

# Pancreatic Cancer Research

A roadmap to change



APPG on Pancreatic Cancer

LESS  
THAN **4%**  
SURVIVAL RATES

VERY FEW  
TREATMENT  
OPTIONS

RESEARCH

INCREASED  
SURVIVAL

BETTER  
PATIENT  
CARE

“Over the last 40 years, improvements in prevention, detection and treatment have revolutionised cancer medicine and survival has doubled. However, progress has not advanced equally for all forms of the disease. Lung, pancreatic, oesophageal cancers and brain tumours share poor five-year survival and have realised only limited improvement in the past decade... Despite highlighting lung, oesophageal and pancreatic cancers as areas of priority in our previous strategy, we have not seen research effort increase as much as we would like. We recognise the need to be more proactive in order to build capacity and make headway in tackling these cancers.”

*Cancer Research UK's 2014 Research Strategy, Beating Cancer Sooner.*

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



# BACKGROUND

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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.

In November 2013 the APPG published its first report, ***Time to Change the Story: A plan of action for pancreatic cancer***. The report was the result of a six month Inquiry which took evidence from patients, carers, family members, clinicians, researchers, charities, policy makers and others, both in writing and over five oral evidence sessions in Parliament. A number of recommendations were made concerning the need to improve awareness, early diagnosis, treatment and care for pancreatic cancer.

However, the 2013 Inquiry did not touch upon the subject of pancreatic cancer research. To have done so would have complicated the Inquiry and resulted in not enough attention being paid to what is a complex and important issue. Instead the Group resolved to hold a separate inquiry into research the following year.

This report – ***Pancreatic Cancer Research: A roadmap to change*** – is the result of that second Inquiry, undertaken between March and September 2014, which set out to establish what needs to be done to improve both quality and quantity of pancreatic cancer research in the UK. The terms of reference are attached as Appendix 1.

As before, the Inquiry took evidence in writing as well as over the course of four oral hearings, receiving evidence, comments and suggestions from researchers in both academic and clinical settings, charities, research funders, government agencies, medical professionals, industry and professional bodies. A full list of respondents is included in Appendix 2.

The APPG would like to thank everyone who submitted their views, as well as the many members of the public who attended the oral evidence sessions in Parliament. The input received has been drawn on extensively for this report and helped to frame the recommendations contained within it.

# FOREWORD

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Around 8,800 people are diagnosed with<sup>i</sup>, and around 8700 people die from<sup>ii</sup> pancreatic cancer across the UK each year. The disease is responsible for over 5% of all cancer deaths in the UK<sup>iii</sup>, making it the country's fifth largest cause of cancer deaths but predicted to become the 4th largest by 2030<sup>iv</sup>. Moreover, whilst survival rates for most cancers have been rising, five-year survival rates for pancreatic cancer have remained stubbornly and shockingly low for the past 40 years, at less than 4%<sup>v</sup>. This is the cancer that holds the unwanted title of having the worst survival rate of any of the 21 most common cancers<sup>vi</sup>.

The All Party Parliamentary Group on Pancreatic Cancer (APPG) is in no doubt that the kind of change needed to make any significant impact on those appalling statistics will only be achieved through research: research that will aid earlier diagnosis and screening; research that will result in more and better treatments; and research that will hopefully offer opportunity for a cure. That is why we decided to conduct a specific Inquiry looking at how we can improve both the quality and quantity of pancreatic cancer research in the UK.

This report sets out our findings and recommendations, which have been informed by a wealth of insight and expertise, from those involved in setting research strategy through to industry, charities, funders and, of course, researchers themselves. We have learned much and hope that this report does justice to the quality of contributions we received. At the same time, we must acknowledge that this Inquiry has only scratched the surface of the issues and challenges that impede pancreatic cancer research activity and we will, as a Group, continue to monitor whether progress is made in future.

Two over-riding conclusions have emerged from our Inquiry. Firstly, when it comes to research it is clear that the UK has many advantages – not least a number of world-class researchers, excellent research facilities and the fact that the NHS offers a huge cohort of patients and patient data. However, we heard over the course of our Inquiry that there is much more that needs to be done to build on these positives and to overcome the obstacles that get in the way of pancreatic cancer research. In brief, we need measures that will enable us to develop a healthy community of researchers, ensure the network and research infrastructure exists to support their work, and to overcome attitudes or processes impeding research activity.

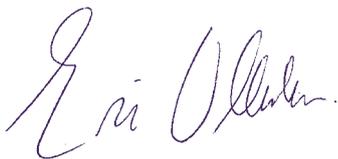
The second conclusion is quite simple: the UK is not spending a sufficient amount on site-specific pancreatic cancer research. There are some promising signs that this situation might slowly be changing but without a significant increase in research funding it is highly unlikely that we will achieve the advances needed to move towards beating the disease.

**“I think if you simply looked at the history of science, I don’t think you can, as a scientist, start to make guarantees about research. It’s not like a sausage grinder; you don’t put research in and it comes out and you solve the problem. It just doesn’t work that way.... However, I think there is a guarantee you can make: if you don’t carry out research, you are not going to move; nothing is going to happen.”**

*Professor Peter O’Hare, Chair of Pancreatic Cancer UK’s Scientific Advisory Board, 1st oral evidence session*

However, both of these issues are interlinked. The low level of pancreatic cancer research funding is due in part to a relatively small pancreatic cancer research community, producing a small number of research applications. In turn, the pancreatic cancer research community is small, in part because of the low level of investment into research of the disease. It is a vicious circle that we must break.

**We hope that this report goes some way towards establishing how that could be achieved.**



*Eric Ollerenshaw OBE MP,  
Chair of the All Party Parliamentary Group on Pancreatic Cancer.*

# SUMMARY OF KEY RECOMMENDATIONS

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

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- 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 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.
- 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.
- 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.
- 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**.
- **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 Agency will mean this new process is brought in as quickly as possible.

- 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.
- 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.
- **NICE needs to amend its drug approvals system** to ensure more cancer drugs pass its appraisal process, especially for cancers of unmet need. This will allow a solid baseline of standard treatments which novel therapies can then be trialed on top of. If the NICE system cannot be changed to this extent for drug approvals, a separate system should be set up to allow researchers access to the required drugs for clinical trial purposes.
- **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.
- **More inducements to encourage top quality** international pancreatic cancer researchers to relocate to the UK should be offered, with the Government taking a lead in marketing the UK to world-leading scientists working in the area.
- 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.
- **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 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.

# FUNDING

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## CURRENT RESEARCH FUNDING LEVELS:

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Given that pancreatic cancer is the fifth most common cause of cancer death in the UK<sup>vii</sup>, is one of the few cancers where mortality rates are actually increasing not decreasing, and that it is predicted to overtake breast cancer as the fourth leading cancer killer in the UK by 2030<sup>viii</sup>, it might be reasonable to expect to find a commensurate level of resource directed towards research into this deadly disease. Instead, the APPG heard time after time from witnesses involved in this Inquiry that there has been a longstanding underinvestment into site-specific research funding for pancreatic cancer.

