

## Pancreatic cancer

### Consultation on draft scope Stakeholder comments table

02 December 2015 – 13 January 2016

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association for Palliative Care of GB and Ireland	General (p3)	General	<p>The draft scope says that pancreatic cancer is the 5<sup>th</sup> leading cause of cancer death in the UK, the UK has one of the worst survival rates, life expectancy at diagnosis is 4-6 months and only 3% survive to 3 years or more.</p> <p>Given this, we are surprised and disappointed that there is no mention of palliative care or referral to palliative care services for patients with pancreatic cancer. We would suggest that this should be included in the final guideline and that it be made clear that patients should be referred to palliative care teams based on need, and not only once disease-modifying treatments have been exhausted.</p> <p>Not all patients with pancreatic cancer will need referral to specialist palliative care services. Referral should be needs-based rather than diagnosis- or prognosis-based.</p>	Thank you for your comment. Referral to palliative care services is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a> . Therefore we do not propose to include it in this guideline.
AUGIS incorporating GBIHPBA	General	General	AUGIS would fully support key issues and questions as set out in the consultation document	Thank you for your comment
Celgene	3	73-78	In addition to exploring whether referral to a regional centre/MDT <i>for review</i> improves outcomes, it may also be relevant to investigate whether the setting of care <i>for management</i> influences outcomes.	Thank you for your comment. We agree that this is an area of variation but we do not think there will be evidence of sufficient quality to inform recommendations. Therefore this topic was not prioritised for inclusion in this guideline.
Celgene	4	107-108	The meaning of wording '[excluding NICE technology appraisals]' is unclear; please would NICE clarify their intent and rationale on this point?	We have clarified that any interventions covered by NICE technology appraisals will be excluded from the question. This is because guidelines do not normally investigate interventions/areas that are the subject of existing NICE guidance.
Celgene	4	88	There are certain specific aspects of management that Celgene	Thank you for your comment.

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		onwards	<p>would like to highlight as important, but not explicitly referred to within this draft Scope, eg;</p> <ul style="list-style-type: none"> <li>- There appear to be significant variation in treatment rates geographically across the UK. This issue should be explored, to understand its extent and reasons, and the guideline could consequently offer guidance intended to reduce variation. The National Lung Cancer Audit detailed such information and the treatment rates for this condition subsequently improved.</li> <li>- Some HCPs treat based on a fixed number of cycles rather than treating to disease progression, which may be sub-optimal. A clinical consensus and guidance would be useful.</li> <li>- The primary – and appropriate – determinants for treatment selection are performance status and 'biological age'. Despite this, market research suggests that chronological age continues to be a determining factor, and the guideline should clearly address this issue.</li> <li>- As for other cancers, treatment sequencing is relevant for this pancreatic cancer. Therefore, the guideline should not just identify the most effective (singular) treatment, but provide guidance on appropriate 1<sup>st</sup> and 2<sup>nd</sup> line onward therapies.</li> </ul>	<p>We agree that there is variation in practice across the UK in pancreatic cancer. The intention of the guideline is to reduce this.</p> <p>This level of detail will be discussed by the GC when they finalise the review questions and review protocols during their first few meetings. The guideline will explore the evidence base on treatment and make appropriate recommendations based on this evidence.</p>

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			It may be helpful for the final Scope to detail these components of management specifically.	
Department of Health	General	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment
NHS England	General	General	Thank you for the opportunity to comment on the above Clinical Guideline. I wish to confirm that NHS England has no substantive comments to make in regards to this consultation.	Thank you for your comment
Pancreatic Cancer UK	1	34-41	We agree that the focus of the guideline should be on pancreatic ductal adenocarcinoma (PDAC). Pancreatic Neuroendocrine Tumours (NETs) present different problems and many types have different treatment options to PDAC. Therefore we believe that the treatment of NETs needs to have its own specific guideline.	Thank you for your comment. Clinical guideline topics are referred by the Department of Health and NHS England  NICE guidelines are a key source for the development of NICE quality standards and therefore new guidelines developed by NICE are usually chosen from a library of topics for quality standards and then agreed with the relevant commissioning body (NHS England or the Department of Health).
Pancreatic Cancer UK	3	55-56	Although we have concerns over the pancreatic cancer-specific sections of the NICE Referral Guidelines for Suspected Cancer that were published in June 2015, in particular the inclusion of age thresholds and advice on using ultrasound, we agree that identifying pancreatic cancer in primary care and subsequent	Thank you for your comment. We agree.

