

## Unlocking more trials for the future - How to improve clinical trials for pancreatic cancer

**We believe that clinical trials are key to testing new models of care and support and identifying promising treatments that can improve survival as well as palliative care for pancreatic cancer patients. This briefing sets out our policy calls and our commitment for ensuring a step change happens in the field of clinical trials for pancreatic cancer patients.**

### **Methodology:**

In developing our policy messages we have undertaken research that has involved looking at some existing literature on clinical trials and pancreatic cancer, much of the literature available on this topic was international. We also received data from the NIHR Clinical Research Network on the numbers of studies including trials relevant to patients with pancreatic cancer that exist across the UK by local NHS trust and NIHR local clinical research network area. In addition we conducted a survey of patients, carers and families and also health professionals to better understand their engagement about opinions about clinical trials in this field. In addition we undertook desk based research and conducted semi-structured telephone interviews with a number of healthcare professionals and researchers.

### **Improving clinical trials – our policy calls:**

- 1. For the percentage of pancreatic cancer patients recruited to clinical trials to double from 4.6% against incidence<sup>1</sup> in 2014/2015<sup>2</sup> to 9% in 2020 across the UK.**
  - The National Institute of Health Research (NIHR) currently has high level objectives for overall trial participation<sup>1</sup>. This should include specific targets for low surviving and low participant cancers, such as pancreatic cancer.

*Ensuring that this target is met will need system-wide determination. Specifically, NIHR should ensure that this remains a focus of the National Cancer Research Institute (NCRI) Clinical Studies Group (CSG) for Upper Gastro-Intestinal (GI) and the pancreatic sub-group. Among NIHR's Clinical Research Network's objectives for last year was a specific focus on trial participation in dementia and*

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<sup>1</sup> 2013 incidence figures have been used

<sup>2</sup> Data provided to Pancreatic Cancer UK by the NIHR Clinical Research Network (CRN) National Coordinating Centre. The 4.6% figure relates to the percentage of patients taking part in solely dedicated pancreatic cancer trials against incidence.

*neurodegenerative trials, we think the same focus and prioritisation and focus should exist for pancreatic cancer.*

- The Chief Scientist's Office Scotland (CSO) should move beyond the SHARE Programme<sup>ii</sup> to facilitate patients undergoing treatment, such as pancreatic cancer patients, to be informed and take part in clinical trials research. They should also set targets for trial participation.

*It is a current aspiration of the Scottish Government to enable patients to participate in clinical trials as set out in the Scottish Government's Health and Social Care Research Strategy<sup>iii</sup>. The plans set out in this document discuss a matching service to enable GPs and hospital consultants to match eligible patients to existing studies. This is a progressive and interesting proposal and it will be interesting to see whether such a service, if set up, is successful.*

From data provided to us by NIHR's Clinical Research Network (CRN) we know that the numbers of patients with other cancers taking part in trials dedicated to their tumour type mostly represents a higher percentage when measured against the incidence of the disease than it does for pancreatic cancer. For example, participation of breast cancer patients in site specific trials in 2014/15 measured against the latest available incidence<sup>iv</sup> figures is 22.3%. This figure is 19.6% for ovarian cancer patients and 12% for oesophageal cancer patients.

From research that we conducted, including journal articles and interviews, it is clear that there are some disincentives for patients to take part in trials such as the time taken to enrol and participate and this is something that needs to be addressed. Especially for pancreatic cancer patients who may be very poorly and less able to travel when diagnosed, this was a point raised by a number of clinicians who responded to our survey and who we conducted interviews with on the topic.

*'The main concern is the length of time to get the screening procedures done...using NHS resources, and especially if additional biopsies are required....Patients may [decide to] proceed with standard of care outside of a trial due to their concerns over the delays in starting treatment.'* (Clinician respondent to clinical trials survey)

Another clear factor, as evidenced in our literature review is clinicians' attitudes. Where clinicians are positive about trial participation patients are much more likely to take part. However, given the prognosis for many pancreatic cancer patients there are disincentives to clinicians as well as for patients. Clinicians may feel reluctant to recommend trials where they feel that someone is not well enough or may not have much time left and where they feel the benefits of participation are unclear.

