Time to Change the Story: A plan of action for pancreatic cancer

APPG on Pancreatic Cancer

The report of the parliamentary inquiry into pancreatic cancer

> This is a very recent and raw experience for both myself and for Jane's family, and one that we would wish others will be spared if early detection of the disease, faster and more joined up referral and earlier onset of treatment is established through greater awareness, more streamlined and effective procedures, and improved research into pancreatic cancer.
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> *Geoff Haworth, APPG pancreatic cancer Inquiry, written submission*

The Secretariat to the All Party Parliamentary Group on Pancreatic Cancer is provided by Pancreatic Cancer UK.

FOREWORD

On behalf of the All Party Parliamentary Group on pancreatic cancer, I would like to thank the more than 50 people and organisations who contributed formally to this Inquiry. A very special and heartfelt note of thanks must be offered in particular to the many patients, families and carers who took the time to share their personal experiences and views.

This evidence has been moving and insightful in equal measures. The detail of this testimony and the accounts of patient experiences have shaped an overriding conclusion from the Inquiry that misconceptions about pancreatic cancer may represent the single most significant barrier to achieving improved survival and better patient experience. These misconceptions are held by individuals right across the board - from the public through to health professionals and policymakers.

The contributions from patients, their families and carers would suggest to us that there is an erroneous belief that pancreatic cancer is rare, affecting small numbers of mostly elderly, male patients. That it is a silent killer with indistinguishable symptoms – and once diagnosed that it is almost certain that there is nothing that can be done to change the course of the disease or to offer a prolonged life of good quality.

It is our view that these beliefs, unless challenged, will continue to cast a shadow over the good efforts of those who supported this Inquiry - and who are deeply concerned about the need to do better for all those affected by pancreatic cancer.

IN REALITY:

- Pancreatic cancer is not rare. Its incidence is lower than other common cancers like breast, bowel and lung. However, in terms of mortality pancreatic cancer is the 5th most common cause of all cancer deaths in the UK. **By 2030 pancreatic cancer is predicted to overtake breast cancer as the 4th most common cancer killer.** [1]

- The risk of pancreatic cancer does increase with age. However, **nearly 35% of all diagnoses of pancreatic cancer occur in people under the age of 65**.[2]

- Pancreatic cancer affects men and women equally: **of the nearly 8500 new cases of pancreatic cancer in 2010 in the UK around 4200 (49%) were male and 4300 (51%) were female.** [3]

- Pancreatic cancer symptoms are often non-specific. However, research also shows that **many people do experience these symptoms for some time before diagnosis -and do seek medical attention.** [4]

IT PARTICULARLY CONCERNS US THAT THESE MISCONCEPTIONS RESULT IN:

- Low levels of awareness about the disease and the extent to which it represents a leading cancer killer in the UK - and lack of recognition of the need to direct investment and focus that is proportionate to the impact of this disease.

- A lack of urgency in relation to action to ensure that everyone affected by pancreatic cancer is diagnosed as early as possible - and once diagnosed receives the most prompt and up-to-date treatment possible. If pancreatic cancer is diagnosed before it has advanced, it can be treated. Even if patients are diagnosed at an advanced stage, treatments are available that may extend life and that will almost certainly improve the quality of their life.

In addition, evidence submitted to this Inquiry suggests there are serious shortcomings in consistent access to high level quality care, including support and information. The APPG was particularly struck by the variation in patient experience – at every stage from diagnosis through to palliative care.

This Inquiry has found that for far too many pancreatic cancer patients, care at present has poor outcomes and is:

- Not patient centred
- Poorly co-ordinated
- Inefficient

The remainder of this report provides an overview of the Inquiry proceedings and sets out specific recommendations that have arisen from it. Key recommendations include **the need to raise awareness of pancreatic cancer and its symptoms and to undertake a whole-sale review of referral pathways and diagnostic services (like CT scans) that are available to GPs. This report also calls for a comprehensive audit of pancreatic cancer treatment in order to understand why everyone diagnosed with this disease may not have access to the same high quality care. Together, these measures should help to improve earlier diagnosis - and the earliest possible input to pancreatic cancer patients from experts at specialist centres.**

This Inquiry was an ambitious undertaking and we were aware from the outset that there would be areas that we would not be able to do justice to over its course. Two such areas are research (not included in the original Inquiry terms of reference) and international comparisons relating to survival. As part of the forward work programme for the APPG it is our intention to delve further into these areas.

It is our hope that through this Inquiry and the work of the APPG that will follow on from it, we can help put into motion the changes required to alter the landscape of this disease.

Eric Ollerenshaw,
Secretary, All Party Parliamentary Group on Pancreatic Cancer

BACKGROUND

The All Party Parliamentary Group (APPG) on pancreatic cancer was established in May 2012 by a cross-party group of Parliamentarians who are interested in improving survival rates and the experience of all those affected by the disease. The inaugural meeting saw the election of officers – Lord Patel as Chair, Baroness Morgan of Drefelin as Vice-Chair, Nic Dakin MP as Treasurer, and Eric Ollerenshaw MP as Secretary.

THE INQUIRY

The Inquiry into pancreatic cancer was launched at the March 2013 meeting of the APPG and took place between May and September 2013. The terms of reference for the Inquiry sought views on how to improve pancreatic cancer survival rates as well as the experience of pancreatic cancer patients. The APPG expressed a specific interest in submissions concerning:

- Improving early diagnosis
- Access to treatment and care
- Patient experience
- How survival rates can be improved

Over 50 submissions were received, from a range of patients, family and carers, healthcare professionals, researchers, charities and NHS organisations. A list of respondents is included in Appendix 1.

Following a review of written evidence, the APPG held five sessions, chaired by Eric Ollerenshaw, MP, taking oral evidence from patients, their families and carers, GPs, secondary care clinicians and other health professionals including nurses, charities, the Department of Health and NHS officials.

The APPG would like to thank everyone who sent written submissions, gave oral evidence or attended our sessions. The inquiry has produced such a wealth of information that it is simply not possible to make reference to, or draw examples from, all of the individual submissions and contributions we have received. Please be assured that every submission has been read and has influenced the deliberations of the Inquiry and the content of this report.

