



# Hope for the future: Tackling inequalities in pancreatic cancer care

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# Foreword

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Pancreatic cancer is a devastating disease. It is difficult to diagnose and difficult to treat effectively; to date it has proved to be stubbornly immune to the improvements seen for many other cancers.

The story of pancreatic cancer is one of inequality, both compared to other forms of cancer, but also within pancreatic cancer. This latter form of inequality should, while causing us frustration, offer us hope: simply by adopting good practice, we can and should be able to do better on the basis of what we know now, let alone what we hope to discover in the future.

This report documents the inequalities that exist and identifies the areas in which rapid improvement could be made.

## We know significant inequalities exist

Pancreatic cancer patients are experiencing considerable and persistent disadvantages, compared to other cancer patient communities, at almost every stage of their cancer journey:

- Survival is the lowest of all the common cancers and has failed to improve in nearly fifty years
- Mortality continues to rise, in stark contrast to national cancer mortality figures which have fallen over the last decade
- Patients report worse experiences of care, are diagnosed later and have their treatment options severely limited

## We know the challenge is significant

There is no escaping that pancreatic cancer is an extremely difficult cancer to diagnose and treat; symptoms of pancreatic cancer often present late and, compared to other tumours, it is particularly aggressive and resistant to treatment.<sup>1</sup>

We also know that awareness of pancreatic cancer is low amongst the public and policymakers. Scientific progress on understanding and treating pancreatic cancer will take time.

At times, these challenges have appeared insurmountable.

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## **We know we can do better on the basis of what we know now - and we owe it to patients to act**

The data presented in this report bring to light challenges that exist for patients diagnosed with pancreatic cancer, but also highlight that there are real opportunities for improvement. For example, some areas of the country are doing better than others in terms of diagnosing pancreatic cancer early and providing a positive experience of treatment and care. We must learn from and emulate them.

If we are going to tackle the inequalities pancreatic cancer patients face and to finally make progress in reversing the declining outcomes for the condition, we need to identify what can be done now, and what can be done to facilitate improvements in the future.

We are calling for action now to begin the process of improvement.

Everyone has a part to play and we are ready to help tackle these inequalities and start making meaningful progress on pancreatic care, treatment and outcomes.

Change is difficult, but not impossible and long-overdue improvements for pancreatic cancer patients are achievable. We hope this report provides the starting point for a discussion about how to make this happen.

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# Executive summary

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There is broad consensus about the need to transform cancer services in England. The vision of the *Five Year Forward View* sets a clear ambition to deliver better prevention, swifter diagnosis and improved treatment and care for all cancer patients.<sup>2</sup> The report of the Independent Cancer Taskforce acknowledged that despite progress in the last fifteen years in terms of survival and mortality for many cancers, there is still more needed to deliver cancer outcomes comparable with the best in the world. This is especially true for pancreatic cancer, where progress has been elusive.

NHS England has now published an update on the next steps it intends to take to improve cancer services. *Achieving World Class Cancer Outcomes: Taking the strategy forward* intends to realise the ambitions set out in the Cancer Taskforce's report. It signals a renewed emphasis on driving earlier diagnosis of all cancers and tackling variation:<sup>3</sup>

“ If someone is diagnosed with cancer, they should be able to live for as long and as well as is possible, regardless of their background or where they live. They should be diagnosed early, so that the most effective treatments are available to them, and they should get the highest quality care and support from the moment cancer is suspected.

The challenge for all cancers to achieve world-class cancer outcomes for all patients is significant, but for pancreatic cancer, the challenge is greater still. The inequalities that exist between pancreatic cancer and other cancer forms are not only considerable, but are increasing. Unless action is taken, these inequalities will continue to worsen, putting pancreatic cancer patients at a considerable increasing disadvantage to patients with other forms of cancer.

This report presents the available data on pancreatic cancer and attempts to quantify the inequalities faced by pancreatic cancer patients, to help drive greater recognition of the disadvantages faced by the community. However, in doing so, the report also highlights the opportunities for action that can be taken now that will start to drive improvements in the longer term.

We know that there are particular challenges associated with the diagnosis and treatment of pancreatic cancer, but we are also certain that we could be doing better for pancreatic cancer patients in England.

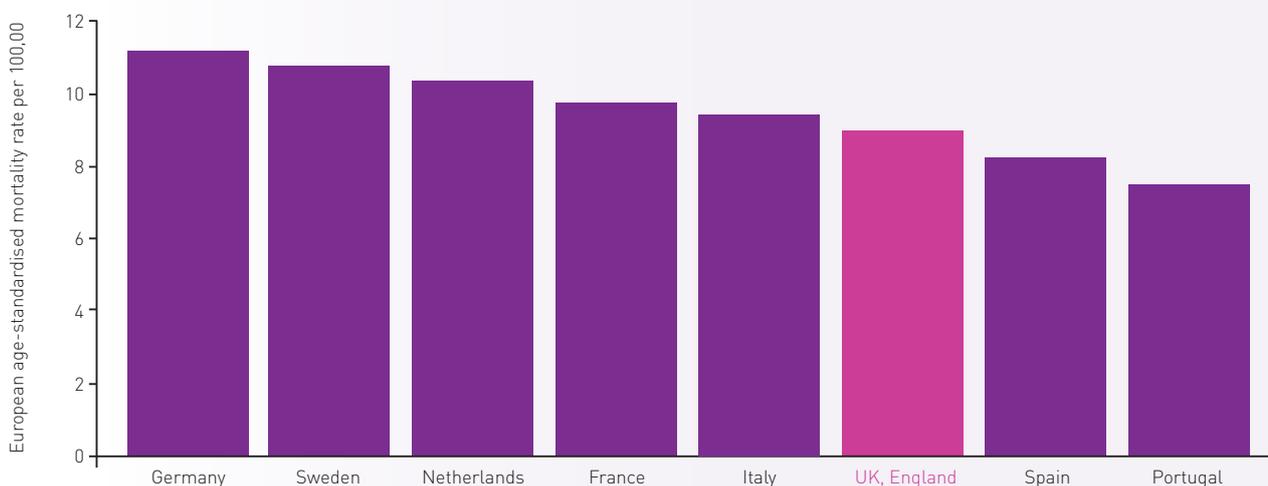
Driven by the data we are calling for urgent action to address the inequalities faced by pancreatic cancer patients.

We know this because:

- The example of lung cancer demonstrates that improvements can be made in other poorer prognosis cancers. For example, the improvement in survival in lung cancer in England has been dramatic over the last 20 years with almost twice as many patients alive a year after diagnosis now as was the case in 1990<sup>4</sup>
- Other high-income countries are achieving better outcomes.<sup>5</sup> Five year survival for pancreatic cancer in England is below the European average<sup>6</sup> and, if we could achieve the outcomes delivered elsewhere then more people would live for longer
- There are variations in services and outcomes across England, suggesting that – if every area performed as well as the current best – outcomes would be better

These variations suggest that we can and should do better, by emulating the example of other poor prognosis cancers, by achieving the level of outcomes achieved elsewhere and by eradicating unwarranted variation across England.

### Estimated age-standardised mortality from pancreatic cancer, Europe, 2012<sup>71</sup>



SOURCE: EUCAN

# Recommendations

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Inequalities in pancreatic cancer are endemic. Action is required to increase investment in research so that we might better understand how to diagnose pancreatic cancer earlier and treat it more effectively.

However, it is important that the scale of the challenge should not deter us from action now. This report reveals significant variations in care. Simply by addressing these, we can make a big difference.

Below we make a series of recommendations which, if implemented, will begin the process of tackling the inequalities which occur both within pancreatic cancer and in comparison with other cancers.

## RECOMMENDATION 1

### **Introduce a national clinical audit for pancreatic cancer**

We need to know more about variations in clinical care and the impact these have on outcomes. NHS England should commission the Health Quality Improvement Partnership (HQIP) to work with clinicians to introduce a national clinical audit for pancreatic cancer. This would provide a comprehensive, joined-up assessment of performance across all aspects of pancreatic cancer care, allowing providers to benchmark against accepted standards, helping to tackle variation and identify where improvements can be made.

## RECOMMENDATION 2

### **Increase investment in research for pancreatic cancer**

The Department of Health and other research funders should identify pancreatic cancer as a research priority, review current funding and establish a goal to increase investment in research, in line with commitments already made by Cancer Research UK, so that the level of expenditure better reflects the relative impact of pancreatic cancer.

## RECOMMENDATION 3

### **Investigate every opportunity to develop new treatments**

The need for new treatments is urgent. Statutory, voluntary sector and commercial funders of research should introduce a presumption that every promising new molecule or technology will be considered for its potential applicability to pancreatic cancer. Where deemed appropriate, trials should be expedited.

## RECOMMENDATION 4

### **Reform the way in which treatments are assessed for use in the NHS**

Current processes do little to reflect the specific challenges of treating poor prognosis conditions, such as pancreatic cancer. Reforms to NICE's methodology are urgently required to address this, ensuring that the relative benefit that a new treatment can deliver is given recognition. One way to achieve this would be to give greater flexibility both to the way in which the End of Life criteria are assessed and also applied. This would mean that drugs for cancers with few other treatment options would stand a greater chance of approval.

## RECOMMENDATION 5

### **Accelerate the identification and spread of good practice**

The National Clinical Director for Cancer should bring together a wide range of pancreatic cancer experts, including clinicians, patient groups and researchers, to identify and exchange good practice, which could then be tested in the cancer vanguards. Changes which prove to be successful should be rapidly incorporated in service specifications and contracts.

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#### RECOMMENDATION 6

### **Ensure that the CCG Improvement and Assessment Framework acts as an effective mechanism for encouraging improvements in standards of local pancreatic cancer services**

The development of the Cancer Scorecard and the CCG Improvement and Assessment Framework are extremely welcome. However, there is a danger that issues within particular cancers could be obscured. This is a particular risk for cancers with poor outcomes and substantial variations in quality, such as pancreatic cancer. NHS England should consider the case for establishing cancer-specific scorecards to inform analysis of the overall scorecard. This approach should be tested with pancreatic cancer.

#### RECOMMENDATION 7

### **Implement the recommendations of the Independent Cancer Taskforce**

The Independent Cancer Taskforce provides an important roadmap for improvement and it should be fully funded and implemented. In particular, NHS England should ensure that rapid progress is made on recommendations relating to earlier diagnosis, increasing diagnostic testing capacity and the piloting of multi-disciplinary diagnostic centres for vague or unclear symptoms.