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			referral to secondary care should not form part of this Guideline. To broaden the Guideline's scope in this way would dilute the much needed potential benefits to be gained from clarifying the best ways to treatment and care for patients once they have been diagnosed.	
Pancreatic Cancer UK	3	68-72	<p>We are very pleased to see that the draft scope includes a question on the information and support needs of pancreatic cancer patients and, just as importantly and often overlooked, their carers.</p> <p>Patients should have access to high-quality information and support throughout their care, including information on their diagnosis, treatment options, side effects, symptom-management, what support is available to them and their key workers contact details. This helps ensure they are fully involved in their care and gives them the power and confidence to make informed decisions about their care.</p> <p>Information should be relayed to patients both verbally and in written-form, so that patients can refer to this information at a later date.</p> <p>Unfortunately, we know that all too often the information and support given to pancreatic cancer patients falls short of the</p>	Thank you for your comment. The guideline will explore the evidence base on the information and support needs of people with pancreatic cancer and make appropriate recommendations based on this evidence.

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			<p>standard of information and support received by other cancer patients. Shockingly, the 2014 National Cancer Patient Experience Survey (NCPES) showed that only 62% of patients in England were given written information about the type of cancer they had, compared to 72% for all cancer sites. The NCPES also shows that only 71% of pancreatic cancer patients were given information on what to expect following discharge from hospital, compared to an average of 85% for other cancers.</p> <p>It is also vital that carers are given information on caring for someone with pancreatic cancer and on where they can find support, so we strongly welcome the draft scope's recognition of this. The information and support given to carers is also lacking, with the NCPES showing that only 55% of the family members of pancreatic cancer patients felt they were given all the information they needed to help care for the patient at home.</p> <p>Ensuring patients have access to a Clinical Nurse Specialist (CNS), is an important aspect of making sure their information and support needs are met. The CNS acts as a keyworker for pancreatic cancer patients, coordinating their care. They provide a single point of contact for patients and their carers if they have any questions. Pancreatic Cancer UK's own analysis of the NCPES found that 87% of patients had access to a CNS. However, it is</p>	

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			<p>unclear how many patients have access to a specialist pancreatic cancer CNS.</p> <p>We hope that access to a CNS will be covered by this section of the consultation, as it is vital to ensure all patients have access to a pancreatic cancer CNS who can ensure their needs are being addressed.</p>	
Pancreatic Cancer UK	3	73-78	<p>Pancreatic Cancer UK welcomes that the Guideline recognises the importance of patients' cases being reviewed by specialist teams. We hope that the National Cancer Intelligence Network can find the resources to provide data in this area.</p> <p>We strongly support the draft scope looking at Multidisciplinary Teams (MDTs) as these are essential to ensuring each patients receive the most appropriate treatment and care.</p> <p>Although the initial focus of an MDT is on a patient's primary treatment, MDTs should be able to review cases if the patient's condition stabilises or improves – e.g. after dietetic intervention or if a tumour responds well to treatment – to ensure their recommendations stay relevant and that patients are still on the best care pathway.</p>	Thank you for your comment. The guideline will explore the evidence base on referral to specialist teams and make appropriate recommendations based on this evidence.
Pancreatic Cancer UK	4	86-87	We are pleased to see those with familial pancreatic cancer and hereditary pancreatitis included in the draft scope as high-risk	Thank you for your comment.

