

# The Need for Speed

## Diagnosing Pancreatic Cancer Earlier, Giving Patients a Chance of Living Better for Longer



*“Whatever you can do, or dream you can, begin it.  
Boldness has genius, power, and magic in it.”*  
Goethe

**November 2017**

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on Pancreatic Cancer



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# INTRODUCTION

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The All Party Parliamentary Group on Pancreatic Cancer was established in 2012 with the aim of working with all key stakeholders to champion improving survival and experiences of pancreatic cancer patients. To tackle stubbornly low survival, the APPGPC launched its third inquiry on early diagnosis in December 2016, building upon its prior inquiries and reports. Its first report *“Time to Change the Story: A plan of action for pancreatic cancer”* looked at pancreatic cancer as a whole and was published in November 2013. The second report *“Pancreatic Cancer Research: A Roadmap to Change,”* was dedicated to research and what could be done to improve the quality and quantity of pancreatic cancer research.

This, the first inquiry focused solely on early diagnosis, builds on the outcomes of these earlier reports. Over the course of three months, the APPG on Pancreatic Cancer considered a wide range of written and oral evidence. The oral evidence was heard through five different sessions. Stakeholders who contributed to the inquiry included patients, carers, family members, clinicians, researchers, policy makers and others. Please see Appendices 1, 2 and 3 for a full list of those who contributed. The APPG would like to thank everyone who sent written submissions, gave oral evidence or attended our sessions. Without your assistance, we could not have created this report.

Throughout the Inquiry, panel members assessed the progress made toward past APPG recommendations on early diagnosis. In addition, the group analysed to what degree the early diagnosis initiatives taken forward by NHS England and other NHS entities benefit pancreatic cancer patients. Finally, members examined what barriers to early diagnosis still exist, what current initiatives appear most promising and likely to be successful, and how MPs and peers can best champion and facilitate the early detection of pancreatic cancer moving forward. After the evidence was compiled and reviewed, six clear themes emerged. These themes now form the basis for our six key recommendations.

The report will be used to urge policy makers in Westminster and the devolved nations to implement its recommendations to improve outcomes for pancreatic cancer patients across the UK.

# FOREWORD BY THE CHAIR



Thank you to everyone who has contributed to this inquiry. We have been privileged to hear many moving stories and meet many inspirational people. These have given us the strong evidence base from which to write this report.

Over the course of the inquiry and our review of both the written and oral evidence, it became very apparent that the best word to describe pancreatic cancer in the past was “stuck.” I helped form the All Party Parliamentary Group on Pancreatic Cancer (APPGPC) after one of my constituents lost her mother in law and husband to the disease 40 years apart. Shockingly her husband’s chances were no better than his mother’s! Despite advances in science since the 1970s, pancreatic cancer stubbornly maintains the lowest five year survival of the 20 most common cancers; between 3.8% and 6.6%<sup>i</sup> across the UK.<sup>ii</sup> Moreover, 10 year survival still stands at 1%.<sup>iii</sup> These appalling statistics stem at least in part from the fact that pancreatic cancer is often diagnosed at a late stage, when treatment is no longer an option.

The good news is that since our first APPG inquiry in 2012 we are starting to see some positive developments; some hope. We are starting to gain some traction. As Professor Willie Hamilton at the University of Exeter stated during his testimony, physicians are more willing to investigate for this cancer. According to Professor Hamilton’s own analytics, the time to diagnose pancreatic cancer has decreased by 30 days over the course of the last decade.<sup>iii</sup> Given this progress, five year survival has increased ever so slightly from 3.4 to 6.6% since 2003.<sup>iv</sup> Public awareness initiatives, increased GP education and diagnostic tools, faster referral pathways and one-stop clinics are starting – slowly - to change the diagnosis story for pancreatic cancer patients. Moreover, pancreatic research is improving and with increased funding should one day make the breakthrough necessary to transform the lives of pancreatic cancer patients. Hopefully, these steps towards early diagnosis will translate into increased survival rates sooner than later.

To ensure that we continue to move forward and leave the dismal statistics of the 1970s behind, we need to ensure that this progress is nurtured and expanded. To diagnose pancreatic cancer sooner, so patients can live better and longer, the APPGPC is calling for:

- (1) increased research funding directed at the early diagnosis of pancreatic cancer
- (2) a pancreatic cancer specific symptom awareness campaign and/or a series of generic symptom campaigns, addressing vague symptoms associated with pancreatic cancer
- (3) improved tools, education and guidelines about pancreatic cancer for general practitioners and others
- (4) better diagnostic pathways
- (5) fast-track surgery and faster access time to all other treatments, when possible
- (6) full implementation and support for the NHS England Cancer Strategy and Cancer Alliances.

Through these efforts the APPGPC will continue to champion better outcomes for pancreatic cancer patients by working with all stakeholders (patients, carers, family members, clinicians, researchers, charities and policy makers). Together we can drive progress and improved pancreatic cancer survival into the future.

More than anything else I hope that this report gives further impetus to providing greater focus on early diagnosis of pancreatic cancer and an acceleration in reaching that elusive goal.



*Nic Dakin MP,  
Chair of the All Party Parliamentary Group on Pancreatic Cancer*

# EXECUTIVE SUMMARY

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## BACKGROUND

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Pancreatic cancer will be the fourth biggest cancer killer by 2026 , unless significant improvements in survival are made now.<sup>v</sup> The main reason for this death toll and the low survival associated with pancreatic cancer is late diagnosis. Currently, only 10-20% people with pancreatic cancer are diagnosed when they are still eligible for resection surgery, the only potentially curative treatment for pancreatic cancer.<sup>vi</sup>

The reasons for late diagnosis are multifaceted. First, the symptoms of pancreatic cancer are often common, vague and therefore hard to recognise. In some instances there are no early stage symptoms. As a result, significant research funding dedicated to the development of a test that can diagnose high risk patients before symptoms appear is essential to transforming the prognosis of this disease. To date, funding for pancreatic cancer research has been limited.

Second, the public do not know the symptoms of pancreatic cancer. A 2016 ComRes poll commissioned by Pancreatic Cancer UK found that 74% of people across the UK could not name a single symptom of pancreatic cancer. A UK wide survey of GPs conducted by Pancreatic Cancer UK in 2012 found that half were not confident they could identify the signs and symptoms of pancreatic cancer in patients.<sup>viii</sup> A survey of 400 GPs commissioned by Pancreatic Cancer Action found that only 3% of respondents felt fully confident and informed about the symptoms of pancreatic cancer .

According to the 2015 National Cancer Patient Experience Survey for England, 76% of all cancer patients visited their GP only once or twice before they were referred for further testing, compared to 62% of pancreatic cancer patients.<sup>ix</sup> Pancreatic Cancer UK's 2015 Symptoms and Diagnosis Survey revealed an even starker picture with 63% of respondents reporting that they or their family member had to visit their GP three times or more before diagnosis. A shocking 23% said they had to visit seven times or more.<sup>x</sup>

Given these factors as well as others, 45% of pancreatic cancer patients were diagnosed through Accident and Emergency in 2013.<sup>xi</sup> This is important as presentation via emergency admission normally occurs when the disease is more advanced. Therefore, it is associated with significantly poorer survival rates than other routes to diagnosis. For example, one year survival for patients presenting via emergency presentation is just 10% rather than 26% for those diagnosed with pancreatic cancer as a result of GP referral. <sup>xii</sup>

Diagnosing pancreatic cancer earlier is one clear way we can tackle this disease and improve survival rates. The APPGPC believes early diagnosis is the key to increasing the numbers of people eligible for surgery and improving the chances of inoperable patients receiving new, emerging therapies.

# SUMMARY OF KEY RECOMMENDATIONS

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Based upon current evidence, we believe that pancreatic cancer patients will be diagnosed sooner, thereby giving these patients better outcomes, if the recommendations of this Early Diagnosis Inquiry are adopted. The following is a summary of the six key recommendations.

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## 1. INCREASED RESEARCH FUNDING

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The APPGPC calls on:

- (a) Funders to commit to increasing funding for pancreatic cancer so it reaches a collective total of £25m per year by 2022, as previously called for in its 2014 report.<sup>xiii</sup>
- (b) The National Institute for Health Research, Health and Care Research Wales, the Chief Scientist Office and the Health and Social Care Public Health Agency to follow Cancer Research UK's example and commit to doubling their annual investment in pancreatic cancer research.
- (c) Universities and research institutes to prioritise pancreatic cancer research, increasing the volume of applications they put forward to funders.
- (d) The UK Government to ensure that the UK's departure from the EU does not put at risk UK involvement in important international research and patient access to clinical trials.

