Pancreatic Cancer Research and Care: A health check

A progress report on the APPG on Pancreatic Cancer’s 2013 and 2014 inquiries

December 2015

The report was researched and funded by Pancreatic Cancer UK who provide the Secretariat for the All-Party Parliamentary Group on Pancreatic Cancer.

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House of its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in the report are those of the group.
CONTENTS

ABOUT THE ALL PARTY PARLIAMENTARY GROUP ON PANCREATIC CANCER 03
FOREWORD BY THE CHAIR 04
SUMMARY OF PROGRESS MADE SO FAR 05
RECOMMENDATIONS MET 07
RECOMMENDATIONS ON WHICH PROGRESS HAS BEEN MADE 08
RECOMMENDATIONS NOT MET 16
The All-Party Parliamentary Group (APPG) on pancreatic cancer was established in 2012, by a leading group of parliamentarians with an interest in making a difference for pancreatic cancer.

An All-Party Parliamentary Group is primarily an interest group and provides a forum for MPs and Peers to meet and interact with stakeholders, to share ideas about issues and discuss ways to change the political landscape for the subject they are concerned with. The APPG provides an excellent forum for keeping pancreatic cancer high on the political agenda, for example through debates and oral and written questions. The purpose of the APPG is to raise the profile of pancreatic cancer in Parliament, to raise issues of relevance with government and policy makers; and to influence policy to improve life for pancreatic cancer patients and survivors.

Pancreatic Cancer UK plays an important role by acting as the secretariat for the APPG. The Group is also supported by a range of other interested stakeholders including Pancreatic Cancer Action, Pancreatic Cancer Research Fund, NETS Patient Foundation and the Pancreatic Society of Great Britain and Ireland.

The Officers of the APPG are:

Nic Dakin MP (Chair)
Baroness Morgan of Drefelin
Lord Aberdare
Lord Patel
Mark Durkan MP
Stuart Andrew MP
The All Party Parliamentary Group on Pancreatic Cancer (APPG) was formed in May 2012 by a cross-party group of Parliamentarians who want to see improved survival rates and better patient experience for all those affected by the disease.

Since its launch, the APPG on Pancreatic Cancer has published two authoritative reports considering issues surrounding pancreatic cancer.

The first report, *Time to Change the Story: A plan of action for pancreatic cancer*, published in 2013 was the result of a six month inquiry during which evidence was taken from patients, carers, family members, clinicians, researchers, charities, policy makers and others. The report sets out an action plan for improving early diagnosis, access to treatment and care, patient experience and survival rates.

The 2014 report *Pancreatic Cancer Research: A roadmap to change*, followed the APPG’s second inquiry, which ran from March to September 2014, during which we heard further evidence from experts in research and the charity sector. The report considers how to improve the quality and quantity of pancreatic cancer research in the UK.

The key recommendations to emerge from the APPG’s inquiries include the need to raise awareness of pancreatic cancer and its symptoms, a wholesale review of referral pathways, and for diagnostic services (like CT scans to be made available directly to GPs. The reports also call for a comprehensive audit of pancreatic cancer treatment in order to understand why everyone diagnosed with the disease may not have access to the same high quality care and for a significant increase in research funding.

This follow-up report considers what progress had been made on implementing the recommendations resulting from the APPG’s inquiries. It draws on feedback given by experts who contributed to the APPG’s first two reports and highlights areas that require further attention.

Nic Dakin MP,
Chair of the All Party Parliamentary Group on Pancreatic Cancer
Since the publication of the APPG’s reports, progress on implementing their recommendations has been made in some areas.

Of most note is the decision to initiate the development of a National Institute for Health and Care Excellence (NICE) pancreatic cancer Clinical Guideline and Quality Standard for the first time. This was a key recommendation from the APPG’s 2013 report and, once the Guideline has been developed, could represent a way of ensuring improved care for pancreatic cancer patients across the country.