The National Cancer Research Institute (NCRI) was founded in 2001 to develop plans for cancer research and is the only national register of spending on cancer research. It is comprised of 22 member organisations, including charities and government bodies, which spend a minimum of £1 million a year on cancer research. Drawing on NCRI data, evidence submitted to the Inquiry showed that pancreatic cancer received only 1% of NCRI site-specific research funding in 2013: that equates to just £5.2 million a year in cash terms<sup>ix</sup>.

We recognise that within the total NCRI partner spending, generic cancer research is also funded which might lead to advances across all tumour types: and also that there is general funding for infrastructure and overhead costs which, again, pancreatic cancer researchers will be utilising. However, these common outlays will also benefit other cancer types' research and so we believe that the NCRI site-specific data provides the most robust insight into how pancreatic cancer research investment compares to investment in other forms of cancer.

**“ It’s [funding] low compared to other things. If you think about what’s happened, say, in the last 20, 30 years, there’s only really one substantial gain, and that’s come out of an industry-funded study that brought Abraxane into the pancreatic arena.”**

*Mr Satvinder Mudan, 4th oral evidence session.*

Moreover, we note that NCRI partner spending on pancreatic cancer increased more than twofold between 2002 and 2011, a point made by Ministers when replying to recent parliamentary questions on the subject<sup>x</sup>. However, the APPG believes that these figures only serve to demonstrate the incredibly low base pancreatic cancer research was starting from and, more significantly, how poorly the cause has been served over the past decades.

The reality is, as the NCRI's own report, *Cancer research spend in the UK 2002-2011*, makes clear:

**"...some other cancers [including pancreatic] which started the decade with a very low level of investment have also shown a large proportionate increase, albeit that actual investment is still relatively low<sup>xi</sup>."**

The table below shows how NCRI partner funding for pancreatic cancer compared with funding of research for the four most common cancers.

Cancer site	Deaths per year(2012)	5-year survival rates (2011)	NCRI partner research spend (2002) £	NCRI partner research spend (2013) £	Amount on research per death per year £
Breast	11,716	87%	23.0m	40.3m	3440
Prostate	10,837	85%	10.9m	22.2m	2049
Colorectal	16,187	59%	15.2m	25.0m	1544
Pancreatic	8,662	<4%	1.5m	5.2m	600
Lung	35,371	10%	4.4m	14.1m	399

Although a crude measure, it does provide a useful benchmark, demonstrating the disparity in research spend between these different cancers. It shows that pancreatic cancer - and lung cancer for that matter - falls well short of funding in relation to other types of cancer, especially when considering comparative survival rates.

Breaking down the NCRI site-specific pancreatic cancer spend into contributions from individual NCRI partner members has proven difficult, as these are not reported separately in the organisation's annual reports. However, we know from written evidence provided to the APPG Inquiry that in 2013 Cancer Research UK spent £3.5 million; the Medical Research Council £0.75 million; and that the contribution from the Department of Health was just £0.7 million. This latter figure is particularly disappointing.

To touch briefly on the amount of research spending by the pharmaceutical industry - whilst we did hear from drug companies over the course of our Inquiry, we were unable to quantify exactly how much they collectively devote to specific pancreatic cancer research. We would want to believe that their investment is substantial but we cannot put a value on it. Furthermore, based on the very few new treatments that have come to the market that are used to treat pancreatic cancer we must accept that historically pancreatic cancer has not been a significant focus for industry.

It would also seem likely that, as with research funding from the NCRI, pancreatic cancer will be receiving proportionately less than might be expected given the intransigence of the disease, simply because the number of patients who would potentially benefit from new drugs is relatively small.

Finally, the APPG heard how the UK's pancreatic cancer charities also contribute much needed additional sums to research. Because none of them are members of the NCRI this investment is not reflected in the NCRI returns. Their combined spend has, to date, generally been limited to small-scale project grants with a total annual spend of less than £2 million per annum. Although small compared to the spend of larger research funders like Cancer Research UK, we were told by witnesses that these extra sums are greatly valued as they can enable researchers to develop the data needed to be able to secure much larger programme grants.

**"The presence of pancreatic cancer charities has changed that [availability of small research grants] in a big way, so we can get small sums of money to do project work. However, to do a programme of work, which requires multiple projects working together to make a leap in pancreatic cancer diagnosis or therapy, we find it very difficult to fund that."**

*Mr Hemant Kocher, 1st oral evidence session*

**"...getting drug companies to fund trials for one relatively small-volume tumour, where the outcomes aren't very good anyway, doesn't make economic sense for them. They're not going to pour money into something like pancreas cancer because it's never going to generate lots of money, unless you've got an agent which you can use across several tumour types.... But a pancreatic specific agent is not going to generate lots of industry funding."**

*Mr Satvinder Mudan, 4th oral evidence session.*

At the same time, it must be noted that these charities are increasingly supporting more significant projects – for example Pancreatic Cancer Research Fund is in the process of supporting a pancreatic cancer-specific tissue bank in conjunction with Barts Cancer Institute, and Pancreatic Cancer UK are supporting a £400,000 early diagnosis project. It is to be hoped that as the pancreatic cancer charities grow this investment in research will increase.

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## **THE CASE FOR INCREASED FUNDING:**

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In responding to a backbench e-petition debate on pancreatic cancer on 8th September, the Public Health Minister, Jane Ellison MP, acknowledged one of the factors that contributes to the low level of pancreatic cancer research:

**“...fundamentally this is hard: it is a hard disease that is hard to diagnose and research. The scientific opportunity is not as readily there as it is in some other areas of human medicine.<sup>xii</sup>”**

The APPG believes it is this very difficulty that necessitates a step change in both the amount of funding for pancreatic cancer and in the way funds are allocated.

Evidence submitted to the Inquiry by Pancreatic Cancer UK provided some insight into a minimum level of research investment that needs to be achieved before real progress can start to be made in tackling survival rates. This was the conclusion of a 2012 policy briefing<sup>xiii</sup>, which suggested that survival rates would only start to shift if a minimum level of £10 – 12 million annual investment is achieved.

The figure came from a high level analysis of other cancers, like prostate and bowel, which suggests that is the point where funding starts to grow in a more rapid and, importantly, in a more sustainable manner following the establishment of a critical mass of researchers working in the field generating competitive research proposals and a solid research infrastructure. The briefing note set 2015 as a target date for reaching that minimum level, with further targets of £12m by 2017 and £25m by 2022.

**“... one of the things that is quite apparent is the direct correlation between the lack of improvement in survival for pancreatic cancer and the lack of research funding over decades. There’s a graph in my written submission that actually shows this quite nicely, where you can see that breast cancer you start off here, and the injection of funding is going like this and the survival rates are doing exactly the same; they’re mirroring the funding graph. There is a direct correlation, which is why we’ve seen tremendous successes in those cancers versus that for pancreatic cancer.”**

*Ali Stunt, founder and CEO of Pancreatic Cancer Action, 1st oral evidence session*

That point – an improvement in outcomes for other cancer types once a minimum spending level has been reached – was reinforced in oral and written evidence received from Pancreatic Cancer Action. They supplied figures and graphs showing sharp increases in survival rates for breast, prostate and bowel cancer, mirroring similar increases in research spending into those diseases.