**RATIONALE:** The development of a test that can diagnose high risk patients before symptoms appear or are recognised as symptoms of pancreatic cancer is necessary to change the landscape for pancreatic cancer patients forever. Although this is an ambitious goal, there is currently a considerable amount of promising research into diagnostic testing. In order for this research to come to fruition and for a test to become a reality, pancreatic cancer research, in particular research focused on early diagnosis, needs much more funding. Specifically, the APPG on Pancreatic Cancer estimates that we will need a sustained level of £25 million a year to make the breakthroughs necessary to change the story for pancreatic cancer patients.<sup>xiv</sup> We estimate that pancreatic cancer research funding as a whole falls short of this goal. Although Cancer Research UK, a member of the National Cancer Research Institute, has committed to doubling or trebling its investment in pancreatic cancer research and other cancers of unmet need, we estimate that pancreatic cancer research funding, as a whole, falls far short of this goal. We also recognise the need for high quality applications so that funders are able to increase spend on pancreatic cancer research. Whilst we hope that an increase in funding will incentivise more high quality applications, universities and research institutes should also proactively encourage pancreatic cancer research so that there are more projects available to fund.



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## 2. MORE AND EXPANDED PUBLIC AWARENESS CAMPAIGNS

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The APPGPC calls for:

- (a) Public Health England to roll out the Be Clear on Cancer abdominal symptoms campaign nationally.
- (b) The development, pilot and launch of a Public Health England campaign dedicated to pancreatic cancer symptoms and/or a series of generic symptoms campaigns for symptoms associated with pancreatic cancer, including back pain, unexplained weight loss, new onset diabetes not associated with weight gain and nausea and vomiting.
- (c) The impact of pancreatic cancer awareness campaigns should be monitored and evaluated.

**RATIONALE:** Given that pancreatic cancer is expected to become the fourth biggest cancer killer by 2026, there is clearly a strong case for the development of a pancreatic cancer specific symptoms awareness campaign, like those already in place for the other major cancer killers. We welcome the piloting of the Be Clear on Cancer abdominal symptoms campaign, which should be rolled out nationally if successful. Failing a pancreatic cancer specific campaign, other generic symptoms campaigns focused on other symptoms associated with pancreatic cancer should be piloted. Awareness of pancreatic cancer symptoms will remain dismally low unless the public are educated about the signs of pancreatic cancer.

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## 3. INCREASED GP SUPPORT

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The APPGPC calls for:

- (a) Increased Support for GPs through Cancer Decision Aid Tools. To achieve this aim, all GPs must have access to Cancer Decision Aid Tools and be educated about their use. Professional bodies and the NICE guidelines must support their integration, and researchers must analyse the tools' benefits, uptake, and impact.
- (b) Increased Support for GPs through more GP education about pancreatic cancer.
- (c) Increased Support for GPs through updated NICE referral guidelines that reflect the number of individuals with pancreatic cancer under the age of 60.
- (d) An analysis of the National Cancer Diagnosis Audit to determine how well GPs are supported and whether they are recognising the symptoms of pancreatic cancer.

**RATIONALE:** General practitioners, who have ten minutes per consultation, need as much support as possible to ensure that they recognise symptoms quickly and investigate or refer patients as soon as possible. Decision Aid Tools and additional education about pancreatic cancer through enhanced curriculums and continuing education tools helps GPs recognise the symptoms of pancreatic cancer, evaluate the patient's risk and investigate or refer if necessary. Audits of GPs' practices,

through the programs like the National Cancer Diagnosis Audit, can help GPs and others understand how well GPs are recognising the symptoms of cancer and how quickly they are referring those individuals for further investigation. Finally, we seek a review of the age threshold found in the NICE referral guidelines when new evidence regarding symptoms becomes available, to ensure that GPs consider patients under the age of 60 at risk for pancreatic cancer.

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#### 4. FASTER DIAGNOSTIC PATHWAYS

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The APPGPC calls for:

- (a) Clinical Commissioning Groups and others to continue to fund and increase funding for rapid diagnostic pathways for patients that present with vague symptoms (or non-specific but concerning symptoms) and where cancer is suspected, such as multi-disciplinary diagnostic centres (MDCs), one-stop clinics or direct access to diagnostics.
- (b) Clinical Commissioning Groups to authorise GPs Direct Access to CT Scans.
- (c) Health bodies to provide the appropriate education to GPs on CT scans.
- (d) NHS England to create a clear plan to address lack of diagnostic capacity caused by workforce shortages and prior lack of investment.

**RATIONALE:** Patients who are ultimately suspected for pancreatic cancer still experience long waiting times before investigation and diagnosis. Furthermore, patients with vague symptoms often undergo numerous separate referrals for different investigative tests. This “ping-ponging” causes further delay to diagnosis. This is unacceptable given the fact that early diagnosis greatly impacts prognosis. Although waiting times are unlikely to have a significant impact on a shift in the stage of diagnosis, sufficient diagnostic capacity is essential to achieve earlier diagnosis. To ensure earlier diagnosis, continued and increased funding is needed for Multidisciplinary Diagnostic Centres for vague symptoms where tests can be expedited. Where referral via this route is not possible GPs should have direct access to CT scans.

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#### 5. FAST TRACK SURGERY AND OTHER TREATMENTS

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The APPGPC calls for:

- (a) Clinical/Specialised Commissioning Groups to consider making, based upon the latest available evidence, the small upfront investment to implement these pathway changes in Manchester and Birmingham and around the country so these pilots become fixtures and the gains made do not disappear. The Government and NHS England must consider developing national guidance supporting fast track surgery and faster access to treatments based upon the latest available evidence.

- (b) The APPGPC calls on the pancreatic cancer community (including clinicians, charities and parliamentarians) to work together to educate others, including practices and hospitals, about the potential advantages to the patient and NHS as a whole when they are referred to fast track pathways and treatment.
- (c) An audit of pancreatic surgery and other treatments around the country to assess progress on delivering more timely diagnosis and treatment.

**RATIONALE:** Once a patient is diagnosed with pancreatic cancer, he or she must receive cancer treatment as soon as possible. If a patient is operable and jaundiced and has to wait for surgery they are very likely to require biliary drainage. Existing high quality evidence demonstrates lower rates of complications when patients proceed directly to surgery without biliary drainage. Furthermore biliary drainage is unpleasant, consumes hospital resources and does not help the patient in the long term. Some patients may become inoperable when there are delays to surgery or suffer severe complications due to biliary drainage. As a result the patient will have lost their chance of a potential cure. Fast track surgery affords patients the best chance of tumour removal and should be available to all eligible patients fighting this aggressive and fast moving disease. If it is felt by the specialist team that the best treatment option would be neoadjuvant therapy the patient should also receive this treatment as quickly as possible. In this instance, the patient will require biliary drainage to ensure that the chemotherapy is delivered safely.

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## 6. CANCER STRATEGY AND CANCER ALLIANCES

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The APPGPC calls for the successful implementation of the NHS England Cancer Strategy and Cancer Alliances, because they are essential to establishing the foundations needed for early diagnosis.

**RATIONALE:** Recommendations in the Cancer Strategy for England, especially those concerning diagnostic capacity and workforce shortages, should be implemented to ensure increasing demand for services is met and earlier diagnosis achieved. Without the infrastructure of the Cancer Alliances, we will be unable to efficiently implement early diagnosis initiatives and learn from other regions.