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			groups, as the familial risk of developing pancreatic cancer can often be overlooked.	
Pancreatic Cancer UK	5	111-113	<p>We are extremely pleased to see a question on nutritional intervention included in the draft scope. As such an essential aspect of pancreatic cancer treatment, it is vital that this issue be addressed by the Guideline.</p> <p>However we feel the scope should go further and include looking specifically at the impact of dietetic intervention. Whilst it is true that pancreatic cancer patients should receive a dietetic assessment, in order to assess the level of dietary symptoms they are experiencing and whether they are experiencing malnutrition, it is vital that this then leads to an intervention where appropriate.</p> <p>The express mention of dietetic intervention is necessary to adequately reflect the importance of pancreatic cancer patients having access to a specialist dietitian. This is essential to ensuring they receive the correct information and intervention. A sub-analysis of the 2014 Cancer Patient Experience Survey for England, looking at the experience of just pancreatic cancer patients, found that only 48% (313 out of a total of 655) of pancreatic cancer patients said they had seen a dietitian.</p> <p>The dietary symptoms experienced by pancreatic cancer patients are complex and different from those experienced by patients with other malignancies. For example, pancreatic cancer can lead to</p>	<p>Thank you for your comment. We anticipate this issue may be covered in the review question about nutritional interventions. It will be discussed by the GC when they finalise the review questions during their first few meetings. The guideline will explore the evidence base on nutritional interventions and make appropriate recommendations based on this evidence.</p>

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			<p>Pancreatic Enzyme Insufficiency (PEI), which reduces the ability to digest and absorb nutrients from food. It is important that patients are properly supported to manage PEI, which means more than just being given a bit of written information and a prescription.</p> <p>Patients need input from a specialist dietician to understand how to take enzymes appropriately and how to adjust levels for different foods. We know from conversations with patients via our support line and survivor days that without this specialist input, patients often find themselves taking enzymes wrongly for years. When they do finally receive the correct intervention, the impact it has on them is huge, affecting their wellbeing and daily lives. Evidence from PCUK Support Line users shows that even when pancreatic cancer patients do see a dietitian they only have access to very junior, non-pancreatic specialist dieticians who do not have experience of managing PEI. In addition, we hear that even when it is available the majority of patients are waiting two to three months for dietetic assessment, and the majority of these still do not go on to commence PEI.</p> <p>Some pancreatic cancer patients can also become diabetic. There is increasing evidence of the importance of addressing type 3cDM diabetes, which is particular to pancreatic cancer and pancreatitis, and is almost unheard of amongst many health professionals. It is</p>	

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			<p>important that patients have access to specialist dieticians who can properly inform the patient of how best to manage this type of diabetes.</p> <p>The dietary complications associated with pancreatic cancer can cause dramatic weight loss, reducing the likelihood of a patient being assessed as fit for treatment. PEI has been proposed as a leading cause of the high rate of patients diagnosed with pancreatic malignancy who are unfit for active treatment . Consequently, failing to provide patients with appropriate dietetic interventions can decrease survival times and have a deleterious effect on quality of life.</p> <p>Treatments for pancreatic cancer, including surgery and chemotherapy, can also cause problems with diet, eating and nutrition. It is important that patients have these side-effects properly managed to help them better cope with and complete the treatment, which in turn impacts on survival .</p> <p>A study by The Christie NHS Foundation Trust Hospital found that the median overall survival among patients where dietetic intervention was taken was 14.6 months. It was less than half this, 6.9 months, in patients where no action was taken to address dietary complications . These findings illustrate the significant</p>	