SUMMARY OF KEY RECOMMENDATIONS

THE ALL PARTY PARLIAMENTARY GROUP ON PANCREATIC CANCER INQUIRY REPORT – SUMMARY OF RECOMMENDATIONS:

1. The APPG recommends that should the Decision Aid Tool pilot currently being run by MacMillan Cancer Support be shown to help GPs identify patients with a pancreatic cancer concern, steps must be taken by the Department of Health and relevant professional bodies to ensure that all GP practices take on board this new technology.

2. Professional bodies should promote and support uptake of the pancreatic cancer educational tools currently available for practicing clinicians - and also review the medical training curriculum to ensure that sufficient attention is given to the disease. This is particularly important given the fact that pancreatic cancer is predicted to become the 4th leading cause of cancer death by 2030.

3. A pancreatic cancer specific symptom awareness campaign should be considered as a further pilot under the National Awareness and Early Detection Initiative (NAEDI). It is recommended that this pilot be run in an area where the primary care Decision Aid Tool is also being used to establish whether efforts to both empower GPs to better identify patients with pancreatic cancer concerns as well as to increase public awareness of specific symptoms will help to improve early detection.

4. A whole-sale review of pathways between primary and secondary care for referral and investigation of pancreatic cancer patients is required. A coordinated approach to piloting and evaluating new models, including direct GP access to CT scans, named diagnostic specialists, specialist diagnostic centres and rapid access clinics is required. This approach should be supported by the Department of Health as well as NHS England.

5. An audit of deaths of those pancreatic cancer patients diagnosed via an emergency admission route should be undertaken. We also recommend that GPs undertake periodic audits of diagnosis of less common cancers as part of their annual appraisal process - and that this be linked to revalidation.

6. The APPG recommends that the proceedings of the Inquiry will be taken into account in the review of the referral for suspected cancer guidelines currently being undertaken by NICE. The APPG also recommends that NICE review the 'carcinoma of unknown primary' guidelines to ensure that there is clarity and understanding about their application.

7. Public Health England should review whether specific patient groups known to have an increased risk of pancreatic cancer, for example, patients diagnosed with sudden onset type 1 and 2 diabetes or pancreatic cystic lesions, should be monitored and screened. Guidelines for the management of these conditions should take into account the need for pancreatic cancer surveillance.

8. A comprehensive national audit of pancreatic cancer treatment, similar to that commissioned by the Healthcare Quality Improvement Partnership (HQIP) for bowel cancer, should be prioritised. We also recommend that pancreatic cancer NHS waiting times data be reported separately from the Upper GI waiting times dataset. Coordination of data collection and audit activity across the UK would provide a complete picture across the four Nations.

9. NHS England should request the development of a NICE pancreatic cancer Quality Standard. This would provide a solid benchmark for patients as well as clinicians to understand what they should expect by way of the standards of care.

10. All treatments proven to show benefit to pancreatic cancer patients should be made available on the NHS as quickly as possible.

11. The complexity of the needs of pancreatic patients is such that everyone diagnosed must have an assigned Clinical Nurse Specialist (CNS) - including patients who are not receiving treatment from specialist pancreatic cancer centres. Importantly, all nurses must have the time and resource required to properly support the pancreatic cancer patients under their care.

12. Dieticians should be considered as essential members of the pancreatic cancer Multidisciplinary Teams (MDTs) that review pancreatic cancer patients. All pancreatic cancer patients, regardless of whether they are treated at a specialist or local district general hospital, should have their case reviewed by a dietician and this should be reflected in any pancreatic cancer guidelines.

IMPROVING EARLY DIAGNOSIS

IMPROVING EARLY DIAGNOSIS, IMPROVING SURVIVAL

Pancreatic cancer is the fifth leading cause of cancer death in the UK. Five year survival rates are less than 4% - a figure that has barely changed in the past 40 years. Surgery remains the only option for cure. However, although it is estimated that about 20% of patients diagnosed with the disease may be eligible for surgery, less than 10% go on to have curative surgery.[5] This is mainly because by the time they are diagnosed the disease is either too advanced locally or has already spread to other organs.

The 2010 National Cancer Patient Experience Survey (NCPES) found that 40% of pancreatic cancer patients visit their GP three times or more before being referred to hospital for investigation. Additional analyses produced by the National Cancer Intelligence Network (NCIN) shows that half of all pancreatic cancer patients are diagnosed as a result of an emergency admission to hospital – this is double the average rate of diagnosis as a result of emergency presentation of all other cancers.[6-7]

Pancreatic cancer patients diagnosed as a result of emergency admission have especially poor rates of survival – this is because emergency admission patients are much more likely to be at an advanced stage of the disease than patients who come to be diagnosed via other routes, such as GP referral. One year survival for patients diagnosed as a result of emergency admission to hospital is only 9% compared to 26% for patients diagnosed as a result of a GP referral.[8]

'A 2012 survey of over 250 GPs undertaken by Pancreatic Cancer UK found that although most GPs could list one or two possible symptoms, half of those surveyed (49%) said that they were not confident that they could identify the signs and symptoms of possible pancreatic cancer in a patient.'

Pancreatic Cancer UK, written evidence submitted to the APPG pancreatic cancer Inquiry

'There is a myth that needs dispelling amongst the medical community that if the [pancreatic cancer] patient has symptoms, you've already got someone who's not going to survive.'

Dr Andrew Millar, Consultant gastroenterologist, Pathway Director for HPB (London Cancer), APPG pancreatic cancer Inquiry, oral evidence session

Much of the evidence submitted to the APPG Inquiry reinforced the importance of improving early diagnosis as well as the challenges and barriers that stand in the way of achieving this aim. Many of the patients that gave evidence told of repeated visits to GPs as well as to hospital, including A&E departments, before a diagnosis was made.

The clinicians that contributed to the Inquiry also highlighted the challenge of early diagnosis, including the lack of tools, either imaging or biochemical, that are available for use for screening for pancreatic cancer at an earlier stage. All acknowledged that the non-specific nature of symptoms, including stomach or back pain, bowel and digestive problems and weight loss, can stump even the most experienced practitioner.