# RESEARCH

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## THE PROBLEM:

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Historically, pancreatic cancer research, including research focusing on early diagnosis, has been massively underfunded. Despite having the worst prognosis of any malignancy and being the cause of 5% of cancer deaths in the UK,<sup>xv</sup> pancreatic cancer receives just 1.4% of research funding.<sup>xvi</sup> As a result, the number of researchers, and the corresponding scientific breakthroughs in pancreatic cancer has paled in comparison to other cancers. Many researchers have noted the shortage of available funding, including the funding for the completion of studies into pancreatic cancer.<sup>xvii</sup>

## PAST RECOMMENDATIONS:

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The APPG's 2014 inquiry into research recognised the importance of increasing research spend and of more research into early diagnosis:

**"There is a strong case to establish more research that will help to improve early diagnosis. This includes research that may lead to the development of screening tools."<sup>xviii</sup>**

**"All funders should take on board the case for short-term, ring-fenced, strategically commissioned funding for quality driven, peer reviewed pancreatic cancer research. This should be in line with a commitment to collectively reach a minimum of £10 million site specific spend from 2015 and to increase funding to £25 million over the course of the next decade."<sup>xix</sup>**

**"In particular, the Department of Health needs to review its own contribution to pancreatic cancer research, increasing substantially its current contribution of just £0.7 million, looking to at least match Cancer Research UK's stated goal of doubling or trebling its annual investment in the next spending round."<sup>xx</sup>**

## PROGRESS:

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In recent years we have seen some increase in funding. The NCRI's funding for pancreatic cancer research increased slightly from £5.5 million in 2013/2014 to £10.9 million in 2015/2016.<sup>xxi</sup> We also strongly welcome the commitment by NCRI-member organisation, Cancer Research UK (CRUK), to double or treble its research into pancreatic and other cancers of unmet need. As a result, CRUK's spend on pancreatic cancer research increased from £8.6 million in 2013/14 to over £18 million, a figure which includes research "relevant to all types of cancer," in 2015/2016.<sup>xxii</sup> CRUK also reported an encouraging upward trend in the number of applications for pancreatic cancer research.<sup>xxiii</sup> According to Dr Helen Campbell, Portfolio Manager of the Research Networks, Cancer Research and Clinical Research Facilities at the Department of Health, the disappointingly low level of funding, has historically been due to a lack of high quality applications. However, she noted that the Department of Health is starting to see more research proposals coming through. Hopefully, as funding increases so will interest in pancreatic cancer and thus the number of high quality applications and funded projects.

The APPG on Pancreatic Cancer heard from a range of early diagnosis researchers carrying out exciting and promising studies. The work of Professor Eithne Costello at the University of Liverpool, funded by Pancreatic Cancer Action, seeks to distinguish cases of new onset diabetics from those where diabetes stems from pancreatic cancer. If these cases can be successfully identified, she believes “we will be detecting half of all cases [of pancreatic cancer], perhaps even more.”<sup>xxiv</sup> Likewise, Pancreatic Cancer UK funded EUROPAC Registry, led by Dr Bill Greenhalf at the Liverpool Centre of EUROPAC, is focused on detecting pancreatic cancer early in people with a history of familial pancreatic cancer. Finally, this November Pancreatic Cancer UK will be mobilising the research community through an ‘Early Diagnosis Research Sandpit’ in an effort to create a coordinated UK-wide early diagnosis research programme including biomarker discovery and validation, which should in the future see people diagnosed earlier and more quickly.

In regard to scientific advancements, most people acknowledge, as Maggie Blanks, CEO and Founder of the Pancreatic Cancer Research Fund (PCRF) explained, “The Holy Grail would be a detection method that could be applied further up the pathway of advancement, so the disease is found earlier, when possibly there are no symptoms”.<sup>xxv</sup> To date these early detection biomarkers have not been sufficiently specific. As a result, they are mainly used to monitor patients.<sup>xxvi</sup> However, biomarker research is making progress. Maggie Blanks described in detail a promising test funded by Pancreatic Cancer Research Fund based on biomarkers in urine. According to Steve Pereira, a researcher and consultant at University College Hospital whose work is sponsored by Pancreatic Cancer UK, “We are now approaching 90%/95% accuracy with some of the biomarker profiles coming out.” Professor Pereira explained that following some initial success, more significant funding will be needed to support prospective large scale studies. Going forward he estimated that studies would need to “range from 3,000 or 5,000 to 15,000 [participants]”. He added that these studies are multi centre and that if moved into primary care, GPs need to be provided with all the necessary resources to support them in taking and analysing blood and urine samples.<sup>xxvii</sup>

Given the increased requirements of these studies, it is unlikely that small charities will be able to provide sufficient funding. However, it is hoped that encouraging initial results will provide the impetus for Government and major donor funding. Dr Helen Campbell from the Department of Health noted that pancreatic cancer research funding is “an important area and the Government would welcome more high quality research applications that we [Department of Health] could fund.”<sup>xxviii</sup> “She is “sure researchers will be delighted to put in research on the back of [a biomarker breakthrough] and we would be delighted to fund them.”<sup>xxix</sup>

The 2014 APPG Inquiry found that funding must reach a sustained level of £25m each year to achieve the kind of breakthroughs needed to significantly improve survival outcomes for pancreatic cancer patients. Despite nominal increases in research funding since this report was published, we remain far from achieving this objective.

Furthermore, some witnesses expressed concern about the potential impact of the UK’s exit from the EU on research funding, international collaboration and access to clinical trials. A survey by Pancreatic Cancer UK found that 92% of researchers felt that Brexit could negatively impact access to EU research funding.<sup>xxx</sup>

In the last 3-5 years, Professor Steve Pereira noted a really large international appetite for collaboration. He explained, “we are now routinely in the UK community talking about [inter]national

studies.<sup>xxxii</sup> In addition, through Horizon 2020 (2014–2020), the European Union’s research and innovation programme, UK researchers have access to an EU grant of 30 million euros for early cancer diagnosis across 25 centres.<sup>xxxii</sup> This kind of collaboration will facilitate and is vital to the collection of enough samples to give statistical support to any pancreatic cancer biomarker study.<sup>xxxiii</sup>

When the UK leaves the EU, the UK must further strengthen the global collaborations it has built and ensure its position as a global leader in clinical research so that global pancreatic cancer research continues at the same rate. It is therefore more vital than ever that we see a real commitment from the UK Government to securing funding for pancreatic cancer research.

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## RECOMMENDATIONS:

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To make the scientific breakthroughs necessary to diagnose pancreatic sooner, the UK needs to further develop its pancreatic cancer research infrastructure and provide substantially more funding. Much of this research investment should focus on identifying new approaches and/or biomarkers or a profile of biomarkers that could potentially be used for screening and early diagnosis. Specifically, biomarker screening could be used, at least initially, on those with high risk profiles.

To achieve this, the APPGPC calls on:

- (a) Funders to commit to increasing funding for pancreatic cancer so it reaches a collective total of £25m per year by 2022, as previously called for in its 2014 report.<sup>xxxiv</sup>
- (b) The National Institute for Health Research, Health and Care Research Wales, the Chief Scientist Office and the Health and Social Care Public Health Agency to follow Cancer Research UK’s example and commit to doubling their annual investment in pancreatic cancer research.
- (c) Universities and research institutes to prioritise pancreatic cancer research, increasing the volume of applications they put forward to funders.
- (d) The UK Government to ensure that the UK’s departure from the EU does not put at risk UK involvement in important international research and patient access to clinical trials.

**“If we want to save lives, then I think the focus has to change towards screening or biomarkers or prevention...”**

*Professor Willie Hamilton, University of Exeter, Oral Evidence Session Transcript Pages 8-9.*

**“We have done a lot of work looking into patients at high risk and screening those, and I think absolutely that is what should be done.....”**

*Dr Andrew Millar, Lead at University College London Hospitals’ ACE MDC for vague symptoms, Oral Evidence Session*

**“The Holy Grail would be a detection method that could be applied further up the pathway of advancement, so the disease is found earlier, when possibly there are no symptoms.”**

*Maggie Blanks, CEO and Founder, Pancreatic Cancer Research Fund, Oral Evidence Session*

**“Science and research is a global endeavour.”**

*Sara Bainbridge, Policy Manager, Cancer Research UK, page 25 oral evidence session*

# PUBLIC AWARENESS

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## THE PROBLEM:

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Public awareness of the symptoms of pancreatic cancer remains dismally low. As previously mentioned, a ComRes survey carried out by Pancreatic Cancer UK in 2016 found that 74% of the public could not promptly name a single symptom of the disease. Likewise, Ali Stunt, Chief Executive and Founder of Pancreatic Cancer Action, noted that 95% of respondents from their most recent public survey knew nothing or almost nothing about pancreatic cancer. Moreover, individuals with symptoms delayed seeking a GP's opinion, because 40% thought they would be wasting their GP's time, 38% found it difficult to make an appointment and 20% did not want to discuss symptoms with a receptionist.<sup>xxxv</sup>

## PAST RECOMMENDATIONS:

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The APPGPC's 2013 report included the following recommendation:

**"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."**

<sup>xxxvi</sup>

## PROGRESS:

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It is excellent to see that charities, like Pancreatic Cancer Action, have engaged in their own national symptom awareness campaigns, such as the posting of symptom awareness posters in public toilets. However, to get a greater reach we need UK-wide, NHS run campaigns.