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			<p>impact the correct dietetic intervention can have on survival among pancreatic cancer patients. Dietary complications associated with pancreatic cancer can also significantly reduce quality of life if not dealt with.</p> <p>A 2013 study into the supportive care needs of pancreatic cancer patients found that a major quality of life theme was "difficulty in managing gut symptoms and complex dietary issues". In particular, the study exposed a lack of information about malabsorption and managing symptoms of pancreatic exocrine insufficiency, which was "compounded by a lack of routine dietary consultation: perceived reluctance of clinicians to prescribe enzyme supplements and poor understanding of dose to diet guidelines". As such, the study concluded that enzyme supplement therapy with clear dosage guidelines and dietary advice could "markedly improve quality of life", and was "an essential supportive care" for pancreatic cancer patients.</p> <p>This is corroborated by stories we hear through our Support Line and survivor days of patients only being prescribed 10,000 units of Creon Total Dissolved Solids (TDS). Giving patients too small a dosage means they will find the treatment ineffective at addressing PEI and can lead many patients to stop taking PERT.</p>	

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			<p>Failing to address dietary symptoms not only leaves patients facing considerable discomfort, but can also impact patients' daily life in practical ways. For example, it can leave patients reluctant to go for meals or leave the house in case they are 'caught short'. With the 'urgency' often associated with PEI, patients find themselves always needing to know where the toilets are and that they will have access to a toilet, as well as worrying about experiencing pain after eating. It is vital that patients receive the correct dietetic advice from the onset to ensure they live as well as possible for as long as possible.</p> <p>We frequently hear from patients about the importance of being given the correct advice. One patient told us:</p> <p>"Being given the correct information on how to take enzymes, especially after invasive surgery can help your recovery enormously, making sure they are doing the right job in the right place at the right time.</p> <p>Dieticians should know the correct advice to give patients, as enzymes are taken differently for other illnesses, consequences can be severe stomach pain and diarrhoea."</p> <p>Unfortunately, healthcare professionals too often fail to recognise</p>	

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			<p>the symptoms of PEI or malnutrition in patients, meaning too few pancreatic cancer patients are referred to a specialist dietician or receive information on PERT or PEI. Of the 695 people who called our Support Line last year, 22% rang specifically for advice on diet or about PERT, and we estimate that we end up talking about diet in 80% of Support Line contacts.</p> <p>Meanwhile, analysis of the 2014 Pancreatic Cancer Patient Experience Survey (commissioned by Pancreatic Cancer UK as a follow up to the general 2013 Cancer Patient Experience Survey) shows that only 71% of patients who responded to the survey said they received PERT. There were also variations in the standard of care offered across different age groups and regions of the UK. Older patients (75+) were less likely to be offered PERT than other age groups, and there is no reason that they would be less likely to require PERT.</p> <p>Lack of access to PERT is also a particular problem among patients who have not undergone surgery. A 2010 study concluded that the under-recognition and under-treatment of PEI in patients with advanced disease is an ongoing issue that needs urgent action.</p> <p>One patient told us how she was not referred to a dietician following her Whipples in 2009. This meant she was not properly</p>	

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			<p>advised by her GP on the correct PERT dosage and led to her suffering severe pain and discomfort for 4 years:</p> <p>“I suffered with loose, pale stools and considerable discomfort in my gut. I had some nights when I had really sharp agonising pain. The discomfort increased when I went onto drugs for osteoporosis in late 2013 and it was after this that I first spoke to a specialist nurse at PCUK. She advised me on how much Creon to take and it seemed that it was the first time I was talking to someone that really knew what they were talking about.</p> <p>“After attending a PCUK survivors’ event, I was surprised to hear that some GPs were often reluctant to prescribe PERT. I came back and asked my GP for an increased prescription, as I realised my situation might be improved by an increase in PERT. So what now? My stools are for the most part normal and generally I don’t have discomfort or pain in my gut. My GP practise has been very supportive, but lacking in understanding, meaning basically it has been me leading them on my prescription. A consultant at my specialist hospital has said to me that they simply don’t have time to deal with PERT issues.”</p> <p>Another patient spoke of his slow recovery following surgery, due to a lack of access to PERT:</p>	

