Diagnosis Manifesto for Scotland
My dad had undergone a series of tests as a result of weight loss, loss of appetite, stomach/back pain and changes in his bowel movements. After a number of blood tests and a couple of visits to his GP he was sent for a scan.

He had an appointment with his GP a few weeks later to discuss ongoing symptoms. At this appointment he was advised out of the blue that the scan result had come back and he had pancreatic cancer. He had attended the GP on his own as he was not aware that his scan result had come back. He was left to drive home on his own. He was shattered by this news but he knew nothing about pancreatic cancer and its prognosis at that point. No biopsy had been done – that came later – yet his GP advised he had pancreatic cancer and offered no other possible explanation.

Pancreatic cancer was only confirmed for sure a few weeks later following an endoscopy. A week or so after the endoscopy his oncologist – who he met for the first time that day – confirmed that he had pancreatic cancer.

The doctor asked us (my dad, mum, sister and me) if we had done any reading on pancreatic cancer and when I said I had he asked me to say what I had learned about prognosis. I was appalled at this as I did not want to be the one to break the news to my dad that his inoperable pancreatic cancer was likely to result in death within months. I declined to answer the question and the oncologist went on to say that prognosis was 4 to 6 months and, whilst chemo was possible, it was unlikely to make much of a difference. He was very factual. I didn’t mind that but my mum found the whole experience to be brutal and very insensitive.

My dad sat in silence with a look on his face that I will never forget. We were quite clear that there was no hope of anything other than a relatively quick death. It was traumatic.

PK, Edinburgh
CALLS FOR ACTION

1. **Research** – research is urgently needed into the early diagnosis of pancreatic cancer, such as developing and validating biomarkers which may ultimately lead to the development of screening tests of the kind used to detect other cancers.

2. **Public awareness** – common signs and symptoms of pancreatic cancer should be communicated as part of the Scottish Government’s Detect Cancer Early campaign.

3. **Better training and support tools for GPs** – GPs need support to improve their knowledge of pancreatic cancer, and its signs and symptoms. In addition to training, GPs should be provided with effective, computerised Decision Aid Tools to supplement their knowledge.

4. **Referral guidelines** – Scotland improved its referral guidelines for suspected pancreatic cancer in the summer of 2014 and these now need to be utilised consistently by GPs across the country.

5. **Faster referral pathways** – once cancer is suspected, patients need to be put on swift referral pathways to confirm diagnosis quickly before the tumour spreads, which might make the difference between a patient being eligible for surgery or not.

6. **Communication** – diagnosis needs to be communicated to the patient in a sensitive manner and in an appropriate location.

7. **Information** – at the time of diagnosis, patients and their families need to be provided with written information about the disease, as well as details of organisations they can contact for further advice, information and support.

8. **Cancer Nurse Specialists** – to ensure all patients and families receive appropriate information and support, all patients must have access to a Cancer Nurse Specialist, preferably a Pancreatic or Hepato-pancreato-biliary (HPB) Cancer Nurse Specialist. This includes those not undergoing active treatment.

9. **Monitoring of patient experience** – a Scottish Cancer Patient Experience Survey should be introduced so that patient care for pancreatic cancer patients – and those with other cancer types – can be evaluated and improved.

10. All of the above points should be tackled in a refreshed Cancer Strategy for Scotland.
INTRODUCTION

DIAGNOSIS ‘MANIFESTO’

PANCREATIC CANCER IS THE 11TH MOST COMMON CANCER IN SCOTLAND BUT THE 6TH BIGGEST CAUSE OF CANCER DEATH

770 people are diagnosed with, and 742 people die from the disease each year. One-year and five-year survival rates in Scotland are just 15.7% and 3.2% respectively, lower than the UK average, and these survival rates have remained virtually unchanged over the past 40 years.

Over half of all Hepatoa-pancreato-biliary (HPB) patients in Scotland are only considered for a palliative care plan at first discussion by their Multi-disciplinary Team (MDT)/healthcare team. A further 28% have supportive care only and just 17% of patients are initially considered for potentially curative treatment. This is largely because of late diagnosis: half of pancreatic cancer patients are diagnosed via emergency admission, double the rate of other cancer types. We know that patients admitted this way have much worse survival outcomes than those diagnosed following a GP referral.

