Pancreatitis: diagnosis and management

Consultation on draft scope
Stakeholder comments table

05/07/16 – 02/08/16

ID	Type	Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
1	SH	British Society of Gastrointestinal and Abdominal Radiologists (BSGAR)	General	General	The draft scope covers all of the issues I feel need discussion.	Thank you for your comment and for participating in the consultation process.
2	SH	Department of Health	General	General	Thank you for the opportunity to comment on the draft scope for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment and for participating in the consultation process.
3	SH	Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	General	General	'Pancreatic Cancer Pain Management including pharmacological management' should be added as a key scope area, as this is not covered in the pancreatic cancer guidance	Thank you for your comment. The management of pancreatic cancer is beyond the remit of this guideline. NICE is currently developing separate guidance in this area, please see: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0802.
4	SH	Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	General	General	The document should adequately cover the issues surrounding opioids (such as in the FPM resource Opioids Aware (http://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware) As most pancreatitis patients, especially the chronic ones, are on inappropriately high doses of opioids.	Thank you for your comment. The guideline committee will consider this if recommendations are made related to opioid use.
5	SH	NHS England	General	General	I would prefer it if NICE would include lifestyle interventions please, specifically routine referral to alcohol liaison care team for any patient whose pancreatitis is	Thank you for your comment. We have added lifestyle interventions to the scope with a draft question on the effectiveness of stopping or reducing alcohol

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					thought to be due to alcohol. Stopping drinking alcohol is really important for people whom alcohol has caused acute pancreatitis - best opportunity (though not guarantee) of preventing progression to chronic pancreatitis. Chronic pancreatitis is associated with massive morbidity and premature mortality and costs the health and social care services a fortune.	consumption. It is also the intention to link this guidance to other guidelines which cover lifestyle and well-being recommendations. All NICE guidance related to Lifestyle and well-being is listed on the NICE website at the following address: https://www.nice.org.uk/guidance/lifestyle-and-wellbeing
26	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	All additional information or revisions made be PBRU PPI (the patient public initiative group at the Pancreatic Biomedical Research Unit in Liverpool) are in red and any text copied from the original document is in black. A survey was conducted asking patients with pancreatitis about their experiences of the diagnosis and treatment of their condition. The survey was advertised on UK-based online pancreatitis support groups, and also patients were told about it at the PBRU Patient and Public Forum 2016. The survey was conducted between 25th April and 23rd May 2016. 145 patients filled out the survey. This document has been compiled using the responses from the survey, in addition to patient stories and observation posted on UK-based online pancreatitis support groups. The various recommendations have been compiled from various sources: the free-text submissions on the survey responses, discussions in the PBRU PPI Group and online support groups, and also the author's own opinions. Collated and written by [redacted] and approved and revised before submission by the PPI group members.	Thank you for your comment. We have received a copy of the survey which will be shared with the committee.
27	SH	Pancreas Biomedical Research Unit Patient	2	40	Use of antibiotics for people with acute pancreatitis (including both who should get them and the type of antibiotics) Potential to reduce ineffective practice with cost saving.	Thank you for your comment. The use of antibiotics is included in the scope.

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		Public Initiative			Patient concerns about the type of antibiotics and possible side effects. A patient in the PPI group has suffered significant hearing loss as a result of having had the antibiotic gentamicin.	
28	SH	Pancreas Biomedical Research Unit Patient Public Initiative	3	40	Referral of people with acute and chronic pancreatitis Uncertainty in referral criteria. Potential for resource implications and benefit for improving clinical outcome of patients. • Referral to a pancreas centre is of great importance for both chronic and acute pancreatitis patients because consultants at local hospitals do not necessarily have the knowledge or experience to effectively treat pancreatitis patients effectively. • The patient survey found that patients that are are treated at a specialist pancreatic centre are generally happy with their treatment; those treated only at a local hospital are much less happy with their treatment. • Appendix 1 compares the confidence of patients in their consultant, dietitian and ward nurses at local hospitals and at a pancreas centres. It has been observed in support groups and in the survey that consultants at local hospitals can be very reluctant to refer both chronic and acute patients on to a pancreas specialist. This culture needs to be changed so that referring pancreatitis patients to a specialist centre becomes the norm. • Upon diagnosis of pancreatitis, patients should be referred to a pancreatic centre where they can be treated by pancreatic specialist doctors and/or surgeons, pancreatic specialist dietitians and pain clinics with expert knowledge in pain management.	Thank you for your comment. Referral of people with acute or chronic pancreatitis is covered in the scope.

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					• Potential to be cost saving as the use of less invasive procedures could significantly reduce the length of time in ICU and the overall time spent in hospital. • ACUTE • In researching for this document, there were examples of patients that were treated at their local hospital had more invasive and risky procedures which are no longer used routinely in pancreas centres. Once transferred to a pancreas centre, they have been informed that they would have had a less invasive alternative if they been transferred at an earlier date. • • CHRONIC • 53% of patients said that their consultants at their local hospital (commonly a general gastroenterologist or a general surgeon) didn't refer them to a pancreas specialist. • 54% of patients felt that they had extra hospital admissions that would not have been necessary had they been referred to an appropriate clinician in the first place. • Many patients eventually give up trying to get their consultant to refer them to a pancreas specialist and pay for a private appointment with a pancreas consultant. Many patients that have done this feel that they wouldn't have been seen by a pancreas specialist if they hadn't paid for a private appointment.	
29	SH	Pancreas Biomedical	3	40	Wide variation in practice exists. Potential to improve mortality, quality of life and to reduce inequalities across	Thank you for your comment. Referral of people with acute or chronic pancreatitis is covered in the scope.