The most exciting development is the Be Clear on Cancer's abdominal symptoms campaign, which was piloted in the East and West Midlands from February 9 to 31 March 2017. Radio, print, digital, and out of home advertising focused primarily on three main symptoms (diarrhoea, bloating and discomfort.)<sup>xxxvii</sup> The leaflet for the public also encouraged individuals to visit a physician if they experienced constipation, nausea/feeling sick, or unexplained weight loss for three weeks or more.<sup>xxxviii</sup> The pilot, which included a pancreatic cancer case study, will be evaluated by pre and post campaign surveys and an assessment of the demand on health services. Tim Elliott, Senior Policy Advisor for Cancer, Acute Care and Provider Policy, Department of Health explained, "If [pilot] is successful we will go national with it, so individual rarer cancers will get some data, and see what impact it has."<sup>xxxix</sup>

However, we recognise that the focus on abdominal symptoms or “tummy” troubles does not address some common symptoms associated with pancreatic cancer, including back pain, unexplained weight loss, nausea or vomiting, steatorrhea, (pale, smelly faeces that may float), fatigue, or difficulty swallowing. Moreover, the pilot focused on men and women over 50 from lower socioeconomic groups, and their key influencers, such as friends and family.<sup>xi</sup> In light of the campaign’s design, we are still concerned that many individuals, especially those who are younger and present with a cluster of symptoms other than abdominal ones, will not benefit from the campaign.

Therefore, we still seek a future pancreatic cancer specific campaign, which discusses who is at higher risk for the disease, as well as its symptoms. By focusing on patients whose symptoms are getting worse and determining whether they have other risk factors like obesity, chronic pancreatitis, new onset diabetes, Consultant Gastroenterologist and Hepatologist at North Middlesex University Hospital Dr. Andrew Millar believes that GPs and specialists will be able to identify possible pancreatic cancer patients sooner. Given pancreatic cancer is set to become the fourth biggest cancer killer by 2026, it seems a pancreatic cancer specific awareness campaign is well overdue.

Failing a pancreatic cancer specific campaign, generic symptoms campaigns looking at other vague symptoms associated with pancreatic cancer should be piloted.

Moreover, we need to continue to move toward empowering patients with knowledge about pancreatic cancer and its symptoms. As Dr Millar explained, we “actually need to start educating the population, not just telling them.”<sup>xii</sup> In a similar vein, Pancreatic Cancer UK and Macmillan have developed in conjunction with GPs and people affected by pancreatic cancer a Top Ten Tips for patients worried about pancreatic cancer facilitating better patient communication with their GP about the signs, symptoms and the diagnosis of pancreatic cancer. In order to facilitate the best consultation possible, the tips help patients identify symptoms and risk factors and suggest that individuals record the frequency of their symptoms. The tips also encourage patients to revisit their physician if symptoms haven’t improved or if they have been asked to follow up.



## RECOMMENDATIONS:

To ensure more patients are able to spot the symptoms of pancreatic cancer, we desperately need national campaigns to improve public awareness of the symptoms which is currently dismally low.

The APPGPC calls for:

- (a) Public Health England to roll out the Be Clear on Cancer abdominal symptoms campaign nationally, if evidence suggests it is effective. Similar awareness campaigns should also be launched in Wales, Northern Ireland and Scotland. These campaigns should incorporate television ads, which are generally thought to create the biggest<sup>xliii</sup> impact and are able to reach a national audience.
- (b) The development, pilot and launch of a Public Health England campaign dedicated to pancreatic cancer symptoms and/or a series of generic symptoms campaigns for symptoms associated with pancreatic cancer, including back pain, unexplained weight loss, new onset diabetes not associated with weight gain and nausea and vomiting.
- (c) The impact of pancreatic cancer awareness campaigns should be monitored and evaluated. Primary care systems should collect data regarding patient awareness, patient delay and patient action to identify where progress has been made and where further action is needed.

xliii

**“It was only because he read an article in the Daily Mail about pancreatic cancer he said: “I should go and get checked out”...”**

*James Farrell, carer,  
oral evidence session*

**“I honestly feel if there was an association between the symptoms my dad was displaying and pancreatic cancer, if that association was widespread and widely known my dad might have gone six months earlier, who knows he could have been eligible for a procedure...”**

*James Farrell, carer,  
oral evidence session*

**“I think MPs can help enormously by raising awareness of pancreatic cancer within their own constituencies, and [calling] for public health campaigns, educating and informing people about this disease.”**

*Debbie Wells, carer,  
oral evidence session*

**“I would say to politicians, just shout, shout about this cancer, let your voices be heard, let pancreatic cancer be heard and be acknowledged, because for me one of the things I find so frustrating is the lack of interest because the profile is so low, so what we need to do is get that profile right up there”**

*Debbie Wells, carer,  
oral evidence session*

# GP SUPPORT

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## THE PROBLEM:

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Pancreatic cancer is associated with vague, non-specific symptoms. It is therefore particularly difficult for GPs to diagnose, as symptoms can often be attributed to other, more common conditions. We often hear of patients making repeat visits to their GP before a diagnosis is made. The 2015 NHS England Cancer Patient Experience Survey showed that 38% of pancreatic cancer patients have to visit their GP three times or more before they were referred to hospital.<sup>xliv</sup> This finding was reinforced by a Pancreatic Cancer UK survey carried out online between December 2014 and March 2015 across the whole of the UK. The survey heard from 274 UK based respondents, which included current patients and their family members, as well as those who had lost loved ones to pancreatic cancer. It found that 23% of patients visited their GP seven or more times before diagnosis and 15% visited five or six times.<sup>xlv</sup> GPs themselves report needing more information on pancreatic cancer. According to Pancreatic Cancer Action's 2015 study of 400 GPs only 3% of GPs felt fully informed and confident about identifying the symptoms of pancreatic cancer.<sup>xlvi</sup>

## A. Cancer Decision Support Tool

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### PAST RECOMMENDATIONS:

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In its 2013 report, the APPGPC recommended that the Department of Health and relevant professional bodies encourage GP practices to use Decision Aid Tools, also known as Cancer Decision Support (CDS) tools so they ultimately become embedded in all GP surgeries, as their efficacy continues to be affirmed.

In our 2015 follow-up report, 'Pancreatic Cancer Research and Care: A Health Check', we reported that the audit of the pilot found that the DATs could raise awareness of symptoms, remind users of risk and influence the management of some patients.

### PROGRESS:

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Macmillan is working with each of the main GP IT providers to integrate CDS tools. In regard to providers, Egton Medical Information Systems (EMIS) Health has integrated the QCancer tool in England, which uses the algorithm of Julia Hippisley-Cox, a Professor and sessional GP in Nottingham, and In Practice Systems (INPS) Vision has integrated a CDS using Professor Willie Hamilton's algorithm. The third main provider, TPP SystemOne, however, is still in the process of integrating the tool into their system free of charge. Decision Aid Tools are also available in Scotland and Wales via a third party provider.<sup>xlvii</sup>

Implementation of QCancer into the most popular GP system alone, makes it available to 5,000 general practices covering 35 million patients.<sup>xlviii</sup>

According to Professor Julia Hippisley-Cox's written evidence, the software prompts GPs to think about cancer, checks symptoms, records outcomes, and stratifies risk. Since take up of QCancer has only really taken off in the last year, it is too early to assess uptake, impact and ultimately its effect on early diagnosis.