Surveys also show that pancreatic cancer patients have a worse patient experience than those with other cancer types, for instance they are less likely to have access to a Cancer Nurse Specialist or be provided with enough information about the disease.

Our ‘Diagnosis Manifesto’ is a call to action, setting out the radical change needed to boost the current dreadful survival rates and improve the patient experience. From more and better research to increased awareness, improved referral pathways and much more consideration of the patient and their feelings through the whole diagnostic pathway, there is much that must be changed.
When faced with a set of such awful statistics, it is sometimes easy to lose sight of the fact that each number represents a personal story. And so, as we explain why we need to introduce particular changes, we use the words of Scottish patients, their family members, or those who have lost loved ones to the disease.

Their words powerfully explain what is wrong at the moment, and how an advance in research, or a change in process, or an improvement in awareness, might help to ensure others do not have to go through what they have gone through and, ultimately, help more people survive pancreatic cancer in the future.

“ My mother died of pancreatic cancer and when I went to the GP with the same starting symptoms 1 year before my diagnosis the GP did no blood or urine tests and sent me for an ultrasound which showed nothing. Since then I have been told an ultrasound probably won’t detect it and I should have had a CT scan. That was 1 year ago. If it had been found at that point I would not be going through this now... ”

RC, West of Scotland
Pancreatic cancer currently receives just 1% of UK cancer research funding, despite being the cause of 5% of all cancer deaths.

Whilst there is a need for research generally in the field of pancreatic cancer – including new and better treatments, palliative care, prevention, and basic tumour biology – if more patients are to be eligible for surgery, which currently provides patients with the best outcomes, there needs to be a particular research focus on radically improving early diagnosis techniques.

There has been some promising research on how biomarkers might provide the basis for pancreatic cancer screening but much more work is needed. More research also needs to be carried out into early-presenting symptoms, or clusters of symptoms, which can be conveyed to the public and GPs.

Scotland is a world leader when it comes to pancreatic cancer research, with top facilities and researchers across the country. Pancreatic Cancer UK already supports Scottish-based research into pancreatic cancer and we were delighted to announce, in December 2014, a match-funding grant from the Scottish Government, of up to £75,000 to help fund two of our Research Innovation Fund projects (RIF). The RIF aims to spur creative and cutting edge ideas and approaches, including those successful in other cancer types that show promise for pancreatic cancer.

We hope that this match funding will be the start of ongoing collaboration leading to a further increase in research funding across Scotland in the future.

“We badly need more research into diagnosing pancreatic cancer at an early stage. A screening test, in particular, could have helped pick up my nana’s cancer much sooner, which in turn might have meant she had treatment to live longer.”

Kim, Edinburgh

A major area of research will be to enable the development of screening tests like those used to detect other cancers like prostate or bowel cancer.
PUBLIC AWARENESS

RESEARCH HAS SHOWN LEVELS OF PUBLIC KNOWLEDGE OF PANCREATIC CANCER, LET ALONE SIGNS AND SYMPTOMS OF THE DISEASE, IS VERY LOW.

A 2014 Pancreatic Cancer UK poll showed only 37% of Scottish respondents knew ‘something’ or ‘a lot’ about pancreatic cancer, compared to 73% for breast cancer or 53% for prostate cancer. 18% said they ‘had heard of it but knew nothing about it’. 3% had not heard of it at all.

Knowledge of common symptoms was even less – for example only 24% of Scottish respondents associated jaundice or back pain with pancreatic cancer.

Clearly there is a role for charities like Pancreatic Cancer UK to help get the message out there. But to truly make a difference we need to see common signs and symptoms communicated as part of national awareness campaigns. The Scottish Government’s Detect Cancer Early programme offers such an opportunity and we hope that pancreatic cancer will be included in the scheme in the near future. Failing a pancreatic cancer specific campaign, we would like to see some common symptoms – such as weight loss, change in bowel habit or abdominal pain – included in a generic cancer awareness campaign.