There has also been some movement regarding early diagnosis. Revised NICE referral guidelines for suspected cancer have been published and included a separate section on pancreatic cancer for the first time; again something the APPG called for. The referral guidelines also included the APPG recommendation for all GPs to be given direct access to CT scans, as did the new Cancer Strategy for England. Scotland updated its own referral guidelines in September 2014, again including a separate pancreatic cancer section.

In addition, the Accelerate, Coordinate, Evaluate (ACE) programme, set up by NHS England, is looking at innovative concepts and pathways that could support earlier diagnosis. We are pleased to see that Multidisciplinary Diagnostic Centres (MDCs) are being trialled as part of this scheme, and look forward to the results of the trials as they emerge.

The APPG research report of 2014’s main recommendation concerned the need for a significant increase in research funding for pancreatic cancer. Whilst the spending levels called for in ‘A Roadmap to Change’ have not yet been met, we are pleased that the NCRI increased its funding for pancreatic cancer research from £5.2m in 2013 to £7m in 2014: www.ncri.org.uk/what-we-do/research-database/. Cancer Research UK’s (CRUK) commitment to double or treble its research into pancreatic and other cancers of unmet need is also welcome. We hope this trend in increased pancreatic cancer research funding continues.

However, in reviewing other recommendations made in our reports, we found that many of the APPG’s recommendations are yet to be implemented. For example, other major research funders and the Department of Health have failed to commit to matching Cancer Research UK’s pledge to double or treble funding for pancreatic cancer in the next spending round. Moreover, little progress has been made on embedding a culture of research within the NHS. Although NHS England published and consulted on a draft Research and Development Strategy back in 2014, there has been no further movement in developing a final version of the strategy.
Worryingly, a lack of access to new treatments for pancreatic cancer persists, demonstrated most starkly by the removal of life-extending drug Abraxane from the Cancer Drugs Fund list in November 2015 and the refusal of the National Institute of Health and Care Excellence to approve the drug for routine use in England. In addition, no further work has been conducted into variations in survival rates across the UK and the EU.

It is vital that we monitor closely the implementation of those policies that meet the APPG’s recommendations to ensure the full potential for positive change is realised, whilst continuing to call for the implementation of those recommendations not met.
**RECOMMENDATIONS MET**

**TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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”.

We are pleased that in May 2014, NHS England referred the development of a pancreatic cancer Clinical Guideline and Quality Standard to NICE. The new Guideline should positively impact on patient experience and treatment in secondary care by providing the most up-to-date and effective surgical, oncological approaches as well as interventions such as radiotherapy. We urge NICE to ensure the new Guideline also includes guidance on well-being, nutrition and diet-related issues.

The new guidelines are in the process of being developed with an expected publication date of January 2018.

**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 6**

"A single approvals process for setting up clinical trials should be introduced, to reduce bureaucracy and ensure trials can be initiated more quickly and easily across the UK. We hope the creation of the Health Research Authority will mean this new process is brought in as quickly as possible”.

We welcome progress on achieving a single Research and Development approvals system, with the Health Research Authority having begun the rollout of the new single assessment and approval system.
RECOMMENDATIONS ON WHICH PROGRESS HAS BEEN MADE

TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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.”

Results from the Macmillan pilot showed that the Cancer Decision Support tool could “raise GPs’ awareness of cancer symptoms and both alert and remind users to potential risk, as well as influence the management of some patients, particularly with respect to prompting investigations”. It found that use of CDS influenced GPs’ decisions in 9% of suspected pancreatic cancer cases: www.ncri.org.uk/what-we-do/research-database/.

Following the pilot, some GP practices and specialist units have adopted the tool, whilst Macmillan has been working with GP software companies to develop integrated versions of the CDS tool, as well as setting up learning sessions.

We support the continued rollout of the tool, which should be accelerated to ensure the technology is embedded in all GP surgeries. It is also important to monitor the effectiveness of the tool to determine whether improvements can be made.

TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER: RECOMMENDATION 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.”

Since the report’s publication, the charity Pancreatic Cancer Action, in conjunction with the British Medical Journal, has completed the development of its learning module for hospital doctors. This follows the e-learning module the charity had already developed in partnership with the RCGP. However, more needs to be done to promote the uptake of these training modules.