The Inquiry heard that for many GPs, these are not symptoms that will raise an immediate concern about pancreatic cancer and many patients will be treated for other conditions, like IBS, in the months leading up to diagnosis. In addition, as GPs on average see only one new pancreatic cancer patient every five years, it is not a disease that is likely to be at the front of their mind when dealing with patients with these symptoms. These points raise important questions about low levels of awareness of pancreatic cancer amongst clinicians, as well as the need to ensure that they are supported to identify patients that may be of concern.

However, the Inquiry also heard from Dr Rosie Loftus, Lead GP Advisor for Macmillan Cancer Support, about the development of an electronic Decision Aid Tool which is currently being piloted within primary care. The tool, which is designed specifically to help GPs take decisions about referrals for suspected cancer, including pancreatic cancer, works by providing GPs with a symptom checker and shows details of consultations about symptoms from the previous six months. The tool also has the capacity to audit the whole of the practice's patient population and stratify patients into low, medium or high cancer risk categories.

'We need to focus on early diagnosis as a priority... I celebrated last week, six years of survival. So those of us who are diagnosed in time for surgery, which is what we want to achieve, have a tenfold increase in their chance of surviving five years – so we've got to get those patients to surgical resection.'

Ali Stunt, CEO Pancreatic Cancer Action and pancreatic cancer survivor, APPG pancreatic cancer Inquiry, oral evidence session

'With regard to early diagnosis, the most important aspect for us was the fact that Gemma went to her GP on a total of 10 separate occasions between the middle of April 2009 and the end of August, when she was finally referred to a specialist for an ERCP.'

Debbie Wells, APPG pancreatic cancer Inquiry, oral evidence session

A number of witnesses highlighted the fact that medical students will receive very little pancreatic cancer specific information as part of their training, reinforcing low levels of awareness. Ali Stunt from Pancreatic Cancer Action told the Inquiry about her personal experience of being diagnosed with pancreatic cancer and the importance of raising awareness with health professionals. She highlighted the charity's work with the Royal College of GPs on the development of an online educational resource which aims to improve GP awareness of pancreatic cancer, including its signs and symptoms. The charity is now working with the BMJ to look to extend the availability of this resource to clinicians in secondary as well as primary care.

In relation to public awareness, the Department of Health told the inquiry about the Know for Sure pilot public awareness campaign and the effort to raise public awareness of four non-specific symptoms (weight loss, lumps, unusual bleeding and pain) that are generic to a number of cancers. This campaign was still being evaluated at the time of the Inquiry. We have subsequently learned that it is not one of the campaigns that will be rolled out as a regional campaign in the short term as it is felt that further work is required to refine its key messages and understand what communication channels might be best used to deliver the campaign.

The APPG accepts that raising awareness of pancreatic cancer and its symptoms presents a significantly greater challenge than raising awareness of other cancers that will have more specific symptoms. However, we also believe that low levels of public and professional awareness must be addressed as part of efforts to tackle this disease and shift the terrible legacy of low survival. Increased awareness is particularly important given the fact that projections based on current trends predict that pancreatic cancer will overtake breast cancer as the 4th most common cause of cancer death in the UK by 2030.

The APPG is also concerned by oral and written evidence that suggest assumptions are made that pancreatic cancer is extremely rare in younger patients. This has reinforced our view that there is a pancreatic cancer education gap that needs to be filled. It is the strong view of the APPG

'I don't think GPs are ignorant of the symptoms of pancreatic cancer. I think it is more they don't use their knowledge of the symptoms of pancreatic cancer because they're using their knowledge of symptoms of other diseases.'

Professor Willie Hamilton, Professor of Primary Care Diagnostics, Exeter University, APPG pancreatic cancer Inquiry, oral evidence session

'I went to my GP more times in the previous 12 months prior to my diagnosis, than I had in the previous 12 years.'

Lynne Walker, pancreatic cancer survivor, APPG pancreatic cancer Inquiry, oral evidence session

'Perhaps it should be possible to arrange for practices to have an annual review of the diagnosis of their new cancer cases, and for that to become an annual event which could then routinely be discussed by the GP at their appraisal.'

Dr Stephen Large, GP, APPG pancreatic cancer Inquiry, oral evidence session

that measures to increase awareness of pancreatic cancer amongst the public as well as health care professionals – including implementation of the kinds of tools highlighted above – would go some way towards supporting earlier diagnosis of pancreatic cancer.

However, the problem of identifying patients that require further investigations isn't just about awareness or spotting that there may be a problem. Reinforcing much of the patient and carer evidence submitted to the Inquiry, Professor Greg Rubin, GP and Professor of General Practice and Primary Care, Durham University, reflected on cases that have been studied in the course of research which indicate that patients can also experience considerable delays in secondary care, 'bouncing back and forwards between specialists, or not being diagnosed as promptly as you might expect.'

Overall, the Inquiry heard a fairly unanimous view from all witnesses about the extent to which current pathways for referral and investigation do not help to achieve earlier diagnosis - or a satisfactory patient experience.

Currently, patients with non-specific symptoms may have several separate referrals to specialist areas for investigations – each time returning to their GP for the outcome of the test results. Should the referral not identify the source of the problem, the patient may be referred to another specialist area for additional investigations. Under normal circumstances, secondary care consultants do not have authority to make direct referrals to consultants in other specialist areas within hospital.

This process of going backwards and forwards between primary and secondary care – with waits between appointments and test results - is frustrating from all perspectives. For those patients who are eventually diagnosed with pancreatic cancer, and find that they have been diagnosed at a stage too advanced for curative treatment, it is simply heartbreaking.

Whilst there were fairly consistent views between clinicians about the scope for getting pancreatic cancer patients investigated more quickly and efficiently, there were diverging perspectives about how this might be best achieved. Direct access for GPs to CT scans in particular gave rise to a wide range of views.

'The tracking results showed us that people were quite confused and couldn't actually take away the right messaging (from the Know for Sure awareness campaign). ... We were told early on, you have to keep it simple and have one or two messages.'