The APPG notes that there has been recent movement in the right direction in terms of both funding and focus. We welcome the new strategy from Cancer Research UK, *Beating Cancer Sooner*<sup>xiv</sup>, launched in April 2014. This new strategy confirms that their own research institutes will, in future, put more of a focus on pancreatic and other cancers of ‘unmet need’, namely pancreatic, lung and oesophageal cancers and brain tumours, all of which have stubbornly low ten-year survival rates.

Importantly, this strategy also includes a statement of intent that Cancer Research UK will “double or treble” research funding into cancers of unmet need over the next five years. This will be done partly by the additional focus throughout their research institutes but also by prioritising research grants towards studies into cancers of unmet need, as long as those studies meet a baseline standard. Although Cancer Research UK could not, at this time, provide details of exact amounts likely to be spent in future, given that their current recorded NCRI pancreatic cancer-specific research contribution stands at £3.5 million, we might extrapolate that this could mean their annual site-specific figure will reach at least £7 million over the next five years.

This is an important announcement from Cancer Research UK and the APPG applauds its recognition of the need to change its focus onto cancers of unmet need, including pancreatic cancer. We now need to see similar commitment from other research funding partners, including government bodies, to meet the levels of funding required to make a difference.

**“Four out of our five institutes have plans in place to increase the volume of research in pancreatic cancer...Five of the fifteen centres where we fund ... have made a commitment to growing the proportion or the focus on pancreatic cancer research in their locations.”**

*Nick Grant, Director of Strategy, Cancer Research UK, 3rd oral evidence session*

**“One of the important things that we have done within our new strategy and are working on with our funding committees is to say to them where you receive applications across a number of cancer types, we would like you to first of all make a clear decision on is this of acceptable funding quality or not? Then, where we have a number of applications that are of acceptable quality but we don’t have the funds to fund all of them, because typically we aren’t able to fund everything that comes through, we would like you to prioritise applications that are in the four, what we call, cancers of unmet need...such that they will, if they’re of an acceptable quality, receive preferential treatment in our committees.”**

*Nick Grant, Director of Strategy, Cancer Research UK, 3rd oral evidence session*

However, whilst this new prioritisation is welcome, we note that Cancer Research UK's approach does not include ring-fencing money for site-specific research into cancers of unmet need. Instead, there still needs to be a ready supply of funding applications being made and those individual applications will still have to be peer-reviewed and selected from amongst similar applications for research into other cancer types. So for pancreatic cancer to receive more research funding there needs to be a larger pool of researchers making suitable applications that get over that initial hurdle.

And herein lies a problem. The reason given to the APPG Inquiry by Cancer Research UK, and the Medical Research Council, for not awarding more funding for pancreatic cancer in the past has been that not enough quality applications have been received. Looking at the ratio of applications accepted, the MRC, for instance, told us that

**“Between the financial years 2007/8 and 2013/14, 25% of pancreatic cancer-specific fellowships and 20% of pancreatic cancer-specific grants to the MRC Boards were funded. This is comparable to a funding rate of 23% for fellowships and 22% for grants submitted to the Boards across all subject areas over the same time period. ... between 2007/08 and 2013/14 the MRC received 20 fellowships and 26 grant applications.”** (Written evidence from MRC).

So, for more applications to be made – and to be of a high quality – we need more researchers in the field; a larger pancreatic cancer research community. But the Inquiry was also told by witnesses that young researchers are dissuaded from pancreatic cancer studies, at least in part, because they feel the funding is not there to sustain an active and successful career in that area. This is a vicious circle.

As such the APPG believes that there is a short-term case to be made for ring-fencing funding for pancreatic and other cancers of unmet need which have stubbornly low survival rates and low current levels of research funding. Projects to be funded should be strategically commissioned and peer reviewed. Once a critical mass of research is taking place this 'special measures' approach could be dropped. This approach would help alleviate short-term need, maintain quality, and also allow for longer-term sustainable funding in future.

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## **THE APPG ON PANCREATIC CANCER RECOMMENDS:**

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- 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 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.

**“Now, one of the issues we've had historically is, and the reason why pancreatic cancer research hasn't got as much funding as we would have liked, is ... we simply haven't seen... as many applications as we would like come through for funding in pancreatic cancer research.”**

*Nick Grant, Director of Strategy, Cancer Research UK, 3rd oral evidence session*

**“I think we're losing an opportunity in directing young researchers into the field of pancreatic cancer with current funding levels. ...If we have those young researchers in the field of pancreatic cancer going into other areas, then we won't develop the whole pancreatic cancer research group.”**

*Dr Steve Pereira, 1st oral evidence session*

**“I think it's this issue about strategically funding research, as opposed to allowing research to bubble up. I think there are times when actually strategically commissioning research, if you like, or pushing people into certain areas and ring-fencing those areas would be helpful.”**

*Professor Duncan Jodrell, 2nd oral evidence session*

# AREAS OF RESEARCH

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## EARLY DIAGNOSIS:

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During our 2013 Inquiry the APPG heard of the need to improve early diagnosis into pancreatic cancer. Currently, nearly half of all diagnoses are made via emergency admission, usually at a stage when curative surgery is no longer an option.

One of the reasons given for late diagnosis is that signs and symptoms of pancreatic cancer can often be non-specific. This, coupled with the fact that GPs will be likely, on average, to only see one case of pancreatic cancer every 5 years, leads to late referral and diagnosis. In addition to training GPs, the APPG concluded in its 2013 report that they needed to be provided with more, and more effective, tools to aid them in diagnosing patients at an earlier stage.

Over the course of our latest Inquiry the APPG received consistent evidence from witnesses urging priority to be given to early diagnosis research projects. From the development and validation of biomarkers, which may ultimately lead to simple screening tests of the kind used to detect other cancers at an early stage, to the creation of decision aid tools to prompt GPs, these advances in early diagnosis would, we were told, help save lives.

In addition, earlier diagnosis would help make it easier to recruit more patients into clinical trials and allow more information to be successfully gleaned from patients in those trials, which, in turn, will lead to even more research advances.

For these reasons, the APPG agrees that research that could help improve early diagnosis of pancreatic cancer needs to be one of the key priority areas for research investment.

**“... it’s about early diagnosis. It’s about making sure that when we get patients that - at the moment, 15%, roughly... for a potential operation.... That percentage needs to go up if we’re going to improve survival. The only way we’re going to do that is diagnose them early enough so that they can be operated on.**

*Dr Andrew Millar, 4th oral evidence session*

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## OTHER AREAS OF SCIENTIFIC RESEARCH:

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However, we also need to see significant advances in treatment and palliative care and that needs to be supported too.