In addition, further independent evaluations of these electronic tools have occurred. An exploratory study in Australia using a program similar to QCancer showed the risk tool was perceived as useful when patients with complex histories presented.<sup>xlix</sup> Because there have not been policy efforts to raise awareness of early cancer diagnosis in Australia, however, it seemed that physicians would rarely consider using it in a consultation. Other factors that affected use was the practitioner's clinical experience and belief in clinical intuition. Not surprisingly, some practitioners also found it difficult to introduce into the workflow of the consultation.<sup>l</sup> A phase II, randomised control trial looking at the use of a computer aid for detecting gastro-oesophageal cancers is ongoing and may also shed light on the best use and incorporation of these decision tools into primary care consultations.<sup>li</sup> According to Chris Harrison, the National Clinical Director for Cancer for NHS England, the best way to ensure uptake is to firmly establish evidence of its effectiveness.<sup>lii</sup>

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## RECOMMENDATIONS:

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- (1) All GPs should have access to Cancer Decision Aid Tools. The integration of the tool by all three main GP providers must be completed without additional cost to practitioners. In addition, GPs must be supported through education about how best to incorporate the use of DATs in consultations as well as the interpretation and implementation of risk calculations. More health bodies and funders must actively encourage and promote its use.
- (2) We need research to confirm the advantages of using DATs and confirm how to best integrate them into consultations.
- (3) We seek an analysis of uptake and impact must be undertaken as soon as feasible.
- (4) We ask that the NICE Cancer Referral guidelines are updated to reflect the benefit of electronic tools, given their current availability.

**"I have seen too many patients that ping pong from one specialist to another, and we are eliminating that ping pong patient, that is a positive."**

*Professor Hamilton,  
University of Exeter,  
Transcript Page 9.*

## B. GP EDUCATION

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### PAST RECOMMENDATIONS:

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In our 2013 report, the APPGPC recommended greater professional body support for increased use of pancreatic educational tools by clinicians and a review of the medical training curriculum.

We also recommended an audit of pancreatic cancer patient deaths diagnosed via emergency admissions, as well as GP audits of diagnosis of less common cancers as part of their annual appraisal process and the use of these audits during revalidation.

### PROGRESS

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Since the last report, Pancreatic Cancer Action has created another training module to supplement its earlier modules for GPs as well as a module for hospital doctors, which were created in conjunction with the British Medical Journal (BMJ) and the Royal College of General Practitioners (RCGP). Ali Stunt, CEO of Pancreatic Cancer Action, reported that the latest module is an exam for trainee doctors including GPs. Moreover, the Royal College of Physicians hosts the GP module on its website and offers CPD credits and it has been well received by GPs.

Macmillan Cancer Support and Pancreatic Cancer UK working in conjunction with GPs and people affected by pancreatic cancer have developed a set of GP and Patient Top Ten Tips on pancreatic cancer to educate about the symptoms of the disease, to help each other communicate effectively and empower patients to return to their GP if they continue to have concerning symptoms. Macmillan will disseminate this through their GP networks/Primary care programme.

Professor Andrew Hart, Professor of Gastroenterology at Norwich Medical School and consultant at Norfolk and Norwich University, reported that he and co-authors have published a paper on the case for a medical curriculum to train junior doctors in managing patients with pancreatic conditions, including pancreatic cancer. He believes we need to continually expand the areas covered in the training of junior doctors on pancreatic medicine, with greater involvement in the care of patients with pancreatic cancer. There is a need for consultants with expertise in the field to be available in all hospitals. Discussions are occurring with the Royal College of Physicians on progressing this curriculum.<sup>liii</sup>

Finally, the latest round of the National Cancer Diagnosis Audit (NCDA), led by Cancer Research UK and Public Health England, enabled GPs to examine all the cancer diagnoses made in their practice in 2014 and see what happened with these cases, including how many times the patients visited and what their symptoms were.\* This helps GPs to understand patients' pre-diagnostic experiences and to explore why pancreatic cancer patients often visit their GP a number of times before a diagnosis is made. It also helps us determine whether this reflects data from the National Cancer Patient Experience Survey, which showed that 41% of patients visited their GP three or more times before referral.

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## RECOMMENDATIONS:

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Health Education England and the professional bodies must ensure that existing training on pancreatic cancer is incorporated into all practitioner's continuing education. Moreover, we need to see continued funding for training fellowships in pancreatology, because these individuals are the ones most likely to help raise awareness of pancreatic cancer and help educate GPs on pancreatic cancer presentation.<sup>liv</sup>

## C. NICE GUIDELINES

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### PROGRESS:

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The APPGPC was pleased by the inclusion of pancreatic cancer generally and new onset diabetes as a risk factor in the NICE referral guidelines for suspected cancer published in 2015 and the consideration of urgent CT scans for patients with certain risk factors. In addition, we welcome that the guideline recommends referral for patients aged 40 and over with jaundice. However, we believe many younger patients will continue to miss out on early diagnosis, because the guidelines only recommend testing for individuals over the age of 60 when it comes to other symptoms of the disease. Yet, in 2014, there were approximately 1,369 newly diagnosed pancreatic cancer patients under the age of 60 in the United Kingdom.<sup>lv</sup> We recognise that the guidelines do not supersede clinical judgment. Given that so many pancreatic cancer patients still visit their GP multiple times before being referred, however, we believe GPs need stronger guidelines to supplement their own knowledge and experience. In particular, we remain concerned that the age threshold means the update will not result in any improvement for patients under the age of 60 who will continue to be diagnosed too late.

One of the main aims of the NICE guidelines, according to Tim Elliott, was to get GPs to think of cancer sooner when patients present with possible symptoms.<sup>lvi</sup> In this regard many witnesses reported they believed the guideline has been successful. As clinical lead on the 2015 referral guidelines update Professor Hamilton explained that he believes more GPs are willing to investigate cancer.<sup>lvii</sup> To this end, Cancer Research UK facilitators working across England, Scotland

**"I think we are dealing with complex and subtle symptoms in that situation. So, raising awareness in the profession is paramount."**

*Rosie Loftus, Joint Chief Medical Officer, Macmillan Cancer Support, oral evidence, Page 17.*

**"My daughter Gemma went to her GP on 10 separate occasions and was told it was gastritis, IBS (irritable bowel syndrome) and possible gall stones."**

*Debbie Wells, carer, oral evidence, Page 24.*

**"I know she could have had a chance of treatment and possibly survival if her symptoms had been taken more seriously when she first presented."**

*Debbie Wells, carer, oral evidence, Page 24.*

**"Every single GP in this country should be aware of pancreatic cancer and its symptoms, because there is clear evidence that every single constituency is affected by pancreatic cancer."**

*James Farrell, carer, Oral evidence, Page 30.*

and parts of Wales have been promoting the updated NICE referral guidelines and their lower threshold for referring people with symptoms that might have pancreatic cancer.<sup>lviii</sup> The APPGPC also welcomes the development of NICE guidelines on Pancreatic cancer: diagnosis and management in adults.\* The expected publication date is 24 January 2018.

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## **RECOMMENDATIONS:**

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The APPG seeks a review of the NICE referral guidelines for suspected cancer, when there is new evidence or research regarding pancreatic cancer symptoms available.

**“Sadly, there are concerns with some of that information in that there is an age threshold of 60, and we are aware that a lot of people are diagnosed under that age of 60. I think the last statistics we have is something around 1,300 patients under 60”**

*Dianne Dobson,  
Pancreatic Cancer Nurse  
Specialist, Pancreatic  
Cancer UK.*

**“Whilst I welcome the fact that NICE have revised their referral guidelines for suspected cancer to include pancreatic cancer, the age criteria they have imposed on those guidelines would not have made the slightest difference to me and my family, because my daughter was under 60, and all those patients under that age currently now will be seemingly disregarded.”**

*Debbie Wells, carer, oral  
evidence, Page 24.*

# DIAGNOSTIC PATHWAYS

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## THE PROBLEM:

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Traditionally, patients with vague symptoms and even those with more obvious symptoms, have spent weeks “ping-ponging” between GPs, specialists and hospitals before they are diagnosed. For example, if a patient with vague symptoms is sent for an ultrasound and nothing is found (which is highly likely with pancreatic cancer) the patient is sent back to the GP and for further evaluation during a 10 minute appointment are often referred for another test and to another specialist, all of which have their own waiting lists.

Under the traditional pathway (GP to specialist to surgery) there are often a number of problems, delays in the pathway waiting for scans and results, poor patient experience and complications associated with unnecessary interventions.<sup>ix</sup> An audit of patients with pancreatic cancer presenting in Manchester between July 2007 to March 2014 (before the one stop jaundice clinic) revealed that the median time from ultrasound to surgery was 57 days and the median time from a CT scan to surgery was 33 days.<sup>ix</sup> These delays result in delayed treatment, unnecessary procedures, and patient anxiety. During this time period the patient may also become more unwell and his or her symptoms may worsen, making it harder to tolerate treatments.