Tim Elliott, NHS England, APPG pancreatic cancer Inquiry, oral evidence session

'He died 5 months later- he was 49 with a 14 year old son. The consultant believed if this had been diagnosed at the first investigation his life could have been extended by a Whipple procedure – the additional 3 months made a difference especially as his GP suspected this may be the problem.'

Alison Humberstone, APPG pancreatic cancer Inquiry, written evidence

'I think it's about getting the right test, for the right patient, at the right time. Presently a (hospital) doctor who has probably had – no disrespect to my colleagues – two years medical experience can request a CT scan for a patient in hospital – where I can't.'

Dr Rosie Loftus, GP and lead GP advisor for Macmillan Cancer Support, APPG pancreatic cancer Inquiry, oral evidence session

Many of the GPs that gave evidence believe that direct access to CT scans – governed by robust processes and criteria – would be a positive step forward. Other clinicians highlighted the potential downside of direct access, including concerns about the over-use of CT scanning on patient safety and the impact on NHS resources.

Other service models put forward included nomination of 'diagnostic specialists' within secondary care who would take responsibility for oversight of investigations until the root of the problem is identified - without the need for referral of patients back to their GP between investigations and appointments. Other evidence highlighted areas of good practice, for example, a Rapid Access Clinic for jaundiced patients operated by Southampton University Hospitals NHS Trust. The clinic takes direct referrals from GPs enabling patients to have prompt access to ultrasound, treatment for relief of symptoms - and if necessary CT scans followed by surgery. Based on an internal audit the Trust has established that the rapid access clinic reduced pre-treatment stay by at least 4 days. The Inquiry also heard about specialist cancer diagnostic centres, operating in Denmark and Canada, where all patients with suspected cancer are referred for investigation – the use of such models may warrant further consideration.

The benefit that could be gained by achieving earlier diagnosis – and reducing late emergency admission diagnosis – was highlighted in evidence from **Pancreatic Cancer UK in which they outlined an analysis undertaken for the charity by the National Cancer Intelligence Network (NCIN). This analysis showed that a reduction of 25% in emergency presentation diagnoses, with patients diagnosed via other routes like GP referral, could mean an additional 150 patients living for one year or longer. Even a modest reduction of 10% could mean an additional 50 pancreatic cancer patients living a year or longer.**

This finding adds further weight to the suggestion put to the Inquiry about the merit of an audit of deaths of pancreatic cancer patients, diagnosed via the emergency admission route, to better understand the barriers to earlier diagnosis and hopefully ways in which these might be mitigated.

'The patient turns up and the chap says, well it's not reflux and I'm a reflux doctor. Back to your GP; so he goes back to the GP, more delay is coming. The GP says, well it isn't reflux. Maybe now he has some back pain or something. We'll try the spine doctor... and so he goes to the spine surgeon. The spine surgeon says, well it's not spine pain... back to your GP. This is the common scenario... the patient becomes a tennis ball.'

Mr Satvinder Mudan, Consultant Surgeon and Surgical Oncologist, APPG pancreatic cancer Inquiry, oral evidence session

'Diagnosing pancreatic cancer early not only makes sense because we can improve mortality, but also makes sense from an emotional point of view because late diagnosis is a horrific thing to have happen to you, if you are the patient.'

Dr Andrew Millar, Consultant gastroenterologist, Pathway Director for HPB (London Cancer), APPG pancreatic cancer Inquiry, oral evidence session

CANCER REFERRAL GUIDELINES

The guidelines for suspected cancer are currently being reviewed by NICE – at the time of the Inquiry the review had not been completed and therefore we cannot report on any proposed changes to the existing guidelines.

However, the Inquiry did hear views about a little known pathway called 'carcinoma of unknown primary' pathway. The general view from those that contributed to the Inquiry is that clarification about this guideline is required as there is confusion about whether it is a pathway accessible to GPs or whether it is for internal specialist referrals. There is also debate about whether this pathway was developed for referral of patients with non-specific symptoms where there is suspected cancer or for patients that have a suspected secondary cancer related to an unknown primary.

When it comes to improving diagnosis of pancreatic cancer, there may not be a one-size fits all solution. As one witness stressed it is important that any new approach is properly evaluated before its widespread implementation. However, what is certain is that pancreatic cancer patients are currently not well served by the status quo and it is essential we look to what needs to be done to ensure that patients do not face unnecessary delays.

'As far as of the role of GPs is concerned, I think it's important to understand that GPs do not diagnosis pancreatic cancer. What they do is differentiate those people who need further investigation from those that don't.'

Professor Greg Ruben, GP and Professor of General Practice and Primary Care, Exeter University, APPG pancreatic cancer Inquiry, oral evidence session

'I think we've learned the direction of travel, both from the cancer waiting times initiatives and the Be Clear on Cancer campaigns that it can be done – changing behaviour. You will unearth the blocks and one of the biggest will be access to diagnostics.'

Mr Sean Duffy, National Clinical Director for Cancer for NHS England, APPG pancreatic cancer Inquiry, oral evidence session

THE APPG ON PANCREATIC CANCER RECOMMENDS:

- The APPG recommends that should the Decision Aid Tool pilot currently being run by MacMillan Cancer Care be shown to help GPs identify patients with a pancreatic cancer concern, steps must be taken by the Department of Health and relevant professional bodies to ensure that all GP practices take on board this new technology.

- Professional bodies should promote and support uptake of the pancreatic cancer educational tools currently available for practicing clinicians - and also review the medical training curriculum to ensure that sufficient attention is given to the disease. This is particularly important given the fact that pancreatic cancer is predicted to become the 4th leading cause of cancer death by 2030.

- A pancreatic cancer specific symptom awareness campaign should be considered as a further pilot under the National Awareness and Early Detection Initiative (NAEDI). It is recommended that this pilot be run in an area where the primary care Decision Aid Tool is also being used to establish whether efforts to both empower GPs to better identify patients with pancreatic cancer concerns and to increase public awareness of specific symptoms will help to improve early detection.