During the Inquiry we heard about other important projects which have great promise and which may lead to advances in patient treatment and, ultimately, survival. For example, research into the basic biology of pancreatic cancer tumours and stroma; immunotherapy; and personalised medicine, seeking to identify the many different tumour variants and unique genetic profiles of patients to allow more targeted and effective, individualised treatment programmes to take place.

On this latter point, whilst the APPG Inquiry was in progress, the Prime Minister announced £300 million investment, from a number of funding partners, for the 100,000 Genomes Project<sup>xv</sup>. We feel this is a very important scheme that will set the UK up as a world leader in genomics and make a real difference in the fight against cancer and other rare diseases.

We welcome the fact that some cancer types are included in the pilot phase but are disappointed this does not include mapping of pancreatic cancer patients at this time. The APPG believes that this is a missed opportunity and would hope that where new schemes of this potential are introduced it would make sense to prioritise cancers of unmet need, like pancreatic cancer, at an early stage. We hope that measures will be taken to expand the project and include pancreatic cancer as part of the study as soon as possible.

Whilst the development of new drugs to combat cancer is taken almost for granted, we also heard evidence regarding the need for more research into other treatments. In particular we heard how advanced radiotherapy machines were lying idle as the evidence base for use was not sufficient for NICE to approve the technique for routine use on the NHS. At the moment advanced radiotherapy techniques like stereotactic ablative radiotherapy (SABR), such as Cyberknife, are only licensed for research purposes on the NHS. The same is true for other innovative techniques like irreversible electroporation (IRE), such as Nanoknife. The APPG heard that both technologies should be included in the NHS England Commissioning through Evaluation Scheme, to allow more detailed assessment of the technologies' efficacy for pancreatic cancer patients.

As our Inquiry was drawing to a close, the Health Minister, speaking in the 8th September backbench e-petition debate on pancreatic cancer, confirmed that the newly announced Cancer Research UK SABR clinical trials, which will receive £6 million support from NHS England, include one pancreatic cancer trial<sup>xvi</sup>. This is a welcome move and, we hope, a sign of things to come.

**“These [advanced radiotherapy] machines are sitting there... we can't get NHS patients funded to have the treatments because there isn't the evidence... What we've been trying to push for is to have commissioning through evaluation and have an evaluation process, because we'll never get big trials set up for the use of these technologies.”**

*Dr Diana Tait, 2nd oral evidence session*

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## **POLICY AND NHS RESEARCH:**

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There is a need to carry out research beyond the directly scientific and medical as well. As part of our previous Inquiry of 2013 we were told repeatedly of the need to improve the referral pathways for patients, as well as specific calls for GPs to have direct access to CT scans for their patients. In our latest inquiry we heard how we need to create an evidence base to allow these sort of advances to happen: new pathways must be trialled, evidence collected and where new systems have been proven to work, then rolled out around the country.

We heard evidence from various sources pointing to a continued need for more research that will enable us to understand why there are variations in survival rates around the UK – and, indeed, between the UK and other EU countries. With the best five-year survival rates in England four times those of the worst performing areas, finding reasons for the discrepancies and trying to replicate success seems likely to deliver a possible quick win in terms of patient outcomes.

Clearly, all of these aspects of research are important and, if anything, the sheer scale and scope of advancement that needs to be made to overcome 40 years of practically no change in outcomes serves to reinforce the need for more funding and the expansion of the pancreatic cancer research community.

**“There is a large body of evidence now that there’s a great deal of variation around the country in the management of people with pancreatic cancer, and that leads to big variations in outcomes, particularly access to surgery, access to nurses and overall survival. I think research aimed at identifying why some people in different parts of the country have better or worse outcomes would be important.”**

*Dr Steve Pereira, 1st oral evidence session*

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## **THE APPG ON PANCREATIC CANCER RECOMMENDS:**

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- 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.
- 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.
- 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 survival rates across the UK and between the UK and other EU countries..

# REGULATION, PROCEDURE AND CULTURE

Over the course of the Inquiry, the APPG heard from various witnesses pointing to the many advantages for pancreatic cancer research in the UK. The NHS provides a huge, centralised cohort of patients and plentiful patient data; we have top-quality researchers and research facilities; and networks that allow a co-ordinated approach to setting up trials.

However, we also heard about a number of factors that seem to prevent these advantages from being fully realised. Some of these factors relate to process and culture within the NHS – but it must be noted that many witnesses who gave evidence to this Inquiry highlighted serious concerns about the impact of EU regulation on the research environment in the UK.

We note that many of these factors about process, cultural and regulatory impediments apply to research efforts into all cancers. However, we would suggest that the impact may be especially problematic for pancreatic cancer research for a number of reasons, including the smaller pool of patients compared to more common cancer patient groups and the fact that many patients are diagnosed at a very advanced stage and average survival times from diagnosis are very short.

The APPG received written and oral evidence pointing to the Cancer Research UK’s clinical trial database which shows that there are relatively few pancreatic cancer trials recruiting new patients at the present time, compared to other cancer types, as set out in the table below<sup>xvii</sup>.

Cancer type	Number of open trials
Bowel cancer	53
Brain tumour	18
Breast cancer	73
Lung cancer	66
Ovarian cancer	38
Pancreatic cancer	11
Prostate cancer	48
Testicular cancer	12

**“Running clinical trials in less common cancers such as pancreatic can be difficult. Due to the small number of patients that are eligible to participate in the trials and the patients’ geographical dispersion it is particularly important that trials can recruit from sites across the country.”**

*Cancer Research UK written evidence*

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## **DELAYS AND BUREAUCRACY:**

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The APPG heard that generally there can be delays in recruiting patients to clinical trials in the UK, with waits of several weeks before a patient is even deemed eligible to take part in a trial. By then the patient's condition may have deteriorated to such an extent that they are then unable to take part in, and benefit from, the trial treatment.

A number of witnesses told us that delays are, in part, down to current bureaucratic processes, in particular the system of multiple R&D approvals. At the present time separate approvals need to be given for the trial to take place on each site it is conducted. We understand that the Department of Health is already working on this problem and that the Health Research Agency (HRA) has been established with a specific remit of introducing a centralised approval system for trials.

The APPG believes that this will be an important step towards faster trial approvals. We hope that the HRA is given the necessary resources to carry out its work, that the single approval system is expedited, and also that this reduction in bureaucracy is replicated across the whole of the UK.

These delays are inhibiting research, not just because patient fitness might have declined too much by the time all the paperwork has been completed, but also because they may lead to drug companies not locating their own research in the UK. We heard from Novartis how pharmaceutical companies have much more choice than ever before when it comes to siting a trial and will take into account, when making a decision, the time it may take to set up a trial and the associated cost implications.

By comparison, other leading countries like Canada and the US have developed rapid, integrated care and research systems that allow patients to be assessed for clinical trial suitability almost immediately and fast tracked into treatment. This will often take place in dedicated trial centres, not in hospitals.