*“We need to improve the trials that take place and then patients will travel and doctors will refer.” (Clinician interviewee).*

Some of our expert interviewees mentioned the problems with capacity and funding as well as culture.

A lack of recruitment to trials may be because *“there are no financial incentives that may be felt by that clinician and the individual department. The money may simply go to the hospital, especially given the deficits that they face.” (Clinician interviewee).*

## **2. For every pancreatic cancer patient to be informed about research trials prior to the commencement of treatment as this can affect eligibility.**

- NHS England should amend the current NHS Constitution NHS pledge to inform patients about research studies for which they may be eligible to include, informing them at the earliest point.

*This is important because once pancreatic cancer patients have undertaken treatments this may make them ineligible for participating in clinical trials.*

- When pancreatic cancer patients are being told about research opportunities should be monitored by Cancer Patient Experience Surveys across England, Wales, Scotland and Northern Ireland.

*Patients across the four nations are currently asked if they were informed about research. However, to monitor when they were asked would require an additional question to ask patients who are informed about research, when they were informed about research.*

- Hepato-Pancreato-Biliary (HPB) Multi-Disciplinary Teams in Specialist Centres across the UK should inform eligible patients either directly or through their local team of relevant trials at the earliest possible opportunity.

*This is already a requirement in England<sup>v</sup> as part of the National Peer Review Programme’s Manual for Cancer Services which is used by the Peer Review Programme to audit performance and the measures also help inform local commissioning. MDTs are required to produce an annual report on clinical trials which include the extent of local provision against the national portfolio of clinical trials. It also includes their performance on recruitment against locally agreed targets and timescales and any improvement plans.*

*We think this must also include reporting a percentage of eligible patients spoken to about clinical trials and at what point in their care journey. Improvement plans should focus on increasing the percentage of people told at the earliest point. From our interviews with clinicians, we also know that specialist centres may inform eligible patients about local and regional trials rather than all trials that may be relevant. Whilst many people with pancreatic cancer will not want to and be unable to travel long distances to take part in clinical trials, we believe that patients should be informed about a wide range of relevant trials to maximise their choices.*

### **3. For researchers, clinicians and patients to be better informed about the existence of pancreatic cancer relevant clinical trials and research.**

- There needs to be easily accessible information that is up to date on the existence of clinical trials, location and eligibility requirements. This should be maintained by charities such as ourselves as well as the UK Clinical Trials Gateway<sup>vi</sup>. These resources ideally should act as a communication gateway between patients, health professionals and researchers.

*Whilst there are currently a number of ways in which patients, clinicians and researchers can find information about clinical trials an easy to access and comprehensive resource was not available for pancreatic cancer. This is why Pancreatic Cancer UK launched our [Trial Finder](#) in May 2016<sup>vii</sup>.*

- UK-wide HPB Specialist Centres and NIHR's Local Clinical Research Network (LCRN) Cancer Leads should ensure that they are disseminating information about the existence of pancreatic cancer trials and encourage participation from patients, clinicians and treatment sites locally. For there to be sufficient focus on pancreatic cancer, LCRN Cancer Leads may want to appoint someone to lead on pancreatic cancer.

*From expert interviews that we have conducted, we believe that this works best where there are regular meetings and opportunities for clinicians and researchers in a field to meet. To support this activity, Pancreatic Cancer UK can provide some support for teams within regional areas to hold meetings or study days to discuss new treatments.*

Whilst consultants have a key role in informing their patients about clinical trials, research nurses and clinical nurse specialists (CNS') were also mentioned by interviewees as having an important role.

*“Specialist nurses can be valuable to ensuring progress, they work between teams and are close to patients, they can help recruit patients.” (Clinician interviewee).*

**4. For the patient voice in pancreatic cancer research to be louder in order to ensure that the trials that take place match the priorities and eligibility of patients better.**

- There should be increased pancreatic cancer patient and patient organisation representation within NCRi CSG and sub-group structures to ensure that the strategic direction for research considers the needs of patients. This can help to ensure that research is more successful, for example, in terms of patient recruitment to trials and ensuring that a wider range of outcomes are measured.