- A whole-sale review of pathways between primary and secondary for referral and investigation of pancreatic cancer patients is required. A coordinated approach to piloting and evaluating the new models discussed at the Inquiry, including direct GP access to CT scans, named diagnostic specialists, specialist diagnostic centres and rapid access clinics is required. This approach should be supported by the Department of Health as well as NHS England.

- An audit of deaths of those pancreatic cancer patients diagnosed via an emergency admission route should be undertaken. We also recommend that GPs undertake periodic audits of diagnosis of less common cancers as part of their annual appraisal process - and that this be linked to the revalidation process.

- The APPG recommends that the proceedings of this Inquiry be taken into account in the review of the referral for suspected cancer guidelines currently being undertaken by NICE. The APPG also recommends that NICE review the 'carcinoma of unknown primary' guidelines to ensure that there is clarity and understanding about their application.

SCREENING OF HIGH RISK PATIENTS

The previous section deals with the diagnosis of patients who have pancreatic cancer. However, the Inquiry also heard evidence about the potential to improve detection of pancreatic cancer by identifying, and monitoring, those patients who may be at higher risk of developing the disease as a result of family history or who have conditions that are pre-disposed to pancreatic cancer, like chronic pancreatitis. We also understand that there is increased interest in whether adults diagnosed with type 1 and 2 (sudden onset) diabetes or found to have pancreatic cystic lesions, should be screened - as these are also being recognised as conditions associated with an increased risk of pancreatic cancer.

The UK currently does not have a formal screening programme for people who are at higher risk of developing pancreatic cancer – although a Hereditary Pancreatitis and Familial Pancreatic Cancer study (EURPAC) is currently underway that is looking at two types of families - those with inherited pancreatitis and those with an inherited predisposition to pancreatic cancer (familial pancreatic cancer).

THE APPG ON PANCREATIC CANCER RECOMMENDS

- Public Health England should undertake a review to establish whether specific patient groups known to have an increased risk of pancreatic cancer, as highlighted above, should be monitored and screened. Relevant guidelines, for example, for the management of pancreatic cystic lesions and diabetes, should take into account the need for pancreatic cancer surveillance.

ACCESS TO TREATMENTS

The *Improving Outcomes in Upper Gastro-intestinal Cancers Guidelines* published in 2001 set out a service specification for treatment of pancreatic cancer based on a centralised model of care with patients receiving surgical treatment at a designated number of specialist units.

Patients who have operable pancreatic cancer are required to undergo complex surgery that involves procedures to remove the tumour and reconstruction with other organs.

This service specification was introduced on the basis of evidence from other countries that showed that patients treated at hospitals where surgeons do a high volume of surgery do better than those treated at hospitals with lower patient volumes.

A number of submissions to the Inquiry highlighted the fact that data generated by the National Cancer Intelligence Network (NCIN) shows that there are variations in survival rates as well as rates of referral to specialist centres between Cancer Networks.[9] The Inquiry also received evidence highlighting low UK survival rates compared to other EU countries as well as Canada, the US and Australia.[10]

Although the exact reasons for these variations are unknown there is some concern that within the UK not as many patients as could be are referred to specialist centres – and further concern that some patients are experiencing unnecessary delays at local level before being referred for review to specialist MDT teams.

Delays in patient referral to specialist teams and in decisions about the full range of treatment options open to them may be affected by a number of factors including; a fatalistic attitude on the part of some clinicians, lack of understanding of the referral processes that should see patients referred at the point there is a suspicion of pancreatic cancer vs. a conclusive diagnosis, or just poor management of patients with suspected pancreatic cancer at local level.

'We must deliver the right treatments that we know are clinically effective in the most effective way, with the right specialisms looking after them, with the right experiences so they're getting the right treatments.'

James Palmer, National Clinical Director for Specialised Services, NHS England, APPG pancreatic cancer Inquiry, oral evidence session

'I have had a good experience of diagnosis and treatment and am now cancer free, so I would like all pancreatic cancer patients to be able to have access to the same range and quality of services that I had, and hopefully to have the same outcome.'

Pancreatic cancer survivor, APPG pancreatic cancer Inquiry, written submission

'All in all, there was considerable delay of more than 3 months from the early detection of the pancreatic tumour in the CT scan results in June to the surgery in October – a delay which ultimately cost X her life.'

Written submission (pancreatic cancer carer)

Evidence submitted to the Inquiry from patients and their families and carers highlights examples of what would appear to be all three of the above shortcomings. The APPG is satisfied that the centralised model of pancreatic cancer treatment, whereby patients are looked after by expert teams at specialist centres, is the right one. However, we do have concerns that there are patients who experience delays in referral to these centres - or who are missing out on the opportunity of specialist treatment all together.

Our conclusion is that there is a case to be made for securing specialist input for all patients with suspected pancreatic cancer at the earliest opportunity possible. This may mean a number of things need to happen, including a lowering of the threshold for access to investigations to support earlier diagnosis as well as a strengthening of relationships between District General Hospitals and specialist centres with a view to ensuring all patients are promptly referred for expert review.

We were also interested to hear that unlike some other cancers like lung and bowel, regular audits of pancreatic cancer treatment are not undertaken - and it is not anticipated that funding to undertake this work will be made available as it has for other cancers. It would seem to us that given that the Improving Outcomes Guidance is now over 13 years old it would be important to undertake a thorough audit. In order to be confident that all patients have access to the best possible chance of survival we must be confident that the processes between local and specialists centres are working as well as they should be: and this requires good quality audit data.

The APPG has previously taken up the issue of making NHS waiting time data for pancreatic cancer patients available – as a separate dataset from Upper GI data as it is currently presented. This would enable the NHS to use data that is already available to better understand pancreatic cancer patient pathways to treatment and to help improve

'Naturally, I'm upset that my wife died at an early age from this disease. I did not understand why it took so long to diagnose and get treatment. I thought perhaps we were unlucky. Unfortunately I now know that our experience was common, not unusual. I also know that much of this is avoidable as our experience in France, reinforced by many studies, shows.'

Dave Wallace, APPG pancreatic cancer Inquiry, written submission

'The RF hospital had stated that L hospital would carry out a liver biopsy, but the staff at the L hospital were saying that the RF would do it – it seemed that no-one wanted my father as a patient. Meanwhile the GP had not received any correspondence and thought that that operation would have taken place already.'