From what we heard over the course of the Inquiry, we do not need similar dedicated centres here in the UK, as long as we can join up clinical care and research and embed a culture of research in hospitals across the NHS.

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## THE FOLLOWING QUOTES SPEAK FOR THEMSELVES:

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**“At the moment these patients are often quite unwell at first presentation. Their performance status ... often deteriorates quite rapidly. ...Therefore this presents challenges to us in that a lot of patients aren’t fit enough to go on to experimental treatment trials by the time that they come to us. If we could certainly increase the speed of the diagnostic journey ...maybe [patients will be] more fit to be able to undergo the existing treatments we have and then enter into clinical trials and better treatments in the future.”**

*Professor Jeff Evans, 3rd oral evidence session*

**“I think the big thing is it’s not actually the MHRA and the ethics system that causes the major delays, it’s getting the R&D approvals in multiple sites. A trial may open in one site on 1st January and it may be a year later before the other sites are open. I would, therefore, support the Health Research Authority’s initiative to centralise R&D approval for clinical trials, because I think that will accelerate trials opening and will make trials more accessible for our patients.**

*Professor Duncan Jodrell, 2nd oral evidence session*

**“The Health Research Agency should be supported in its aims to harmonise and streamline the regulation and governance of research that takes place in the NHS.”**

*Cancer Research UK written evidence*

**“The criteria we use to decide where we place our trials are very much partly about the research environment. This is: how quickly can trials be set up? How quickly can patients be recruited into the trials? What is the cost and what is the quality of the research?”**

**In relation to quality, the UK obviously is a country with very high-quality research. Unfortunately, that’s not necessarily a distinguishing factor anymore, because there are so many other countries these days where research is of very high quality. In terms of the other elements, so speed of trial set-up and patient recruitment and cost, there are certainly still things that need to be done to improve on those, even though in the last few years there have been improvements and we have certainly found that we’ve been able to place a lot more trials in the UK than previously.”**

*Barbara McLaughlan, Novartis, 2nd oral evidence session*

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## A RESEARCH CULTURE IN THE NHS:

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The APPG heard regularly from witnesses how research needs to be much better integrated into the day-to-day clinical work of the NHS. Clearly, patient care is the priority; however, by not maximising its involvement in the research process today the NHS is potentially holding back improvements to treatments and care for the future.

We were told there needs to be a culture of research across all staff groups in the NHS, not just medical staff. There needs to be a culture that recognises research is an integral part of health service activity and that it should be embedded in daily activity. Part of this shift should mean that all patients are informed of clinical trials that might be suitable for them.

We heard several calls from witnesses that more research time needs to be written into staff job plans. Moreover, rapid clinical assessment needs to be integrated with an assessment of research possibilities at the first interaction with the patient, with a named and suitably qualified person to deal with research and clinical trial possibilities on specialist Multi Disciplinary Teams (MDTs).

We are aware that the NHS England Service Specifications for Cancer already make reference to having discussions about clinical trials at MDTs. However, this is not the same as making sure there is a designated research person to represent research interests at meetings and to make sure a patient's potential research care is given appropriate attention. Moreover, the number of witnesses who raised the point about research needs being discussed at first presentation to an MDT implies that the current system needs to be improved upon. We would hope that this is something that can be implemented across the whole of the UK.

**"...we must embed research into the way the whole community, preferably nationally, works."**

*Dr Andrew Millar, 1st oral evidence session*

**"We need to re-engineer the way we approach pancreatic cancer.... What it needs is rapid assessment, direct integration with research, and overcoming those barriers between clinical care and research that tend to be growing further apart but coming closer together."**

*Professor Andrew Biankin, 2nd oral evidence session*

**"Actually, I'm surprised at the number of colleagues of mine for whom the multidisciplinary team meeting is not actually factored into their job plans.... For me, that should be the route into research, but if these multidisciplinary teams are not appropriately resourced in terms of sessional commitments and time to discuss patients appropriately, then that will be lost."**

*Professor Duncan Jodrell, 2nd oral evidence session*

Moreover, it would appear that the UK is struggling to keep up with other countries in terms of diagnostic tests that are increasingly required in order to prepare the ground for particular studies. There is a need, for instance, for molecular testing to identify patients with specific tumour types for trials. We also heard from separate witnesses there is a need to ensure routine and timely collection of biopsies and blood samples for research purposes. At the present time a clinical biopsy is often conducted separately from a research biopsy, which is carried out almost as an afterthought, if at all. This duplicates effort and increases the cost of research work. There is clearly a need to join up these processes, ensuring there are additional, trained personnel on hand to both obtain all relevant permissions and to carry out necessary tasks, expediting samples to the relevant research locations as quickly as possible.

The APPG is aware that NHS England consulted on a Draft Research and Development Strategy which closed back in January 2014. Responses to the consultation are still being analysed as we write this report and it is not clear when a final Strategy will be forthcoming. We were disappointed not to be able to take evidence from NHS England directly on the Draft Strategy's contents but, from reading the Draft's text, the APPG feels that, whilst it contained statements that make the right noises, it was weak on specifics. For instance, it did not address deeply enough the key problems with the structures that are impeding research at the present time. As such, it does not set out remedies to those existing problems. The final version of the Strategy will need to be more robust and specific if it is to tackle the problems we have identified and bring about a genuine culture change within the NHS.

**"I think where we are behind is in relation to molecular testing. In other countries, you have a better system of making sure that the diagnostic tests that are required to do the trials and to identify the patients whose tumours have particular molecular characteristics are done and funded by the health system, which isn't the case here, where only at the moment if you have a NICE-approved drug then the testing will be funded. In other countries, they are much further advanced and they see it as a key priority."**

*Barbara McLaughlan, Novartis,  
2nd oral evidence session*

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## EU REGULATION:

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We heard concerns from industry and from others about the negative effect of EU legislation and potential legislation. In particular we were told that the EU Clinical Trials Directive had 'slowed down academic research<sup>xviii</sup>' without necessarily improving research quality. However, we also heard from Cancer Research UK that the change from a Directive to a Regulation<sup>xix</sup>, due to come into effect in 2016, may lead to 'a more proportionate approach to trial regulation'. Clearly this is something that will have to be monitored.

Perhaps more worrying is the possible effect of the new EU Data Protection Regulation, still under construction. This would potentially require every patient to 'opt-in' to their information being stored for research, putting at risk, for instance, the huge strides being made by the National Cancer Intelligence Network, which has become a world leader in the storage and use of patient data. It would also impede the work of many researchers, especially in the area of personalised medicine.

The APPG believes that the Government needs to work with other EU partner states to make the case against more restrictive controls in this area, as existing safeguards in place in the UK are perfectly adequate and allow researchers to carry out important work. Moreover, there is broad public support for patient data to be used in a way that benefits research, as long as strict privacy protocols are retained.