*Pancreatic cancer patients should be represented on the NCRi Consumer Forum and also on the CSG Upper GI pancreatic<sup>viii</sup> sub-group alongside patient organisation representation.*

- Researchers should proactively involve patients in setting priorities for research, trial design and monitoring progress and success.

*Patient involvement in research can be challenging for pancreatic cancer patients who may be ill and who may have a short survival expectancy. To help address this issue we have set up a Research Involvement Network<sup>ix</sup> to enable researchers to contact interested pancreatic cancer patients, in order to shape research.*

- We need a national priority setting exercise for pancreatic cancer in the future that proactively takes into account the needs of patients. Ideally, this should take place as part of the development of a Pancreatic Cancer Research Strategy.

*We believe that there would be value in bringing together patients, patient organisations and the research and clinical community to set priorities for pancreatic cancer research. This has been done for prostate cancer and other disease groups.*

- The NHS's across the UK should set out up to date plans on how they will ensure that relevant and effective patient and public involvement in research becomes the norm for research funders.

*In England, this was a recommendation in the recent Cancer Taskforce Cancer Strategy for England 2015-2020 and was recently accepted by NHS England. We are keen to see concrete plans to turn this aspiration into a reality and to see metrics that can ensure this involvement leads to change and has impact.*

**5. We need a greater strategic focus for pancreatic cancer research which galvanises a broad range of voices and focuses on what patients want. This should aim to achieve consensus on what are the most promising models**

**of care and treatments for the future, especially for improving survival. It should also assess what the critical success factors for clinical trial research are.**

- We support calls that there needs to be a UK wide Strategy on Research for Cancers of Unmet Need or Low Surviving Cancers. This should be led by the Secretary of State for Health and the Departments leading on Health across England, Scotland, Wales and Northern Ireland.

*The Cancer Strategy for England 2015-20 and Cancer Research UK have recognised the need to make breakthroughs in research for cancers with low survival rates and with few treatment options. To make sure this happens, we believe there needs to be UK wide strategy to ensure that progress is made. This would have a similar intention to the Recalcitrant Cancer Research Act in the US. This was a recommendation of the All-Party Parliamentary Group (APPG) on pancreatic cancer in 2014. This overarching strategy should provide the infrastructure and focus on ensuring that research and clinical trials can take place for cancers of unmet need.*

- We need a Pancreatic Cancer Research Strategy across the UK with buy in from Governments to fund and facilitate aspirations. This should be led by the NCRI Upper GI CSG and the pancreatic sub group.

*We have been calling for this since our previous corporate strategy, Strategy for Hope 2013-16 was published. This strategy should be produced by the pancreatic sub-group of the Upper GI CSG of the NCRI. In producing the strategy there should be wide engagement with the pancreatic cancer community including patient representatives and organisations.*

*For the strategy to have impact it will be important that national Governments and their research institutions provide funding and prioritisation for its aims. This includes, ensuring an appropriate workforce, such as physicists to undertake new radiotherapy treatments for pancreatic cancer patients as well as molecular scientists to facilitate breakthroughs for personalised medicine for pancreatic cancer.*

*“We need to separate pancreatic cancer out more from Upper GI, especially given the appallingly few treatment options and low survival rate. ...Oesophageal and gastro cancers have different surgeons and oncologists to pancreatic cancer.”  
(Clinician interviewee)*

One of the key barriers to undertaking a strategic approach to pancreatic cancer research is the lack of collaboration and diversity of voices. There is a need for collaboration to include international voices in helping to set future agendas too. As well as a wide range of professionals that include surgeons and oncologists as well

as professionals from palliative and psycho-social fields. Involving patients and patient organisations also offers an opportunity for fresh thinking as well as ensuring that the research that does take place reflects the priorities of patients and the people affected by pancreatic cancer, ensuring their buy-in.