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		Research Unit Patient Public Initiative			the UK. Important that patients are either referred to a pancreas centre or that consultants at a local hospital take advice from a pancreas centre. Potential to be cost saving as the use of less invasive procedures could significantly reduce the length of time in ICU and the overall time spent in hospital.	
30	SH	Pancreas Biomedical Research Unit Patient Public Initiative	3	40	Management of pancreatic ascites and pleural effusion for people with pancreatitis (acute and chronic) Wide variation in practice. Different treatments exist. Important that patients are either referred to a pancreas centre or that consultants at a local hospital take advice from a pancreas centre. Potential to be cost saving as the use of less invasive procedures could significantly reduce the length of time in ICU and the overall time spent in hospital.	Thank you for your comment. Management of pancreatic ascites and pleural effusion is covered in the scope.
31	SH	Pancreas Biomedical Research Unit Patient Public Initiative	3	40	Diagnosis of chronic pancreatitis Uncertainty over effectiveness of newer techniques for diagnosis. Variation in practice. • This patient survey found that where the onset of pancreatitis is fast and patients are suddenly acutely ill, diagnosis tends to be very quick. However in cases where the onset of the disease is slow, it can be very difficult to diagnose. This is acknowledged in section 3.1 of the original scoping document. • Appendix 2 is a table showing how long it took patients in the survey to get a diagnosis of pancreatitis. 41.3% of patients in our survey were not diagnosed in this time frame. Over 25% of	Thank you for your comment. Diagnosis of chronic pancreatitis is covered in the scope. .

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					patients take 1-5 years to be diagnosed, but over 10% took more than 5 years to get a diagnosis. • Slow diagnosis can be attributed to poor care, patients not having their symptoms taken seriously or because it can take a long time before pancreatic damage starts to appear on scans. To quote this document (Taken from the first paragraph about chronic pancreatitis in section 3.1) "Some patients however have a more insidious onset. The intensity of pain may range from low to severe even in patients with little evidence of pancreatic disease on imaging" • Many patients felt had treatment started much earlier, they would have had a much better outcome. The survey looked at the reasons why patients had such a delayed diagnosis of their condition: • • 56% of patients felt that their GP had not taken their symptoms seriously. • 32% of patients said that their GP had refused to refer them to a specialist. • 50% of patients felt that their hospital consultant had not ordered the correct tests to diagnose pancreatitis. • 47% of patients experienced delays because paperwork for a referral wasn't sent away or completed properly. • 73% of patients felt that their symptoms were not taken seriously by their consultant. • 53% of patients were misdiagnosed as having IBS.	

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					- 63% of patients were misdiagnosed with something else. - 50% of patients received treatment for a misdiagnosed condition. - 48% of patients were told they were going to receive a particular test or treatment that didn't happen. - - investigations or treatment. Patients had attended A&E because they felt too unwell to cope at home. Many of these patients felt that they were treated like a hypochondriac or a drug seeker - GPs and A&E doctors are generally the first clinicians involved in diagnosing patients when the patient develops pancreatitis symptoms. Patients were asked if they felt that the GPs and A&E doctors they encountered had enough knowledge to diagnose and treat them effectively with/for pancreatitis. APPENDIX 2 is a chart showing whether the patient felt that their GP or A&E staff had enough knowledge to treat them effectively. - Many patients had their pain dismissed as being psychosomatic or psychological by their GP and/or their hospital consultant resulting in a referral to a psychologist/psychiatrist.	

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					This causes a further delay in symptoms being investigated properly and is an upsetting and difficult experience for the patient. • Patients that have had a acute pancreatitis attack know what that feels like, it is a very distinctive pain that feels like nothing else. Many patients continue with the same pain after a confirmed attack, but until damage starts to show up on scans, this is often dismissed. • In forums, patients have observed a lack of consistency in the diagnosis of pancreatitis. For example, a patient can be told by one doctor that they have chronic pancreatitis and by another that they don't. One patient could be given a diagnosis of pancreatitis, but another patient with similar findings on a scan under a different doctor may be told that they do not have chronic pancreatitis. A firm diagnosis is very important to a patient because it validates their pain and symptoms to themselves, their families, their work place and the benefits system. • • Patients find it upsetting to be told that they have a condition by one doctor and then to have this revoked by another doctor. • Some patients have even experienced this with different staff	

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					from the same team e.g. the consultant says one thing and a registrar on the same team says something different. • An MRCP with secretin is an excellent scan for diagnosing chronic pancreatitis, but this is not currently available to all patients, particularly not available for patients treated at local hospitals rather than pancreas centres. • Could the guidelines recommend a method/criteria for the diagnosis of chronic pancreatitis that is followed by all	
32	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	• Before patients had a diagnosis, 58% of patients had attended A&E and were sent home without having any tests, investigations or treatment. Patients had attended A&E because they felt too unwell to cope at home. Many of these patients felt that they were treated like a hypochondriac or a drug seeker • GPs and A&E doctors are generally the first clinicians involved in diagnosing patients when the patient develops pancreatitis symptoms. Patients were asked if they felt that the GPs and A&E doctors they encountered had enough knowledge to diagnose and treat them effectively with/for pancreatitis. APPENDIX 2 is a chart showing whether the patient felt that their GP or A&E staff had enough knowledge to treat them effectively. • Many patients had their pain dismissed as being psychosomatic or psychological by their	Thank you for your comment. Diagnosis of chronic pancreatitis is covered in the scope.