Mark Evison, APPG pancreatic cancer Inquiry, written submission

service delivery. Alongside this, discussions at the APPG Inquiry would suggest that the development of a National Institute for Health and Care Excellence (NICE) pancreatic cancer Quality Standard would go some way to providing healthcare professionals, and importantly patients, with a solid benchmark to use to understand what can and should be done by way of access to the highest standard of treatment.

Finally, it is hard not to be struck by the lack of treatments that are available for pancreatic cancer patients - the Inquiry heard only about a small number of recent treatments being used and it was not clear if these treatments are being made consistently available. We anticipate that as part of future APPG investigations into the pancreatic cancer research landscape we may learn more about this issue. In the interim, given the lack of options for curative treatment or for extending life, it is essential that any new treatments shown to be effective are made available to all patients as quickly as possible.

THE APPG ON PANCREATIC CANCER RECOMMENDS

- A comprehensive national audit of pancreatic cancer treatment, similar to that commissioned by the Healthcare Quality Improvement Partnership (HQIP) for bowel cancer, should be prioritised. We also recommend that pancreatic cancer NHS waiting times data be reported separately from the Upper GI waiting times dataset. Coordination of data collection and audit activity across the UK would provide for a complete picture across the four Nations.
- NHS England should request the development of a NICE pancreatic cancer Quality Standard.
- All treatments proven to show benefit to pancreatic cancer patients should be made available on the NHS as quickly as possible.

'We've done that (centralise surgery) very well. The problems are under the new structure of the NHS. I represent specialised commissioning which is at the tertiary level. There is a deconstruct between us and primary care and the CCG (Clinical Commissioning Group) commissioners. This is a problem we've got to address and we've got to find a way through this, because we're not responsible for diagnosis.'

Professor Graeme Poston, Chair, Specialised Commissioning Reference Group, APPG pancreatic cancer Inquiry, oral evidence

'At pancreatic Cancer UK we hear about patient experience everyday through our specialist nurses on our support line - sadly we hear about all of the issues raised in the National Cancer Patient Experience Survey. It also concerns us greatly that we hear a lot of stories that suggest that there are inconsistencies right across the NHS when it comes to access to treatment for pancreatic cancer treatment. We think that too many people are not getting the full benefit of all the options that should be available to them.'

Alex Ford, CEO Pancreatic Cancer UK, APPG pancreatic cancer Inquiry, oral evidence

PATIENT EXPERIENCE

For patients, as well as their families and carers, the quality of their experience is impacted by many factors, including the speed at which they are diagnosed and start active treatment, clarity of communication between them and the health professionals involved in their care and the adequacy of the information and support provided at all stages of the process.

Evidence from consecutive National Cancer Patient Experience Surveys (NCPES) has consistently shown that the experience of pancreatic cancer patients is less satisfactory than many other cancer patient groups. And although the Inquiry did hear evidence about good patient experience, much of the evidence submitted highlighted failings across a range of important areas, including communication and sensitivity, coordination of care, and provision of information and support.

We know that access to a Clinical Nurse Specialist (CNS) is proven to be a key factor in better patient experience. However, CNSs with specialist pancreatic cancer expertise are located at designated specialist centres – whilst the majority of pancreatic cancer patients are treated at District General Hospitals because they are not eligible for surgery. Therefore significant numbers of pancreatic cancer patients will not have access to this vital resource.

We are of the firm belief the complexity of the needs of pancreatic patients is such that everyone diagnosed must have an assigned Clinical Nurse Specialist (CNS) with pancreatic cancer expertise - including patients who are not receiving treatment from specialist pancreatic cancer

'...we feel that a person diagnosed with pancreatic cancer is at a significant disadvantage in the care that they receive due to the very poor prognosis of the disease. Of the various departments of the NHS we encountered throughout Nila's journey, we saw that any fighting chance she has was taken away from her by their attitude towards pancreatic cancer. Nila was a determined individual with the willpower to match. Unfortunately, the NHS wasn't as determined as she was.'

Arti and Aman Pau, APPG pancreatic cancer Inquiry, written submission

'I must say that each doctor, consultant, nurse and other healthcare professional that I have met or spoken to has been very helpful, informative and sympathetic. But unfortunately, the system as a whole seems to have let my father fall through the cracks.'

Written submission, APPG pancreatic cancer Inquiry

centres. By this we mean that, the nurse specialists working at District General Hospital level - who will be, for example, oncology nurses or Upper GI nurses, must have access to a named pancreatic cancer clinical nurse specialist in order to be able to access expert input to patient care. Importantly, all nurses caring for pancreatic cancer patients, must have the time and resource required to properly support all of the patients under their care.

There were a number of common patient experience themes in the written and oral evidence relating to patient experience including, patients being given bad news in inappropriate surroundings – or just badly without being given the time or support to process the news, poor pain management and lack of access to expert dietary support. We were also very struck by testimony relating to the very different experience of care within an NHS setting compared to that delivered within a hospice environment. On the basis of this evidence the APPG questions if the NHS could learn from some lessons about patient-centred care from the hospice sector.

'We were given very little information...I asked what kind of pancreatic cancer David had and the answer was 'the bog standard one'! We asked for advice on getting David into a clinical trial and were dissuaded by the oncologist saying that we should be enjoying the time David had left. He also said it would make no difference... this was a time when David appeared to be really well and could have easily travelled to regional centres... I also asked if there was any local support for pancreatic cancer patients and the reply was 'there were no support groups because patients did not live long enough and anyway people didn't want to talk about it!'

Lynda Pain, APPG pancreatic cancer Inquiry, written submission

'The whole process, from actually getting the diagnosis proved through to breaking the diagnosis to them, is torturous. It is really a very emotional journey for them and their families. ...For those of us who are lucky enough to have a job such as mine, you are constantly taking phone calls from people who either need dietary advice or just reassurance or support – or just to be heard.'

