?

- Double the number of people accessing our flagship national Support Line to reach 20% of those diagnosed every year, and aspire to maintain 100% user satisfaction rates for this service.
- Aim to ensure that everyone diagnosed with pancreatic cancer knows of our services within one month of diagnosis.
- Provide support across the treatment and care spectrum, from symptoms and diagnosis, to information on treatment options, quality of life (including diet and isolation) and end of life care.
- By 2022, ensure that every healthcare professional with an interest in pancreatic cancer has access to a wide programme of study days and support.

Strategic objective 2: **Drive up NHS standards and improve care**

We need to demand the best treatment and care for people diagnosed with pancreatic cancer and their families. We will work with the pancreatic cancer community to define what we mean by 'best', and champion this standard to improve patients' lives.

We know we can do this; we successfully made the case for the development of the NICE pancreatic cancer clinical guidelines and now we want to work in partnership with patients, carers, health professionals and policy-makers to drive improvements in quality of life and survival.

We have listened to people affected by pancreatic cancer, and the experts who see them every day. There is much we can all do to improve quality of life; from diet to emotional support both before, during and after treatment.

How will we do this?

- Evidence and define gold standards for treatment and care, sharing good practice and building a network of excellence.
- Support the development and implementation of 'gold standard' practices for patients across the UK.
- Help drive a change in attitudes and improve optimism towards pancreatic cancer in the NHS.
- Significantly expand our health professional training and networking programme across the UK.
- Champion and share a Pancreatic Cancer UK Patient Charter, empowering people diagnosed with pancreatic cancer to demand the best treatment and care.
- Invest at least £1 million over five years in Pancreatic Cancer UK's Clinical Pioneer Awards Scheme, funding innovative interventions to improve treatment and care for current patients and families.
- Continue to use our expert knowledge to ensure that patients have early access to interventions pre, during and post treatment – including vital dietary interventions – essential for optimum care throughout the treatment pathway.

Clinical Pioneer Awards

We will commit £1 million over the next five years for new projects that take the learnings from our gold standard work, demonstrating solutions in treatment and care.

10 yrs

£25m

Strategic objective 3:

Achieve a UK research investment position where game changing breakthroughs will lead to transformation.

We believe that a minimum annual investment of £25 million into pancreatic research will start to lead to transformation for patients.

For our part, we will commit to increase investment in the most cutting-edge, innovative research across the UK and to fund the best and brightest leaders of the future.

How will we do this?

- 2016 is our 10th anniversary; we will use this milestone to launch a targeted £10 million fundraising campaign.
- Announce a £2 million investment into strategic pancreatic cancer research, through:
 - A £1 million Grand Challenge award to fund brilliant minds to find significant breakthroughs.
 - A £500K commitment to a Pancreatic Cancer UK Future Leaders Academy – hothousing the best young minds of the future.
 - The fourth round of our Research Innovation Fund.
- Lead a strategic review into UK pancreatic cancer research facilitating a network of researchers, funders, health professionals, patients and carers to transform research with us.
- Based on our review findings, launch our new research strategy in 2017.

Strategic objective 4:

Deliver an enhanced programme of targeted campaigning to drive significant change in health policy and NHS practice.

Every day we talk to healthcare professionals, researchers and policy-makers about how we can find the breakthrough to transform pancreatic cancer.

As well as a programme of targeted pancreatic cancer campaigning, over the next five years we will work in collaboration with those working with rare and less common cancers, and cancers of unmet need. We will use our collective energy and expertise to achieve great things.

How will we do this?

- Campaign to support enhanced UK research investment and NHS care and standards improvement.
- Work with researchers, NHS partners and industry to launch a pioneering campaign aimed at transforming pancreatic cancer patients' access to treatments. This will include looking at the potential offered by personalised medicine and immunotherapy.
- Champion a coalition to drive change for cancers of unmet need.

“Pancreatic Cancer UK has helped me enormously since my diagnosis. There is far too little knowledge and awareness outside of the pancreatic cancer community, and if we can improve that, things will be better for patients. Pancreatic Cancer UK is the best organisation to help us get there.”

Giles Margerison



£10m

2022

Strategic objective 5:

Aim to raise £10 million sustainable income year on year by 2022.