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## DRUG APPROVALS REGIME:

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Problems also exist due to the National Institute for Health and Care Excellence's drug approval process. Firstly, we heard that trial placement will, in part, be determined by whether pharmaceutical companies believe their drugs will be taken up for routine use in the country concerned. However, there are other knock-on effects: if drugs are not approved for standard use on the NHS, trials cannot be carried out on different, new drugs in combination with those standard drugs. This puts the UK at a disadvantage if researchers working with other healthcare systems around the world are able to access those standard drug treatments for their patients. The current situation with Abraxane is a case in point.

**"The importance of data for medical research cannot be underestimated, particularly for less common cancers and in the development of personalised treatments. We continue to be very concerned that amendments to the EU Data Protection Regulation will prevent or severely impair scientific research studies using personal data."**

*Cancer Research UK  
written evidence*

**"It's difficult to find out whereabouts the EU [data] directive is, but in essence, if you took it at face value then it could stop us doing what we do. It would stop that level of analytical work. It could potentially stop a lot of research work as well."**

*Chris Carrigan, Director of the National Cancer Intelligence Network and Information Services. 4th oral evidence session.*

**"Equally, when we look at trial placement, one of the issues we do look at is whether patients are likely to get access to the drugs that we develop once we've done all the trials."**

*Barbara McLaughlan, Novartis,  
2nd oral evidence session*

The APPG is worried that as NICE rejected 60% of all cancer drugs in 2012, and seems destined to continue to reject a majority of cancer drugs in future, this will hold back future research advances. For pancreatic cancer, which has very few treatment options at the present time, this is a particular concern.

However, if NICE cannot or will not amend its appraisal system so that more cancer drugs are approved for routine use on the NHS, consideration should be given to creating a separate system that would allow researchers to access drugs for use in a clinical trial setting. We recognise there may then be issues both around cost and governance but it would at least mean that UK research was not so greatly disadvantaged by NICE's strict approval regime.

**“Having NICE approval for a new drug would help build clinical trials which use that drug as a baseline. If the NICE, for example, does not approve this new drug which has come out for pancreatic cancer, we, as clinicians, can't use that drug to trial other drugs on top of it.”**

*Mr Hemant Kocher, 1st oral evidence session)*

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## **THE APPG ON PANCREATIC CANCER RECOMMENDS:**

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- 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 Agency will mean this new process is brought in as quickly as possible.
- 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.
- 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.
- NICE needs to amend its drug approvals system to ensure more cancer drugs pass its appraisal process, especially for cancers of unmet need. This will ensure a solid baseline of standard treatments which novel therapies can then be trialed on top of. If the NICE system cannot be changed to this extent for drug approvals, a separate system should be set up to allow researchers access to the required drugs for clinical trial purposes.

# RESEARCH CAPACITY, LEADERSHIP, COLLABORATION AND INFRASTRUCTURE

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## RESEARCH CAPACITY:

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Over the course of our Inquiry there was a clear recognition of the need to proactively encourage more researchers into the field of pancreatic cancer research. Earlier in our report we discussed the need to boost funding, pump-priming research into the disease, as part of that process. However, the culture of nihilism that we heard exists – that the field of pancreatic cancer is a career cul de sac – needs to be challenged and we clearly need to do more to open up career opportunities and also retain existing researchers in the field.

The APPG heard from several witnesses of the need for more pancreatic cancer- specific research fellowships and young researcher programmes. We heard, for instance, how Pancreatic Cancer UK has worked with the Medical Research Council to deliver a Future Research Leaders scheme. This approach of targeting funding at younger researchers with huge potential needs to be rolled out further by other funding organisations in order to ensure young talent enters the pancreatic cancer field.

The flip side of recruitment is retention and it was encouraging to hear that Cancer Research UK are specifically looking into the issue of retention. If we can establish in more detail the reasons behind researchers leaving the field we can obviously then design initiatives to prevent that brain drain in future. There needs to be a survey of researchers that have left the field to try and establish what could have been done differently to make them stay.

**“In essence there’s a lack of capacity in the UK community with an interest in working in this field. ... A lot of the thinking over the last year or two has been how do we change that? How do we get more people interested in working in the area?”**

*Nick Grant, Director of Strategy  
Cancer Research UK, 3rd oral  
evidence session*

**“I think if we had designated research fellowships within established training centres and an established training network, we would encourage more young people into this disease.”**

*Professor Duncan Jodrell, 2nd  
oral evidence session*

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## **LEADERSHIP:**

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To combat the sense of nihilism and to act as a spur to younger researchers taking up the baton we also need to encourage more established figures, at the top of their game at an international level, to locate their work here in the UK. Having more top researchers working from British facilities will enable more mentoring and act as an inspiration to young scientists. Cancer Research UK highlighted how Professor Andrew Biankin and his team's decision to relocate to Glasgow from Australia has given just such a boost.

The APPG believes that more relocations will, in part, follow naturally if some of the previously mentioned problems around recruiting to clinical trials are addressed and the NHS can demonstrate that it is fully committed to a culture of research. Guarantees about the availability of funding would also assist. However, more proactive outreach by the Government to try and lure more world leading researchers to the UK would be welcome.

Finally, we heard evidence from Pancreatic Cancer UK calling for the creation of dedicated pancreatic cancer research 'champions' whose role it would be to help promote the cause in the UK. Whether we need a specific, named role to act as a kind of research czar is unclear but we certainly need to see leading lights taking on a cheerleading role, actively marketing and promoting pancreatic cancer within the wider research community. Such a figure or figures would, we feel, certainly help to inspire a future generation of scientists to enter the field.

**“There are, however, pockets of excellence in pancreatic cancer in the UK, which provides a foundation on which to build capacity. Of note is the recent recruitment of Professors Andrew Biankin and Sean Grimmond to the University of Glasgow, who will provide a crucial leadership role and in mentoring junior researchers.”**

*Cancer Research UK written evidence*

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## **COLLABORATIVE WORKING:**

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Another way of tackling research capacity would be to develop a UK-wide pancreatic cancer network of excellence, building on the Cancer Research Institutes and Centres already in existence and by working with all funders, charities and others as part of a coordinated strategy. We heard from Professor Duncan Jodrell about his role in one of the pancreatic cancer “Dream Teams” in the US. Dream Teams were set up to “eliminate barriers to creativity and collaboration, in part, by enabling scientists with different expertise from different institutions across the country – and in some cases internationally – to work together.”<sup>xx</sup> Each team is given a specific problem to tackle and consists of a multidisciplinary group of experts that includes laboratory and clinical researchers, young investigators and senior scientists who have not worked together in the past.

This approach seems to be a good way of tackling many areas at once: capacity, infrastructure, collaboration, training and leadership among them. The Dream Team concept is also, by its very name, inspirational and forward looking, and would create something people will aspire to being a part of. The APPG believes that this structure should be pursued in the UK. Any Dream Teams established should be strategically funded from the ring-fenced pancreatic cancer research money, as per our recommendation in an earlier chapter.