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			<p>"I told my surgeon this when I went back for a follow up appointment and asked did I need PERT treatment but he felt I did not require it. It was only after speaking to the PCUK helpline where they provided me with the information and knowledge that I was able to go back to my consultant with all this, and then he agreed to its prescription many months post-surgery."</p> <p>These stories demonstrate the importance of early dietetic intervention in managing the side-effects of pancreatic cancer and treatment, ensuring patients' conditions do not deteriorate, and aiding recovery. They highlight the positive impact the correct dietetic intervention can have on a patient's recovery, survival and quality of life, and how vital it is that patients have access to a specialist pancreatic dietitian who can ensure they receive the correct advice, and that healthcare professionals, are better aware of the importance of dietetic intervention in treating pancreatic cancer. It is therefore essential that the Guideline addresses the need for all pancreatic cancer patients to be given access to a specialist dietician. To ensure the wording of the draft scope allows for this, we feel it is necessary to include specialist dietetic intervention.</p>	
Pancreatic	General	General	Pancreatic cancer patients often have complex supportive care	Thank you for your comment.

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Cancer UK	(p3)		<p>needs, including support dealing with pain management, weight loss, nutritional issues, depression and other emotional and psychological needs. We are concerned that the scope as currently drafted will not allow room for all these issues to be fully addressed.</p> <p>Pancreatic Cancer UK would therefore like to see the inclusion of a separate question within the scope focused more broadly on supportive care, including pain management. This would help ensure that palliative care and all symptom management is covered by the scope.</p> <p>For instance, although the draft scope mentions pain as an outcome (page 5, line 125), there is no reference to pain under key issues and questions. Pain management is often a complex issue for this patient group and many receive inadequate pain relief for neuropathic pain. Patients with advanced pancreatic cancer often experience severe abdominal pain that can be caused by nerves from the pancreas collecting in the coeliac plexus. Although strong pain killers, such as opioids can be used to relieve pain, these often cause uncomfortable side effects, such as constipation and are not completely effective for neuropathic pain. Patients should be given the option of a coeliac plexus nerve block when the pain is unmanageable, and also be prescribed</p>	<p>We have added a clinical question on 'the role of sympathectomy or neurolytic techniques in the management of pain from locally advanced pancreatic cancer'. Other aspects of pain management are covered by existing NICE guidance (Palliative care for adults: strong opioids for pain relief and Neuropathic pain in adults) and therefore will not be covered here.</p>

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			<p>appropriate neuropathic analgesia prior to this.</p> <p>Depression is also a known symptom of pancreatic cancer. It has a greater incidence among pancreatic cancer patients than among patients with other malignancies, and patients often present at their doctor with depression prior to being diagnosed. A 1967 study found that found that 76% of patients with pancreatic cancer had depressive symptoms prior to surgery as compared to 20% of patients with colon cancer<sup>1</sup>. It is essential that depression in pancreatic cancer patients is properly identified and addressed, as studies show that depression can have a negative impact on overall survival and quality of life<sup>2</sup>. It is therefore important that pancreatic cancer patients have access to psychological support. However, we hear from patients contacting the PCUK Support Line that the emotional and psychological support they need is too often not provided.</p> <p>All of the above highlights the need to ensure that pancreatic cancer patients receive a holistic needs assessment and this issue could also be addressed through the inclusion of a question looking at the supportive care needs of patients.</p>	<p>Thank you for your comment. Service delivery aspects of psychological support services are covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a> Therefore we do not propose to include it in this guideline.</p> <p>Thank you for your comment. Assessment of patients needs is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a> Therefore we do not propose to include it in this guideline.</p>

<sup>1</sup> Fras et al, 1967. Comparison of psychiatric symptoms in carcinoma of the pancreas with those in some other intra-abdominal neoplasms. Am J Psychiatry; 123:1553-62