#### RECOMMENDATION 8

### **Address gaps in the provision of specialist care**

Variations in outcomes suggest that good practice guidance is not always implemented. Feedback from experts indicates that gaps in specialist workforce provision remain a major challenge. As the commissioner of the bulk of pancreatic cancer services, NHS England should work with hospitals to identify any gaps and agree action plans to fill them. Where necessary, future funding and contracts should be made contingent on the delivery of these action plans, to encourage uniform access to specialist nurses for pancreatic cancer patients.

#### RECOMMENDATION 9

### **Launch a public awareness campaign for pancreatic cancer**

Building on the success of other Be Clear on Cancer campaigns, which have encouraged a significant increase in cancer referrals, Public Health England should commission a public awareness programme of the signs and symptoms of pancreatic cancer, to encourage people to see their GP and help encourage earlier diagnosis.

#### RECOMMENDATION 10

### **Establish ambitious goals to improve survival and patient experience**

The aspirations of the Independent Cancer Taskforce are warmly welcomed but it is important that poorer prognosis cancers are not neglected in the drive to improve overall performance. To guard against this, NHS England should establish goals to improve survival and patient experience for pancreatic cancer, with a view to achieving outcomes comparable with the best in the world. A commitment should be made to regularly audit progress against specific milestones and timelines.

# Inequalities in pancreatic cancer: the evidence

Pancreatic cancer is a notoriously difficult cancer to diagnose and to treat.<sup>8</sup> There are often few symptoms in its early stages, meaning that too many people are only diagnosed after their cancer has spread. This means that pancreatic cancer patients often experience worse outcomes than patients with other forms of cancer.

There has been a dispiriting lack of progress in pancreatic cancer outcomes. Unlike the majority of cancers, five and ten year survival has shown little improvement since the 1970s.<sup>9</sup> Over the last ten years mortality from pancreatic cancer has risen by 8%, in direct contrast to the overall trend for cancer, which has seen mortality decrease by 10%.<sup>10</sup> Across Europe, pancreatic cancer has risen to being the fourth and fifth most fatal type of cancer for women and men respectively in 2012, having been outside the top five for both women and men in 1995.<sup>5</sup>

Pancreatic cancer patients in England face a range of additional disadvantages across the pathway, including:

- Later diagnosis<sup>11</sup>
- Poorer experience of care<sup>12</sup>
- Fewer treatment options<sup>13</sup> and restricted access to effective treatments<sup>14</sup>
- Lower investment in research<sup>15</sup>

Similarly, progress has been slow in implementing policy to drive improvements in pancreatic cancer, as acknowledged by the All-Party Parliamentary Group (APPG) on Pancreatic Cancer in its assessment of progress made since its 2013 and 2014 inquiries. Progress has been particularly frustrating in areas such as the funding for pancreatic cancer research and access to treatment.<sup>16</sup>

The purpose of this report is to examine the available evidence on many different aspects of pancreatic cancer, starting with factors that affect outcomes: awareness of pancreatic cancer; diagnosis; provision of staff; and access to treatment. It then goes on to examine outcomes – incidence, survival and mortality.

Comparisons have been made, where possible, to lung cancer, breast cancer, ovarian cancer, colon cancer and Non-Hodgkin lymphoma. These cancers provide a useful point of comparison to highlight inequalities for pancreatic cancer patients, because they either: achieve consistently better outcomes (breast, colon and Non-Hodgkin lymphoma); have similar patient populations (ovarian); or have traditionally had a poor prognosis (lung).

The primary focus of the report is England (as 83% of the UK pancreatic cancer population resides here), although where comparable data are only available at a UK level, this is presented. The evidence also suggests that not only is pancreatic cancer performing poorly against other cancers, but also against other countries. Data for comparable countries have also been included in this report to benchmark the performance of the UK. There are also significant gaps in the data available for pancreatic, in comparison to other cancers. Finally, the evidence demonstrates significant regional variations across England between care, patient experience and outcomes for pancreatic cancer.

By bringing together the available data, the picture is clear; the inequalities for pancreatic cancer patients are significant and the variation is unacceptable.



## Chapter 1

# Awareness, diagnosis, provision of staff and access to treatment

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The inequalities faced by pancreatic cancer patients begin even before they are diagnosed:

- Awareness of pancreatic cancer and its signs and symptoms is low, reducing the chances of earlier diagnosis and effective treatment<sup>17</sup>
- When people are diagnosed, it is often at a much later stage than other cancer patients, frequently following emergency presentation (which is associated with more advanced disease)<sup>3</sup>

Once diagnosed, pancreatic cancer patients are also subject to a range of other disadvantages throughout their care and treatment:

- Patients have more limited access to specialist care provision<sup>18</sup>
  - There are fewer treatment options available and restricted access to effective treatments<sup>14</sup>
  - Research into pancreatic cancer has been chronically underfunded for decades<sup>15</sup>
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Three quarters of UK adults cannot name even one pancreatic cancer symptom<sup>22</sup>

## Awareness

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The primary route to diagnosis involves a person becoming aware of symptoms and going to their GP about their concerns. This provides the best chance of earlier diagnosis of pancreatic cancer, and of more effective treatment. However, awareness of pancreatic cancer is poor:

- According to a patient survey by Pancreatic Cancer Action, almost half (43%) of those surveyed had not heard of pancreatic cancer before their own diagnosis<sup>19</sup>
- Three quarters of UK adults cannot name even one pancreatic cancer symptom<sup>17</sup>

Awareness amongst the public in general of pancreatic cancer is much lower than for other cancers. According to a survey of the public across the US and Europe:<sup>20</sup>

- There is lower awareness of pancreatic cancer amongst the public compared to other cancers. When asked to think of a cancer, only 2% of respondents in the UK stated pancreatic, compared to 46% for breast cancer, 18% for lung cancer and 8% for bowel
- There is a low level of knowledge and understanding about pancreatic cancer. 64% of respondents in the UK felt they knew almost nothing about pancreatic cancer, almost three times as many who stated this for breast cancer

There are some signs that this is changing. For example, in recent years there has been an increase in the political activity surrounding pancreatic cancer, with a 51% rise in the number of mentions of pancreatic cancer in Parliament, between 2011/12 and 2015/2016.<sup>21</sup> However, this progress needs to be placed in context. Over the last year, breast cancer received twice as many parliamentary mentions than pancreatic cancer.<sup>22</sup>

In order to secure action in the prioritisation of policy that could deliver improvements for pancreatic cancer it will be vital to continue to increase recognition of the issues pancreatic cancer patients face amongst policymakers.

# Diagnosis

As with many other cancers, diagnosing pancreatic cancer before it has spread is critical to achieving long-term survival. The later a cancer is diagnosed, the harder it is to treat.

Yet, in the early stages, pancreatic cancer often has few recognisable symptoms. This means that it is particularly difficult for GPs to detect and diagnose the condition. A UK study has revealed that around one in three pancreatic cancer patients require three or more visits to their GP before they are referred to a specialist. As you would expect, the more GP visits patients had to make, the more their diagnosis was delayed. For pancreatic cancer patients who visited their GP more than five times, their diagnosis was delayed on average by more than three months.<sup>23</sup>

“What I did was put my faith in the fabulous, wonderful surgeons, oncologists and nurses I have met along the way, gritted my teeth and just got on with it.”



## CASE STUDY

### Early diagnosis

Ali was 41 when she was diagnosed with a ductal adenocarcinoma in the body of her pancreas. Until a month before the diagnosis, she had no recognisable symptoms and considered herself to be fit and healthy, exercising regularly, not smoking and only drinking in moderation. She had no family history of pancreatic cancer.

Ali went to the GP surgery in considerable pain but none of the doctors she saw there considered she had anything more serious than dyspepsia or irritable bowel syndrome. An after-hours emergency doctor (prescribing morphine for the pain) came closest by suggesting pancreatitis. The next day, a concerned locum GP telephoned the Surgical A&E department to discuss admitting Ali but, between them, they decided she was not in sufficient pain. Pain, though, meant Ali ended up in A&E a few days later, only to be sent home with painkillers. She was told she needed a scan but there was no one available to operate the machine as it was a bank holiday.

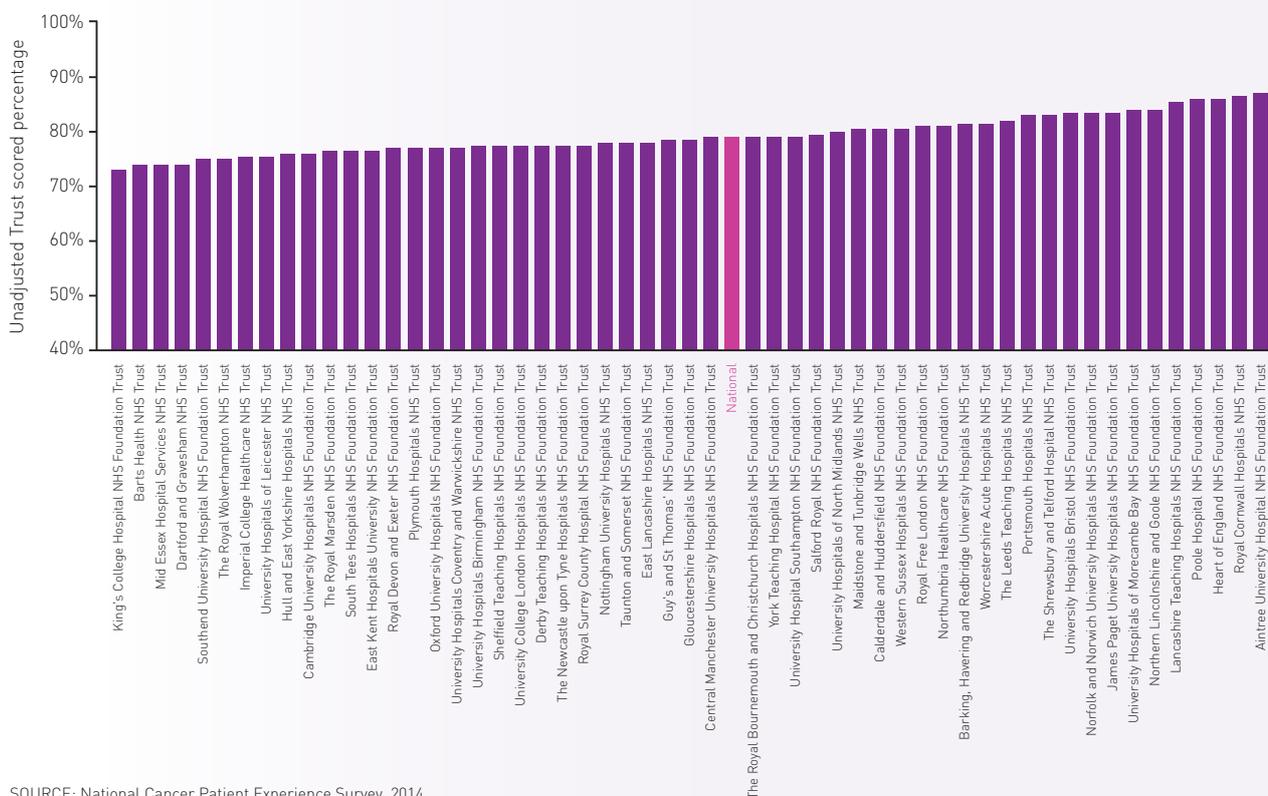
Ali thinks she is one of the lucky ones, probably because she was so persistent in visiting the GP surgery and because she had private health insurance through her husband's work. The locum GP wanted Ali to have an ultrasound but it would have taken four weeks to be seen on the NHS. Private health insurance meant that she could meet the consultant surgeon within a couple of days. She was admitted to hospital straightaway, all the tests were done and she was operated on the following week. Ali had a distal pancreatectomy and splenectomy during which the surgeons excised all of the tumour they could see. Luckily no metastases were present and only one of her lymph nodes was affected.