Furthermore patients who are suspected for pancreatic cancer still experience long waiting times before investigation and diagnosis, because many GPs lack the ability to access diagnostics themselves or the ability to refer them to a multidisciplinary diagnostic clinic for vague symptoms or a cancer exclusion clinic.

To address the current barriers to early diagnosis, the traditional diagnostic pathway needs to be reconsidered so that patients have quicker access to diagnostic tests carried out by specialists.

## PREVIOUS RECOMMENDATION:

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In its 2013 report, the APPGPC called for “a whole-sale review of pathways between primary and secondary for referral and investigation of pancreatic cancer patients”. It also advocated “a coordinated approach to piloting and evaluating the new models discussed at the inquiry”, which included GP direct access to CT scans, named diagnostic specialists, specialist diagnostic centres and rapid access clinics.

## PROGRESS

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Currently, a number of pilots are testing new clinics and pathways for pancreatic cancer diagnosis. During the course of the inquiry alone, we heard evidence regarding the Manchester Jaundice clinic and the development of additional one stop jaundice clinics throughout Greater Manchester, the Multidisciplinary Diagnostic Centre (MDC) Project within University College London Partners (UCLP),

and the cancer exclusion clinic at St. Georges University NHS Trust as part of the Royal Marsden Partners vanguard. Many of these programmes were initially funded by the ACE programme and each have a slightly different focus and criteria. With the exception of the jaundice clinics, the patients referred to the clinic are presenting with non-specific, vague cancer symptoms which are difficult to categorise within the Two Week Rule referral framework. In some instances, the clinic also accepts patients who cannot wait two weeks for a Two Week Rule appointment. As Dr Andrew Millar, Lead at the University College London Hospitals' ACE MDC for vague symptoms, explained they should "be seen as an integrated pathway between primary and secondary care."<sup>lxvi</sup>

Via these one-stop clinics, all diagnostic tests are completed on the same day, when possible. For example, instead of doing things sequentially over a period of weeks, a patient at the Manchester cancer jaundice clinic could in one day have a clinical evaluation and ultra sound scan, blood tests and a CT scan, if necessary. Previously, this process would take three or four weeks.<sup>lxvii</sup>

The one-stop clinics' efficiency also positively impacted on patient experience. When patients were asked about their experience, most felt that the length of time they waited for a test to be done or waited when attending clinics and appointments "was about right."<sup>lxviii</sup> In addition, the cost and resources associated with general practitioner visits is greatly reduced, because the repeated GP visits are eliminated.

The ACE vague symptoms pathway report<sup>lxiv</sup> concluded that "the time to diagnosis can be improved for patients with non-specific and concerning symptoms that do not meet current urgent referral guidelines, by providing vague symptom based diagnostic pathways and by innovations to streamline the process."

It goes on to note that speeding up the time to diagnosis can improve patient experience, as well as enable appropriate treatment to start earlier.

The second wave of ACE is specifically testing multi-disciplinary diagnostic centres and subject to evaluation, one-stop multidisciplinary diagnostic centres should be rolled out across the UK, becoming the standard referral pathway for patients with vague symptoms.

Nonetheless, the report goes on to highlight that when staging data was available the majority of cancers were identified at stage III or IV when many patients were only eligible for palliative care. As such, it is vital that initiatives to promote public and practitioner awareness of the symptoms of pancreatic cancer, as well as research into diagnostic tests, are continued alongside efforts to redesign the diagnostic pathway.

The 2015 NICE referral guidelines for suspected pancreatic cancer included direct access to CT scans for general practitioners under the 2 week rule, if the patient was over 60, experienced weight loss and one of 7 symptoms selected by NICE. Unfortunately, many GPs still cannot access CTs directly. Therefore, outside of the clinics mentioned above, a patient who is sent for a CT scan, must wait a considerable amount of time for the CT scan and/or the results, due to a lack of diagnostic capacity.

According to Brian Nicholson's work, only 1/3 of GPs had direct access to CT scans as of last year.<sup>lxv</sup>



Pancreatic Cancer Action's analysis similarly shows 28% of GPs had direct access. Despite concerns that direct access to CTs would overload the system, this has not occurred in areas like Epsom and St. Helier, where there were only 50 requests from GPs last year.<sup>bvi</sup> More concerning is perhaps the lack of diagnostic capacity to meet the diagnostic needs of the patients that are referred by GPs or clinics. Ultimately, patients are experiencing lengthy waiting times, because there are not enough radiologists to interpret the images or take the scan in the first place. NHSE National Clinical Director for Cancer Professor Chris Harrison explained to the APPGPC that the NHS are taking a number of actions to try and address what undoubtedly is a capacity issue. However, we need to understand whether the Government pledge in September 2015 to invest up to £300m more by 2020 to improve diagnostic capacity has led CCGs to increase spending on diagnostic capacity as recommended. We also need Health Education England to fulfil its promise to report on and plan for changes to the cancer workforce. We are concerned that diagnostic capacity has not progressed as required. As a result, waiting times and the time to diagnosis will only extend.

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## RECOMMENDATIONS:

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From the evidence received by the APPGPC, it appears that having a pathway whereby vague symptoms can be investigated efficiently is essential to diagnosing cancer earlier. Multi-Disciplinary Centres provide one way to achieve this. Patients presenting with vague symptoms should be referred to MDCs where this route to diagnosis is available.

Where this pathway is not available, it is also beneficial for GPs to have direct access to CT scans to speed up patient access to these important diagnostic tests.

As such, the APPG on Pancreatic Cancer calls for:

- (a) Clinical Commissioning Groups and others to continue to fund and increase funding for rapid diagnostic pathways for patients that present with vague symptoms (or non-specific but concerning symptoms), such as multi-disciplinary diagnostic centres (MDCs), one-stop clinics or direct access to diagnostics.
- (b) Clinical Commissioning Groups to authorise GPs Direct Access to CT Scans, especially in those regions where patients do not have access to faster clinics.
- (c) Professional bodies must ensure that GPs are educated about CT scans in order to support them in this new role.

**“The main failing [in the NHS] is with the pathways [two week rule], it is looking for people with advanced cancer in the majority of cases.”**

*Andrew Millar, Lead at University College London Hospitals' ACE MDC for vague symptoms pg. 20.*

**“I think we will also save money because we will not spend a huge amount on resources, back and forth to primary care wasting time until the disease is more advanced.**

*Andrew Millar, Lead at University College London Hospitals' ACE MDC for vague symptoms, Page 23*

- (d) NHS England should create a clear plan to address lack of diagnostic capacity caused by workforce shortages and prior lack of investment. To ensure this occurs, we join Cancer Research UK's call for Health Education England's Cancer taskforce report, sufficient investment and a clear plan to address workforce shortages in the future.<sup>lxvii</sup>

**"If we can get people rapid diagnosis we will save money as well as save lives."**

*Andrew Millar, Lead at University College London Hospitals' ACE MDC for vague symptoms, Page 23.*

**"It takes 6 months to get from symptom to specialist...."**

*Mr Satvinder Mudan, Consultant Surgeon, Royal Marsden Gastrointestinal Unit, Page 32.*

**Patients "need to be processed more rapidly though the system so that I can pick up the ones who can be cured...."**

*Mr. Satvinder Mudan, Consultant Surgeon, Royal Marsden Gastrointestinal Unit, Page 43.*

**"In Nottingham you can get a CT scan done quite quickly but the report takes 10 weeks."**

*Julia Hippisley-Cox, Professor of Clinical Epidemiology & General Practice, University of Nottingham, Oral evidence, Transcript Page 38.*

# FAST TRACK SURGERY AND OTHER TREATMENTS

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## THE PROBLEM:

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While the prime focus of this inquiry has been to look at early diagnosis, there is strong agreement that early diagnosis can only be effective if it is followed by speedy referral to treatment. As such, the APPGPC also received evidence that moved on from just focusing on early diagnosis and began to look at what should happen next. Although this evidence is relatively new and 5 year survival data is not yet available, it was also interesting and exciting, drawing our attention to the positive, hopeful developments in this area. Traditionally, anywhere from 6 weeks to 2 months passes before an operable pancreatic cancer patient with jaundice has his or her pancreas resected. This delay stems in part from the common practice of treating jaundice with a stent\*, while the patient waits for resection surgery. Although a stent is often not necessary if surgery occurs quickly,\*\* it is typically required because the wait before surgery is lengthy as scans and appointments are organised in series rather than in parallel and there is a lack of communication/coordination between local hospitals and specialist centres. The traditional pathway from diagnosis to surgery often results in poor patient outcomes, poor patient satisfaction and increased cost. Furthermore high quality evidence from randomised trials demonstrates fast track surgery is safe; in fact there are reduced overall complications when patients proceed directly to surgery without a stent.