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					GP and/or their hospital consultant resulting in a referral to a psychologist/psychiatrist. This causes a further delay in symptoms being investigated properly and is an upsetting and difficult experience for the patient. • Patients that have had a acute pancreatitis attack know what that feels like, it is a very distinctive pain that feels like nothing else. Many patients continue with the same pain after a confirmed attack, but until damage starts to show up on scans, this is often dismissed. • In forums, patients have observed a lack of consistency in the diagnosis of pancreatitis. For example, a patient can be told by one doctor that they have chronic pancreatitis and by another that they don't. One patient could be given a diagnosis of pancreatitis, but another patient with similar findings on a scan under a different doctor may be told that they do not have chronic pancreatitis. A firm diagnosis is very important to a patient because it validates their pain and symptoms to themselves, their families, their work place and the benefits system. • • Patients find it upsetting to be told that they have a condition by one doctor and then to have this revoked by another doctor. • Some patients have even experienced this with different staff from the same team e.g. the consultant says one thing and a registrar on the same team says something different. • An MRCP with secretin is an excellent scan for diagnosing chronic pancreatitis, but this is	

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					not currently available to all patients, particularly not available for patients treated at local hospitals rather than pancreas centres. • Could the guidelines recommend a method/criteria for the diagnosis of chronic pancreatitis that is followed by all hospitals covered by the NICE guidelines? •	
33	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	• Could the criteria include an indication of chronic pancreatitis where a patient has previously had confirmed acute pancreatitis attacks and continues to have the same pain/symptoms afterwards regardless of what is showing on scans or amylase levels? • What can be done to prevent patients from feeling that their pain is not taken seriously prior to diagnosis? How can cases of pancreatitis be distinguished from other types of abdominal pain if blood amylase levels are not rising? There are many examples of patients in support groups that have eventually been diagnosed with chronic pancreatitis that have never had high amylase levels recorded in blood tests. Of course this doesn't mean they haven't had high amylase levels, just that it hasn't been recorded. • Could the guidelines include a suggested list of tests to try if a patient presents with severe upper quadrant abdominal pain even when early tests are coming back clear? How do the costs of these tests compare to the costs (financial and human) of late diagnosis? • What should patients that have continued with the same symptoms after they have had a	Thank you for your comment. Diagnosis of chronic pancreatitis is covered in the scope. The appropriate diagnosis of pancreatitis will be covered by the scope and specific questions will be considered by the committee during development.

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					confirmed acute attack or a number of acute attacks, but don't have anything showing up on scans be diagnosed with? A the moment, patients are generally told that everything is fine, leaving them in a state of limbo even though the patient feels absolutely terrible. A patient that feels terrible, will find it frustrating and upsetting to have clear scans because clear scans means no diagnosis. No diagnosis means that there isn't any treatment so they are probably stuck feeling terrible. Patients can have the disappointment in not having a diagnosis misinterpreted as the patient wanting to be ill, missing that actually they are ill and want nothing more than to feel better. • Early diagnosis and early treatment e.g. gallbladder removal could potentially reduce the number of patients developing chronic pancreatitis. This would be cost saving financially as well as very significantly improving the quality of life for patients.	
34	SH	Pancreas Biomedical Research Unit Patient Public Initiative	3	40	Assessment of aetiology for people with chronic pancreatitis or idiopathic recurrent acute pancreatitis. Wide variation in practice. More traditional, expensive and riskier interventions may tend to be preferred rather than cheaper, effective alternatives. 1. Many patients are labelled as idiopathic without ever being tested for autoimmune or hereditary pancreatitis. Should these tests be routine for patients presenting with acute or chronic pancreatitis where there is no other clear explanation?	Thank you for your comment. Assessment of aetiology in acute and chronic pancreatitis is covered in the scope. Recommendations made will depend on the evidence found.

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					2. A number of patients have reported in support groups that eventually biliary sludge or microstones were found to be blocking the common bile duct a long time, sometimes years after the onset of symptoms. It is unclear whether this is a later development or could in fact be the cause for pancreatitis in the first place. Would it be beneficial for patients where there is no known cause and gallstones have not shown up on any scans to have a HIDA scan or other tests that could potentially be better at detecting biliary sludge? 3. Of the 14/145 (9.7%) of patients that have been diagnosed with alcoholic pancreatitis in the survey, 11 out of the 14 patients agreed that alcohol was partly the cause, but felt that there were other factors which had led to developing pancreatitis. This was largely because in retrospect they felt that they had symptoms prior to drinking heavily. One patient says that s/he started to have symptoms as a child, but was not believed or taken seriously. S/he said that they struggled with the pain and began self-medicating with alcohol to cope with it. There were also examples of patients that much later on were diagnosed with biliary sludge or gallstones. The question is whether alcohol is entirely the cause of pancreatitis in these patients or whether the onset of pancreatitis was due to something else entirely, butalcohol has then significantly accelerated the onset of pancreatic damage? Is it possible to determine whether alcohol was the original/primary cause of the patient developing pancreatitis? 4. 9/13 patients felt that because they had been	

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					diagnosed with alcoholic pancreatitis, they had not received the same level of investigation into their illness as other pancreatitis patients. Should the aetiology for patients with pancreatitis still be investigated even when heavy drinking is a major factor. 5. Care should be taken with labelling patients as alcoholics. 63.8% of patients said they have been accused of being alcoholics at some point during their illness even when alcohol is not considered to be the cause of their pancreatitis. This is quite commonly in A and E when they are being treated by medical staff that they haven't met before or by an unfamiliar GP. Patients find this offensive and upsetting.	
35	SH	Pancreas Biomedical Research Unit Patient Public Initiative	4	40	Malabsorption or malnutrition in people with chronic pancreatitis Very high priority for patients. Majority of patients are affected. Low cost interventions have potential for reducing hospital admissions and improving quality of life. ● 34.5% of patients have not been given any advice on diet. ● 40.8% of patients said that they have never been referred to a dietitian. ● 28.2% of patients said that the dietitian wasn't knowledgeable enough about their condition to be helpful. ● The traditional advice on diet for pancreatitis patients is to eat a low fat diet. This is still the advice on the NHS pages about pancreatitis (http://www.nhs.uk/Conditions/Pancreatitis-chronic/Pages/Treatment.aspx).	Thank you for your comment. Malabsorption or malnutrition in people with chronic pancreatitis is covered in the scope.