Thanks to an excellent surgical team, Ali's operation was successful. She went on to have chemotherapy and radiotherapy and is feeling well today.

Ali hopes that in 2017, she will be one of the one percent of pancreatic cancer patients to live beyond ten years.

There are also significant variations in how quickly pancreatic cancer patients feel they were able to see a hospital doctor.

FIGURE 1  
Patients with upper GI cancer who felt they were seen as soon as necessary, by NHS Trust, 2015<sup>24</sup>

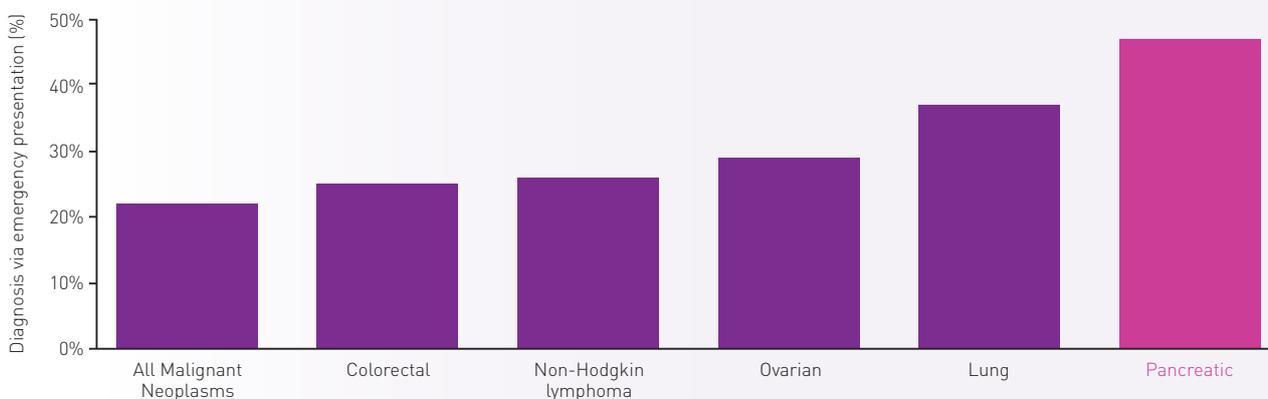


SOURCE: National Cancer Patient Experience Survey, 2014

These challenges have a significant impact on patients:

- Almost half (47%) of pancreatic cancer patients are diagnosed following emergency presentation, compared to 22% of all cancers<sup>11</sup>
- Only 10-20% of pancreatic cancer are diagnosed at a stage when curative surgery remains an option<sup>25</sup>

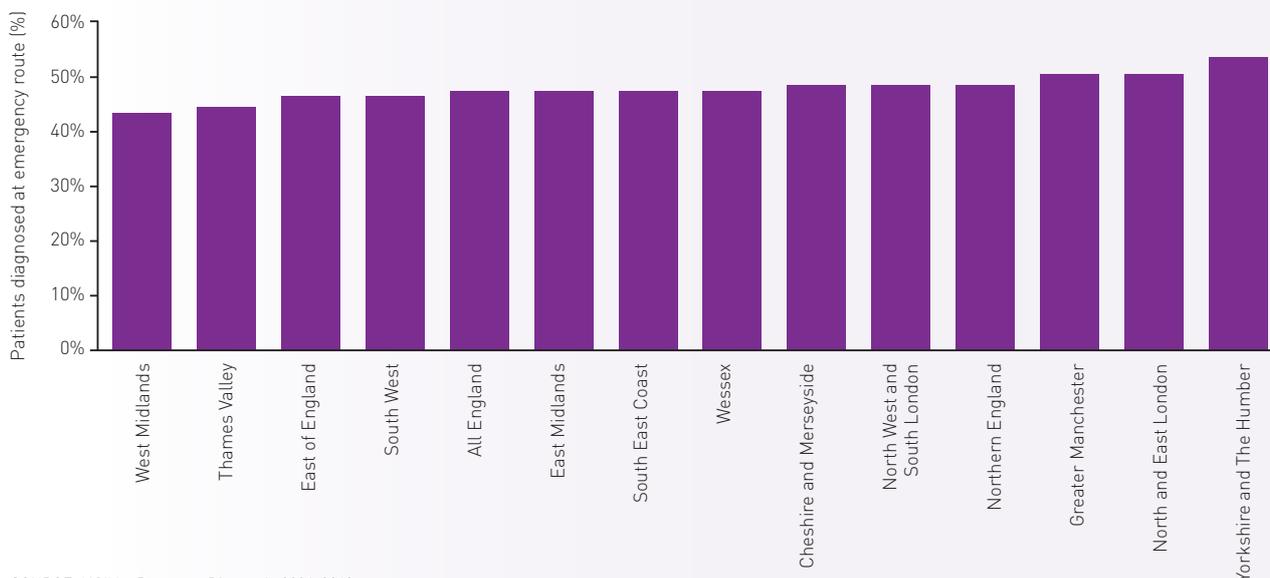
FIGURE 2  
Percentage of patients diagnosed through emergency presentation, 2006-2013<sup>11</sup>



SOURCE: National Cancer Intelligence Network, Routes to Diagnoses 2006-2013

A greater proportion of pancreatic cancer patients are also being diagnosed through emergency presentation in some areas of the country than in others.

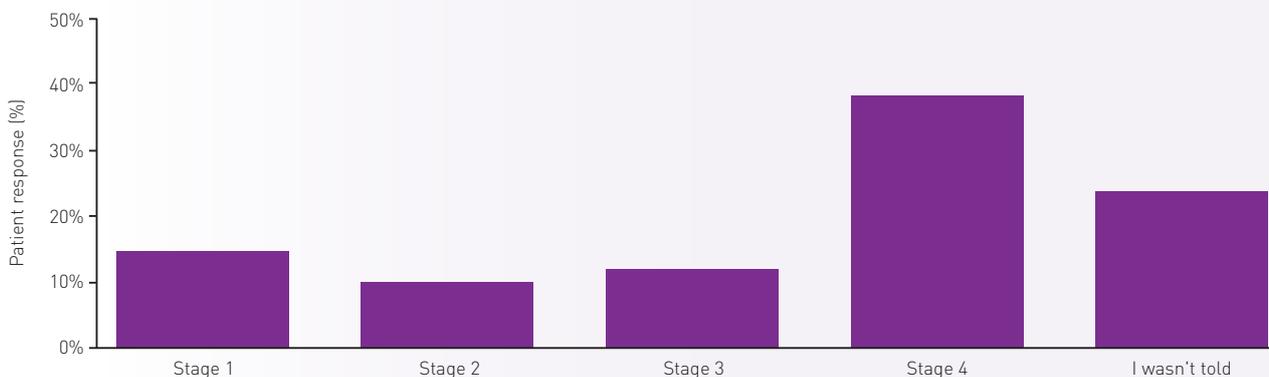
**FIGURE 3**  
**Percentage of pancreatic cancer patients diagnosed through emergency presentation by Strategic Clinical Network, 2014<sup>26</sup>**



SOURCE: NCIN – Routes to Diagnosis 2006-2013

According to a patient and carer survey carried out by Pancreatic Cancer Action in 2015, the vast majority of pancreatic cancer patients surveyed had been diagnosed at Stage 4 (which means the cancer has spread from where it started to another organ).<sup>27</sup> A stage 4 diagnosis usually means that a patient will die from their disease.

**FIGURE 4**  
**Stage at diagnosis, Pancreatic Cancer Action Patient and Carer Survey 2015<sup>19</sup>**



SOURCE: Pancreatic Cancer Action Patient and Care Survey 2015

Patients diagnosed with cancer as a result of emergency presentation have poorer chances of survival and more limited treatment options.<sup>28</sup>

Later diagnosis of pancreatic cancer also incurs a significant cost to the health service. Research has found that the average cost of an emergency admission where pancreatic cancer is the primary diagnosis is nearly £5,000 in England, which is around three times the average cost per patient (about £1,500), of all emergency hospital admissions combined.<sup>29</sup>

# Access to diagnostics

As the signs and symptoms of pancreatic cancer can often be non-specific, it is vital that when pancreatic cancer is suspected, GPs have adequate access to diagnostic tests. Over the last ten years, the volume of imaging tests used for the diagnosis of conditions, such as cancer, has increased. The volume of MRI scans has increased by 220% and the number of CT scans by 160% over this period.<sup>30</sup> However, there is evidence to suggest that some GPs consider access to diagnostic testing a barrier for pancreatic cancer.

In a survey of GPs, conducted by Research Now for Pancreatic Cancer Action:<sup>31</sup>

- The majority of GPs asked stated that they found it difficult to access CT scans. The main difficulties were due to lack of direct access to CT scans and also having to justify the need to request a scan

For pancreatic cancer patients, surgery provides the best chance of cure or long-term survival.<sup>32</sup> Ensuring people are diagnosed when they are suitable candidates for surgery, and increasing the proportion of patients that undergo surgery, is therefore an important way to help to increase survival of pancreatic cancer patients.<sup>33</sup>

# Provision of staff

Clinical Nurse Specialists (CNSs) provide expert advice and support; patients tell us that they are an invaluable part of the clinical team. [Access to CNSs is associated with:](#)

- A more positive experience of treatment and care<sup>34</sup>
- Effective care planning and reducing emergency admissions<sup>35</sup>

CNSs can play an important role in enabling care to be delivered closer to home and in improving patients' and their families' ability to self-manage symptoms and side effects of treatment.<sup>35</sup>

“ I provide care and support for patients and families affected by pancreatic cancer.



