

**Pancreatitis: diagnosis and management**

**Consultation on draft guideline - Stakeholder comments table  
12 March 2018 – 25 April 2018**

*Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.*

<b>Stakeholder</b>	<b>Document</b>	<b>Page No</b>	<b>Line No</b>	<b>Comments</b> Please insert each new comment in a new row	<b>Developer's response</b> Please respond to each comment
Association for Clinical Biochemistry and Laboratory Medicine	Full	general	general	If the definition of Chronic Pancreatitis is accepted as a structural diagnosis rather than a functional one, it can be accepted that imaging tests are the first line tests. However it is possible to return a diagnosis of CP with no discernible structural abnormalities in the presence of documented exocrine pancreatic insufficiency. The main accepted diagnostic test of declining exocrine pancreatic function is the faecal pancreatic elastase type 1 (FPE1) test. For diagnosis of the active inflammatory stage of Acute or Recurrent Acute Pancreatitis, serum lipase or serum pancreatic amylase is preferred because each demonstrates much greater sensitivity with no loss of specificity compared to serum total amylase. To distinguish Acute-on-chronic or Recurrent Acute Pancreatitis, or to document an underlying decline in exocrine secretory capacity, a test of exocrine pancreatic	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We agree that imaging tests are the first line tests. We have made it clearer that this guideline assumes that people with chronic abdominal pain will already have been investigated using CT scan, ultrasound scan or upper gastrointestinal endoscopy to determine a cause for their symptoms. Our focus was to review the evidence on what tests should be done if a definitive diagnosis of chronic pancreatitis had not been made with initial imaging. Faecal elastase was one of the index tests evaluated but insufficient evidence was found to make a recommendation about which test or tests should be used.</p> <p>The diagnosis of acute pancreatitis was excluded from the scope of this guideline so we are unable to make any recommendations in this area. .</p>

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				function (eg FPE1) may usefully be performed during the quiescent phase when symptoms of acute pancreatic inflammation have subsided.	
Association for Clinical Biochemistry and Laboratory Medicine	Short	general	general	Pancreatitis is often a progressive disorder characterised by decreasing exocrine secretory capacity therefore serial investigations of Exocrine Pancreatic Insufficiency (EPI) are usually required for surveillance. These should be performed at a time when the patient is free of symptoms of active pancreatic inflammation.	Thank you for your comment and for contributing to the consultation process. We recommended follow up and monitoring at least every 12 months for pancreatic exocrine insufficiency. The clinician will decide to do further clinical and biochemical assessments. We agree that it would be normal for tests of pancreatic insufficiency to be carried out when the patient is free of symptoms of acute inflammation and have added this information in the full guideline in the section on linking evidence to recommendations.
Association for Clinical Biochemistry and Laboratory Medicine	Short	general	general	A plain X-Ray of the abdomen may demonstrate the presence of pancreatic calculi and this finding is thought to be pathognomonic of Chronic Pancreatitis irrespective of other features or biochemistry	Thank you for your comment and for contributing to the consultation process. The guideline pathway starts after initial first line imaging has occurred and the committee agreed that current clinical practice is that patients will be investigated using CT scan, ultrasound or upper gastrointestinal endoscopy. Plain X-Ray of the abdomen is not commonly used in the diagnostic work up for chronic pancreatitis and we did not prioritise a question investigating its role.
Association for Clinical Biochemistry and Laboratory Medicine	Short	15 - 18	pp15 - 18	Research into Type 3c - need to understand: the natural history and evolution of changes in HbA1c; potential role of other markers of hyperglycaemia / glycation of proteins when a variant Hb is present; any	Thank you for your comment and for contributing to the consultation process. Our research recommendation is focused on determining the most effective insulin therapy regimen in this population because the answer to this question will enable evidence-based recommendations for the management of type 3c diabetes. As we did not review the evidence for the diagnosis of type 3c diabetes we are unable to make a research recommendation in this area. The