<sup>2</sup> Angelino AF, Treisman GJ, 2001. Major depression and demoralization in cancer patients: diagnostic and treatment considerations. Supportive Care in Cancer. Volume 9, [Issue 5](#), pp 344-349

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			<p>We believe that the scope is right to tackle dietetic assessment, weight loss and nutritional issues - such as supplements – in a wholly separate question (page 5, lines 111-113) and in terms of outcome (page 5, line 124) - and we discuss this in more detail later on in a separate comment of our response.</p> <p>The Guideline provides an opportunity to address disparities in the provision of supportive care by setting out what standard of care pancreatic cancer patients should receive. Part of this should be clarifying that supportive care should be seen as an ongoing and important aspect of pancreatic cancer patients' care throughout their care pathway.</p> <p>Moreover, involving supportive and palliative care teams early on in the care pathway is important for improving quality of life by ensuring the correct management of pain and symptoms throughout the patient journey. It also helps optimise patients' physical and psychological condition from the outset, so that they are in a better condition to undertake treatment.</p> <p>Through our services we frequently hear from patients that they are very unwell at the time of diagnosis, but that their condition</p>	<p>Thank you for your comment.</p> <p>Provision of supportive care for people with pancreatic cancer is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a>. The Department of Health 2001 guidance on Improving outcomes in upper gastro-intestinal cancers also covers supportive care. Therefore we do not propose to include this issue in this guideline.</p> <p>Thank you for this information. We have a question on the specific information and support</p>

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			<p>improves through the provision of good quality information and the correct intervention for their symptoms. For example, many patients have lost weight and muscle mass at the time of diagnosis but a prescription of Pancreatic Enzyme Replacement Therapy (PERT) at this point can ensure they are able to regain some weight and muscle mass, enabling them to better tolerate appropriate treatments. Worryingly, we too often hear of supportive care not being introduced until it is too late.</p> <p>Through discussions with our Patient and Carers Board, we have heard of patients having to fight for supportive care. This includes access to a specialist dietician and psychological support. Meanwhile, carers have stressed the huge difference supportive care can make to their quality of life by relieving them of some of their responsibilities or enabling them to better cope with them. In part, this is due to a reluctance on behalf of both the healthcare professional and the patient to open up discussions around palliative care at an early stage.</p> <p>The Guideline should therefore address how healthcare professionals can ensure effective communication with patients and carers on supportive care. This means sensitively addressing the issue, as well as clarifying that supportive care should not be seen as synonymous with end of life care, and has an important</p>	<p>needs of people with pancreatic cancer and a question on nutritional interventions. In addition the Department of Health 2001 guidance on Improving outcomes in upper gastro-intestinal cancers makes recommendations on information provision.</p> <p>Thank you for this information. We have a question on the specific information and support needs of people with pancreatic cancer. Psychological support is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a>. Therefore we do not propose to include this issue in the guideline.</p> <p>We have a question on the specific information and support needs of people with pancreatic cancer.</p>

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## Pancreatic cancer

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			<p>role to play in symptom management.</p> <p>It is vital that patients receive the correct symptom management and have all their needs addressed. Patients should also be supported to self-manage their symptoms. Unfortunately, we know that this is not always the case. The 2011 Pancreatic Cancer UK report, A Study for Survival, noted many stories of disjointed care and inadequate treatment relating to the management of pain and other serious side effects.</p> <p>It is therefore important that the Guideline addresses all aspects of symptom management and supportive care, to tackle inconsistencies in standards of care and ensure all patients have all their needs met.</p> <p>We also have other concerns round the communication of treatment and care options to patients and their families. We frequently hear reports of patients not having their options communicated to them effectively. For example, we hear of patients only being told that chemotherapy might give them an extra two months 'if they are lucky', but that the treatment may cause more symptoms and side effects than it is worth. While this may be the case for some patients, this information should always be balanced with information on how chemotherapy may help to</p>	<p>Thank you for this information – we agree.</p> <p>Supportive care is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a>. Therefore we do not propose to include this issue in this guideline.</p> <p>We have a question on the specific information and support needs of people with pancreatic cancer. In addition the Department of Health 2001 guidance on Improving outcomes in upper gastro-intestinal cancers makes recommendations on communication.</p>