*“You need to be collaborative and not empire build. People will do it if they are encouraged to do it.” (Clinician interviewee)*

*“We need to not waste money as a sector and be more strategic. When people do get money, recruitment may be low as people do not buy into the study.” (Clinician interviewee)*

Another key risk identified was the fact that in order to deliver on strategic aims there needs to be sufficient funding, incentives and capacity in the system. For example, specialist centres would need to be incentivised to focus on trialling innovative treatments that may be more costly but more effective for pancreatic cancer. Given finite resources available one clinician raised concerns that in practice pancreatic cancer would be a lesser priority in specialist cancer treatment centres.

*“As specialist cancer centres are currently setting priorities that will be cost based there is a risk that pancreatic cancer will be regarded as a lesser priority due to lower volumes and success.” (Clinician interviewee).*

*“To deliver precision radiotherapy we do not have enough physicists and specialist radiotherapists. These people will also be siphoned off to undertake radiotherapy for lung or prostate which can be more lucrative” (Clinician interviewee).*

**6. We need to ensure that we have the infrastructure in place for pancreatic cancer to benefit from the future generations of clinical trials on stratified and personalised medicine.**

- NHS' across the UK should develop Personalised Medicine Strategies that are coordinated and which include looking at how breakthroughs can be made for rarer and low surviving cancers.

*NHS England have said that their Board will consider whether such a strategy should be developed in summer 2016. We think this is essential and that as well as having a focus on rarer and low surviving cancers there needs to be clear plans for how research in this area can be conducted and how future treatments can be developed and realised.*

- We need a UK wide approach to support biobanking across a range of disease groups as part of a UK wide approach to personalised and stratified medicine.

*Tissue collection and biobanking is essential to ensure that future research breakthroughs in pancreatic cancer can be made and that there is efficient sharing of knowledge across the research community. There are a number of biobanks for pancreatic cancer in England<sup>xxi</sup>, some are local and a recent promising initiative funded by Pancreatic Cancer Research Fund is the Pancreatic Cancer Tissue Bank<sup>xii</sup>, where tissue is collected by six participating hospitals. However, there needs to be Government investment and support to ensure the sustainability of these initiatives and to ensure that more specimens are collected across the country. There also needs to be a joining up between different samples that may exist with a standardisation of tissue collection protocol.*

- NHS' across the UK should ensure that tissue collection from pancreatic cancer patients increases by mandating collection with consent, upon diagnosis; and ensure that specimens are collected as part of resection surgery.

*NHS England in their response to the Cancer Strategy have said that by September 2016 they will develop proposals to ensure that all teenagers and young adults are asked about tissue collection for future research upon diagnosis. This same focus is required for pancreatic cancer which is a low surviving cancer with limited treatment options and no molecular treatment breakthroughs to date. One of the most effective ways for ensuring tissue is collected efficiently and across the country is to ensure that, with consent, tissue is collected at the time of resection surgery for pancreatic cancer patients. This could be mandated through the NHS service specification for this type of surgery.*

*This activity should also be funded. At present pure biobanking is not registered with NIHR or funded by them. We think that this should change, as financial incentives will help to ensure a wide range of hospitals across the UK take part in biobanking.*

At present the NIHR doesn't seem to obviously directly fund a number of biobanks apart from the Human Tissue Research Bank.<sup>xiii</sup> However the NCRI does host the Confederation of Cancer Biobanks (CCB)<sup>xiv</sup> with the aim of sharing best practice between biobanks, standardising practice, providing advice and support and facilitating access between biobanks and data-sharing. This collaborative infrastructure is important but stops short of a national pancreatic cancer biobank.

*"In the future we need more personalised medicine which is linked to tissue collection and biopsies...This should also be linked to a national register where data can be shared." (Clinician interviewee).*

There was a feeling in interviewing clinicians and experts that we need greater capacity for tissue collection as well as a more strategic approach to the agenda of personalised medicine and the infrastructure required.

“We need good quality pathology and tissue samples especially where moving to molecular stratification, we need to collect efficiently.....Problem that only specialist centres are able to do this at the moment.” (Clinician interviewee).

“...lots of things are happening that are not joined up.” (Clinician interviewee).

The need to link this agenda to funding structures as well as to applied research questions and clinical trials was also raised by experts.

*“Tissue collection should be on the NCRI portfolio so that it can bring in NIHR resources and this would encourage more hospitals to take part.”* (Clinician interviewee).