The Pancreatic Society of Great Britain and Ireland’s (PANSOC) initiative to develop a curriculum for training in medical pancreatology for junior gastroenterologists is also to be welcomed. However, it is disappointing that the RCGP’s review of its training curriculum in 2014, did not result in any increased focus on the diagnosis of pancreatic cancer.
Insufficient attention to pancreatic cancer in the medical training curriculum is a problem across the UK and was recognised by the National Assembly for Wales Health and Social Care Committee following its inquiry into progress on implementing the Welsh Government’s Cancer Delivery Plan. We support the Committee’s recommendation that "the Minister for Health and Social Services [should work] with the Wales Deaneary and the General Medical Council to ensure that GP’s training and continuing professional development raises awareness of cancer symptoms, early diagnosis, and the tools and resources to support GPs in their roles". We agree with that assessment and would like to see a similar focus on training GPs in England in their knowledge of cancer symptoms, especially symptoms of less common cancers.

**TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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."

Health Secretary Jeremy Hunt’s announcement on 13th September 2015 that NHS England would look at adopting the Cancer Taskforce’s recommendation that by 2020 95% of people should be given a diagnosis or the all-clear within four weeks of GP referral, is a welcome recognition of the need to speed up the referral process. Nonetheless, it is necessary to review the referral pathway in order to achieve this aim.

Since the report’s publication, some progress has been made on implementing this recommendation with some GPs already having direct access to CT scans.

Updated NICE Referral Guidelines require urgent direct access CT scans to be given within 2 weeks for people over 60 with weight loss and one other listed symptom of pancreatic cancer. Whilst this is welcome, we believe the age-thresholds need to be removed, otherwise a number of younger patients presenting with possible symptoms of pancreatic cancer might not be referred for a scan. Scotland updated its own referral guidelines back in September 2014, with no age-thresholds included.

The new Cancer Strategy also gives cause for optimism. We strongly welcome the recommendations that GPs should be able to urgently refer patients for diagnostic tests even if a patient does not specifically meet the criteria set out in the NICE referral guidelines; that GPs should have direct access to key investigative tests like CT scans by the end of 2015; and that new, innovative ways of ensuring faster diagnosis, including MDCs for when patients present with recurring vague symptoms, like abdominal pain should be introduced. However, we need to make sure there are enough resources available to provide appropriate capacity for diagnostic specialists and equipment, such as radiographers. We note that the November 2015 Comprehensive Spending Review set aside £300m for cancer diagnostics and we will be monitoring how this money is spent over the coming years, and whether it is enough to deliver the capacity needed.
“In 2015, the National Cancer Intelligence Network (NCIN) carried out a Routes to Diagnosis Study showing that patients who had an emergency presentation had a 1-year relative survival rate of 10% compared to 20-34% for patients who had diagnosis under the 2-week wait, GP referral, or other outpatient setting.” Add: “Worryingly, the NCIN data also showed that 45% of pancreatic cancer patients were diagnosed via the emergency route. It is therefore, vital that data on routes to diagnosis continues to be collected to monitor whether progress is being made on delivering earlier diagnosis”. www.ncin.org.uk/publications/routes_to_diagnosis.

During its inquiry, the APPG heard evidence on the benefit of reducing diagnosis through emergency admission. In 2014, the National Cancer Intelligence Network (NCIN) carried out a Routes to Diagnosis Study showing that patients who had an emergency presentation had a 1-year relative survival rate of 9% compared to 20-32% for patients who had diagnosis under the 2-week wait, GP referral, or other outpatient setting.

However, no national co-ordinated audit of cancer diagnosis in primary care has been carried out since that published by the Royal College of General Practitioners (RCGP) in 2011. Although limited audits are carried out by GPs in certain areas, the results of these are not properly recorded and their inconsistent nature make them largely meaningless.

In the absence of a national audit, we support the new Cancer Strategy’s call for all GPs to be required to undertake a Significant Event Analysis for any patient diagnosed with cancer as a result of an emergency admission.

“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.”