Greater collaboration, as part of a Dream Team approach or otherwise, is also something we heard needs to be improved within the pancreatic cancer research community in the UK. Whether it be between individual researchers or between institutes we need to take measures to give researchers more opportunity to share their work, their ideas and their progress so greater advances can be made. More conferences, networking possibilities and symposia are required. The APPG understands that the number of pancreatic cancer-specific conferences have increased substantially even over the past two years and this trend needs to continue.

**“I think we have a real opportunity at the moment in the UK to develop a network of excellence...akin to the Dream Teams that we have seen developing in the USA....I think as part of a network of excellence, we would institute training programmes that would be shared amongst the various centres. Therefore, we would ensure that we train the next generation of scientists and clinicians and also, I think, clinical nurse specialists and people who work in similar roles, who are fundamentally important to the care of our patients and are often overlooked. I think that network of excellence will also give the opportunity of coordinating industrial collaboration, so that trial participation is more efficient and we produce both rapid and high-quality trials.”**

*Professor Duncan Jodrell, 2nd oral evidence session*

Because of the need for innovation to develop ways to identify pancreatic cancer at an earlier stage, we heard evidence from a number of witnesses, including Cancer Research UK and the Royal College of Radiology, urging that cross-discipline research projects were properly funded. In particular, imaging projects cutting across the fields of engineering and physics, as well as pancreatic cancer, were highlighted as being of importance.

We also heard that there is need for greater collaboration in the form of shared research papers. The APPG understands the need to advance careers by gaining credit for research advances. In a way, this is perhaps an even greater need in a research field where funding is limited. However, as we heard from very eminent researchers, sharing credit in joint papers, maybe with dozens of authors, may help drive advances further. This is something the research community needs to work out amongst itself.

**“I was interested to see that there has been set up in the States what’s called a ‘dream team’... for pancreatic cancer, where a big injection of governmental money, along with some charitable, it has to be said, ... was offered to a dream team that could be put together from some of the leading research institutions in the US, with a number of priority areas that they had to focus on. Maybe we can see something like that in the UK...”**

*Maggie Blanks, founder and CEO of Pancreatic Cancer Research Fund, 1st oral evidence session*

**“Aside from the relatively low number of pancreatic cancer researchers in the UK, the activity that does exist is dispersed across a handful of independent locations. There is limited co-ordination of research activities across these centres, but a clear willingness to instigate a more collaborative culture.”**

*Cancer Research UK written evidence*

**“Novel approaches are needed and increasing collaborative links between physicists, engineers and pancreatic cancer researchers will be key to the development of better diagnostic techniques.”**

*Cancer Research UK written evidence*

**“One of the problems that we have in the UK is that amongst academics we’re still set up to try and compete with each other. I think as we go forward we have to find a way of crediting senior academics for team science and, rather than having the single-author paper in Nature which makes your career, that you actually get credit for being on a 25-author paper which actually makes an impact on a disease.”**

*Professor Duncan Jodrell, 2nd oral evidence session*

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## **INFRASTRUCTURE:**

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Increasing research capacity will not have the desired effect unless the available researchers have access to the facilities and material they need to carry out their inquiries. Cancer Research UK also told us that with an increasing focus on personalised medicine and the collection of genome sequence data for individual patients, investment is required in the infrastructure needed for sharing of large data sets to address research questions.

As with so much of our Inquiry, this subject is interlinked with other weakness: we addressed earlier in this report the need to actually make sure biopsies are taken and taken in a timely fashion. However, we also need the facilities to store those tissue samples and to then make them accessible for researchers. We heard from witnesses that current samples are available but are small in number. We also heard of a need to standardise processes for collection of samples and the sharing of data between storage locations. The APPG was particularly pleased to hear of the project being funded by Pancreatic Cancer Research Fund, in conjunction with the Barts Cancer Institute, to create a new pancreatic cancer-specific tissue bank. This is a major investment for a small charity and is to be applauded.

**“... there are a lot of structural barriers which we are trying to overcome. For example, you need a large pool of samples, pancreas cancer being a relatively uncommon disease, short survival; we need serial samples. That has been lacking in a coordinated attempt so far. Now, with the help of Pancreatic Cancer Research Fund, we’re setting up a national pancreas tissue bank, which will allow various researchers to pool their resources together, which will help researchers such as Steve to test a biomarker very quickly, validate it in a large pool of samples, with the serial samples taken before and after treatment, for example, to be able to validate this and go into large-scale clinical trials very early.”**

*Mr Hemant Kocher,  
1st oral evidence session*

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## **THE APPG ON PANCREATIC CANCER RECOMMENDS:**

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- 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.
- More inducements to encourage top quality international pancreatic cancer researchers to relocate to the UK should be offered, with the Government taking a lead in marketing the UK to world-leading scientists working in the area.
- 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.
- 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.

# STRATEGY

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The APPG heard how US legislators have taken a lead in prioritising pancreatic cancer research on the other side of the Atlantic. In September 2012 Congress unanimously passed the Recalcitrant Cancer Research Act<sup>xxi</sup>, which required the director of the US National Cancer Institute to prepare a special strategy for ‘recalcitrant cancers’ in the US. The Act defined a recalcitrant cancer as a cancer type with a five-year survival rate of less than 20% and that kills more than 30,000 US citizens a year.

**“My view is that we need to have a strategic approach with this; I think there needs to be a UK strategy for pancreatic cancer research funding, and it needs to involve all stakeholders.”**

*Ali Stunt, CEO and founder, Pancreatic Cancer Action, 1st oral evidence session*

The result of the Act has been more focus on, in particular, pancreatic and lung cancer research in the US, as well as a welcome increased focus on and awareness of those cancer types more generally. The APPG believes that this sort of national leadership should be shown by the UK Government, with the Secretary of State for Health working with his counterparts in the devolved administrations to produce a UK-wide recalcitrant cancers research strategy.

If a British strategy were to use the US definition of “recalcitrant”, it would cover pancreatic cancer, which has a five-year survival rate of just under 4%; lung cancer (10%); oesophageal cancer (15%); brain tumours (19%); and stomach cancer (19%).

It is fair to say that whilst most witnesses to our Inquiry made a call for a specific pancreatic cancer research strategy to bring about greater focus and funding, the view was not unanimous. We heard from Cancer Research UK that the UK cancer research funding model - where funding comes from a variety of organisations, most of them in the charity sector – means a national strategy of the kind used in the US – where the Government is the main funder of research – would be limited in its potential impact over here. We also heard views that specific pancreatic cancer working groups, set up to include relevant charities and funders, would provide relevant consultative and communicative forums to discuss research priorities.

During the backbench e-petition debate on pancreatic cancer of 8th September, Jane Ellison MP, the Public Health Minister told Members that the NCRI largely fulfils that strategic role in the UK<sup>xxii</sup>. However, whilst it is clearly the case that the NCRI pancreas sub-group has an important role to play in co-ordinating research direction from an existing pot of funds, it is not the same as having a higher level strategic direction and prioritisation for pancreatic cancer research, or for recalcitrant cancers more widely. In that sense, the sub-group is perhaps more tactical than strategic.

