Pancreatic cancer workshop
10.11.15

Table 1. Summary of the workshop group member discussions according to each section of the scope.

Topic		Notes
	Who is the guideline for	
a)	• Pancreatic surgeons • Hepatobiliary surgeons • Upper GI surgeons • General surgeons • Endocrine surgeons • Gastroenterologists • Oncologists • Histopathologists • Radiologists • Palliative care specialists • Nutritional specialists • Clinical nurse specialists • Pancreatic cancer MDTs • Hepatobiliary cancer MDTs • Upper GI cancer MDTs • Endocrine tumour MDTs • Cancer services managers • Hosptial Trust Chief Executives Commissioners of pancreatic cancer services (including Clinical Commissioning Groups and NHS England Specialised Commissioning) Healthcare professionals in primary care Healthcare professionals providing end of life care It may also be relevant for: • People using pancreatic cancer services, their family members and carers, and the public.	It was suggested that the histopathologist bullet was changed to cellular pathologist so that this covers both histopathologists and cytopathologists involved in pancreatic cancer.
1.1	**Who is the focus?** **Groups that will be covered**	
a)	Adults (18 years and over) referred to secondary care with suspected pancreatic cancer	
b)	Adults (18 years and over) with newly diagnosed or recurrent pancreatic cancer	
	Groups that will not be covered	
a)	Adults (18 years and over) in primary care with suspected pancreatic cancer	
b)	People with peri ampullary cancers, neuro-endocrine tumours, sarcoma and lymphomas of the pancreas or metastatic cancers to the pancreas.	There was some concern that peri ampullary cancer is difficult to define and could confuse readers. The patient advocates supported this view and suggested that patients would not distinguish between these types of cancer and

Topic		Notes
		just perceive that they have cancer in their pancreas. It was suggested that excluding peri-ampulary cancers from the scope could allow people to opt out of following the recommendations in the NICE guideline. It was explained that due to resources and the limit in the number of topics that can be addressed in a guideline - covering peri-ampulary cancers would mean missing the bigger picture of pancreatic cancer. It was noted that until the point of diagnosis it is not possible to determine whether it is pancreatic cancer or peri-ampulary cancer so 'opting out' of the NICE guideline would not be appropriate.
1.2	**Settings that will be covered**	
a)	All settings in which NHS care is provided.	
1.3	**Activities, services or aspects of care** **Key areas that will be covered – see notes from 1.5**	
	Areas that will not be covered	
a)	Identification in primary care of people with suspected pancreatic cancer and their referral to secondary care.	
1.5	**Key issues and questions**	
1	**Information and support needs for people with pancreatic cancer and their families.**	
1.1)	What are the specific information and support needs of people diagnosed with pancreatic cancer and their families(e.g. at first diagnosis, during treatment, post treatment)?	It was queried what 'support needs' meant. It was advised that this could encompass anything of a supportive nature. A change in wording to 'supportive care needs' was suggested as an alternative.
2	**Referral to specialist teams**	
2.1)	Does referral of all patients with suspected pancreatic cancer to a regional centre/MDT for review improve patient outcomes?	It was noted that data is available on the number of patients diagnosed with pancreatic cancer who are discussed at MDT, but there may not be data for people with suspected pancreatic cancer. It was asked if there would be data on differences in outcome by region. Data on treatment mortality will be available but not necessarily for survival. A change in wording to the question was suggested - to remove the word 'outcome' and

Topic		Notes
		change the question to 'should patients be referred'. Another suggested change in wording was to use 'patient management outcomes'.
3	**Diagnosing suspected pancreatic cancer**	
3.1)	What is the diagnostic accuracy of CA 19-9, cytology and imaging investigations in the following groups of patients with suspected pancreatic cancer in secondary care? - obstructive jaundice - no jaundice with pancreatic lump - pancreatic cysts - other high risk groups e.g. familial pancreatic cancer and hereditary pancreatitis (PRSS1 mutations).	It was suggested that there is variation across the UK in whether a patient receives a biopsy before surgery. It was suggested that it might be more appropriate to ask 'what investigative tests should be performed to confirm diagnosis?'.
4	**Staging pancreatic cancer**	
4.1)	What is the most effective investigative pathway (for example, combinations of CA19-9, endoluminal ultrasound, CT, MRI, PET-CT, laparoscopy,with ultrasound) for staging pancreatic cancer into resectable, borderline resectable, locally advanced and metastatic disease?	This was noted as a well worded question by many members of the workshop. However, it should say 'lapraroscopy +/- ultrasound' and include cytology.
5	**Management of pancreatic cancer**	
5.1)	What is the optimal surgery for resectable pancreatic cancer?	It was suggested that the wording be changed to 'management' in order to cover adjuvant and neo-adjuvant treatments. It was noted that other questions already cover adjuvant and neo-adjuvant treatments. This one is specifically about surgery. It was suggested that the term 'borderline' - as has been done in topic 5.4. It was suggested that the question should be split by anatomical site rather than stage. However, it was explained that this would make the searching of the evidence more difficult.
5.2)	What is the most effective adjuvant therapy (chemotherapy, chemoradiotherapy or radiotherapy) following resection of pancreatic cancer?	No comments were made.
5.3)	What is the most effective treatment (chemotherapy, chemoradiotherapy, or other local therapies) for locally advanced pancreatic cancer?	It was suggested that this question should include metastatic disease. Locally advanced and metastatic disease are treated differently and have different outcomes so this would need to be added as a separate topic.
5.4)	What are the optimal neoadjuvant therapies (chemotherapy, chemoradiotherapy, do nothing)	One attendee suggested that this question looked at 'optimal management' rather than