Sophie Noble, Clinical Nurse Specialist, APPG pancreatic cancer Inquiry, oral evidence

'Just to give my opinion on the big issues for pancreatic cancer over the past few years in terms of peer review.... CNS availability and resource, - just not enough of them. So the CNS has not been available at breaking bad news sessions, not there when treatments are discussed, not there to give the right information because there's not enough of them and not having the right cover when they're off on annual leave, maternity leave or sick leave.'

Anna Eccleston, Operations and Information Manager, National Peer Review Programme, APPG pancreatic cancer Inquiry, oral evidence

THE FOLLOWING QUOTES SPEAK FOR THEMSELVES:

'The NHS is trying to shift its traditional culture towards patients. To promote patient choice, they have adopted the slogan: 'Nothing about me without me.' Either the report on the CT scan was overlooked by someone, or a decision was taken not to tell Len until after Christmas and the New Year, in the mistaken belief that they were protecting him from distressing news over the festive season... It is difficult not to conclude that they thought it best just to let nature take its course.'

Olga Janssen, APPG pancreatic cancer Inquiry, oral evidence

'Once we were home with my daughter the palliative care and district nursing service kicked in with remarkable speed and efficiency. Suddenly, people were communicating, requests were being followed up immediately and what was most impressive was that Gemma was placed at the heart of everything. Instead of people doing things 'to her', they started doing things 'with her' and involving us.'

Debbie Wells, APPG pancreatic cancer Inquiry, oral evidence

'Pancreatic cancer is seen as an 'old person's disease'. True, statistically you are more likely to get pancreatic cancer over 60. They had apparently never seen such a young person with advanced pancreatic cancer. Statistically she was unlucky. My sister is not a statistic and should not be lost in the realm of NHS statistics.'

Christopher Thomson, APPG pancreatic cancer Inquiry, written evidence

'I was at the consultation with the Professor and could see how concerned he was about my father's condition. The Professor assumed that the stent in my father's bile duct (to relieve jaundice) had slipped, and we had to explain that he had no stent – and that since his diagnosis in February (over three weeks earlier) no-one had treated him beyond pain control.'

Mark Evison, APPG pancreatic cancer Inquiry, written submission

'I did have a lot of time with the dietician, I was very lucky. The problem was that what the dietician and I cobbled together, as a diet, once I was allowed to start eating food again, the hospital never delivered it. So my breakfast was very carefully planned, my fruit allowance, would turn up four days later than it should have done – a banana with my name on it.'

Lynne Walker, pancreatic cancer survivor, APPG pancreatic cancer Inquiry, oral evidence

THE APPG ON PANCREATIC CANCER RECOMMENDS

- We are of the firm belief the complexity of the needs of pancreatic patients is such that everyone diagnosed must have an assigned Clinical Nurse Specialist (CNS) - including patients who are not receiving treatment from specialist pancreatic cancer centres. Importantly, all nurses must have the time and resource required to properly support the pancreatic cancer patients under their care.

- Dieticians should be considered as essential members of the pancreatic cancer Multidisciplinary Teams (MDTs) that review pancreatic cancer patients. All pancreatic cancer patients, regardless of whether they are treated are a specialist or local district general hospital, should have their case reviewed by a dietician and that this should be reflected in any pancreatic cancer guidelines.

'Let's be ambitious and say We can do better than that. We don't want to be on a par with the rest of Europe or the rest of the world. We want to exceed that.'

Maggie Blanks, CEO, Pancreatic Cancer Research Fund APPG pancreatic cancer Inquiry, oral evidence

CONCLUSIONS

This inquiry has provided the APPG with enormous insight into a wide range of views and experiences.

We were aware at the outset that this undertaking was ambitious and that it would not be possible to scrutinise every issue to the level we might wish to. In the case of research we decided not to try and cover this important issue under the umbrella of this Inquiry – but to commit to tackle this issue as part of our on-going, post-inquiry efforts. We also have decided that there is significantly more to learn about why survival rates vary – both within the UK and between the UK and other countries. Because of this we will also be revisiting this issue in a more concerted way over the course of the coming year.

At the same time we believe that the quality of submissions and representations to the inquiry has meant that we have been able to make some very strong recommendations for action that we believe if implemented will make a difference to the lives of those affected by pancreatic cancer. In many respects this report sets out a national plan for pancreatic cancer.

Again, we must thank all of those who made the time and effort to contribute to this Inquiry. We also know that the Inquiry and publication of this report is but a first step – the efforts of the APPG and all those who support this work will now turn to ensuring that we turn these recommendations into action. This will be reflected in the APPG's work plan for the coming year.

'The surgeon had expected him to just survive 3 months based on the severity of his pain, it was always a struggle to find treatment for a 48 year old who was doing well and fit. In the end he had gemcitabine/cisplatin chemotherapy – 13 cycles over 1 year, radiotherapy, tried and failed with continuous infusion 5-FU and finally tried immunotherapy (with a thalidomide analogue drug on a named patient basis) as he was just not prepared to give up and not look to science and research to save his life. He had responded to treatment but when he came off it the cancer returned. By the time the thalidomide analogue was obtained the cancer was too far advanced to be able to know whether it would be effective. He survived 27 months inoperable but with mostly good quality life. Sadly medical science let him down.'

Sue Ballard, APPG pancreatic cancer Inquiry, written submission

LIST OF INDIVIDUALS AND ORGANISATIONS WHO SUBMITTED EVIDENCE TO THE INQUIRY

WRITTEN EVIDENCE INDIVIDUAL ACCOUNTS

Patient/Carer

- Sue Ballard (husband died of pancreatic cancer)
- Camilo Colaco (mother died of pancreatic cancer)
- Mark Evison (father is a pancreatic cancer patient)
- Geoff Haworth (wife died of pancreatic cancer)
- Mark Horner (GP and survivor of pancreatic cancer)
- Alison Humberstone (husband died of pancreatic cancer in 2006)
- Denis Hutchings (mother died of metastatic pancreatic carcinoma aged 56)
- Susan Jefferd and Jennifer Farr (mother is a pancreatic cancer patient)
- Olga Janssen (friend died of pancreatic cancer aged 67)
- John Lancaster (wife died of pancreatic cancer)
- John Nathan (medical doctor and pancreatic cancer survivor)
- Lynda Pain (husband died of pancreatic cancer)
- Arti and Aman Pau (mother died of pancreatic cancer)
- Jane Rymer (husband died of pancreatic cancer aged 65)
- Linda Shepherd (father died of pancreatic cancer aged 76)
- Ali Stunt (survivor of pancreatic cancer, and Founder and Chief Executive of Pancreatic Cancer Action)
- Chris Thomson (sister died of pancreatic cancer aged 25)
- Lynne Walker (survivor of pancreatic cancer)
- Debbie Wells (daughter died aged 27 of pancreatic cancer)
- Dave Wallace (wife died of pancreatic cancer aged 64)
- 3 survivors of pancreatic cancer or relatives of those who died of pancreatic cancer who did not consent to be named.