Updated NICE referral guidelines for suspected cancer were published in June 2015. We are pleased that the APPG’s inquiry was considered during the review process and that the revised guidelines offer some improvements.

These include a dedicated section for pancreatic cancer for the first time, as well as a prompt for GPs to consider an urgent direct access CT scan for patients with symptoms chosen for inclusion by NICE.

However, we are concerned that some common symptoms of pancreatic cancer (such as non-responsive dyspepsia) have been omitted from the referral guideline and by the inclusion of age thresholds, which could lead to delays in the detection of pancreatic cancer in younger people. A Pancreatic Cancer UK Symptoms and Diagnosis Survey suggests that nearly 60% of patients would not have been referred for a CT scan under the cluster of symptoms route, as they either did not have weight loss AND at least one of the other symptoms chosen by NICE, or they had those symptoms but were under the age threshold.
We are also concerned that GPs are being advised that when a CT scan is not available, an ultrasound would be a suitable alternative. We firmly believe resources should be made available to ensure there is enough capacity for CT scans.

In addition, we regret that, following consultation with stakeholders, NICE decided not to review the NICE guidelines on metastatic malignant disease of unknown primary. The guidelines have instead been put on the static list, meaning the next review might be as late as 2019.

**TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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."

The 2014 NHS England Cancer Patient Experience Survey found that 90% of pancreatic cancer patients were given the name of a CNS in charge of their care. Whilst we welcome that most patients have access to a CNS, given the positive impact CNSs have on patient experience, it is essential to ensure that the remaining 10% are not forgotten and receive the same quality of care.

The Cancer Strategy’s call for NHS England and the Trust Development Authority (TDA) to encourage providers to make sure all patients have access to a CNS or other key worker from diagnosis onwards is a welcome step towards achieving universal access to a CNS.

Nonetheless, it is also essential to ensure CNSs have access to enough resources to be able to provide a good quality service. In a survey of CNSs carried out by Pancreatic Cancer UK in 2015, half of respondents disagreed with the statement “I am able to spend as much time with my patients as necessary”: [www.pancreaticcancer.org.uk/media/405277/pancreatic-cancer-uk-clinical-nurse-survey.pdf](http://www.pancreaticcancer.org.uk/media/405277/pancreatic-cancer-uk-clinical-nurse-survey.pdf) The Cancer Strategy recognises the pressure CNSs are under by highlighting the role support workers can play in freeing up CNSs.

However, whilst support for CNSs may alleviate some of their workload, the fact remains CNSs are the best people to work with patients. As such, there should be a focus on training and recruiting more CNSs with the appropriate degree of specialisation to look after pancreatic cancer patients within the NHS to ensure demand is met. We also need to ensure their time is ringfenced, so they do not spend too much time carrying out general tasks. The 2015 CNS survey also found that nearly a quarter of respondents were having to spend shifts on general or other wards to cover shortages.
TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 12

“Dietitians 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.”

The NHS England 2013/14 service specification for pancreatic cancer patients sets out that all pancreatic cancer patients should “have access to full dietetic inpatient and outpatient services”.

It also states that “dietitians should be available to see patients during regular outpatient clinics and be available for consultation on ward rounds and multidisciplinary team meetings.” This requirement should be reflected in the NICE guidelines when published.

However, in practice, the provision of dietary advice is inconsistent, whilst dieticians are still considered additional members of MDTs rather than core ones.

To meet the APPG’s recommendation, the Department of Health and NHS England should ensure all pancreatic cancer patients are offered good quality dietary advice by making specialist dietitians core members of pancreatic MDTs and monitoring patients’ access to dietary advice to address any gaps in provision.

PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 1

“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.”

In March 2015, Stand Up to Cancer, Cancer Research UK and the Lustgarten Foundation’s announced that $12m was being set aside for pancreatic cancer and that Dream Teams made up of researchers across the USA and UK (with at least 25% of any partnership research to be based in the UK) would be invited to bid for parts of that funding. This approach is an interesting illustration of strategically, ring-fenced funding and represents an important step in pancreatic cancer research. Although it remains yet to be seen whether the scheme can be relied upon as a consistent source of funding, we hope it sets a precedent for similar schemes in the future.