We have big ambitions, and the energy and expertise to transform pancreatic cancer research, treatment and care. Our supporters are our lifeblood, and without them, we could never achieve our ambitions.

Change of this scale needs significant funding, and we know that our team and our supporters are ready to take on the toughest fundraising challenge.

How will we do this?

- Launch a major fundraising campaign to mark our 10th anniversary in 2016, to help us to meet our commitment to invest £10 million in research by 2022.
- Support our Development Fund Board in their major donor ambition to raise £10 million by 2022 to fund our work.
- Diversify our income, leading to more funds coming from corporates, trusts, major donations and legacy.
- Ensure that our fundraising costs stay down, retaining an income ratio of 20 – 25%, and that 70p of every pound donated is spent on charitable activities like our services and research.

Strategic objective 6:
Continue to be UK's
leading specialist pancreatic
cancer organisation.

How will we do this?

- Build and mobilise a bigger, stronger, more vibrant and more vocal UK pancreatic cancer community. We will help to create innovative ways to enable survivors, patients and families to connect to and support each other and the charity.
- Develop a series of national annual summits; bringing together health professionals, researchers and policy-makers to facilitate thought leadership and innovation.
- Work with our PCUK250 expert panel to track opinion, optimism and experience on the ground.
- Develop 'peer' partnerships with other leading charities and health organisations to achieve our ten year vision.
- Take a leading position in international pancreatic cancer coalitions and networks.
- Continue to measure and improve public awareness of pancreatic cancer.

“Pancreatic cancer brings despair and darkness. Pancreatic Cancer UK brings hope and light through research, education and through supporting patients and families with compassion. That’s why I became involved, and I am thrilled with the progress the charity’s making.”

Simon Collins

UK Chairman and Senior Partner, KPMG LLP, Trustee of Pancreatic Cancer UK and Chair, Development Fund Board.



5

**Taking it
on together**

We have big ambitions, and we know that it will be hard work. But we have proven over the last three years that we have the determination, the support and the energy to make change happen.

We cannot do this alone. We need to continue to support the whole pancreatic cancer community in demanding the best for everyone affected by the disease.

You can help us take on this challenge.

**Fundraise
for us**

Support us

Fundraise for us

Our supporters are as tough as we are, taking on physical challenges here and abroad to raise money for our work.

Whatever your passion, there will be an event in our calendar to suit you, where you can meet other Pancreatic Cancer UK supporters and volunteers, have fun, challenge yourself and help us reach our goals.

If physical challenge events are not your thing, you could join the thousands of people raising money for us every year by organising their own fundraising activities – cake bakes to dinner parties; barn dances to football matches. We are here to support you with advice, fundraising packs and materials for your event.

Support us

Making small, regular gifts is often a more manageable way to support us, and gives us the vital funds we need to carry out our work. And, as a Regular Giver, you'll very much be a part of the Pancreatic Cancer UK team. We'll send you updates so you can see what you're enabling us to achieve.

Remember us

Join us

Remember us

A gift in memory of a loved one, a friend or a colleague is a wonderful way to celebrate their life whilst making a difference to the lives of others affected by pancreatic cancer. How you remember someone who has died is a highly personal decision. However you choose to give, a gift in memory can be a positive way to remember a loved one's life and will help transform the future for people with pancreatic cancer.

Gifts in Wills are also a vital source of income for Pancreatic Cancer UK. Those that have been kind enough to remember us in their Will either choose to state a specific amount or they ensure their family and friends are fully provided for first and leave us a percentage of the remainder of their estate.

We fully appreciate that this is a sensitive and important decision not to be made hastily; so we are happy to talk this through with you.

Call 020 3535 7090

Email fundraise@pancreaticcancer.org.uk

Visit pancreaticcancer.org.uk

Leaving us a Gift in your Will is a really simple way to make a significant contribution and leave a legacy of hope for those with pancreatic cancer and their families.

Join us

Volunteering is a really special way to support us. We have over 10,000 people who give us their time and we couldn't exist without them. Volunteers bring extra skills and personal experience to our work, and we are always happy to hear from supporters who would like to help us in this way.

There are many different ways to get involved; cheering on our runners at a marathon, campaigning to raise awareness, collecting a cheque on our behalf, setting up a Support Group in your local area or even sharing your story on our website or with the media.

Pancreatic Cancer UK

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