## CASE STUDY

### Clinical Nurse Specialist

As a Clinical Nurse Specialist, I provide care and support for patients and families affected by pancreatic cancer, a type of cancer with a very poor outcome and appallingly low survival rates (unchanged in over 40 years).

Every single day working as a CNS, I try to make a difference; sadly that difference is limited to relieving symptoms, providing support, expediting scans etc.

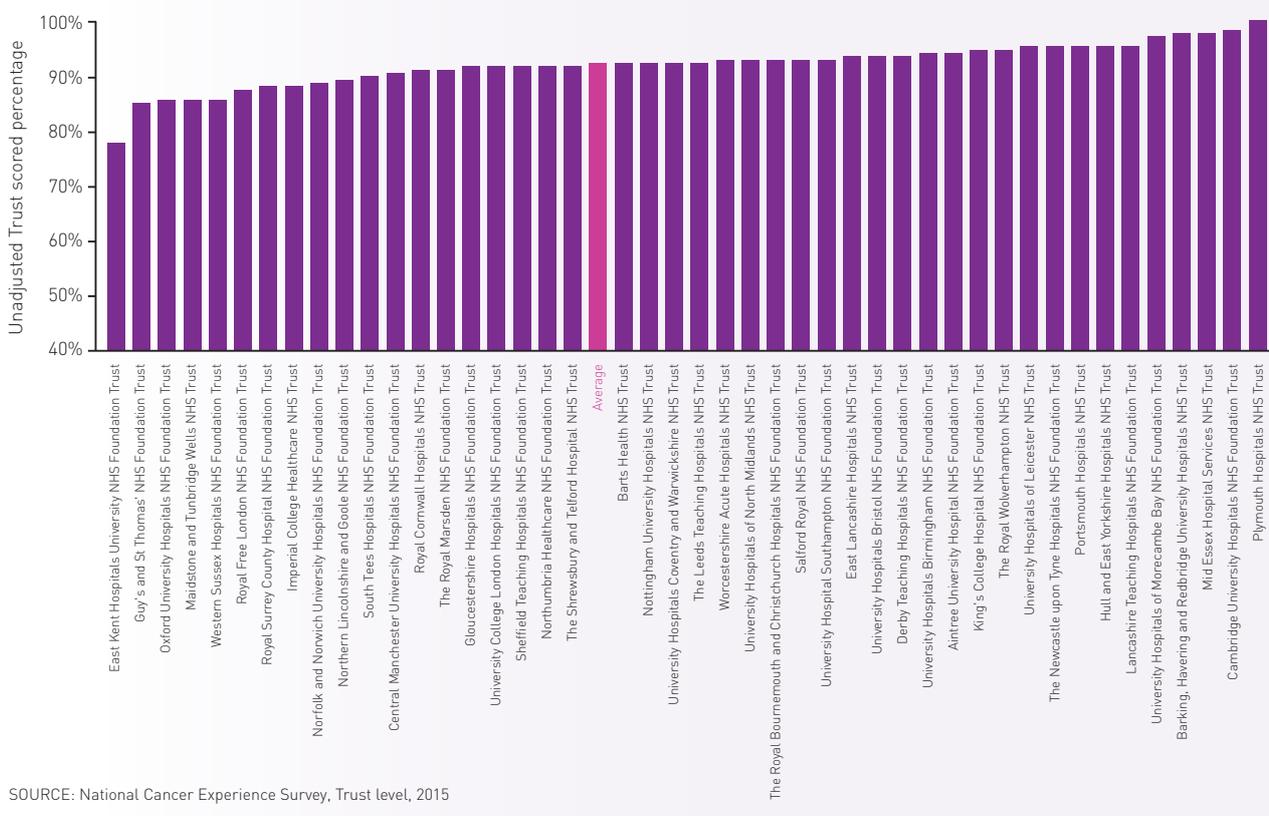
I see the devastation which this disease causes. I wish with all my heart there was more I could do to help, that I could give more hopeful news when I see the patients and families, that I could say there were more treatment options available but I can't.

Yet many patients with pancreatic cancer feel that they are not able to access CNSs to help support their care:<sup>12</sup>

- Although 92% of upper GI cancer patients said they were given the name of a CNS, only 87% said they found it easy to contact them
- If these findings are extrapolated to all pancreatic cancer patients in England, it suggests that around 1,050 patients would experience difficulties in accessing a CNS<sup>36</sup>

There is also evidence to suggest that access to CNSs for pancreatic cancer patients varies considerably across the country. For example, patients at Plymouth Hospitals Trust, are around 58% more likely to report being able to contact their CNS than patients at East Kent Hospitals University NHS Foundation Trust.

FIGURE 5  
Upper GI patients who felt they were able to contact a Clinical Nurse Specialist, 2014<sup>24</sup>



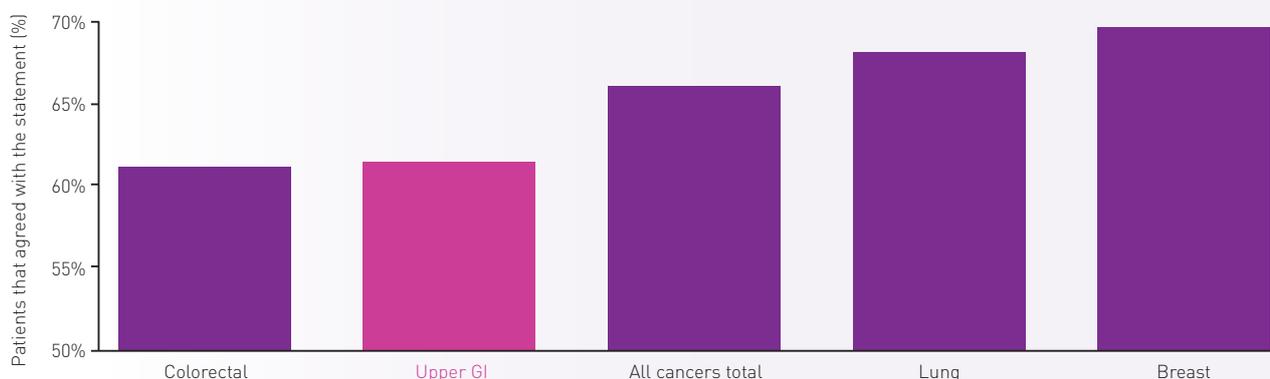
SOURCE: National Cancer Experience Survey, Trust level, 2015

Uniformity of access to CNS is critical to ensuring that patient experience for pancreatic cancer patients improves.

Problems with staff provision appear to be wider than just the CNS workforce. According the National Cancer Patient Experience Survey, patients with upper GI cancers were less likely to think that there was enough staff provision in general.

FIGURE 6

**Patients who agree with the statement that there were enough nurses on duty, 2015<sup>12</sup>**



SOURCE: National Cancer Experience Survey, Trust level, 2015

## Access to treatment

Although outcomes for pancreatic cancer have remained poor and effective treatments have been limited, there are promising new treatments which offer the opportunity to extend survival and improve quality of life. However, problems in making these treatments available risk minimising the positive impact they can have for patients in England.

There are long-standing issues with the National Institute for Health and Care Excellence’s (NICE) appraisal of cancer drugs, and patients in England have historically had lower levels of access to cancer treatments than patients living in many comparable European countries.<sup>37</sup> This is particularly true for treatments for pancreatic cancer.

FIGURE 7

**Cancer treatments available through NICE and the CDF**

Cancer type	Number of treatments available through NICE <sup>41*</sup>	Number of treatments available through CDF <sup>42**</sup>
Lung	12	2
Breast	8	4
Colorectal	7	2
Ovarian	3	1
Non-Hodgkin Lymphoma	2	2
Pancreatic	1	0

\* Where treatments have received either a 'recommended' or 'optimised' decision

\*\* Information correct at the time of publication



There are promising new treatments which offer the opportunity to extend survival and improve quality of life

Key issues in the appraisal of pancreatic cancer drugs by NICE include:

- **Evidence requirements and uncertainty in data.** For conditions with smaller patient populations, there are difficulties associated with providing the level of evidence currently required by NICE to demonstrate clinical improvement
- **Inflexibilities in 'end of life criteria'.** Drugs that can assist patients at the end of their lives can be approved by NICE at a higher cost threshold than other treatments. However, this usually means providing above 3 months of life extension to patients. This disadvantages patients with poorer prognosis cancers, such as pancreatic, where survival time can be as little as 2-6 months and new treatments might offer proportionally a significant step forwards but yet not reach the 3 month requirement. Recent proposed changes to NICE assessment processes look unlikely to adequately tackle this issue.

The Cancer Drugs Fund (CDF), which was set up in 2010 to improve access to cancer drugs that would not otherwise be routinely available, has significantly increased access to cancer treatment in England. However, a series of recent cuts to the list of recommended treatments have impacted negatively on pancreatic cancer patients, with the removal of the only treatment available for pancreatic cancer via the CDF in September 2015.<sup>14</sup>

As a result, there are a very limited number of treatment options for pancreatic cancer, available to patients in England through the NHS:

- There is now no treatment for metastatic pancreatic cancer available on the CDF<sup>14</sup>
- Patients in England are unable to access treatments for pancreatic cancer that are available elsewhere in the UK. For example, Albumin bound Paclitaxel (Abraxane) is available through the NHS in both Scotland<sup>38</sup> and Wales,<sup>39</sup> but not in England
- The last and only NICE approved treatment for pancreatic cancer was in 2001 (Gemcitabine), for which there is only a 10% response rate<sup>40</sup>
- Pancreatic cancer patients in England have far more limited access to cancer treatments than patients with other forms of cancer (see Figure 7)

## CASE STUDY

# Welsh cancer patient

A cancer drug gave one patient renewed hope when it was announced that it will continue to be used in Wales, despite English patients being denied access to it.

Abraxane is used to treat patients with metastatic pancreatic cancer and was confirmed for continued use by the All Wales Medicine Strategy Group.

The wife of one Welsh patient has told how the drug, used in combination with gemcitabine, has given them renewed hope and an improved quality of life.

Carole Johnson, 61 and from Cilcain in Flintshire, had watched husband David, 63, deteriorate after aggressive chemotherapy. She said: "It feels like someone has said here is the springtime, you can have it.

"We could see the end and now we can't and it's a really nice feeling. We just feel we have been given some hope."