It is also important that any awareness raising message encourages patients not to think they are wasting their GPs’ time, to present with symptoms at an early stage, and not be afraid to return to their doctor if symptoms do not resolve.

“ If my mum had been scanned just a few weeks earlier there’s a good chance her cancer would have been detected before it spread to her liver and she might have been eligible for surgery and potentially still be with us today. Pancreatic cancer needs much more awareness, and GPs need to be far better trained to spot it. ”

Lauren, Aberdeenshire
Pancreatic cancer is not a rare cancer, but it is a less common cancer. GPs are, on average, likely to see only 1 new case of pancreatic cancer every 5 years, although some will perhaps see only 1 in their entire career.

A UK wide survey\textsuperscript{6} of GPs carried out by Pancreatic Cancer UK showed that whilst most GPs could list one or two symptoms, half were not confident that they could identify the signs and symptoms of possible pancreatic cancer in a patient.

This helps explain why patients end up visiting their GPs on multiple occasions, and are often diagnosed with other complaints, before they are finally referred for tests for pancreatic cancer.

The 2013 NHS England Cancer Patient Experience Survey showed that more than 40\% of pancreatic cancer patients have to visit their GP three times or more before they are referred to hospital, compared to 75\% of all cancer patients who are referred after just one or two visits to their GP\textsuperscript{7}.

This trend was reinforced by another Pancreatic Cancer UK survey carried out at the end of 2014 across the whole of the UK. We surveyed current patients and their family members, as well as the families of those who have lost their lives.

Respondents told us 23\% of patients visited their GP seven or more times before diagnosis and 15\% visited five or six times, which probably explains why 38\% of patients had to wait longer than three months from first presenting with symptoms until being diagnosed.

\textit{We had 3 weeks with dad from diagnosis to him passing. He deteriorated on what felt like fast forward. He had been back and forth to the GP, his symptoms all seemed to point to pancreatic cancer yet it was only found after he collapsed and demanded a CT scan!}

\textit{Ishbel, Dundee}
As a result, many patients end up being admitted via an emergency admission route, by which time expected outcomes are much poorer. We know from a 2014 study that patients diagnosed via an emergency admission have a 12 month relative survival of just 9%, compared to 24% for those referred by their GP, or 20% who are referred via a 2 Week Wait.

Repeat visits to the GP and hospital mean valuable time is lost which allows the tumour to grow and spread. This might make the difference between a patient being eligible for surgery or not. Currently just 17% of Scottish HPB patients – including pancreatic – are initially considered for curative treatment, largely down to late diagnosis. This needs to change.

“\n
It took far too long for diagnosis. My father was at his GP at least twice a month for over a year with stomach pain, new onset diabetes and weight loss and it was blamed on gastro problems. \\

Stacey, Kilmarnock”
WHilst it is true that symptoms of pancreatic cancer can be late-occurring and non-specific, the fact remains that symptoms do exist and that many patients present to their GP with these for months before diagnosis.

Common symptoms can include: abdominal pain; jaundice; weight loss; loss of appetite; change in bowel habits; new onset diabetes not associated with family history or being overweight; back pain; indigestion or heartburn.

GPs should be encouraged to utilise online pancreatic cancer training modules – for example those produced by the Royal College of GPs in conjunction with the charity Pancreatic Cancer Action. They should also be offered support by way of computerised Decision Aid Tools (DATs).

Macmillan Cancer Support has trialled a DAT across primary care, which works by providing GPs with a symptom checker, shows details of consultations from the previous twelve months, stratifies patients into low, medium or high cancer risk categories, and issues on screen prompts to consider cancer when certain thresholds of risk are reached. Pancreatic Cancer UK supports the use of DATs and hopes that this technology can be embedded into GP IT systems across the UK as soon as possible.

GPs can also be helped by clear referral guidelines for cancer. We are pleased to note that Health Improvement Scotland updated its Referral Guidelines for Suspected Cancer in 2014. These were a big improvement on previous guidelines as, for the first time, they included a section on pancreatic cancer and also included late onset diabetes and non-responsive heartburn/indigestion as symptoms to warrant referral. We hope these guidelines will be utilised widely by GPs across Scotland.