*“Collecting samples for the sake of it is pointless - you need to have a therapeutic question in mind in the context of clinical trials” (link with funding) Data sharing and bio banks are important but they need to be part of a clinical trial structure.”* (Clinician interviewee).

**7. We need a greater spread of studies across the UK to ensure all pancreatic cancer patients can take part in research; and that recruitment to trials is speedier and more successful.**

- Specialist Centres should play a leadership role in ensuring that local acute sites take part in clinical trial research. Either by setting up trials or ensuring patients are informed of relevant trials at the specialist centre.

*Whilst we appreciate that many of the clinical trials taking place on pancreatic cancer treatments take place at cancer specialist centres<sup>xv</sup> where there are HPB multi-disciplinary teams to treat people with pancreatic cancer - we believe that there is scope for more trials to also take place in local acute trust sites. This is particularly important for pancreatic cancer patients who may be older or feeling unwell and less able to travel.*

*There are specialist centres such as Coventry who operate a hub and spoke model with their local acute sites which has enabled them to take part in trials. For example, post-surgery patients have been able to receive chemotherapy follow up as part of a trial at their local hospital. Specialist centres and NIHR funding combined should ensure that local acute sites are successful in trial recruitment and delivery.*

*The benefit of this way of working is that patients are more likely to be willing to participate in clinical trials. Faster and greater recruitment to trials is key to improving the quality of research and the speed at which new treatments can develop.*

*Importantly, for the patients taking part in trials and their families it also ensures that the burden of trial participation in terms of travel time is limited. This is important as many pancreatic cancer patients may be feeling unwell at the point at which they may be entered into a trial and the population in general tends to be older.*

The fact that local acute sites still have to apply for research approval, even if they are a small part of a larger study lead by a specialist centre for example, was highlighted. There is a debate needed on whether this needs to remain the case or whether there is a further rationalisation of the research approval process that could happen to incentivise trial participation by more local acute sites.

*“R&D (research and development) processes need to change so that follow up treatment could take place locally but they would need to go through the same regulatory loops and ethical processes. It would be good to allow shared patient management and risk sharing. This is something that the Department of Health should consider.” (Clinician interviewee).*

- Where people do have to travel to take part in trials, reasonable expenses should be paid by trial sites and accommodation provided where possible.

*We know from our research into pancreatic cancer trials that the existence of trials and number of patients taking part varies greatly across the UK. This can mean that patients need to travel far. We need to be mindful of the patient burden, which clinicians are and make it as easy for people to participate as possible. We are aware of some specialist centres that do provide accommodation and fund travel expenses where possible. There is also the Elizabeth Coteman Fund, a charity that provides grants for patients to take part in trials<sup>xvi</sup>.*

We have received data from NIHR’s Clinical Research Network on pancreatic cancer research studies, including clinical trials. Taking place across their LCRN and NHS trust areas across the UK. It is clear that there is great variation across the UK in terms of numbers of studies and trials or studies that recruit within a trust or LCRN area. The majority of trusts do not appear to take part in pancreatic cancer relevant studies including trials, and are therefore excluded from this list.

Table 1: 2014/15 Data on the numbers of Studies including clinical trials that pancreatic cancer patients can take part in by Trust and NIHR Local Clinical Research Network (LCRN) area with HPB specialist centres highlighted.<sup>3</sup>

<b>LCRN</b>	<b>Trust</b>	<b>Studies</b>	<b>Participants</b>
<b>East Midlands</b>	<b>Nottingham University Hospitals NHS Trust</b>	<b>2</b>	<b>8</b>
<b>East Midlands</b>	<b>United Lincolnshire Hospitals NHS Trust</b>	<b>1</b>	<b>1</b>
<b>East Midlands</b>	<b>University Hospitals of Leicester NHS Trust</b>	<b>2</b>	<b>14</b>

<sup>3</sup> This information has been provided to Pancreatic Cancer UK by the NIHR CRN National Coordinating Centre. These figures cover all studies including trials that patients with pancreatic cancer can take part in. This means that they may not be pancreatic cancer site specific. The information excludes trusts where there are no studies including trials that patients with pancreatic cancer can take part in.