To ensure the advantages of early diagnosis are preserved, it is essential that referral to treatment including neoadjuvant therapy and surgery, when possible, occurs as soon as possible. In Manchester, the pilot phase of the ACE programme is coming to the end and the fast track pathway leads, supported by the Manchester Cancer provider board, are seeking funding from the Greater Manchester Heads of Commissioning. Likewise, the funding for Mr. Keith Roberts' pilot programme has come to an end.

## PAST RECOMMENDATIONS:

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In the past the APPGPC recommended a review of pathways between primary and secondary care for referral and investigation of pancreatic cancer patients. We also sought a coordinated approach supported by the Department of Health and NHS England to piloting and evaluating new models, including direct access to CTs.

\* A stent is a hollow metal tube placed within the bile duct to temporarily relieve jaundice.

\*\* We are not referring to those instances where the patient is enrolled in a clinical trial of neoadjuvant (ie before surgery) chemotherapy. Patients receiving such treatment need a stent to relieve jaundice, so chemotherapy can be safely given before surgery.

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## PROGRESS:

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Both Birmingham and Manchester have instituted fast track surgery programmes which ensure that those who are diagnosed with jaundice and with operable pancreatic cancer are operated on within a week from diagnosis. This is achieved, in part through a clinical nurse specialist, who informs the patients, provides information, helps optimise the patients' health before surgery, and coordinates the actual surgery. According to Keith Roberts, each referral generates between 30 and 35 emails.<sup>lxxviii</sup>

Through the Manchester Cancer Jaundice Pathway, led by Professor Derek O'Reilly, Consultant Hepatobiliary and Pancreas Surgeon, "time from ultrasound and CT scan to surgery has decreased from a median of 57 and 33 days pre-pathway to 13 and 9 days respectively post pathway."<sup>lxxix</sup> Similarly, in Birmingham, under Mr. Keith Roberts, Consultant Hepatobiliary and Pancreas surgeon, they found during the pilot study, which went from August 2015 to August 2016, the time from CT scan to surgery was reduced from 65 days to 16 days. By doing the surgery quickly, patients were often able to avoid the insertion of a stent, a procedure which has a risk of significant complications. In addition, the pancreatic surgery often had less complications when the patient did not have a stent.<sup>lxx</sup>

Even more astounding is the increased number of patients who received surgery under the fast track pathway. In the past in some cases the pancreatic cancer advanced, while people waited for surgery, and they were no longer able to have their pancreas resected when the surgery date arrived. According to Keith Roberts, in Birmingham "significantly more patients underwent potentially curative surgery in the 'fast track group, 31/32 [97%] vs. 46/61 [74%]."<sup>lxxi</sup> Likewise, in Manchester, Professor Derek O'Reilly explained, "in 2016 we did 21 patients within one week from presentation with good outcomes, all of them were operable."<sup>lxxii</sup> Not only can the patient benefit, but so can the NHS. In Birmingham, they found that patients proceeding directly to surgery have an average cost of treatment some £3,178 less than those undergoing biliary stenting first. Mr. Roberts emphasized, "Clearly it is cost effective, because you are reducing unnecessary treatments, delays and unnecessary readmissions while waiting for surgery."<sup>lxxiii</sup>

Another benefit, identified in the overview of the Manchester programme, was improved patient experience. Most people rated their care between good and very good and more than 70% stated that it was "extremely likely" that they would recommend its services to friends and family if they needed similar care or treatment. Professor O'Reilly believes that the fast track pathways have made "hard won gains in transforming the thinking about patients with pancreatic cancer from a nihilistic one to a proactive treatment-oriented approach."<sup>lxxiv</sup>

## RECOMMENDATIONS

Once a patient is diagnosed with pancreatic cancer, preferably through a one stop or MDC route, he or she must receive treatment as soon as possible. If resection of the tumour is possible, he or she must receive surgery as soon as possible unless being considered for neoadjuvant surgery. If a patient waits for surgery, some patients will become inoperable and as a result the patient will have lost their chance of a cure. The early indications from fast track surgery are encouraging but the evidence base that this affects long term outcome is not known. Delays from diagnosis to treatment are variable across the country and are often better in parts of Europe. This may be an area for further examination and scrutiny in the future.

The APPGPC calls on:

- (a) **Clinical/Specialised Commissioning Groups to consider making, based upon the latest available evidence, the small upfront investment to implement these pathway changes in Manchester and Birmingham and around the country so these pilots become fixtures and the gains made do not disappear. The Government and NHS England must consider developing national guidance supporting fast track surgery and faster access to treatments based upon the latest available evidence.**
- (b) **The pancreatic cancer community (including clinicians, charities and parliamentarians) to work together to educate others, including practices and hospitals, about the potential advantages to the patient and NHS as a whole when they are promptly referred to fast track surgery and other treatments.**
- (c) **Finally, to gain real support, a national audit analysing the variation in pathways around the country is required. Only by understanding current standards and practices can we hope to improve upon them and hopefully persuade people of the advantages involved in fast track pathways.**

**“One of the chief benefits we found in Manchester and Birmingham, if you do the surgery quickly, you don’t find patients are inoperable, they don’t progress while waiting for surgery.”**

*Professor Derek O’Reilly, Consultant Hepatobiliary and Pancreas Surgeon, Manchester Cancer Jaundice Pathway*

**“Traditional results for being inoperable at surgery runs throughout the UK at between 10% and 15%.”**

*Professor Derek O’Reilly, Consultant Hepatobiliary and Pancreas Surgeon, Manchester Cancer Jaundice Pathway, Page 13*

**“A difference of 49 days can make a difference in being resectable for a quarter of patients...”**

*Mr. Keith Roberts Consultant Hepatobiliary and Pancreas Surgeon, University Hospitals Birmingham, fast track pathway to surgery.*

**“it is shocking, you are quite right, that in 2017 that the standard throughout most of the country is delayed diagnosis and slow track surgery involving probably completely unnecessary stents for most patients..”**

*Mr. Keith Roberts, Consultant Hepatobiliary and Pancreas Surgeon, University Hospitals Birmingham, fast track pathway to surgery, Page 19.*

# CANCER STRATEGY AND CANCER ALLIANCES

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## BACKGROUND:

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The NHS England Cancer Strategy and the Cancer Alliances were designed, at least in part, to ensure the earlier diagnosis of all cancers, including pancreatic cancer. Although the strategy does not focus on pancreatic cancer and other less survivable cancers explicitly, the strategy does include objectives which could advance early diagnosis efforts. The implementation of Cancer Alliances may also move forward early diagnosis initiatives.

## PROGRESS:

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As previously mentioned, the Government's commitment to delivering the cancer strategy was evidenced by its commitment to invest up to £300m more by 2020 to improve diagnostic capacity. However, we are unsure whether these funds have been used for their specified purpose. There has also been a delay on Health Education England's plan for the cancer workforce to determine current diagnostic capacity and actions to address current future shortages.

The Cancer Alliances are also becoming more established. Dr Rosie Loftus explained that the Cancer Alliances are "vehicles to try and get everyone working together, GPs and providers having sensible and mature conversations."<sup>lxxxv</sup> If the alliances have sufficient support, they can with the transformational funding provided by the NHS "be a route to disseminate and utilise early diagnosis innovation."<sup>lxxxvi</sup> While there is a concern that the funding focuses on the big 4 cancers<sup>lxxxvii</sup>, <sup>lxxxviii</sup> the APPGPC is hopeful that this funding can also be used for pancreatic cancer initiatives. In both cases, it is too early to determine how successful implementation has been and the impact to date.

## RECOMMENDATION:

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We must continue to call for the successful implementation of the NHS England Cancer Strategy and Cancer Alliances, because they are essential to establishing the foundation for early diagnosis.

# FINAL SUMMATION

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Survival rates for pancreatic cancer have been stubbornly “stuck” at an unconscionably low rate. Although early diagnosis initiatives are by no means a panacea/cure-all for the difficulties surrounding pancreatic cancer, they are a viable and promising approach to driving forward progress. If the APPGPC’s recommendations are taken seriously and pancreatic cancer research funding, public awareness and support for GPs is increased and faster diagnostic pathways and treatment are instituted, pancreatic cancer patients will have a much better chance of living better and longer. If the APPGPC’s recommendations are implemented, it is much more likely patients and physicians will recognise the symptoms of pancreatic cancer sooner, patient investigations will occur sooner, patients will receive a clear diagnosis sooner and patients may be treated sooner.