My friend recognised symptoms from his mother’s illness and paid for his own scan as he was ignored by the GP.

Kirsteen, Glasgow
Importantly, the new guidelines also encourage GPs to consider referring patients for imaging scans to get to the bottom of symptoms. However, whilst ultrasound scans can sometimes show tumours on the pancreas, this technique is not the most effective for detecting a pancreatic tumour. As the draft NICE referral guidelines for suspected cancer state:

“ultrasound is only able to image the head of the pancreas, and is associated with both false positives and negatives... A CT scan can image the whole pancreas but is associated with the potential risk of radiation late effects... a CT scan would be the most appropriate investigation in primary care.”

Pancreatic Cancer UK agrees and believes that giving GPs the power to refer directly the patients they suspect might have pancreatic cancer for a CT scan is a vital and effective way of achieving faster diagnosis.

Moreover, GPs need to note any change in attendance patterns – people returning to see their doctor who had rarely been to their GP before – and be encouraged to think ‘outside the box,’ and be more ready to consider cancer as a cause. They should also take decisive action when patients have unexplained persistent symptoms that have not responded to treatment.

“Before the CT dad was told he may have a stomach ulcer, or irritable bowel so had cameras up and down, ultrasound scans on his gallbladder and kidneys, bloods, bloods and more bloods and all came back with nothing! If it’s about money and budgets wasting time on lots of small tests seems pointless, surely it’s more cost effective to just do a scan and find out asap! It’s false economy surely! Plus this allows you more time if the results aren’t as you hoped! Again time costs nothing but means the world. ”

Ishbel, Dundee
Some experts have suggested a ‘three strikes and you’re referred’ policy, whereby if a patient visits their GP three times with the same symptom that hasn’t been resolved they should be referred to secondary care for further investigation to try to get to the bottom of the problem once and for all.

And, once the GP has played their part by picking up on symptoms that may flag a pancreatic cancer concern, the patient needs to move swiftly through investigative pathways to a definitive diagnosis. At the moment, too many patients find themselves being bounced back and forth between GP and specialist, with long waits in between tests.

Innovative referral pathways are needed. For instance, where patients with vague symptoms can have multiple tests carried out on the same day, or over several days if required, rather than having to return to their GP after each test only to be referred on again. These multi-disciplinary diagnostic centres (MDCs) would speed up diagnosis, give peace of mind to patients without cancer, allow earlier treatment for those with cancer and, possibly, save the NHS money by cutting down on the multiple referrals and revisits to GPs. This MDC model is already used in countries like Denmark and is soon to be trialled in London.

The key thing is that pathways need to break away from the current model which has the patient going back and forth between GP and specialist, delays diagnosis and creates such fear and frustration, whilst all the time their tumour continues to grow. And for those who ultimately are proven not to have cancer, speedier diagnosis will be a weight off their minds.

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After 6 months of GP appointments, my mum, aged 49, was finally sent for a simple ultrasound scan which showed up a tumour on her pancreas. My mum had been ‘diagnosed’ with a pulled muscle, IBS, and even stress/depression up until this point. But when her pain was so severe that she was on her hands and knees they eventually sent her for a scan. Other than when she was pregnant my mum had barely ever been to the GP, so to this day I can’t understand why they didn’t realise something was seriously wrong for her to have been going that many times in six months. After the ultrasound showed what looked like a tumour on her pancreas they arranged for a biopsy to be taken. This took around 3 weeks. At the biopsy they also did a second biopsy which now also showed some shadows on her liver. The biopsy confirmed she had pancreatic cancer, stage 4, advanced.

Lauren, Aberdeenshire
Pancreatic Cancer UK funded a follow up to the NHS England Cancer Patient Experience Survey (CPES), to develop a picture purely of the pancreatic cancer patient experience and how it compares with other cancer types.

This comparison has demonstrated that pancreatic cancer patients have a worse experience than those patients with other cancer types. Whilst the survey did not include responses from Scottish patients, our knowledge gained by working with patients across the UK suggests that patient experiences are unlikely to vary between England and Scotland.