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					● However, many dietitians now advise the opposite, to either eat a "normal" diet or sometimes a high fat diet. This is from a nutritional point of view because eating a low fat diet can result in malnutrition (insufficient fat soluble vitamins) and weight loss. However, from a symptom point of view (pain, nausea, steatorrhea etc), eating a "normal" or high fat diet can have a detrimental effect on symptoms. ● 43.1% of patients said that fatty food causes pain. ● 39.6% of patients said that fatty food sometimes raises pain levels. ● 52.8% of patients said that eating fatty food causes steatorrhea. ● When asked what other foods affect their symptoms, patients came up with a long and varied list. ● Patients can be prescribed nutritional supplement drinks that contain "part digested" fats and proteins. These are much easier to digest than the fats and proteins found in normal foods, thus helping to maintain full nutrition withminimal impact on symptoms. ● A recurrent problem is that there are not many low fat options for patients in hospitals. This makes the process of starting to eat again after an acute attack or a bad chronic pancreatitis flare up much more difficult. Often there isn't any information available on the fat content of the food so patients have to guess! ● Quite commonly the prescribing information on the bottle of capsules is "Take two capsules three	

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					times a day". There are so many different ways of taking pancreatic enzyme replacement therapy e.g. before eating, as you start to eat, spread out through the meal, the capsule swallowed whole with water, open the capsule and sprinkle on acidic food etc.	
36	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	● The patient should be guided to work out what method works best for them. ● If the pancreas is working properly, the amount of enzymes released varies depending on the fat content of the food eaten. However, only 39.6% of patients have been taught how to vary the amount of enzymes they take depending on the type and amount of food they are eating. (In comparison, cystic fibrosis patients on enzyme replacement therapy are taught to vary the amount of enzymes they take depending on what is being eaten.) ● Creon is the most common brand of enzyme replacement therapy, but some patients suffer adverse side effects. Some patients experience less side effects with other brands of enzyme replacement therapy so other brands need to be made available	Thank you for your comment. Malabsorption or malnutrition in people with chronic pancreatitis is covered in the scope.
37	SH	Pancreas Biomedical Research Unit Patient Public Initiative	4	40	Location, frequency and investigations of follow up for people with chronic pancreatitis Potential for saving on investigations and cost of hospital care. ● Many patients find themselves discharged from their consultant once the consultant feels that s/he cannot perform more procedures. Patients find it upsetting to not have a consultant monitoring their care, they feel very alone and as if nobody cares	Thank you for your comment. Location, frequency and investigations for follow up for people with chronic pancreatitis is covered in the scope.

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					what happens to them. ● Patients feel that their GP has insufficient knowledge of their condition to treat them effectively so they feel uncomfortable to only be under the care of their GP. See appendix 3. Commonly GP's lack the expertise required to answer questions and will ask the patient to contact their consultant to answer a question. ● Patients worry a lot about developing pancreatic cancer so want periodic imaging to check for pancreatic cancer or any other developments that could be treated e.g. stone/calcification removed, drain pseudocysts, stretch a constricted duct etc. If patients are referred back to their GP, how will it be ensured that patients are regularly screened for pancreatic cancer and other developments in their contition? ● If a patient remains under a pancreatic consultant, better care and monitoring and suitable adjustments to medication/treatment etc could potentially reduce need for emergency admissions so could actually be cost saving on the long term. ● If a patient is purely under GP care patient's condition worsens, they have to start all over again with the referral process which can take many months.	
38	SH	Pancreas Biomedical Research Unit Patient	4	40	Surveillance for pancreatic cancer in people with chronic pancreatitis Chronic pancreatitis significantly increases the risk of	Thank you for your comment. Surveillance for pancreatic cancer in people with chronic pancreatitis is covered in the scope.

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		Public Initiative			pancreatic cancer. This risk is much higher in those with hereditary pancreatitis. ● Considered to be a high priority by patients. ● Do all patients need to be tested for hereditary pancreatitis to know if they are in a higher risk category for pancreatic cancer? ● How often should patients be scanned/screened? ● Do they need to be under a pancreas consultant for this or could these tests be arranged elsewhere? ● Identification and monitoring of relatives with the PRSS 1 and other genes lead to early diagnosis of pancreatic cancer. ● Early diagnosis of pancreatic cancer dramatically improves the prognosis for the patient and is also potentially cost saving.	
39	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	40	Information and support needs for people with chronic pancreatitis, and their families and carers Wide variation in support offered. Acute pancreatitis affects large numbers of patient days in hospital/ITU resulting in high level of patient anxiety. Chronic pancreatitis: very important in specific groups of patients. Potential for high impact in reducing inequalities ● Patients do often feel that there isn't adequate support for pancreatitis patients. ● Many patients suffer PTSD after severe acute pancreatitis, particularly where they have had an extended stay in ITU. ● Patients have found it very helpful to have a diary kept of what is happening to them by family members when they are very acutely ill. It can	Thank you for your comment. The appropriate provision of information for people with pancreatitis is covered in the scope. This may include advice on smoking and alcohol cessation. We have not prioritised a question for evaluating the impact of mental health on wellbeing in people with pancreatitis, or on methods to treat mental health conditions comorbid to pancreatitis in the scope. It was believed more generic guidance on wellbeing or mental health conditions would cover these issues. NICE has produced a guideline on Depression in adults with a chronic physical health problem: recognition and management (https://www.nice.org.uk/guidance/CG91).

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					help them to come to terms with it later on. ● Negative impact on mental health. 82% of patients in the survey said that their illness had a negative impact on their mood and mental health. ● 44% of patients said they would like to have access to talking therapies e.g. cogitative behavioral therapy, but most patients have not been offered anything like this on the NHS. ● Some patients are offered pain management courses at their pain clinic. These usually include some mindfulness and CBT. ● Patients get a lot of benefit from peer support. This is generally in the form of support groups.. Pancreas North is a support group that meets monthly, but is only in the Newcastle area. There are also online support groups. There are a number of them on facebook and the Pancreatitis Supporters Forum is an independent online support group. Should there be more regional groups like Pancreas North? Can consultants/pancreas nurses encourage use of support groups? **Impact on mental Health** The mental effects of a very painful condition like pancreatitis are not given sufficient attention. Treating mental health in tandem with physical health will help patients to cope better with their situation. **Support with smoking cessation** ● 52.7% of patients had not been told that continuing to smoke could worsen their condition. ● 61% of patients said that they were not given adequate support to give up smoking. ● Patients are not all aware of the nicotine replacement products available on the NHS.	