David was diagnosed in 2013 and had surgery in August of that year.

He had chemotherapy which yielded some results but the cancer returned more aggressively.

Further chemotherapy kept the cancer at bay and doctors recommended Abraxane.

Carole said: "They said we only have one other drug - Abraxane. That started in December 2015 and the scan has shown shrinkage in the tumour.

"It's the quality of life it has given us. We always said we weren't interested in life with no quality.

"At the start of this things weren't looking very good but David turned a corner. I could see things were improving and when we had the scan they said there was shrinkage. We were very lucky we were offered it."

Unfortunately, David passed away on 19th June 2016 three years after his diagnosis. Access to the latest treatments certainly gave him more time as the average life expectancy for metastatic pancreatic cancer is a mere four to six months.

His widow Carole said, "We had 3 years from diagnosis, thanks to every treatment possible, and some very good times in those 3 years. We are struggling to believe he is gone though, he was so full of life force."

“ We could see the end and now we can't and it's a really nice feeling. We just feel we have been given some hope.”



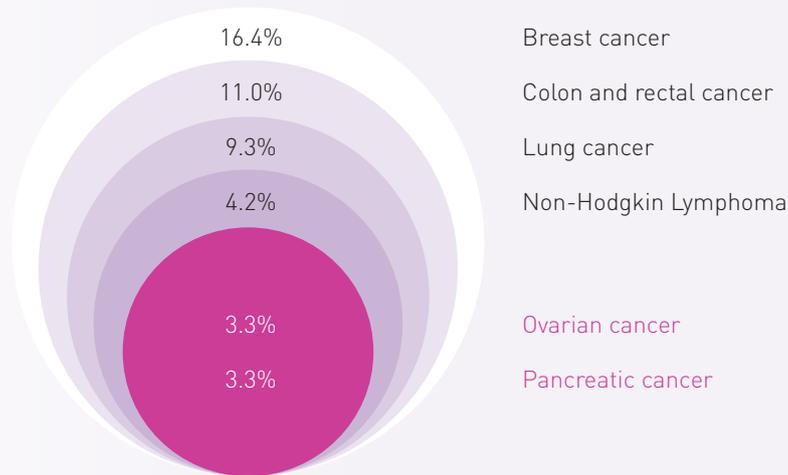
# Research

Investment in research will be crucial to improving outcomes for pancreatic cancer, to encourage earlier diagnosis and for the development of more effective treatments. Yet research into pancreatic cancer has lagged behind other cancers, with lower levels of funding, fewer researchers and less research activity.

The relative lack of funding for research highlights yet another inequality for pancreatic cancer patients. Despite the significant impact of pancreatic cancer, (with 8,080 people diagnosed in England with the condition in 2014<sup>36</sup>) and despite being the fifth biggest cause of cancer deaths in the UK,<sup>43</sup> pancreatic cancer receives a lower proportion of research funding than many other cancers:

- According to the National Cancer Research Institute, in 2015, pancreatic cancer only received 3.3% of the total cancer research spending by cancer site and only 1.6% of the total portfolio spend<sup>44</sup>
- In 2013, despite there being over 2000 more cases of pancreatic cancer that year than ovarian cancer,<sup>45</sup> the research spend per head of newly diagnosed people with ovarian cancer (£1,193) was over twice as much as that for pancreatic cancer patients (£553)<sup>46</sup>

FIGURE 8  
**Percentage of total cancer research spending by cancer site in the UK, 2015<sup>44</sup>**



SOURCE: National Cancer Research Institute

FIGURE 9  
**Spending on research, per newly diagnosed case of cancer in the UK, 2013<sup>44,45,46</sup>**

Ovarian cancer spend per new case	£1193.79
Breast cancer spend per new case	£750.80
Non-Hodgkin Lymphoma cancer spend per new case	£653.19
Colorectal cancer spend per new case	£609.19
<b>Pancreatic cancer spend per new case</b>	<b>£553.83</b>
Lung cancer spend per new case	£311.12

SOURCE: National Cancer Experience Survey, Trust level, 2015

There have been extremely welcome commitments to address the inequality in research funding for pancreatic cancer. For example, Cancer Research UK pledged to “double or treble” research funding into pancreatic cancer and cancers of unmet need in 2014.<sup>47</sup> However, the APPG on Pancreatic Cancer’s 2015 report noted that the Department of Health failed to commit to matching this pledge and that little progress had been made on embedding a culture of research into pancreatic cancer within the NHS.<sup>16</sup>

“ Treatment for pancreatic cancer is improving and it could change from being a death sentence if it can be picked up early enough.”



## CASE STUDY

### Researcher

Dr Eithne Costello has worked on pancreatic cancer for the past 16 years, and is part of a large pancreatic cancer research team at the University of Liverpool. Her particular focus is on biomarker discovery and development for the early diagnosis of disease. She is a member of the National Cancer Research Institute (NCRI) Molecular Biomarkers Advisory Group.

Eithne said: “Treatment for pancreatic cancer is improving and it could change from being a death sentence if it can be picked up early enough. Yet 80% of the patients are beyond treatment with curative intent by the time they are diagnosed.”

“Late diagnosis of pancreatic ductal adenocarcinoma (pancreatic cancer) and the limited response to current treatments results in an exceptionally poor prognosis. Advances in our understanding of the molecular events underpinning pancreatic cancer development and metastasis offer the hope of tangible benefits for patients.”

In February 2015 The Liverpool Pancreas Biomedical Research Unit hosted the 2nd National Pancreas Diseases Patient and Public Forum. Dr Costello led a session discussing the research priorities of pancreatic cancer patients. Identifying biomarkers to detect individuals at high risk was identified by delegates as a priority. The lack of research effort on the high-risk group of newly diagnosed diabetics was highlighted as a priority area.



## Chapter 2

# Incidence, survival, mortality and patient experience

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Looking at the evidence set out in Chapter 1, it is not surprising that outcomes for pancreatic cancer lag behind those for other cancers. Yet outcomes also appear to be poorer than for other countries and variations also occur within England, suggesting scope for improvement.

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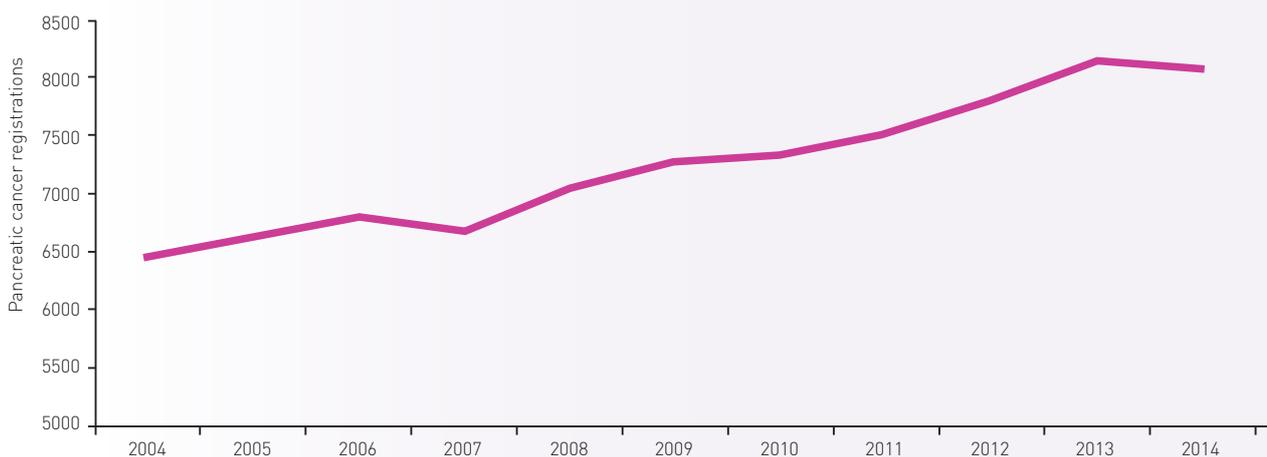
Pancreatic cancer is the tenth most common cancer and accounts for 3% of all new cancers cases<sup>22</sup>

## Incidence in England

Pancreatic cancer is the tenth most common cancer and accounts for 3% of all new cancers cases.<sup>48</sup> The number of people diagnosed with pancreatic cancer in the UK has been steadily rising. In England:<sup>36</sup>

- The number of people diagnosed with pancreatic cancer in 2004 was 6,220, compared to 8,080 in 2014 – an increase of almost 30%

FIGURE 10  
Registration of newly diagnosed cases of pancreatic cancer, England 2004–2014<sup>36</sup>



SOURCE: ONS Cancer Registration Statistics

# Increasing incidence in the UK

Although incidence for all cancers has increased in the UK, the number of people being diagnosed with pancreatic cancer has increased at a faster rate.

## In the UK:

- Between 2002-2004 and 2011-2013 incidence for all cancers has risen by 7%<sup>49</sup>
- Over the same period, incidence for pancreatic cancer in the UK has increased by 10%<sup>50</sup>

This trend is set to continue, with recent analysis suggesting that the actual number of people diagnosed with pancreatic cancer is set to increase by a third by 2030. This means that there could be up to 12,000 new cases of the condition diagnosed each year.<sup>51</sup>