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				potential role for serum Insulin / C-Peptide in diagnosis	diagnosis of diabetes is based on glucose/hba1c measurements and alternative diagnostic measures are beyond the scope of this guideline.
Association for Clinical Biochemistry and Laboratory Medicine	Short	5	10 - 15	Diagnostic Investigations might usefully be embedded in a local investigation protocol to ensure key investigations are performed in a timely manner. Local Clinical Biochemistry laboratory clinicians can help define Ix protocols and help with interpretation of results	Thank you for your comment and for contributing to the consultation process. Service delivery issues are beyond the scope of this guideline. Therefore, the evidence was not reviewed and recommendations cannot be made in this area.
Association for Clinical Biochemistry and Laboratory Medicine	Short	6	22 - 28	As well as dietitian input, consider engaging with local Clinical Biochemists to help ensure nutritional investigation and interpretation of results is timely and appropriate	Thank you for your comment and for contributing to the consultation process. Our review question considered the effectiveness of a specialist nutritional assessment compared with a non-specialist assessment for managing malabsorption or malnutrition in people with chronic pancreatitis, focussing on the role of a specialist dietitian to coordinate nutritional support. Specialist dietitians would decide on when to involve a clinical biochemist or any other healthcare professionals in decision making.
Association for Clinical Biochemistry and Laboratory Medicine	Short	9	23, 24	ACB supports the use of HbA1c for regular surveillance for Type 3c Pancreatitis. The suggested frequency of 6/12 is about right. The diagnostic role of measurement of serum Insulin / C-Peptide levels should be explored	Thank you for your comment and for agreeing with the 6 month assessment via HbA1c. The diagnosis of type 3c pancreatitis is outside the scope of the guideline and therefore we did not address the role of serum insulin/C-peptide levels.
Boston Scientific	Short	7 - 8	Page 7 Line 12-27	We are pleased to see NICE is developing the guideline on Pancreatitis: diagnosis and management.	Thank you for your comment and for the additional references. We note that the majority of the evidence you have cited is non-comparative case-series, which we rarely include within our guidelines for intervention questions as it is important to know the

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			<p>Page 8 line 1 - 19</p> <p>Regarding the management of pancreatic fluid collections (PFCs) we would like NICE to consider the use of lumen apposing metal stents for pancreatic fluid collections. These collections may become infected, necessitating drainage. The endoscopic management of PFCs (pancreatic pseudocysts, pancreatic abscesses, and walled-off pancreatic necrosis) has historically been technically challenging and associated with significant shortcomings. Lumen-apposing metal stents (LAMSs) are being used extensively for transmural drainage of peripancreatic fluid collections such as pseudocysts and walled-off necrosis. The safety and efficacy of using LAMSs in the drainage of postsurgical fluid collections (PSFCs) has been demonstrated in a large multicenter cohort study. Technical success of the procedure ranged from 96% to 100% and clinical success 80% to 100%. Before lumen apposing metal stents became available, plastic stents were conventionally used for drainage, and</p>	<p>effect of a proposed intervention relative to the appropriate comparator. The specific detail of how to do an endoscopic necrosectomy (including guidance on the use of lumen-apposing metal stents)) was not covered in the guideline, because the main focus of the review was to look at invasive and non-invasive techniques, rather than the effectiveness of the specific techniques used within these categories. Consequently, we have not made research recommendations in this area either.</p>
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				<p>although the pigtail feature of the plastic stents prevents migration, their narrow lumen may cause premature occlusion in up to 18% of cases, resulting in frequent stent exchanges or placement of additional stents. These procedures were associated with adverse events and increased healthcare resources utilisation (Bazerbachi et al 2017 <a href="https://doi.org/10.1016/j.gie.2017.08.025">https://doi.org/10.1016/j.gie.2017.08.025</a>).</p> <p>Please see some additional evidence that we believe will provide additional evidence to support the use of lumen apposing metal stents for pancreatic fluid collections: Siddiqui et al 2017 <a href="http://dx.doi.org/10.1016/j.gie.2015.10.020">http://dx.doi.org/10.1016/j.gie.2015.10.020</a> Sharaiha et al 2016 <a href="http://dx.doi.org/10.1016/j.cgh.2016.05.011">http://dx.doi.org/10.1016/j.cgh.2016.05.011</a> Prashant et al 2017 <a href="http://dx.doi.org/10.1016/j.gie.2017.08.011">http://dx.doi.org/10.1016/j.gie.2017.08.011</a></p>	
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				<p>Further research is needed to understand if lumen apposing metal stents provides additional clinical and economic benefits. Looking at outcomes such as: Length of stays, number of interventions, complications and readmissions.</p> <p>We would like to suggest for inclusion in “Recommendations for research”: Lumen apposing metal stents in the management of pancreatic fluid collections.</p>	
British Society of Gastroenterology	Full	20	13	<p>TYPE 3C DIABETES: We would suggest that a comment is made that separate guidance or evidence/research developed for type 3c Diabetes. The current Summary just refers back to type 1 and 2 diabetes guidance making it look redundant. There is a lack of clinical and economic evidence as stated so we appreciate the statements of the committee but would hope it is clarified better.</p>	<p>Thank you for your comment and for contributing to the consultation process. We have made a high priority research recommendation to investigate the most effective insulin regimen for type 3c diabetes, which is included in both the full and the short version of the guideline. We have worked up a brief suggested protocol for this research and have sought input from the NIHR to increase the chances that this research will be funded. We hope that future updates of this guidance will therefore be able to make more specific recommendations for the management of type 3c diabetes.</p> <p>Regarding the references to type 1 and 2 diabetes guidelines we do not agree that this section is redundant. We co-opted a diabetologist to the guideline to help with this area. In the absence of evidence specific to type 3c diabetes we received clear advice that for people not using insulin therapy then the type 2 diabetes guideline recommendations should be followed and for those using</p>