Eastern	Bedford Hospital NHS Trust	2	25
Eastern	Cambridge University Hospitals NHS Foundation Trust	6	78
Eastern	East and North Hertfordshire NHS Trust	2	4
Eastern	Hinchingbrooke Health Care NHS Trust	1	5
Eastern	Ipswich Hospital NHS Trust	1	2
Eastern	Norfolk and Norwich University Hospitals NHS Foundation Trust	2	5
Eastern	Peterborough and Stamford Hospitals NHS Foundation Trust	2	11
Eastern	The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust	1	29
Eastern	West Suffolk NHS Foundation Trust	1	9
Greater Manchester	East Lancashire Hospitals NHS Trust	1	25
Greater Manchester	The Christie NHS Foundation Trust	7	40
Kent, Surrey and Sussex	Dartford and Gravesham NHS Trust	1	1
Kent, Surrey and Sussex	East Kent Hospitals University NHS Foundation Trust	1	1
Kent, Surrey and Sussex	Maidstone and Tunbridge Wells NHS Trust	1	4
Kent, Surrey and Sussex	Royal Surrey County Hospital NHS Foundation Trust	1	3
North East and North Cumbria	County Durham and Darlington NHS Foundation Trust	2	37
North East and North Cumbria	North Cumbria University Hospitals NHS Trust	1	1
North East and North Cumbria	Northumbria Healthcare NHS Foundation Trust	1	1
North East and North Cumbria	South Tees Hospitals NHS Foundation Trust	3	12
North East and North Cumbria	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	2	2
North Thames	Barts Health NHS Trust	2	4
North Thames	Great Ormond Street Hospital For Children NHS Foundation Trust	1	1
North Thames	Royal Free London NHS Foundation Trust	5	51
North Thames	University College London Hospitals NHS Foundation Trust	4	24
North West Coast	Lancashire Teaching Hospitals NHS Foundation Trust	1	1
North West Coast	Mid Cheshire Hospitals NHS Foundation Trust	1	2
North West Coast	Royal Liverpool and Broadgreen University Hospitals NHS Trust	2	8
North West Coast	The Clatterbridge Cancer Centre NHS Foundation Trust	6	27
North West Coast	University Hospitals of Morecambe Bay NHS Foundation Trust	1	1
North West London	Imperial College Healthcare NHS Trust	5	28
South London	Guy's and St Thomas' NHS Foundation Trust	2	5

South London	King's College Hospital NHS Foundation Trust	2	2
South London	The Royal Marsden NHS Foundation Trust	4	35
South West Peninsula	Northern Devon Healthcare NHS Trust	1	1
South West Peninsula	Plymouth Hospitals NHS Trust	2	2
South West Peninsula	Yeovil District Hospital NHS Foundation Trust	2	4
Thames Valley and South Midlands	Oxford University Hospitals NHS Foundation Trust	1	1
Wessex	Hampshire Hospitals NHS Foundation Trust	2	85
Wessex	Isle of Wight NHS Trust	1	2
Wessex	Poole Hospital NHS Foundation Trust	1	1
Wessex	Salisbury NHS Foundation Trust	1	1
Wessex	University Hospital Southampton NHS Foundation Trust	3	56
West Midlands	Heart of England NHS Foundation Trust	1	4
West Midlands	Shrewsbury and Telford Hospital NHS Trust	1	2
West Midlands	University Hospitals Birmingham NHS Foundation Trust	3	10
West Midlands	University Hospitals Coventry and Warwickshire NHS Trust	2	8
West Midlands	University Hospitals of North Midlands NHS Trust	1	2
West Midlands	Worcestershire Acute Hospitals NHS Trust	1	1
West of England	University Hospitals Bristol NHS Foundation Trust	4	14
West of England	Weston Area Health NHS Trust	1	1
Yorkshire and Humber	Calderdale and Huddersfield NHS Foundation Trust	1	3
Yorkshire and Humber	Hull and East Yorkshire Hospitals NHS Trust	1	1
Yorkshire and Humber	Leeds Teaching Hospitals NHS Trust	4	26
Yorkshire and Humber	Sheffield Teaching Hospitals NHS Foundation Trust	4	9
Wales	Abertawe Bro Morgannwg University LHB	1	2
Wales	Betsi Cadwaladr University LHB	2	2
Wales	Velindre NHS Trust	2	7
Scotland	NHS Grampian	1	1
Scotland	NHS Greater Glasgow and Clyde	4	23
Scotland	NHS Lothian	2	6