## Variation in England

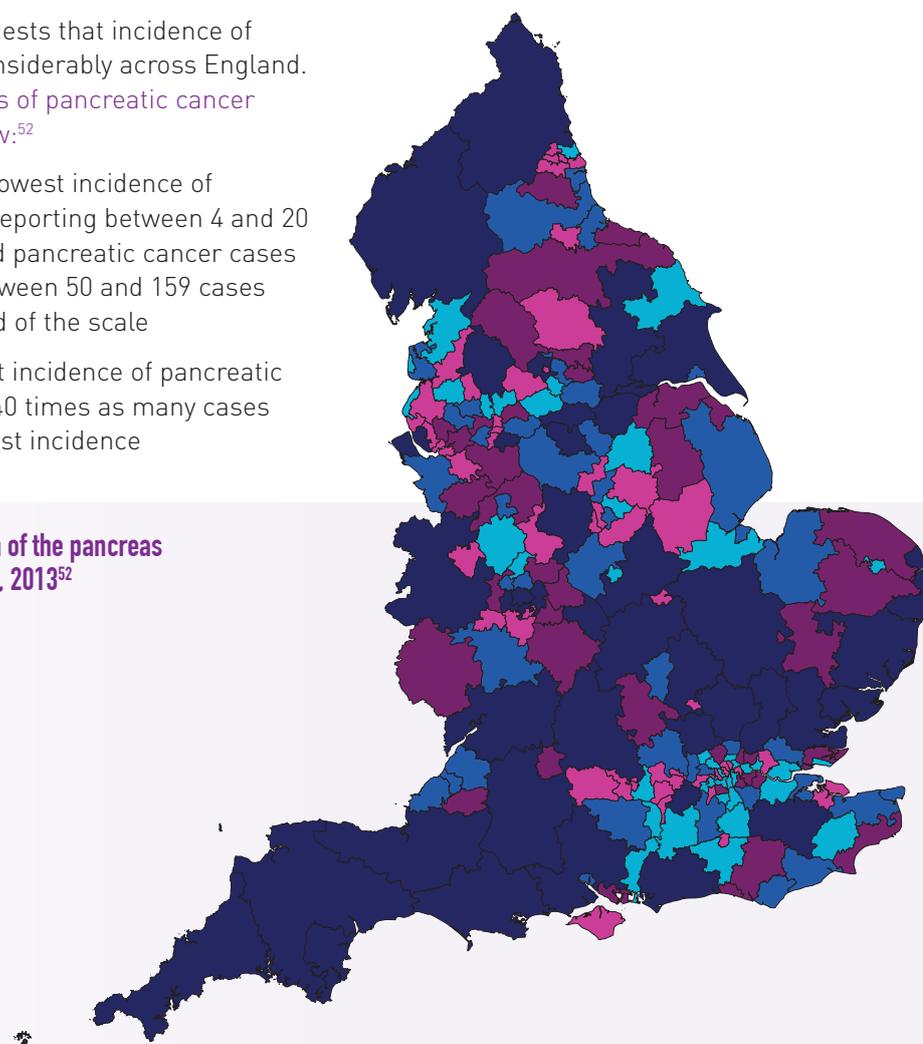
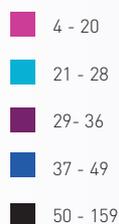
The available data also suggests that incidence of pancreatic cancer varies considerably across England.

Data on the number of cases of pancreatic cancer diagnosed in each CCG show:<sup>52</sup>

- CCGs that recorded the lowest incidence of pancreatic cancer were reporting between 4 and 20 cases of newly diagnosed pancreatic cancer cases in 2013, compared to between 50 and 159 cases for CCGs at the other end of the scale
- The CCG with the highest incidence of pancreatic cancer reported almost 40 times as many cases as the CCG with the lowest incidence

FIGURE 11

### Incidence of malignant neoplasm of the pancreas by Clinical Commissioning Group, 2013<sup>52</sup>



SOURCE: Office for National Statistics

# Survival

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Nowhere are the inequalities for pancreatic cancer patients more pronounced than in relation to survival. In England, around 5% of people diagnosed survive for 5 years or more and less than 1% survive pancreatic cancer for 10 or more years.<sup>53</sup>

Unquestionably, the poorer prognosis for pancreatic cancer compared to other cancers is mainly attributable to the fact that it is a difficult condition to diagnose and treat. People are often not diagnosed until the disease has progressed to an advanced stage and it is causing significant health problems. Pancreatic cancer is also difficult to treat and is very resistant to chemotherapy mainly due to the abundant tissue which surrounds the organ.<sup>8</sup>

“ I want to play my part in changing the future for patients.”



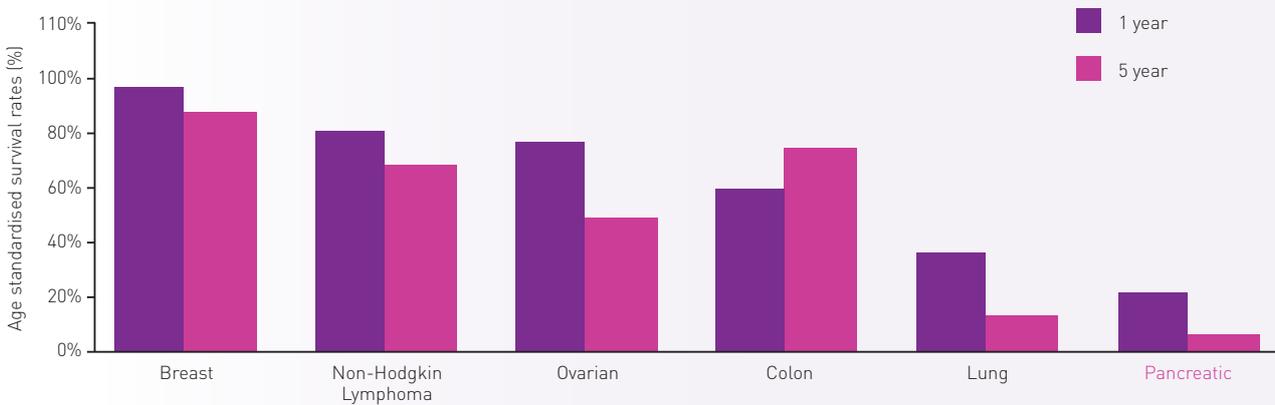
## CASE STUDY clinical oncologist

We have to keep moving forward with this disease. We will have failed as a community if treatments have not improved patient outcomes over the next 10 years. I want to play my part in changing the future for patients, and for that we need new insights and knowledge about this disease and new treatments to help more people to survive. I want to be involved in this.

There's been a growing realisation that pancreatic cancer is not just one disease. Just like recent research which revealed different and distinct types of breast or bowel cancer, we think that the same is true with pancreatic cancer. This could be the reason why current treatments which are similar for all patients, are only modestly effective. We need to move away from a 'one size fits all' approach.

The differences between survival for pancreatic cancer and other forms of cancer are considerable. Patients with pancreatic cancer experience the worst survival of all common cancer types.<sup>54</sup>

FIGURE 12  
**One-year and five-year age-standardised net survival, England, 2009-2013<sup>55</sup>**

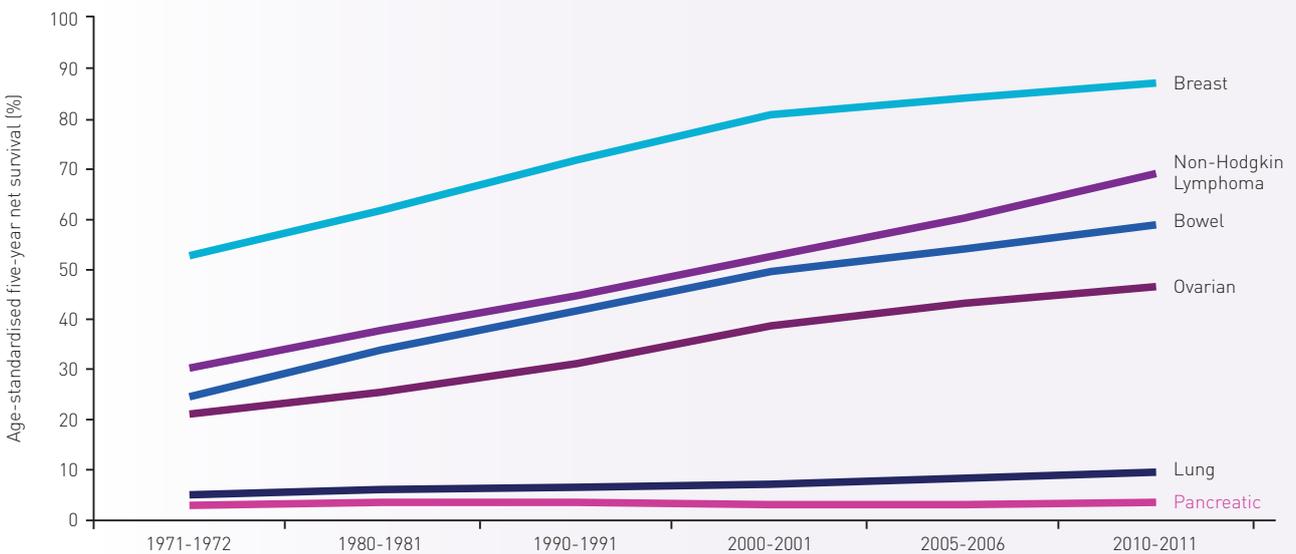


SOURCE: Cancer Survival in England - Adults Diagnosed - 2009-2013

However, there has also been a deeply concerning lack of improvement in these rates since the 1970's. This is in stark contrast to the majority of other cancers. *Between 1971 and 2011, in the UK:*

- Pancreatic cancer survival has failed to increase above 3.3%
- Breast cancer survival has increased by almost twice as much (64%) as pancreatic cancer (37.5%)
- Survival for ovarian cancer was 14 times better than for pancreatic cancer

FIGURE 13  
**Age-standardised five-year net survival, England and Wales, 1971-2011<sup>56,57,58,59,60,61</sup>**

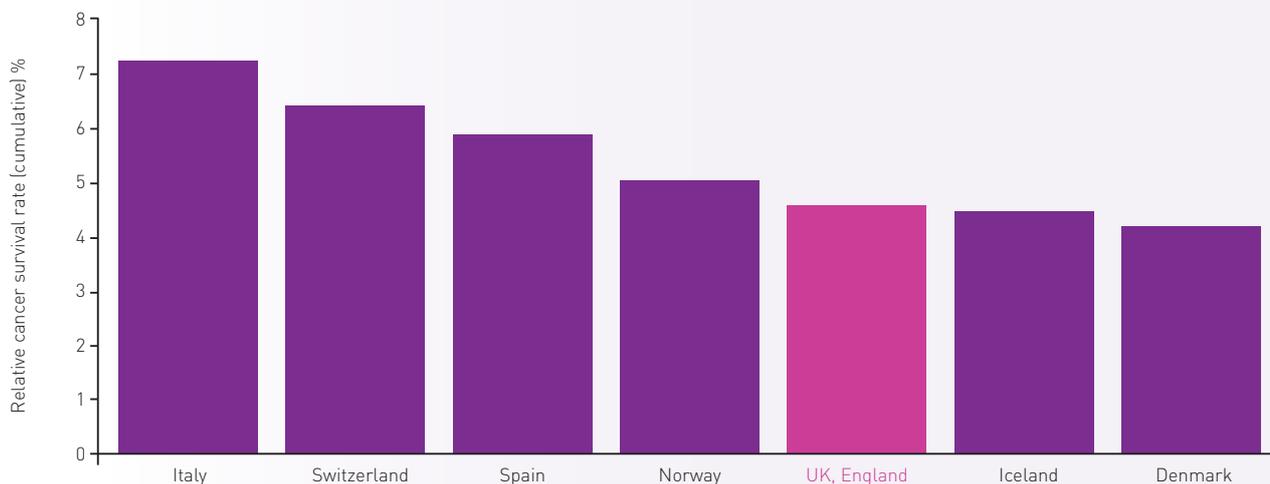


SOURCE: Cancer Research UK

# International comparison

The latest available data suggest that survival in England for pancreatic cancer lags behind that of other comparable countries.