Moreover, the NCRI is made up of many funders including charities of other cancer types who will not have the required interest in pancreatic cancer. The proof is, perhaps, in the pudding because NCRI has not, since its inception, followed a path which has led to enough money being put into pancreatic cancer research. So whilst we recognise that the NCRI carries out an important role in co-ordinating cancer research around the UK, we do not believe it mirrors the important strategic shift signaled by the US Recalcitrant Cancer Research Act.

Likewise, the APPG does not necessarily agree with the argument that a central strategy is not appropriate because of different research funding models between the UK and US. If anything, the fact that there is a more diverse funding backdrop in the UK suggests a greater need for greater coordination, albeit conducted in a way that will allow each charity to maintain their own operational independence of Government to fulfill their charters.

The APPG therefore believes there is a need for a more strategic approach to dealing with pancreatic cancer research – and research into other cancers of unmet need - across the UK. Apart from being a clear statement of intent that the battle against these cancers was being stepped up it should act as a basis for establishing increased, ring-fenced funding and the allocation of funds to key projects. It should also act as a forum for all interested parties to contribute towards an agreed agenda, strategically commissioning research into prioritised areas.

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### **THE APPG ON PANCREATIC CANCER RECOMMENDS:**

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- 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.

**"...the US Recalcitrant Cancer Act of 2012, which requires the director of the NCI, as a Government agency, to put in place a strategy to deal with that those recalcitrant cancers. That's something that we could look to and see if we could examine that model and reuse it in some way in the UK."**

*Professor Peter O'Hare, Chair of Pancreatic Cancer UK Scientific Advisory Board, 1st oral evidence session*

# APPENDIX 1

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## TERMS OF REFERENCE FOR AN INQUIRY INTO PANCREATIC CANCER RESEARCH

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The All Party Parliamentary Group on Pancreatic Cancer is launching a special inquiry into pancreatic cancer research, looking at the barriers to increasing the level of research into pancreatic cancer. This will build on the report *Time to Change the Story: A Plan of Action for Pancreatic Cancer*, which was published in November 2013, but which did not focus specifically on research. It will also build on work undertaken by organisations within the sector, such as Pancreatic Cancer UK's *A cancer of unmet need: the pancreatic cancer research challenge*.

### **The inquiry is particularly interested in hearing evidence, views and experiences relating to:**

- Increasing the level of funding provided to pancreatic cancer research
- Addressing structural barriers and raising the profile of pancreatic cancer in the research community
- Co-ordination and integration of research (basic, translational and trials) to ensure greatest advancement
- Addressing research resource needs, for example, tissue banks
- Increasing numbers of pancreatic cancer clinical trials – and patient access to trials
- The role of research in improving early diagnosis, including research relating to education of health professionals
- International comparisons, including USA legislative approach to developing research strategy

The inquiry will take evidence from a range of stakeholders including charities, clinicians, officials, researchers and others.

### **Terms of reference**

- In this inquiry, the APPG will consider, amongst other issues, the following:
- Increasing the level of funding provided to pancreatic cancer research
- Comparisons of levels of pancreatic cancer research with other cancers
- The role of national funding bodies
- The role of the pharmaceutical industry

## **Addressing structural barriers and raising the profile of pancreatic cancer in the research community**

- The need for a strategy to increase levels of pancreatic cancer research
- The challenges in developing pancreatic cancer researchers
- The role of mentoring in developing younger researchers
- Improving the attractiveness of pancreatic cancer as a research area
- The need to develop a critical mass of pancreatic cancer research
- The role of regional specialist pancreatic cancer centres
- The need for pooled and shared resources, for example, tissue banks, to support research activity
- The coordination and integration of pancreatic cancer research efforts
- The role of research in improving early diagnosis
- The role of primary care in pancreatic cancer research
- The role of research looking at best ways to educate health professionals about pancreatic cancer

## **International comparisons**

- Comparisons between funding in the UK and the rest of Europe
- Comparisons with Australia, the USA and the rest of the world
- The USA legislative approach (The Recalcitrant Cancer Research Act)

# **APPENDIX 2**

## **LIST OF EVIDENCE RECEIVED AS PART OF THE INQUIRY:**

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### **WRITTEN EVIDENCE RECEIVED FROM:**

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- Cancer Research UK.
- Celgene.
- Professor Angus Dalglish (Professor of Oncology, St George's University of London).
- Dr Guiseppe Garcea (Consultant Hepato-Pancreato-Biliary Surgeon & Hon Lecturer, University Hospitals of Leicester NHS Trust).
- Mr John Lancaster (wife died of pancreatic cancer).
- Medical Research Council.
- Novartis.
- Pancreatic Cancer Action.
- Pancreatic Cancer Research Fund.
- Pancreatic Cancer UK.
- Dr Steve Pereira (Consultant Gastroenterologist at The Royal Free and University College Hospitals and researcher into early diagnosis of pancreatic cancer).
- Royal College of Radiologists.

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### **ORAL EVIDENCE:**

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#### **Session one – Monday 12th May 2014**

- Ali Stunt, CEO and founder of Pancreatic Cancer Action.
- Maggie Blanks, CEO and founder of Pancreatic Cancer Research Fund.
- Professor Peter O'Hare, Chair of Pancreatic Cancer UK's Scientific Advisory Board.
- Dr Steve Pereira, Consultant Gastroenterologist at The Royal Free and University College Hospitals and researcher into early diagnosis of pancreatic cancer.
- Mr Hemant Kocher, Professor of Liver and Pancreas Surgery at the Barts Cancer Institute, Queen Mary, University of London and Consultant Surgeon at the Royal London and St Bartholomew's Hospitals.

## Session 2 – Monday 9th June 2014

- Professor Duncan Jodrell, of the Cancer Research UK Cambridge Institute, Professor of Cancer Therapeutics at the University of Cambridge.
- Professor Andrew Biankin, Director of the Wolfson Wohl Cancer Research Institute at the University of Glasgow, where he is also Professor of Surgery.
- Barbara McLaughlan, Head of External Affairs, Oncology, and Ali Rees, Clinical Development Advisor, both of Novartis Pharmaceuticals UK Limited.
- Dr Diana Tait, Vice President and Dean of Faculty of Clinical Oncology, Royal College of Radiologists.

## Session 3 – Monday 7th July 2014

- Mr Nick Grant, Cancer Research UK's Strategy Director,
- Professor Jeff Evans, Professor of Translational Research at Cancer Research UK's Beatson Institute in Glasgow.

## Session 4 – Tuesday 2nd September 2014

- Mr Chris Carrigan- Director of the National Cancer Intelligence Network and Director of Information Services, Public Health England.
- Dr Andrew Millar - Pathway Director for hepato-pancreatic-biliary (HPB) cancer, London Cancer.
- Mr Satvinder Mudan - Consultant Surgeon and Surgical Oncologist, The Royal Marsden, Chair of the Hepato-pancreatic-biliary Pathway Group at the London Cancer Alliance.

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

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