All Trusts with 3 or more studies taking place are generally specialist HPB centres apart from The Clatterbridge Cancer Centre NHS Foundation Trust, University

College London Hospitals NHS Foundation Trust and South Tees Hospital NHS Foundation Trust.

Among the 32 specialist centres that exist across the UK<sup>xvii</sup> only 4 appear to have not recruited patients to pancreatic cancer relevant trials in 2014-15, which is 12.5%. These were the HPB centre operated by Kings College Hospital NHS Foundation Trust in South East London, Royal Stoke University Hospital in the University Hospitals of North Midlands NHS Trust area, Raigmore Hospital in Scotland which is in the NHS Highland health board area and Belfast Hospitals Trust in Northern Ireland.

There are 57 trusts listed in this table in England out of a total of 154 acute trusts listed by NHS Confederation in 2016. This means that 37% of all trusts in England are recruiting pancreatic cancer patients to pancreatic relevant clinical trials.

This data shows that HPB specialist centres are critical to advancing clinical trials research for patients for pancreatic cancer and can play a key role in ensuring that trials take place.

A number of clinician interviewees were split on the ability of all areas to recruit to trials equally and had explanations for the disparity in the trials and studies that do take place.

*“Both academic studies and commercial companies will favour trials taking place in areas where they know high recruitment will take place. So often people will go to the usual suspects to be sure of success. Setting up sites is costly.” “If centres or sites open and don’t recruit they are then viewed negatively.” (Clinician interviewee).*

*“In a region 2-3 hospitals are running the majority of trials. To some extent this makes sense as you need the resources and expertise to run these trials. But for pancreatic cancer people are often older and less fit so travelling is difficult. We therefore need to argue for greater accessibility according to our specific patient groups.” “This means we need to think more about what trials we can do locally.” (Clinician interviewee).*

## **8. We need greater collaboration within the pancreatic cancer research community, with leadership and a positive culture that addresses the nihilism that can exist in the field.**

- We need networking opportunities for health professionals, researchers, clinical trial staff, patients and patient organisations to meet and discuss developments.

*The available literature makes clear the importance of networking opportunities to ensure a step change in research in a given field. For pancreatic cancer we will ensure that we bring the pancreatic cancer clinical and research community together, including with patients, at our Annual Summit. We will also host training days for professionals and support existing local and regional networks. However, there is a key role for NIHR LCRN leads to hold meetings to share knowledge and discuss ideas. We believe that some of these must be pancreatic cancer specific within the overall local clinical research network and the meetings hosted by cancer*

*leads locally. Such opportunities can challenge the nihilism around the disease which we have talked about previously and which can affect clinicians' inclination to participate in and recommend research.*

- NIHR Local Clinical Research Networks and other local research networks across the UK should provide leadership in ensuring that pancreatic cancer trials are taking place and publicised to health professionals and that any barriers to recruitment are discussed locally. They should also have close links with the NCRI CSGs and sub-groups.

*Given the breadth and variation of professionals involved in the field of Upper GI cancers, as stated above, we believe that LCRNs should appoint leaders for pancreatic cancer specifically, to help fulfil the vision of the Pancreatic Cancer Research Strategy that we have called on the NCRI to produce.*

In discussing clinical trials with a number of clinicians and healthcare experts, culture and the need for change was a common theme. The issue of urgency as well as risk aversion was highlighted in relation to culture change.

*"We need to start thinking of pancreatic cancer as a cancer emergency ... We need to approach and think about it differently." (Clinician interviewee)*

*"We keep following what has been done for other cancers and keep failing. For 50 years we have been failing. Does this not suggest that we need to do things differently, but the resistance to move away from traditional approaches is immense. Everything is telling us that we need to do things differently, to innovate, but how can we innovate if we keep doing things the same way? We need a shift of thinking and of culture in order to change outcomes for our patients with pancreatic cancer."*  
*(Clinician interviewee)*

However, there was positivity with a number of clinicians feeling there was scope for the pancreatic cancer community to work more closely together on the issue of clinical trials.