Topic		Notes
	in resectable and borderline resectable pancreatic cancer?	'adjuvant' but this was not shared by any other attendees.
5.5)	What is the optimal management of duodenal obstruction?	No comments were made.
5.6)	What is the optimal management of biliary obstruction?	It was clarified that this question could possibly look at 'type of stent' and 'if a stent is used before or after surgery'.
5.7)	What nutritional interventions (e.g. pancreatic enzyme replacement therapy, liquid nutritional supplements) improve outcomes for patients with pancreatic cancer?	It was suggested that the question should include asking whether a patient should see a dietitian – as this is an issue that charity helplines receive a high volume of calls on.
5.8)	Does smoking cessation improve outcomes for patients with pancreatic cancer receiving resection?	There was agreement by the workshop that this question could be deleted if there is a need to lose a topic.
6	**Follow up of people with pancreatic cancer**	
6.1)	What is the most effective follow-up protocol for patients with pancreatic cancer?	The workshop all agreed that this is a very important question as there is so much variation, but the biggest issue is for the patients who have resected disease.

Additional topics to include

It was noted that management of patients with metastatic disease has been omitted from the scope and should be included. The role of systemic palliative chemotherapy is particularly important. It was noted that if this topic was included in the scope it would be unable to include any interventions currently covered by NICE Technology Appraisals, which may limit the interventions this topic can investigate.

They advised that palliative care is offered from diagnosis of advanced disease rather than end of life, and felt that a more holistic approach to these patients is needed.

It was suggested that a topic on palliative/end-of-life care should be included. Patients with pancreatic cancer are highly symptomatic, there are higher numbers with advanced disease at diagnosis and they have poorer outcomes (compared with other cancer sites). It is believed that if a patient's performance score can be improved they could be offered treatment they would have otherwise been denied. NICE advised that they are updating their supportive and palliative care guidance so if there were any issues/areas specific to pancreatic cancer that would not be covered by this general guideline then a topic could be included. However, although all agreed that palliative care plays a large role in pancreatic cancer the stakeholders were unable to identify any issues which were specific to this cancer site.
There was some debate as to what happens when a patient declines further treatment but there was not enough desire to add a topic from the majority of stakeholders.

1.6	**Main Outcomes**	
	Overall survival Disease-free survival Nutritional status Pain Toxicity of treatments Disease-related morbidity	One attendee asked if 'local control' should be included in this list but it was explained that this list is not exhaustive and therefore would not exclude this.

Topic		Notes
	Treatment-related morbidity Treatment-related mortality Health-related quality of life Patient reported outcome measures	
3	**Context**	
3.1	**Key facts and figures**	
3.2	**Current practice**	
	Other There was debate over the definitions of 'borderline', 'resectable' and 'locally advanced' disease. These are not consistent in the literature and there is no agreed definition. This is important to note when looking at the different evidence. It was suggested that it would be useful to add a statement to the guideline as to how the guideline defines each stage. It was queried whether this guideline would replace the Improving Outcomes Guidance (IOG)_ on upper GI cancers. It was advised that we are able to update service topics (which would replace those sections in the IOG) if needed but the IOG would not be replaced as a whole.	

Table 2. Summary of the workshop group member discussions concerning the proposed GC member and expert advisor lists.

Proposed GC member	Proposed Number	Group discussion	Final decision of number
Pancreatic surgeons	2		
Endoscopist (EUS and ERCP)	1		
Clinical oncologist	1		
Medical oncologist	1		
Diagnostic radiologist	1		
Interventional radiologist	1		
Clinical nurse specialists	2	There was discussion that it would be appropriate to either have one from a non-specialist centre and one from a specialist centre, or one surgical and one non-surgical. It was agreed to see who applies and then take this point into consideration.	
Histopathologist	1	Could this be changed to cellular pathologist – see comment above.	
Dietician	1		
Palliative care	1		
Patient/carer member	2	There was some debate as to whether 2 would be enough – it was explained that it would depend on the quality of applicants and if this is high then 3 would be considered.	

		It was noted and agreed by all that it would be very important to include a charity advocate in this selection.

Expert advisors	**Group discussion**
Cancer services manager	

Additional members?