Whilst no collective commitments have been made on future spend levels for pancreatic cancer research, the NCRI increased funding from £5.2m in 2013 to £7m in 2014. Although funding levels for 2015 are yet to be announced, we are optimistic that the increased NCRI spend, alongside spend by pancreatic cancer charities whose spending is not included in the NCRI figures, will bring the total spend for 2015 close to the £10m mark.

It is also encouraging that the Cancer Research UK Research Strategy commits to doubling or trebling the amount of funding it allocates to research into cancers of unmet need, including pancreatic cancer over the next five years. Although it remains to be seen whether the charity
manages to meet this commitment, the NCRI increase in spending on pancreatic cancer research between 2013 and 2014, which CR UK contributes to, gives cause for optimism that the charity is making progress towards delivering on its commitment.

These recent steps demonstrate a welcome recognition of the need to increase levels of funding into pancreatic cancer research. It is nonetheless essential that we continue to press for more research funding for pancreatic cancer as it continues to lag behind the amount of spend on other cancer sites.

**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 2**

"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"

Whilst the Department of Health has failed to commit to matching CRUK’s goal of doubling or trebling of its investment in pancreatic cancer research, there has been some movement in the right direction. We heard from the Chief Medical Officer back in March that NIHR spending had increased from £0.7m to £1.1m in 2013/14. We hope that there will be sustained increases made over the coming years.

**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 3**

“There is a strong case to establish more research activity on the improvement of early diagnosis. This includes research that may lead to the development of screening tools.”

There is now a broad recognition of the importance of funding research into early diagnosis across the cancer research community.

Notably, NCRI research spend on early detection has increased the most since 2009, in comparison to spend in other areas of research such as treatment, receiving 17 per cent of total research spend in 2014.

Meanwhile, pancreatic cancer charities, including Pancreatic Cancer UK, Pancreatic Cancer Action and Pancreatic Cancer Research Fund (PCRF), as well as CRUK and other big funders continue to invest in research into diagnosis.

Recent research carried out at Barts Cancer Institute, Queen Mary University of London, and funded by PCRF, was highlighted in the national media in July 2015. It involves a protein in urine that can be used to detect pancreatic cancer is a cause for cautious optimism and demonstrates how an extra emphasis on early diagnosis in research can pay off.

It is important to maintain and build upon the momentum for increased research spend into the early detection of pancreatic cancer to pave the way for more advances that could result in the development of screening tools.
PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 8

“The Government should ensure that EU legislation does not impact negatively on research in the UK. The EU Directive on Data Protection, in particular, is a genuine threat which could hold back important advances.”

We are pleased that EU justice ministers have taken on board concerns about the impact of the data legislation on medical research and have tabled amendments to how health and genetic data should be managed. This would allow organisations to process data without explicit consent from patients for clinical purposes, for the provision of health or social care, for the treatment or management of health or social care systems and services, and for public health purposes. It is nonetheless important to continue monitoring the negotiation process until the end of 2016 when the revised are expected to be finalised.

PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 12

“There is a need to ensure that there is an improvement in pancreatic cancer research infrastructure, including greater availability of suitable tissue samples and the sharing of data sets”

The inquiry found that simply increasing funding into pancreatic cancer research would not result in the desired advances without improvement in pancreatic research infrastructure.

Cancer Research UK’s Research Strategy includes a focus on increasing research investment on cancers of unmet need. As part of this, the charity has highlighted the need to improve the infrastructure available to researchers. Meanwhile, PCRF has set up a National Pancreatic Registry and Tissue Bank at the Barts Institute. The project, launched in November 2015, will provide a range of tissue samples and comprehensive data for researchers; saving time and powering future research.

It is unfortunate that NHS England has stalled the delivery of a Research and Development Strategy, which could be a valuable tool for improving research infrastructure and the sharing of data sets.
PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 13

“Greater collaboration between researchers and between research institutes should be enabled. Whilst this can in part be achieved through a simple expansion of networking and conference opportunities, the development of a UK pancreatic cancer network of excellence should be pursued.”