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					APPENDIX 4 is a chart showing how many people accessed nicotine replacement products on the NHS. **Support with Alcohol Cessation** ● 4/14 felt it hadn't been adequately explained to them that continuing to drink alcohol could have serious consequences. ● Only 1/9 patients in the survey were offered the alcohol cessation treatment that they wanted on the NHS. ● Some patients found that they were offered alcohol cessation treatment on the NHS, but there was a long wait for it so had to go privately.	
40	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	**Communication** ● The survey highlighted that many patients don't have adequate information about their diagnoses and treatment. Many clinicians are not explaining diagnosis or treatment in a way that patients can easily understand. Patients also need to have evidence to present to their employer if they are frequently absent or have to go through the process of early retirement on health grounds. ● 63% of patients have said that they have left a clinical appointment not fully understanding the diagnosis or treatment. ● 30% of patients said that they have had a procedure without fully understanding what is happening to them. ● 32% of patients felt that they have not had adequate information before having a procedure	Thank you for your comment. The appropriate provision of information for people with pancreatitis is covered in the scope. This may include information about alcohol and smoking cessation. NICE produce a version of the guideline titled 'Information for the public' for all guidelines. This is written in plain English and summarises the guideline recommendations in a way that is accessible to members of the public. This usually provides links to key charities, such as those relevant to pancreatitis. Lay members of the group help advise on this. NICE has also produced a patient experience guideline (138) (https://www.nice.org.uk/guidance/cg138), which provides guidance on effective communication between healthcare professionals and patients.

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					to make the decision about having it or not. ● 25% of patients said that they would not have made that decision had they had more information. ● 63% of patients said that they never or only sometimes get copies of reports from procedures/investigations or copies of GP letters. 39% of patients never or not always understand the reports/procedures/discharge summaries. ● 86% of patients said they never or only sometimes receive leaflets about the procedure/treatment. ● 62% of people said that they have never been directed to a website to help understand treatment/diagnosis. ● Patients should not be left in a position where they need to research and discover the information themselves because there are a number of obstacles. 65% of patients said that their GP/Consultant never or only sometimes provides written information about their treatment or diagnosis. ● 53% of patients said that they don't always find it easy to research their condition/treatment. ● 53% of patients don't always understand the information that they find on the internet about their condition/treatment. ● 55% of patients said that they can't always tell which websites are trustworthy, reliable and accurate. 60% of patients said that they rely on online support groups to find out information about their treatment/condition. This can be problematic because the information is not always accurate and can make patients worry more.	

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					● There are many websites on the treatment and diagnosis of pancreatitis. Whilst many of these websites are accurate and helpful, there are also many websites containing inaccurate information or alternative/complementary medicine that are not supported by science.	
41	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	● Whilst online support groups can be helpful, again, there is a lot of advice given out that is inaccurate or not supported by research and many patients find it difficult to work out what is accurate and good advice and what isn't. ● ● The majority of websites containing information about the treatment or diagnosis of pancreatitis are academic papers written in language that isn't suitable for the general public to easily understand. ● ● Duration between appointments with a consultant can be quite variable; 70% of patients normally see their consultant once every 6 months or less often. That is a long time to wait to get further explanation about treatment or diagnosis. ● ● Lack of understanding about a patient's own condition or treatment can lead to increased anxiety. ● Patients often don't understand what medication is for or why it needs to be taken in a particular way.**Applying for benefits or early retirement on health grounds** ● ● 45.6% of patients said that they are no longer able to work or attend school/college/university.	Thank you for your comment. The appropriate provision of information for people with pancreatitis is covered by the scope. This review may include signposting to financial advice and support. The appropriate follow-up for people with pancreatitis is also covered in the scope. NICE produces another version of the guideline: "Information for the public" written in plain English that usually provides links to key charities, such as those relevant to pancreatitis. Lay members of the group help advise on this.

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					12.7% of patients said that they have had to reduce their hours and 19.7% said that they are frequently absent from school/college/university. ● Patients are often not aware of the importance of keeping all of the documentation until they are in a position where they need to apply for benefits/early retirement on health grounds by which point it can be too late. ● Although the DWP (Department for Work and Pensions) says that they will contact the patient's GP and other clinicians this frequently does not happen. Many consultants won't write a letter for benefits unless they are contacted directly by the DWP. This often means that there isn't enough evidence provided and the patient doesn't qualify for benefits. ● Nurses with specialist knowledge of pancreatitis are currently very rare, but where they do exist they are huge support and help to patients and take some of the workload off the consultants themselves.	
42	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	40 – This is a topic suggested as an addition.	● We would like pain management to be addressed as a separate point. Pancreatic pain is debilitating and has a huge impact on quality of life. ● ● Pain management is a very high priority for patients. ● Pain management is not necessarily addressed by the consultant responsible for the patient's care. ● Managing pancreatic pain, particularly in chronic pancreatitis is different from managing other types of pain. Ideally patients should be seen by consultants specialising in pancreatic pain.	Thank you for your comment. The scope has specified that pain in people with pancreatitis will be a key outcome across the reviews. Several review questions included in the scope will also address pain management. The guideline committee will also include a pain specialist to ensure that issues specific to pain in people with pancreatitis is covered. However, strategies for managing pain that are not specific to pancreatitis (for example, CBT or pain management courses) have not been prioritised for inclusion in the scope. The location of hospital services is a consideration common to many acute conditions, and therefore has also