Some of the most striking examples of poor pancreatic patient experience variation were around communication and information:

<table>
<thead>
<tr>
<th>Agreed with statement</th>
<th>All CPES</th>
<th>Pancreatic CPES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff gave complete explanation of the purposes of tests</td>
<td>84%</td>
<td>76%</td>
</tr>
<tr>
<td>Patient felt they were told sensitively that they had cancer</td>
<td>84%</td>
<td>73%</td>
</tr>
<tr>
<td>Patient given easy to understand written information about the type of cancer they had</td>
<td>71%</td>
<td>55%</td>
</tr>
<tr>
<td>Patient had confidence and trust in all doctors treating them</td>
<td>85%</td>
<td>74%</td>
</tr>
<tr>
<td>Given clear written information about what they should do/not do post discharge</td>
<td>84%</td>
<td>74%</td>
</tr>
</tbody>
</table>
We believe that information about discrepancies in patient experience of this kind can help drive improvements to patient care. As such, we would like to see a Scottish Cancer Patient Experience Survey developed so that patient care for pancreatic patients – and those with other cancers – can be evaluated and improved.

Pancreatic Cancer UK also carried out an online survey at the end of 2014 across the whole of the UK. Respondents included current patients and their family members, as well as the families and carers of those who have lost their lives. Respondents told us that:

• Whilst the majority of patients and their family members felt the diagnosis was communicated sympathetically, 35% of respondents felt it was not.

• 25% of patients were given their diagnosis on a hospital ward with other patients nearby, and nearly 5% of patients were given the news over the telephone.

This demonstrates there are clear improvements needed in how patients and families are informed. Communicating the diagnosis of pancreatic cancer should be done as sympathetically as possible and in an appropriate location. Privacy should be respected – simply pulling curtains around a bed in a general ward allows other people to overhear the diagnosis and the patient’s reaction. A diagnosis of a terminal condition over the telephone simply should not happen.

“We were told my dad had cancer in a ward bay with the curtains pulled during visiting hours.”

Anon, Scotland

The same survey saw 52% of respondents say they or their family member were not offered support or time to digest the news after the diagnosis was communicated. Incredibly, nearly 23% of patients had nobody with them when they were told of the diagnosis.

Every effort should be made to ensure that a patient about to be given a diagnosis of cancer has a friend or family member with them, to offer support and practical assistance, such as a lift home.

“We had an endoscopy for the second time, he was told no difference since the first one and it was pancreatitis but he would be given official results in a return appointment in a few weeks. So he went to the appointment at the hospital on his own thinking it was pancreatitis.”

Anon, Scotland
Patients should also be given written information to take away with them – many do not know what to ask immediately following the news that they have cancer. Being able to take accessible information home with them, which can be looked at with family members and others as appropriate, is an essential part of providing good care to patients. Working with patients and carers as well as healthcare professionals Pancreatic Cancer UK has developed a special Newly Diagnosed Pack that can be offered at the point of diagnosis. All patients should also be given details of who to contact for more support, advice and to have their questions answered, including details of external charities, for example Macmillan, who offer advice on finances, or Pancreatic Cancer UK, which runs the only support line dedicated solely to pancreatic cancer in the UK.

Finally, there needs to be a sufficient number of Cancer Nurse Specialists (CNSs), to support pancreatic cancer patients through the diagnosis experience and throughout the following treatment or care pathways. We know from surveys that patients that have access to a CNS routinely experience a better care experience than those who do not. Pancreatic cancer often has a poor prognosis and complex symptoms that require careful management. To ensure appropriate knowledge levels of the disease and symptom management, those CNSs should, as far as possible, be pancreatic or Hepato-pancreato-biliary (HPB) CNSs.

Footnotes
2 2011 audit report from the Scottish HPB Cancers National Managed Clinical Network.
4 National Cancer Research Institute (NCRI) report Cancer Research Spend in the UK 2002-2011
7 NHS England Cancer Patient Experience Survey 2013
8 NCIN, Routes to diagnosis for patients diagnosed between 2006-2008.