The APPG heard that collaboration between researchers could help to address barriers to innovative research by increasing capacity, improving infrastructure, providing training and enabling strong leadership.

Drawing from the successful example of pancreatic cancer “Dream Teams” in the US, the report called for the development of a UK pancreatic cancer network of excellence. Whilst a UK-wide network has not been developed, there are examples of good practice within the UK and EU when it comes to developing research networks.

For instance, PRECISION-Panc is a dynamic platform that aims to define, understand, test and implement personalised therapy approaches for people affected by pancreatic cancer. It is composed of a network of approximately 100 clinical and research members from across five centres in the UK (Glasgow, Manchester, Cambridge, Oxford and London) in addition to clinicians from a range of hospitals. The project will integrate with existing infrastructure including the Cancer Research UK Stratified Medicine Programme, the National Cancer Research Institute clinical networks, the Experimental Cancer Medical Centres and Clinical Trials Units. It also builds on and incorporates existing investment in pancreatic cancer research across the UK.

Meanwhile, EUPancreas is a European-wide initiative aimed at uniting pancreas cancer research groups and providing an innovative and unique platform for collaborating and sharing information, ideas and experience. One of its main objectives is capacity building in order to build a strong network of European Centres to facilitate future pancreatic cancer research.

These examples highlight welcome progress on encouraging collaboration between researchers and research institutes. The UK should draw from and build on networking advances through the creation of a UK pancreatic cancer network of excellence.
RECOMMENDATIONS NOT MET

TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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.”

The results of a 2015 ComRes survey carried out on behalf of Pancreatic Cancer UK offer a stark reminder of why a public awareness campaign is still needed. The survey found that 71 per cent of people in the UK could not name a symptom of pancreatic cancer. Given these results, we are disappointed that no pancreatic cancer awareness campaign has been launched in any part of the UK. Failing a pancreatic cancer specific campaign, we would like to see an awareness campaign that focuses on symptoms associated with gastrointestinal cancers, which would include pancreatic cancer.

TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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.”

Currently, there is no formal screening programme for pancreatic cancer, but those with a familial history of pancreatic cancer or hereditary pancreatitis are screened through a EUROPAC study.

Public Health England (PHE) has yet to review whether specific patient groups known to have an increased risk of developing pancreatic cancer should be monitored and screened for pancreatic cancer.

The Pancreatic Society of Great Britain and Ireland (PSGBI) and British Society of Gastroenterology (BSG) are in the process of completing guidelines for the investigation and management of patients with pancreatic cysts. We hope that the guidelines will consider the surveillance of pancreatic cancer.
TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 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."

Currently, no such audit has been carried out and the National Cancer Patient Experience Survey shows the care received by pancreatic cancer patients continues to lag behind those of other cancer patients in many areas. Whilst, in response to a Parliamentary Question asked by Jim Shannon MP, the Minister indicated that the Department of Health would consider developing a national audit clinical audit for pancreatic cancer following the publication of the pancreatic cancer Clinical Guideline and Quality Standard. However, we maintain that an early audit would aid the development of the Guideline, rather than the other way around.

We are disappointed that no progress has been made towards disaggregating data on waiting times experienced by pancreatic cancer patients from data on waiting times for other Upper GI cancers, with the Government arguing that disaggregating data to this level risks disclosing patient identities. This is disappointing given that the NHS could be using data already available to better understand pancreatic cancer patient pathways to treatment and help improve service delivery.

TIME TO CHANGE THE STORY: A PLAN OF ACTION FOR PANCREATIC CANCER, RECOMMENDATION 10

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

There remains very few treatments available to pancreatic cancer patients. A focus on addressing this unmet need by ensuring potential new advances are appraised and made available on the NHS as quickly as possible is still required.

We were extremely concerned at the decision announced in September 2015 by the Cancer Drugs Fund to remove Abraxane from its list of approved drugs as of 4th November 2015. This represents a huge backwards step in terms of access to treatment for patients since the APPG produced its reports. It also has the potential to threaten the status of clinical trials in the UK which are based on Abraxane.