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					● Other pain management techniques other than medication should be looked into e.g. celiac plexus block (both through the back and EUS guided), ketomine infusions and has a very negative effect on quality of life. ● CBT or pain management courses are very effective for helping patients cope better with their pain. Although care needs to be taken when referring a patient because they can get the impression that the clinician thinks their pain is psychosomatic. ● Patients are often treated at a hospital miles away from home so their local hospital may not have all of the relevant notes. This will slow down the treatment and could result in tests that would not be necessary if their full medical history is known. ● Could NICE suggest further research into methods for managing pancreatic pain? ● Could admission routes be developed for these patients that would could avoid A&E? This could potentially remove some strain on A&E services and also as the potential to be cost saving..	not been prioritised for inclusion in the scope. We have not prioritised admission routes and indications for referral for people with acute pancreatitis for inclusion in the scope. Thank you for your research suggestions. During development of the guideline, if gaps and uncertainties are identified in the evidence base which could benefit from further research are identified in the reviews, the committee will consider developing the most important unanswered questions into research recommendations.
43	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	40 – This is a topic suggested as an addition.	Managing type 3c diabetes ● There are only NICE guidelines for types 1 and 2 diabetes, but not for treating type 3c diabetes. Treating type 3c is considerably different which is why some guidance/information on managing type 3c diabetes would be valuable. ● There is very poor awareness of type 3c diabetes, even the Diabetes UK website has very little information on it and it isn't even included on the main list of types of diabetes. 86% of the diabetic patients in the survey had been told that their	Thank you for your comment. The wording has been amended to clarify that this is included in the scope of the guideline.

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					pancreatitis is the cause of their diabetes, but only 36.4% of patients were labeled as type 3c. 27.3% were labeled as type 2 and 36.4% were labeled as type 1. ● Type 3c diabetes is particularly difficult to manage when a patient has had a partial or total pancrectomy. ● Due to the extra difficulties in managing this condition, can routes for funding for diabetic hardware e.g. insulin pumps and continuous blood sugar monitors. ● Many patients with very poor blood sugar control have had to fight a huge battle to get funding for insulin pumps, continuous	
44	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	40 – This is a topic suggested as an addition.	Individual Care plans for patients with recurrent acute or chronic pancreatitis ● Patients with recurrent acute pancreatitis or chronic pancreatitis should have care plans that address daily management, mild flare ups (manageable at home perhaps with support from GP's) and also emergency care plans for acute attacks or chronic flare ups that aren't manageable at home. This could potentially be cost saving by reducing the number of admissions and only admitting patients when in-patient care is the only option. ● Patients frequently have bad experiences in A&E departments.. ● It often takes a day or two after admission for all of the medication that a patient takes at home to be prescribed properly which can be quite problematic. ● The home treatment plan would be under the responsibility of the GP. e.g. home visits by a GP	Thank you for your comment. This area was not prioritised for inclusion in this guideline.

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					to administer antiemetic injections or extra pain relief or to speak on the phone to the patient to adjust doses of medication etc. ● 60.5% of patients said that they have been sent home from A&E when they felt too unwell to cope at home. ● 29.8% of patients said that they have been refused an ambulance when they felt too unwell to cope at home. ● 38.2% of patients have said that they have been refused a home visit by a GP when they felt too unwell to get to the doctors' surgery. Home visits could potentially reduce the need for a patient to attend A&E or a hospital admission. ● 66.6% of patients said that they were not prescribed sufficient pain medication or antiemetic to cope with their symptoms at home, particularly when they have a flare up. ● 43.3% of patients have been told by their GP that they cannot prescribe a particular drug to them. This is particularly common with the drug Ondansetron. Patients have been told that this can only be prescribed for cancer patients. Again, having this effective drug at home could reduce the need for A&E visits and hospital admissions. ● In A&E, the doctors often begin the diagnosis process from the beginning which is frustrating when the patient already has a diagnosis. It is also a waste of NHS time and resources. ● Patients that have suffered many attacks generally know the treatment they need to feel better, but most feel they can't tell the A&E staff because they are then treated like a drug seeker. ● Patients with chronic pancreatitis can suffer a severe flare up without amylase levels rising. This	

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					isn't always understood by A&E staff. ● A lot of patients are treated at multiple hospitals which can become confusing and there is often little or no communication between the consultants and clinicians.	
45	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	● This is particularly problematic when a patient is treated a long way from home so visits their local hospital rather than the hospital where they are treated in an emergency situation. It can be problematic when the A&E doctors do not have access to any of the patient's notes. Patients should have treatment plans either available on the NHS computer system or in a form that they can present themselves when they arrive in A&E or to a paramedic. This will enable treatment to start immediately without needing to try and diagnose the patient every time they attend A&E. ● The home treatment plan would be under the responsibility of the GP. e.g. home visits by a GP to administer antiemetic injections or extra pain relief or to speak on the phone to the patient to adjust doses of medication etc. ● The creation of a process by which a GP can arrange to admit a known pancreatitis patient into hospital directly, avoiding A&E.	Thank you for your comment. The location of hospital services is a consideration common to many acute conditions, and therefore has not been prioritised for inclusion in the scope. However, the location of follow up for patients with chronic pancreatitis is covered in the scope. We have not prioritised admission routes for people with acute pancreatitis, or the appropriateness of treatment plans, for inclusion in the scope
46	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	42	Management of gall stones Covered in NICE guidelines on gallstone disease The "Gallstone disease: diagnosis and initial management" NICE guidelines are excellent. These were only published in 2014, and is most likely that the majority of patients were treated prior to the publication of these guidelines. Hopefully the guidelines are now being	Thank you for your comment. As you note, the management of gallstones is covered by existing NICE guidance and so has not been prioritised for inclusion in this guideline.