The APPGPC will do our best to track the progress made toward these recommendations to ensure that they are not forgotten. Please visit the APPGPC website at [www.pancanappg.org.uk](http://www.pancanappg.org.uk) to see the latest update on our progress implementing these recommendations.

In light of our report, we urge you to join the APPGPC’s efforts and work with us to detect and treat pancreatic cancer sooner, transforming outcomes for pancreatic cancer patients.

To find out more about the work of the APPGPC and how you can support us contact [APPGPC@pancreaticcancer.org.uk](mailto:APPGPC@pancreaticcancer.org.uk)

# APPENDIX 1 - ORAL WITNESSES

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## FIRST SESSION -

Tuesday 24th January from 10am to 12pm in Committee Room 7, Palace of Westminster.

- Dr Rosie Loftus, Joint Chief Medical Officer, Macmillan Cancer Support
- Maggie Blanks, Chief Executive, Pancreatic Cancer Research Fund
- Dr Donna Chung, ACE Wave 2 Multidisciplinary Centre (MDC), Programme Manager and Clinical Information
- Dr Andrew Millar, Lead at University College London Hospitals' ACE MDC for vague symptoms
- Professor Eithne Costello, University of Liverpool, diabetes and pancreatic cancer research
- Dr Bill Greenhalf, Liverpool Centre of EUROPAC

## SECOND SESSION -

Monday 6th February from 12pm to 2pm in Committee Room 8, Palace of Westminster.

- Professor Steve Pereira, UCHL, researcher into biomarkers for detecting pancreatic cancer
- Alex Ford, Chief Executive, Pancreatic Cancer UK
- Mr Satvinder Mudan, Consultant Surgeon, Royal Marsden Gastrointestinal Unit
- Diane Dobson, Pancreatic Cancer Nurse Specialist, Pancreatic Cancer UK
- Professor Julia Hippisley-Cox, Professor of Clinical Epidemiology & General Practice, University of Nottingham
- Sara Bainbridge, Policy Manager, Cancer Research UK

## THIRD SESSION -

Tuesday 21st February from 13:00 – 15:00 in Committee Room 8, Palace of Westminster.

- Professor Andrew Hart, Chair, British Society for Gastroenterology Pancreatic Cancer Section Committee; Former President, Pancreatic Cancer Society of Great Britain and Ireland
- Ali Stunt, Chief Executive and Founder, Pancreatic Cancer Action
- Roy Bowdery, (patient, diagnosed age 60)
- James Farrell, (carer, father died of pancreatic cancer)
- Debbie Wells (carer, daughter died aged 27 of pancreatic cancer)



#### **FOURTH SESSION -**

**Wednesday 22nd February from 09:00 – 11:00 in Committee Room 17, Palace of Westminster.**

- **Professor Hamilton**, Professor of Primary Diagnostics, University of Exeter; involved in the creation of decision aid tools; clinical lead on the NICE revision of cancer guidelines
- **Professor Derek O'Reilly**, Consultant Hepatobiliary and Pancreas Surgeon, Manchester Cancer, Jaundice Pathway
- **Mr Keith Roberts**, Consultant Hepatobiliary and Pancreas Surgeon, University Hospitals Birmingham, fast track pathway to surgery
- **Mr Tom O'Rourke**, Surgeon, specialising in laparoscopic, general and hepatobiliary surgery, Princess Alexandra Hospital, Queensland, Australia

#### **FIFTH SESSION -**

**Wednesday 22nd February, 1pm, Committee Room 17, Palace of Westminster**

- **Professor Chris Harrison**, National Clinical Director for Cancer, NHS England
- **Tim Elliott**, Senior Policy Advisor for Cancer, Acute Care and Provider Policy, Department of Health
- **Dr Helen Campbell**, Portfolio Manager, Research Networks, Cancer Research, and Clinical Research Facilities, Department of Health

# **APPENDIX 2 – APPG PANEL MEMBERS**

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## **FIRST SESSION -**

Tuesday 24th January from 10am to 12pm in Committee Room 7, Palace of Westminster.

- Sir Henry Bellingham MP
- Nic Dakin MP, Chair
- Mark Durkhan MP, Vice-Chair
- Colleen Fletcher MP
- Baroness Masham
- Nick Thomas-Symonds MP, Vice-Chair
- Baroness Masham of Ilton

## **SECOND SESSION -**

Monday 6th February from 12pm to 2pm in Committee Room 8, Palace of Westminster.

- Sir Henry Bellingham MP
- Nic Dakin MP, Chair
- Mark Durkhan MP, Vice-Chair
- Colleen Fletcher MP
- Baroness Masham of Ilton
- John McNally MP
- Nick Thomas-Symonds MP, Vice-Chair

## **THIRD SESSION -**

Tuesday 21st February from 13:00 – 15:00 in Committee Room 8, Palace of Westminster.

- Sir Henry Bellingham MP
- Nic Dakin MP, Chair
- Mark Durkhan MP, Vice-Chair

- Colleen Fletcher MP
- Baroness Masham of Ilton
- John McNally MP
- Nick Thomas-Symonds MP, Vice Chair

#### **FOURTH SESSION -**

**Wednesday 22nd February from 09:00 – 11:00 in Committee Room 17, Palace of Westminster.**

- Sir Henry Bellingham MP
- Nic Dakin MP, Chair
- Mark Durkhan MP, Vice-Chair
- Colleen Fletcher MP
- Baroness Masham of Ilton
- John McNally MP
- Lord Patel, Vice-Chair
- Nick Thomas-Symonds MP, Vice-Chair

#### **FIFTH SESSION -**

**Wednesday 22nd February, 1pm, Committee Room 17, Palace of Westminster.**

- Sir Henry Bellingham MP
- Nic Dakin MP, Chair
- Mark Durkhan MP, Vice-Chair
- Colleen Fletcher MP
- Baroness Masham of Ilton
- John McNally MP
- Nick Thomas-Symonds MP, Vice-Chair

# APPENDIX 3 - WRITTEN EVIDENCE

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## PATIENT/CARER

- **Ronnie Coia** (patient)
- **John Lancaster** (carer, wife died of pancreatic cancer aged 64 (at diagnosis))
- **Jasmin Mas** (carer, mother died of pancreatic cancer)
- **John Nathan** (carer, medical doctor and pancreatic cancer survivor)
- **Sally Pascall** (patient)
- **Lynne Walker** (patient)
- **Debbie Wells** (carer, daughter died aged 27 of pancreatic cancer)

## PROFESSIONAL

- **Cancer Research UK**
- **Tim Elliott**, Senior Policy Advisor for Cancer, Acute Care and Provider Policy, Department of Health
- **Professor Julia Hippisley-Cox**, Professor of Clinical Epidemiology & General Practice, University of Nottingham
- **Professor Helmut Modjtahedi**, Professor of Cancer biology, Kingston University
- **Mr. Satvinder Mudan Consultant Surgeon**, Royal Marsden Gastrointestinal Unit, Lead at the Multi-disciplinary cancer exclusion clinic at St. Georges University NHS Trust.
- **O'Reilly, Derek**, *"The Manchester Cancer Jaundice Pathway"*
- **Over, Paul**, Liver and Pancreatic Research Development Charity
- **Roberts, Keith J.**, *"Early surgery for resectable pancreatic cancer- an opportunity to improve pathways and outcomes."*
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- liii. Professor Andrew Hart, transcript, page 8.
- liv. Professor Andrew Hart, page 18.
- lv. In 2014 the number of newly diagnosed patients between the ages of 1 to 59 years old in England are 1160, Scotland 120, Wales 59, and N. Ireland 30.
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- lviii. CRUK written evidence, page 1.
- lix. Professor Derek O'Reilly, written evidence.
- lx. Professor Derek O'Reilly, written evidence.
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- lxvii. See also CRUK's submission.
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- lxx. A complication from surgery is twice as likely when patients have stents as oppose to going straight to surgery. (page 14)
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- lxxv. Dr. Rosie Loftus, transcript, page 9.
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You can find out more information about the All Party Parliamentary Group on Pancreatic Cancer here:

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