*"Let's challenge the nihilism and see this will be beneficial for patients. We can do it in pancreas if everyone works together." (Clinician interviewee)*

In addition to our 8 Policy Calls above, we want to make clear what our commitments to improving clinical trial participation and activity across the UK are.

## Pancreatic Cancer UK commitments on clinical trials

- We will publicise the existence of pancreatic cancer clinical trials across the UK to benefit patients, clinicians and researchers through our recently launched Pancreatic Cancer UK Trial Finder<sup>xviii</sup>.
- We will enable patients to be more actively involved in setting priorities for and designing clinical trials through our Research Involvement Network<sup>xix</sup>.
- We will include the existence of clinical trials and their importance in our study days and educational and training outputs.
- We will provide some support for regional teams and networks to hold meetings to discuss new treatments and trials.
- We will fund innovation, promising practice and invest in future leaders in the field through our Research Innovation Fund, Clinical Pioneer Awards and Future Research Leaders Fund<sup>xx</sup>.
- We will facilitate opportunities for clinicians and researchers to come together to discuss clinical trials and research.
- We will involve researchers, health professionals, patients and carers in how we fund research through our new research strategy.

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<sup>i</sup> NIHR Clinical Research Network Annual Performance Report 2014/15  
<https://www.crn.nihr.ac.uk/wp-content/uploads/About%20the%20CRN/2014-15%20NIHR%20CRN%20Annual%20Performance%20Report%20FINAL.pdf>

<sup>ii</sup> Scottish Health Research Register Project

<http://www.nhsresearchscotland.org.uk/get-involved/take-part-in-research>

<sup>iii</sup> Delivering Innovation through Research – Scottish Government Health and Social Care Research Strategy, Chief Scientist's Office <http://www.gov.scot/Resource/0048/00488082.pdf>

<sup>iv</sup> Incidence figures from 2013

<sup>v</sup> National Peer Review Programme, Manual for Cancer Services, Hepato-Pancreato-Biliary Cancer Measures, NHS England <http://www.cquins.nhs.uk/?menu=resources>

<sup>vi</sup> <https://www.ukctg.nihr.ac.uk/>

<sup>vii</sup> [pancreaticcancer.org.uk/trialfinder](http://pancreaticcancer.org.uk/trialfinder)

<sup>viii</sup> <http://csg.ncri.org.uk/groups/clinical-studies-groups/upper-gastro-intestinal/>

<sup>ix</sup> [pancreaticcancer.org.uk/research](http://pancreaticcancer.org.uk/research)

<sup>x</sup> <http://biosampledirectory.ncri.org.uk/collections/85>

<sup>xi</sup> <http://pancreasbru.co.uk/research/biobanking.aspx>

<sup>xii</sup> Pancreatic Cancer Research Fund, Tissue Bank

<http://www.pcrf.org.uk/pages/tissue-bank.html>

<sup>xiii</sup> <http://biosampledirectory.ncri.org.uk/collections/88>

<sup>xiv</sup> <http://ccb.ncri.org.uk/about-us>

<sup>xv</sup> [pancreaticcancer.org.uk/specialistcentres](http://pancreaticcancer.org.uk/specialistcentres)

<sup>xvi</sup> <http://www.ecfund.org/>

<sup>xvii</sup> [pancreaticcancer.org.uk/information-and-support/treatments-for-pancreatic-cancer/your-local-specialist-centre/](http://pancreaticcancer.org.uk/information-and-support/treatments-for-pancreatic-cancer/your-local-specialist-centre/)

<sup>xviii</sup> [pancreaticcancer.org.uk/trialfinder](http://pancreaticcancer.org.uk/trialfinder)

<sup>xix</sup> [pancreaticcancer.org.uk/research](http://pancreaticcancer.org.uk/research)

<sup>xx</sup> <http://www.pancreaticcancer.org.uk/research>