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					followed and there will be a reduction in the problems encountered in the survey, but here is an account of problems faced by patients. 28.7% of patients said that their pancreatitis was originally caused by gallstones and 7% of patients said that their pancreatitis had originally been caused by biliary sludge or micro-gallstones. Similarly, to pancreatitis, many patients had to wait a long time before they were finally diagnosed with gallstones/biliary sludge. APPENDIX 5 is a chart showing the amount of time it took for patients to get a diagnosis of gallstones from the onset of symptoms. 35.8% of patients took more than a year to get a diagnosis of gallstones. Some patients in the support groups had experience of small gallstones/biliary sludge being too small to show up on ultra sound, CT, MRCP etc. Some patients said that despite symptoms strongly indicating gallstones, following any of these scans coming back clear, gallstones/biliary sludge was initially ruled out and only found much later on. Patients with this experience feel that had the stones/sludge been found earlier on, they may have had a much better outcome. Patients are quite often discharged from a cholecystectomy (gallbladder removal) without a follow-up appointment. If a patient continues to have symptoms e.g. still have stones trapped in the common bile duct, patients have to start from the beginning with referrals etc, making the whole process much slower. Many patients felt their GP lacked awareness of possible problems following a cholecystectomy, again slowing down the diagnostic process. If a patient continues to have the same symptoms after a cholecystectomy, this needs to be investigated further and not dismissed.	

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47	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	42	Management of diabetes mellitus in people with pancreatitis Management of diabetes mellitus is likely to be the same for patients with pancreatitis as any patient with diabetes. Patients with type 3c disagree because it is much more difficult to control, particularly patients that are post total or partial pancrectomy. More accessibility/funding for patients that struggle to control their blood sugar levels for equipment e.g a continuous blood sugar monitor or insulin pump because blood sugar levels can be much harder to control. Could pancreas centres have specialist type 3c nurses? Better control of diabetes has the potential to be cost saving because it will help prevent or reduce diabetes related complications.	The general management of diabetes will not be addressed in this guideline as it is covered by other NICE guidance. The management of type 3c diabetes will be addressed. Specific questions will be written by the committee when appointed.
48	SH	Pancreas Biomedical Research Unit Patient Public Initiative	5	42	Lifestyle interventions Low priority area for this topic as it is covered by other general guidance. Review of this area would be unlikely to change current practice. Many patients felt insufficient advice and support given for alcohol and smoking cessation. These services exist, but patients are not necessarily able to access them. Perhaps publicity or invitation to use these services and increased accessibility needs to be addressed for patients with alcohol or tobacco addictions.	Thank you for your comment. Information and support needs for people with pancreatitis are covered in the scope. Lifestyle interventions have now been added to the scope with a specific question on the effectiveness of stopping or reducing alcohol consumption.
49	SH	Pancreas Biomedical Research Unit Patient	7	71	1.8 What are the indications for referral of patients with acute or chronic pancreatitis to a specialist centre?	Thank you for your comment. This is covered in the scope.

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		Public Initiative				
50	SH	Pancreas Biomedical Research Unit Patient Public Initiative	7	92	3.7 What is the most clinically and cost-effective intervention for managing malabsorption and malnutrition?	Thank you for your comment. This is covered in the scope.
51	SH	Pancreas Biomedical Research Unit Patient Public Initiative	7	92	Add in this question - What are the indications for tube feeding in patients with chronic or acute pancreatitis?	Thank you for your comment. This will be considered when discussing the protocols for the management of malabsorption and malnutrition for chronic pancreatitis. The specific interventions that will be covered will be specified by the guideline committee when setting the review protocol.
52	SH	Pancreas Biomedical Research Unit Patient Public Initiative	8	109	Add in the following questions:- What is the most clinically and cost-effective pain management strategy in patients with acute pancreatitis? What is the most clinically and cost-effective pain management strategy for patients chronic pancreatitis? What is the most clinically and cost-effective management strategy for type 3c diabetes? What are the indicators for use of insulin pumps and continuous blood sugar monitors in type 3c patients, particularly patients that have had a partial or total pancrectomy?	Thank you for your comment. The scope has specified that pain in people with pancreatitis will be a key outcome across the reviews. Several review questions included in the scope will also address pain management. The guideline committee will also include a pain specialist to ensure that issues specific to pain in people with pancreatitis are covered. The scope also includes consideration of interventions for the management of type 3c diabetes.
53	SH	Pancreas Biomedical Research Unit Patient Public Initiative	General	General	Recommendations for further research:- ● Improving methods of diagnosing chronic pancreatitis particularly in the early stages of the disease where a patient that has had confirmed acute pancreatitis attacks continues to have symptoms, but doesn't show visible changes on scans. ● Research methods of pain management in	Thank you for your research suggestions. During development of the guideline, if gaps and uncertainties are identified in the evidence base which could benefit from further research, the group develops the most important unanswered questions into research recommendations.

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					chronic and acute pancreatitis patients ● Does fat aggravate symptoms in chronic pancreatitis patients? Do all fats cause a problem or are some fats less problematic? ● In chronic pancreatitis support groups, women regularly post about how their symptoms are much worse at certain points during their menstruation cycle (normally just before or when their period comes). Each time this is posted, there is always a long list of patients commenting in agreement. Similarly many pregnant women found that they were much more well for most of their pregnancy. It would be interesting to see if the contraceptive pill or HRT could better control symptoms that are aggravated by changes in hormones. ● A common question in support groups is whether it is OK for pancreatitis patients to drink alcohol when alcohol is not the cause. ● There are examples of families with multiple family members with pancreatitis that have all tested negative for PRSS1, SPINK 1 and CF genes. This suggests that there are additional genes that increase the likelihood of developing pancreatitis that haven't yet been identified.	
20	SH	Pancreas North Pancreatitis Patients Support Group	4-5	103-111	Would these 3 issues be the only possible causes of pain in someone suffering from Chronic Pancreatitis even if it was Hereditary or Auto-immune Pancreatitis? If there are other causes of pain can they be included?	Thank you for your comment. We believe we have covered the main areas for pain, but the committee will consider other areas during discussions on the review protocol. Additionally, the committee membership includes a pain specialist to ensure that this perspective is covered on the guideline.
12	SH	Pancreas North	2	39	Typing error – needs space between in people	Thank you for your comment. This has been amended.