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			<p>manage symptoms and improve outcomes. These sort of communications are not helpful for patients. They should be given appropriate information to be able to make an informed decision about their treatment options.</p> <p>In addition, we are concerned that the draft scope does not adequately cover the coordination of secondary and palliative care.</p> <p>Currently, there are variations in access to palliative care services between different areas of the country, GP practices and even GPs within the same practice.</p> <p>There are also variations in the type and level of care available for each person. This can be due to whether there is a hospice in a patient's local area, whether the patient has access to a team of community nurses (Macmillan, hospice or palliative) and whether the clinician is aware of how to refer the patient to such services.</p> <p>Better coordination is needed between secondary and palliative care services to address these issues and ensure patients receive timely supportive care.</p>	<p>Planning and co-ordination of services is covered by the NICE guidance on <a href="#">Improving supportive and palliative care for adults with cancer</a>. Therefore we do not propose to include it in this guideline.</p>
Pancreatic Cancer UK	General	General	Pancreatic Cancer UK believes the draft scope should include a question on pathways and delays to treatment once a patient is	Thank you for your comment. Cancer waiting times are part of Department of Health Policy and

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			<p>referred into secondary care.</p> <p>Pathway delays can result in patients' conditions worsening whilst they wait for treatment. For example, whilst 20% of pancreatic cancer patients are eligible for surgery on diagnosis, only 10% go on to receive it. In some instances, this is due to delays in investigations prior to surgery or evidence of metastatic disease that was not evident on initial screening.</p> <p>Delays in investigations can be down to some patients waiting for the insertion of a biliary stent, and then for recovery, before being able to undergo other treatment, such as the Whipples procedure which can increase the chances of the cancer progressing.</p> <p>There should also be a follow-up mechanism for pancreatic cancer patients, to ensure they are receiving the correct interventions at the correct time. For example, currently some patients will wait six weeks for their endoscopic ultrasound as they believe this is normal. Tracking patients' progression through the care pathway would help ensure patients do not experience inappropriate delays.</p>	<p>are closely monitored. NICE does not have a remit in this area. We anticipate that pathways to treatment may be covered in the review question about referral to specialist teams. It will be discussed by the GC when they finalise the review questions during their first few meetings</p> <p>Thank you for this information</p> <p>We have a question on the most effective follow-up protocol for people with resected pancreatic cancer.</p>
RCGP	3	79	<p>Diagnosis of pancreatic cancer does not address the challenge GPs face in early diagnosis in sorting symptoms other than abdominal pain, weight loss and jaundice. Unless the gps have tools such as Qcancer and other systems to aid them, patients will</p>	<p>Thank you for your comment. Early diagnosis of pancreatic cancer is covered by the guideline on Suspected cancer: recognition and referral (NG12). Therefore it is not covered by this</p>

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			continue to be diagnosed last often as emergencies.	guideline.
RCGP	4	94	On treatment patients with other cancers often survive longer with the early involvement of palliative care. This should be considered as a method of trying to improve survival rates.	We agree that this is an area of variation but we do not think there will be evidence of sufficient quality to inform recommendations. Therefore this topic was not prioritised for inclusion in this guideline.
Royal College of Nursing	General	General	There are no comments to submit on this document at this stage. Thank you for the opportunity to comment.	Thank you for your comment
Royal College Pathologists	General	General	The RCPATH has no further comments on this draft scope.	Thank you for your comment
University Hospitals Bristol NHS FT	General	General	I have read the document carefully, having attended the Scoping meeting. I have no changes to suggest. The document covers all of the relevant concerns that I can identify.	Thank you for your comment

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[Registered stakeholders](#)

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