FIGURE 14  
Relative five-year survival for pancreatic cancer, ICSS-Std, 2000-2007<sup>62</sup>



SOURCE: Eurocare 5

## Mortality

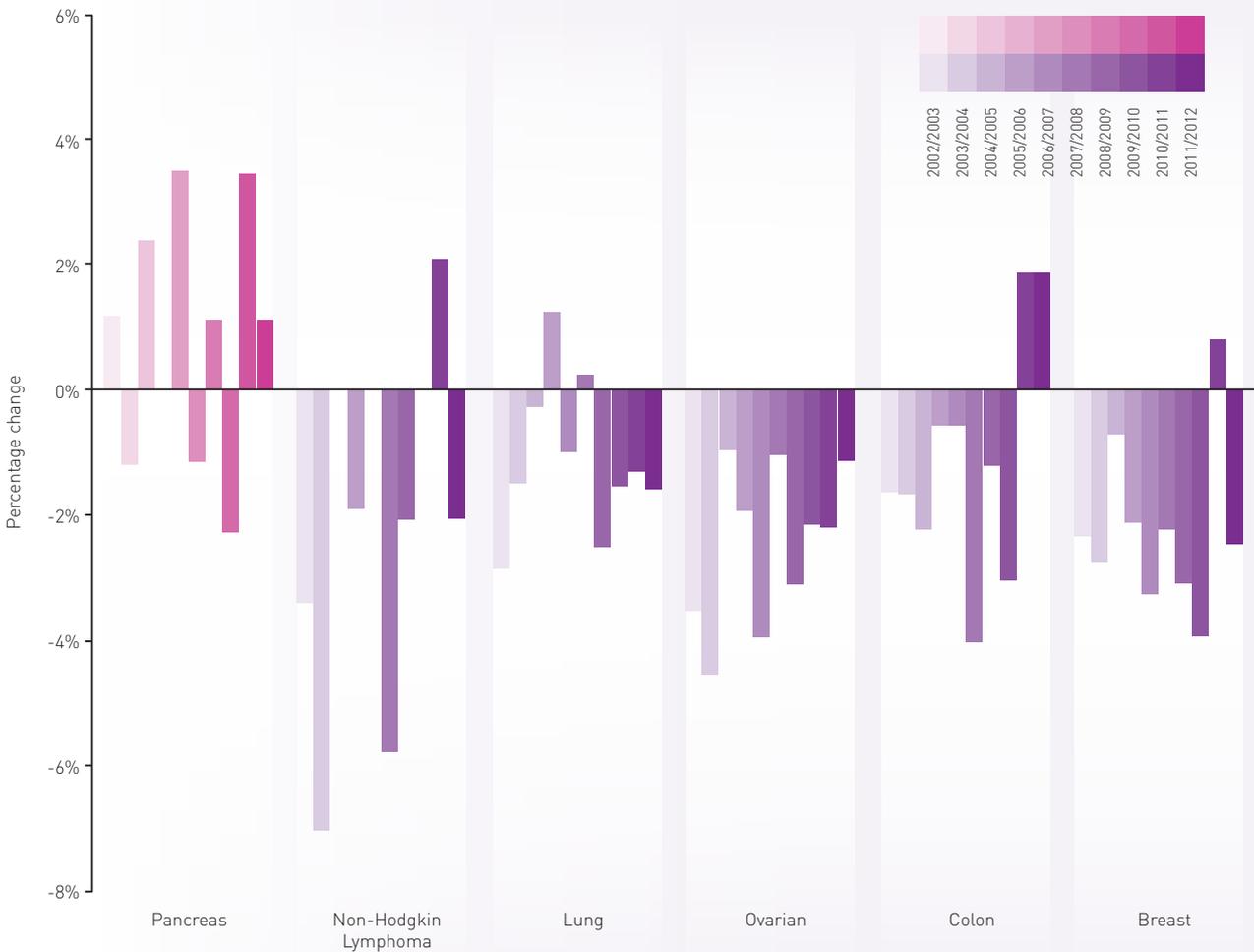
In the UK, cancer death rates have fallen by nearly 10% over the last ten years. In 2013, 284 out of every 100,000 people in the UK died from cancer – around 162,000 people. A decade ago this was 312 in every 100,000. While this progress is encouraging, the analysis reveals, once again, the severe inequalities that exist for pancreatic cancer patients:

- Cancer mortality in the UK has fallen significantly over the last decade but mortality for pancreatic cancer has actually increased by 8% over the same time period<sup>10</sup>
- There were around 7,000 deaths from pancreatic cancer in the UK in 2003<sup>10</sup> and around 8,834 deaths in 2014<sup>63</sup>

It is particularly important that there is a decrease in mortality, as this constitutes the heaviest economic burden of cancer. Therefore, the increase in the mortality rate for pancreatic cancer also increases the economic burden of the disease.<sup>5</sup>

FIGURE 15

Percentage change over time, European age-standardised mortality, UK, 2002-2012<sup>44,65,66,67,68,69</sup>



SOURCE: Cancer Research UK

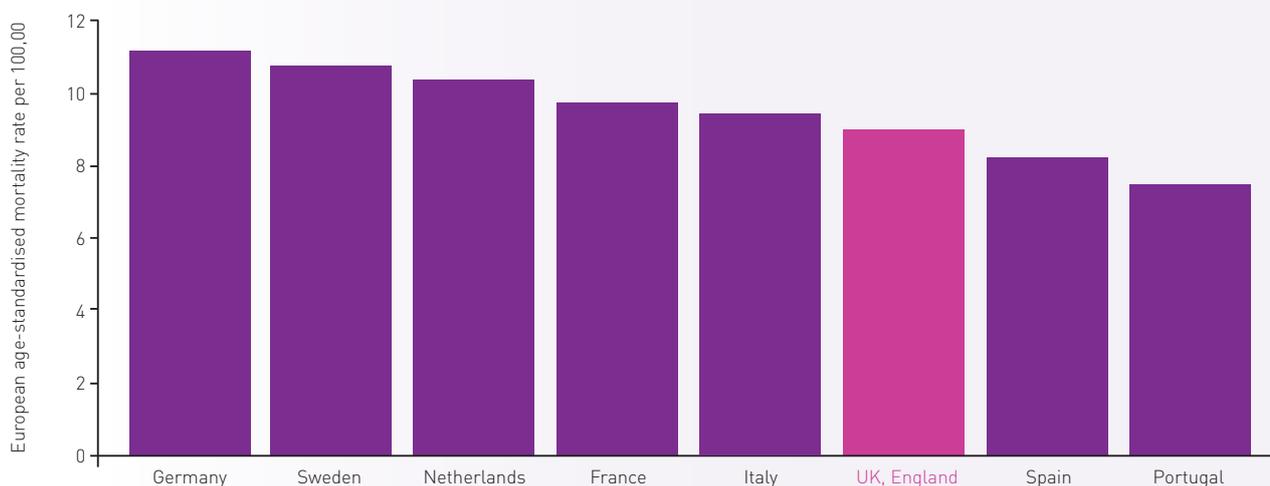
Cancer mortality in the UK has fallen significantly over the last decade but mortality for pancreatic cancer has actually increased by 8% over the same time period<sup>10</sup>

# International comparison

Mortality from pancreatic cancer is not improving across Europe.<sup>70</sup> The evidence suggests that death rates for pancreatic cancer in the UK are also lower than for some other comparable European countries.

FIGURE 16

## Estimated age-standardised mortality from pancreatic cancer, Europe, 2012<sup>71</sup>



SOURCE: EUCAN

# Variation in England

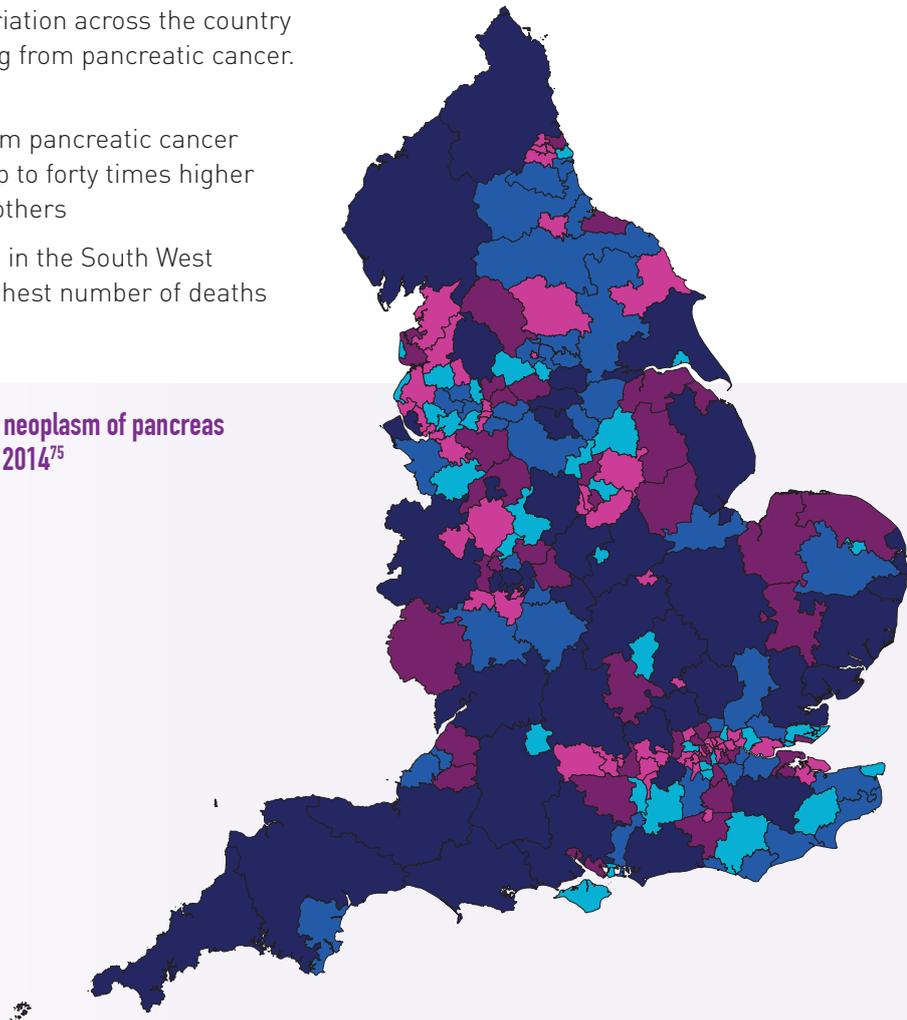
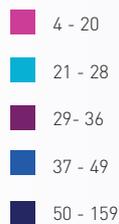
Again, there is significant variation across the country in the number of people dying from pancreatic cancer.