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		Pancreatitis Patients Support Group				
21	SH	Pancreas North Pancreatitis Patients Support Group	5	125	Should a specialist centre be included as a possible place for follow-up? If someone suffers from a form of Pancreatitis that gives them a very high risk of Pancreatic Cancer, should they be followed-up in a specialist centre that will offer the best screening methods and expertise in assessing results?	Thank you for your comment. The draft question has been amended and now reads: Where should the follow up of people with chronic pancreatitis take place - primary, secondary or tertiary care?
25	SH	Pancreas North Pancreatitis Patients Support Group	11	260	Typing error – needs space between people with	Thank you for your comment. This has been amended.
7	SH	Royal College of General Practitioners	General	General	The RCGP welcomes this document but feels that it is more secondary care based. However it would be appropriate to indicate a reason to not include investigation and diagnosis of acute pancreatitis. [redacted]	Thank you for your comment. The diagnosis of acute pancreatitis in current practice is relatively straight forward being done via a standardised test in hospital. This is not an area where practice is considered to vary across the country and therefore has not been prioritised for inclusion in this guideline. Further, the guideline scope includes indications for referring people with acute pancreatitis for specialist input or to a specialist centre.
8	SH	Royal College of General Practitioners	General	General	Evidence from CPRD published in the British Journal of General Practice suggests that there is potential for earlier diagnosis in in primary care with a medical of 3 contact with a GP before diagnosis was made. Evaluating point of care testing should be considered.	Thank you for your comment. We believe this comment applies to patients with chronic pancreatitis which is usually diagnosed in secondary care. The committee will consider this during development of the protocol for the question on diagnosis and investigations.

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					The paper also highlights the increased risk during cholecystectomy and consideration needs to be focused on ways to minimise the risks Evaluating pancreatitis in primary care: a population-based cohort study (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4001169/) Nisha Hazra, Martin Gulliford Br J Gen Pract. 2014 May; 64(622): e295–e301. Published online 2014 April 28. doi: 10.3399/bjgp14X679732 PMCID: PMC4001169 [redacted]	
9	SH	Royal College of Nursing	General	General	This is to inform you that the Royal College of nursing have no comments to submit to inform on the Pancreatitis: diagnosis and management draft scope consultation. Thank you for the opportunity to participate. We look forward to participating in the next stage.	Thank you for participating in the consultation process.
10	SH	Royal College of Paediatrics and Child Health	General	General	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the Pancreatitis consultation, unfortunately we have not received any responses.	Thank you for participating in the consultation process
14	SH	Thermo Fisher Scientific	2	39-41	Procalcitonin can be used to predict if there is a bacterial infection, i.e. who should and shouldn’t be offered antibiotics. It is the most sensitive tool available to detect pancreatic infection.	Thank you for your comment. This will be considered when the committee discusses the management of necrosis in people with acute pancreatitis.
17	SH	Thermo Fisher Scientific	4	82	The draft scope appears to be favouring phophylaxis. Given clinical trials have suggested that prophylaxis may not be all that effective in regard to avoidance of infection of necrosis and associated complications, I’m not sure this is the best avenue. 1. *de Vries AC, Besselink MG, Buskens E, Ridwan*	Thank you for your comment and the references you have provided. The scope covers the effectiveness of prophylactic antibiotics in order to assess what role it should have in the care of people with acute pancreatitis. Evidence found in this area will be presented to the group for their consideration.

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					BU, Schipper M, van Erpecum KJ, Gooszen HG. Randomized controlled trials of antibiotic prophylaxis in severe acute pancreatitis: relationship between methodological quality and outcome. ***Pancreatology****. 2007;7:531–538* 2. *Isenmann R, Rünzi M, Kron M, Kahl S, Kraus D, Jung N, Maier L, Malfertheiner P, Goebell H, Beger HG. Prophylactic antibiotic treatment in patients with predicted severe acute pancreatitis: a placebo-controlled, double-blind trial.* ***Gastroenterology****. 2004;126:997–1004* 3. *Dellinger EP, Tellado JM, Soto NE, Ashley SW, Barie PS, Dugernier T, et al. Early antibiotic treatment for severe acute necrotizing pancreatitis: a randomized, double-blind, placebo controlled study.* ***Ann Surg*** *2007 May;245(5):674e83.* 4. *Wittau M, Mayer B, Scheele J, Henne-Bruns D, Dellinger EP, Isenmann R. Systematic review and meta-analysis of antibiotic prophylaxis in severe acute pancreatitis.* ***Scand J Gastroenterol.*** *2011 Mar;46(3):261-70*	
18	SH	Thermo Fisher Scientific	4	85	The studies named (and others, comment 2) have demonstrated that prophylaxis is not clinically effective. Further, prophylaxis may introduce increased hospitalisation costs and antimicrobial resistance	Thank you for your comment. The scope covers the effectiveness of prophylactic antibiotics. Evidence found in this area will be presented to the group for their consideration.
19	SH	Thermo Fisher Scientific	4	85	A small body of evidence has shown that procalcitonin is clinically effective at reducing antibiotic use safely in acute pancreatitis – 1. *Mofidi R, Suttie SA, Patil PV, Ogston S, Parks RW. The value of procalcitonin at predicting the severity of acute pancreatitis and development of infected pancreatic necrosis: systematic review.* ***Surgery*** *2009 Jul;146(1):72e81.* 2. *Cai Y, Chlebicki MP, Goh YC, Kwa AL. et al. A*	Thank you for your comment. This will be considered when the committee discusses the management of necrosis in people with acute pancreatitis

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					procalcitonin-based guideline promotes shorter duration of antibiotic use safely in acute pancreatitis, ***Journal of Infection*** *, Volume 69 , Issue 4 , 412 - 415*	

**There were no links to, or funding from, the tobacco industry disclosed by commenters.*

Registered stakeholders