Professional

- Professor David Cunningham, Consultant Medical Oncologist and Head of the Gastrointestinal Unit, The Royal Marsden
- Professor Angus Dalgleish, Professor of Oncology, St George's University of London
- Giuseppe Fusai, Consultant Surgeon and Clinical Lead Hepato-Pancreato-Biliary Surgery, Royal Free Hospital
- Professor Willie Hamilton, Professor of Primary Care Diagnostics, University of Exeter; clinical lead on the NICE revision of cancer guidelines
- Laszlo Igali, Consultant in Histopathology, Norfolk and Norwich University Hospital
- Mr Colin Johnson, Reader in Surgery, University Hospital Southampton
- Dr Stephen Large, retired GP
- Satvinder Mudan, Consultant Surgeon and Senior Lecturer in Surgery, University of London
- Sophie Noble, Clinical Nurse Specialist, Leicester General Hospital
- Professor Greg Rubin, Professor of General Practice and Primary Care, University of Durham; Royal College of General Practitioners and Cancer Research UK clinical lead for cancer
- Cancer Research UK
- Elizabeth Coteman Fund
- HPB London Cancer Pathway
- University of Liverpool Pancreatic Cancer Research Group
- Macmillan Cancer Support
- National Institute for Health and Care Excellence
- Office for National Statistics
- Pancreatic Cancer Action
- Pancreatic Cancer UK
- Public Health England (National Cancer Intelligence Network)
- Royal College of GPs
- Royal College of Physicians

ORAL EVIDENCE

Session one – evidence from patients, families and carers: Thursday 16th May 2013

- Mark Horner (GP and survivor of pancreatic cancer)
- Olga Janssen (her friend died of pancreatic cancer aged 67)
- Debbie Wells (daughter died aged 27 of pancreatic cancer)
- Lynne Walker (survivor of pancreatic cancer)

Session two – evidence from GPs: Thursday 13th June 2013

- Professor Willie Hamilton, Professor of Primary Care Diagnostics at the University of Exeter and clinical lead on the NICE revision of cancer guidelines
- Dr Stephen Large, retired GP
- Dr Rosie Loftus, GP Advisor to Macmillan Cancer Support
- Professor Greg Rubin, Royal College of General Practitioners and Cancer Research UK Clinical lead for Cancer

Session three – evidence from specialist healthcare professionals: Thursday 11th July 2013

- Professor Angus Dalgleish, Professor of Oncology at St George's University of London
- Dr Andrew Millar, Pathway Director for Hepatic Pancreatic and Biliary Cancer at UCL Partners; consultant gastroenterologist
- Satvinder Mudan, Consultant Surgeon and Senior Lecturer in Surgery for the University of London
- Sophie Noble, a clinical nurse specialist at Leicester General Hospital
- Session four – part one – evidence from charities: Thursday 5th September 2013
- Maggie Blanks, Founder of Pancreatic Cancer Research Fund
- Alex Ford, Chief Executive of Pancreatic Cancer UK
- Ali Stunt, Founder and Chief Executive of Pancreatic Cancer Action, and pancreatic cancer survivor

Session four – part two - evidence from Department of Health and NHS officials: Thursday 5th September 2013

- Jane Allberry, Deputy Director, Early Diagnosis, Department of Health
- Anna Eccleston, National Peer Review Programme, NHS Improving Quality
- Tim Elliott, Early Diagnosis team, Department of Health
- John Lancaster, Patient member of Cancer Services Management Board, Mid Essex hospitals Trust
- Graeme Poston, Chair, NHS Specialised Commissioning Internal Medicine Programme of Care

Session five – evidence from NHS officials: Tuesday 10th September 2013

- Sean Duffy, National Clinical Director for Cancer, NHS England
- James Palmer, National Clinical Director for Specialised Services, NHS England

APPG pancreatic cancer Inquiry – Advisers

- Mr Colin Johnson, Reader in Surgery, University Hospital Southampton
- Dr Jamie Dalrymple, GP, Honorary Senior Lecturer at the Norwich Medical School, University of East Anglia, Chair, Primary Care Society for Gastroenterology
- Catherine Foot, Assistant Director, Policy, The King's Fund

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[2] www.cancerresearchuk/cancer-info/cancerstats/types/pancreas/incidence/age (accessed October 2013)

[3] www.cancerresearchuk/cancer-info/cancerstats/types/pancreas/commoncancers/twenty

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[5] www.cancerresearchuk/cancer-info/cancerstats/types/pancreatic-cancer/treatment/statistics. (Accessed 2011)

[6] National Cancer Patient Survey, 2010, Department of Health

[7] Routes to Diagnosis, 2006-2008, National Cancer Intelligence Network

[8] Routes to Diagnosis, 2006-2008, National Cancer Intelligence Network

[9] Cancer e-Atlas, www.ncin.org.uk/cancer_information_tools/eatlas

[10] Study for Survival, Pancreatic Cancer UK, 2011

The Secretariat to the All Party Parliamentary Group on Pancreatic Cancer is provided by Pancreatic Cancer UK.

It is also supported by a group of stakeholder organisations: Pancreatic Cancer Action, Pancreatic Cancer Research Fund, the Net Patient Foundation and the Pancreatic Society of Great Britain and Ireland

You can find out more information about the All Party Parliamentary Group on Pancreatic Cancer here:

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