The available data show:<sup>72</sup>

- The number of deaths from pancreatic cancer recorded by CCGs were up to forty times higher in some CCG areas than others
- A large proportion of CCG in the South West recorded amongst the highest number of deaths from pancreatic cancer

FIGURE 17

**Number of deaths from malignant neoplasm of pancreas by Clinical Commissioning Group, 2014<sup>75</sup>**



SOURCE: Office for National Statistics

# Patient experience

Patient experience measures provide an important indication of the standard of care received by patients.

The available evidence suggests that patients with upper GI cancers are reporting a worse experience of care, than that for patients with other forms of cancer. [The National Cancer Patient Experience Survey results have shown that:](#)<sup>12</sup>

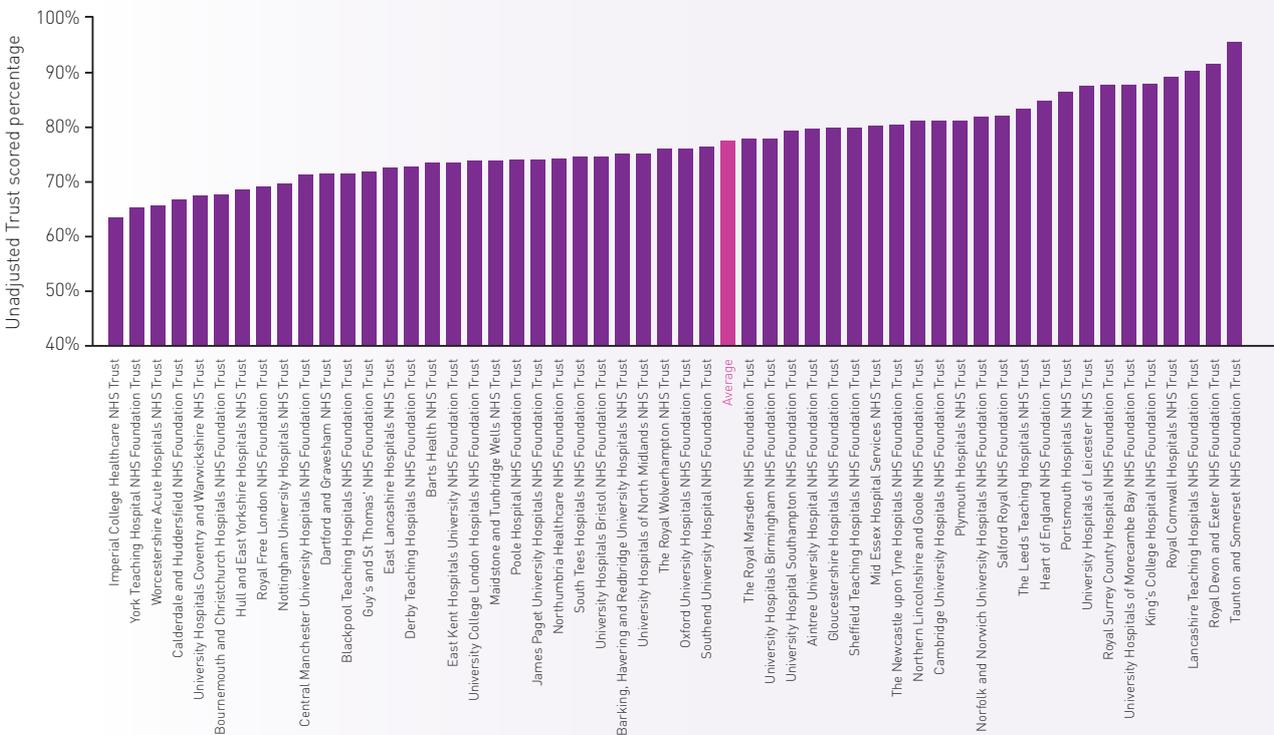
- Close to half of upper GI patients felt they were not told about possible future side effects
- Almost half of patients with upper GI cancer felt that there was no one during their hospital visits they could talk to about their worries and fears
- A third of patients with upper GI cancer felt they were not given easy to understand written information about their type of cancer<sup>73</sup>
- Over a third of upper GI patients felt that their health got worse while they waited for their first appointment with a hospital doctor, compared to 93% of breast cancer patients who thought their health improved, or stayed the same<sup>73</sup>

There was considerable variation in the patient experience reported by patients with upper GI cancer across the country:<sup>24</sup>

- Some NHS Trusts reported almost twice the amount of patients who felt that side effects had been explained than others
- There was almost a three-fold difference between some NHS Trusts in the percentage of patients who felt that staff did everything they could to support them

FIGURE 18

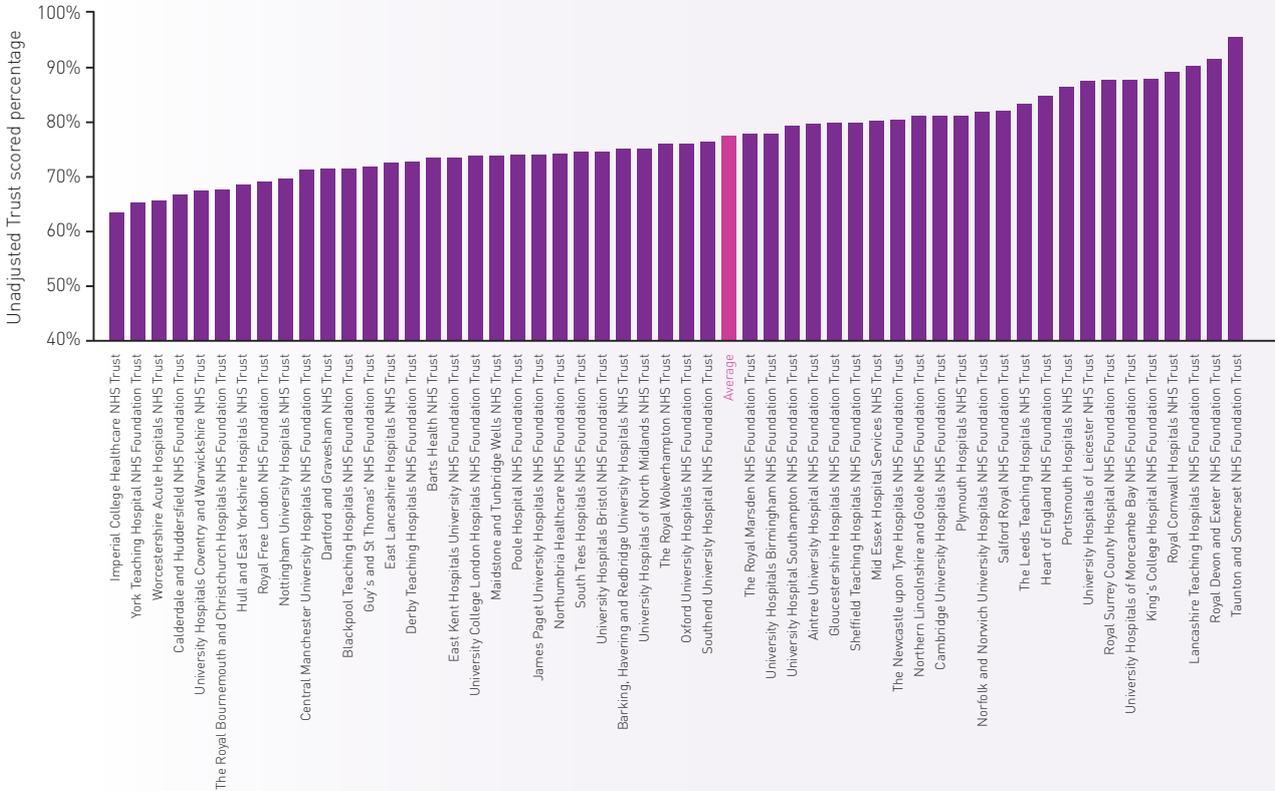
## Upper GI cancer patients who felt that the possible side-effects were explained in an understandable way<sup>24</sup>



SOURCE: National Cancer Patient Experience Survey, 2015

FIGURE 19

Percentage of patients who felt they were involved as much as they wanted to be in decisions about their care<sup>24</sup>



SOURCE: National Cancer Patient Experience Survey, 2015

Close to half of upper GI patients felt they were not told about possible future side effects.

# About us

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Full editorial control for this report rests jointly with Pancreatic Cancer Action and Shire. Shire paid for the writing services of Incisive Health and Pancreatic Cancer Action received no payment from Shire. You can find out more about Shire and Pancreatic Cancer Action, and get in touch with them, below.

## Pancreatic Cancer Action

Pancreatic Cancer Action is a UK charity committed to improving survival for people diagnosed with pancreatic cancer.

The charity's approach is to raise awareness of pancreatic cancer to the public, the medical community and Government, provide education and training on pancreatic cancer to medical professionals and fund research specifically into improving early diagnosis of pancreatic cancer.

Pancreatic Cancer Action is a member of the Association of Medical Research Charities, which is a membership organisation of the leading medical health and research charities in the UK.

Founded by Ali Stunt, who is herself a rare survivor of the disease, Pancreatic Cancer Action has the support of many leading clinicians and researchers in the pancreatic cancer arena along with others whose lives have been touched by pancreatic cancer in some way.

If you would like to contact Pancreatic Cancer Action, please email [enquiries@panact.org](mailto:enquiries@panact.org) or call 0303 040 1770.

## Shire

Newly combined with Baxalta, Shire is now the leading global biotechnology company focused on serving people affected by rare diseases and highly specialized conditions. These diseases are often misunderstood, under-diagnosed, and potentially life-threatening.

Our 22,000 employees come to work every day with a common purpose: to develop and deliver breakthrough therapies that enable people with life-altering conditions to live their lives to the fullest.

At Shire, we are dedicated to expanding, building and sustaining leadership across our key therapeutic areas through our extensive portfolio of products, innovative pipeline and collaborative approach to working with diverse partners around the globe. We strive to earn and keep the trust of our patients, their families and physicians, and all others who support and advance their care.

If you would like to contact Shire, please contact Joe Brice on 07584 612777 or at [joe.brice@shire.com](mailto:joe.brice@shire.com).

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