Moreover, the removal of the 1st new drug for pancreatic cancer in nearly 20 years from the CDF, alongside NICE’s decision not to recommend Abraxane for approval, demonstrates how the drug/technology appraisal system continues to fail pancreatic cancer patients. It is vital that any new treatments coming through for cancers with the poorest survival rates, like pancreatic cancer, are prioritised. Future consultations on the Accelerated Access Review, the successor system to the CDF and, longer term, into how NICE assesses new treatments, must be taken as opportunities to reform the current punitive system and replace it with one that works more fairly for cancers of unmet need, including pancreatic cancer.
**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 4**

“New generic research initiatives, or evaluation schemes, should give priority to including work on cancers of unmet need. For example, the recently announced investment into the Human Genome project should have included pancreatic cancer at its core. Moreover, the Commissioning through Evaluation scheme should include advanced radiotherapy techniques for pancreatic cancer - such as SABR/Cyberknife – and other innovative techniques - such as IRE/Nanoknife”

The Commissioning through Evaluation programme has not made available advanced radiotherapy techniques for pancreatic cancer, despite the scheme including SABR for other cancers. Likewise, IRE treatment for pancreatic cancer has not been progressed. In addition, we remain concerned that the Human Genome project still does not include pancreatic cancer as one of the priority conditions. This lack of progress highlights the need to ensure the prioritisation of research and new schemes on cancers of unmet need.

**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 7**

“There should be proper research representation on MDTs and, more generally, relevant staff need to have adequate time to carry out research activities written into their job descriptions. Moreover, any NHS England R&D Strategy should be robust enough to ensure that a culture of research is embedded into the NHS. We hope these changes will, among other things, help to ensure that more pancreatic cancer patients are told about clinical trials that may be suitable for them to take part in.”

Regrettably, little progress has been made on the development of a research and development strategy since a draft was sent out to consultation in December 2013.

We would like to see a revised and enhanced version of the Draft NHS England R&D Strategy issued in the near future.

**PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 10**

“Funding organisations should seek to create more scholarships, fellowships and other programmes to encourage more young scientists to pursue careers in pancreatic cancer research. A specific Pancreatic Cancer Research Champion or Czar role should be considered as a way of helping to increase the profile of the research field.”

No progress has been made towards the creation of a specific Pancreatic Cancer Research Champion or Czar to help increase the profile of the research field.
PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 14

“The Secretary of State for Health should commission, in conjunction with colleagues in the devolved administrations, a UK-wide strategy designed to increase the quality and quantity of research into cancers of unmet need - our own version of the USA’s Recalcitrant Cancer Research Act.”

We are pleased that Cancer Research UK’s latest strategy document recognised the importance of improving research into cancers of unmet need, committing to increasing its research spend on pancreatic, lung and oesophageal cancers, as well as brain tumours.

Meanwhile, the new Cancer Strategy for England contains some promising proposals that should help improve the volume and quality of cancer research if implemented. However, the strategy does not contain any specific measures pertaining to cancers of unmet need.

We continue to believe that a UK-wide strategy strategic approach towards dealing with cancers of unmet need is needed to ensure the battle against these cancers is stepped up.

PANCREATIC CANCER RESEARCH: A ROADMAP TO CHANGE, RECOMMENDATION 5

‘Whilst not scientific or clinical research per se, more work needs to be conducted, as a priority, to examine why there are such variations in pancreatic cancer survival rates across the UK and between the UK and other EU countries.’

The Department of Health has considered international comparisons from EUROCARE 5, which looks at the survival and care of cancer patients based on European Cancer Registries. However, this data is limited in its use in that it only goes up to 2007. More up-to-date, detailed work considering the reasons for variations in survival rates across the UK and between European countries is still needed.

This work also requires updated survival data. The National Cancer Intelligent Network’s e-Atlas showing variation in cancer survival rates has not been updated since the Health and Social Care Act paved the way for the replacement of Primary Care Trusts by Clinical Commissioning Groups (CCGs) in 2012.

The existing survival data needs to be updated to show the latest variations before research into why variation exists can be carried out.