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					insulin therapy the type 1 diabetes guideline should be followed. Without this guidance there was concern that the type 2 diabetes guideline might be used for all aspects of managing type 3c diabetes and this would not be in the best interest of the patients.
British Society of Gastroenterology	Full	184	1	Methods of management of infected necrosis in people with acute pancreatitis: There is a lot of debate regarding whether metal or plastic stenting methods are better for endoscopic drainage. There are significant price differences also. If it is felt that the available evidence is not available to make this recommendation then a statement should be made or further research suggested as there a a number of ongoing trials.	Thank you for your comment and for contributing to the consultation process. We did not prioritise this for inclusion in the guideline because we believe there to be limited evidence relating to metal stents as it is a relatively recent introduction into the management of infected necrosis in people with acute pancreatitis. Additionally, recommendations on the use of new and existing health technologies within the NHS in England are delivered by the NICE technology appraisal programme. More information on this programme can be found at the following link: <a href="https://www.nice.org.uk/process/pmg19/resources/guide-to-the-processes-of-technology-appraisal-pdf-72286663351237">https://www.nice.org.uk/process/pmg19/resources/guide-to-the-processes-of-technology-appraisal-pdf-72286663351237</a>
Department of Health and Social Care				Thank you for the opportunity to comment on the draft for the above clinical guideline.  I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you for your comment and contributing to the consultation process.
Faculty of Intensive Care Medicine /	Short/Long	General		The guidelines are extensive and essentially very good. The full guidelines are very extensive and people are highly likely to read the	Thank you for your comment and for contributing to the consultation process.

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ICS Joint standards committee			recommendations only. I notice that an anaesthetist/intensivist was not on the main panel and this comes through when reading the document. I presume the assumption is that patients with severe acute pancreatitis are managed on a critical care unit and their organ support is managed as best practice by the critical care team. Apart from a bit on fluids there doesn't seem much more on this. One wonders if regular MDT meetings (surgeons, radiology, dietetics, intensivists etc.) would be useful to manage these complex patients. This would be a good recommendation in my opinion.	<p>One of our committee members is a consultant in anaesthesia and pain medicine, we also co-opted a consultant in intensive care who commented on all areas of acute pancreatitis and provided valuable input into the guideline.</p> <p>We did not review MDT meetings as we thought this would be established practice. It is recommended in the NHS standard contract for hepatobiliary and pancreas services (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>).</p>
Faculty of Intensive Care Medicine / ICS Joint standards committee	Short	1.4.10	For antimicrobial prophylaxis. There is not much on this in the short document or the full document. I personally would like to see more information on when antibiotics should be started, how to decide if they should be started, which antibiotics to start, and how to plan for de-escalation. I can't see anything related to the monitoring of CRP,WCC, procalcitonin etc and this is a continuing area of controversy.	Thank you for your comment and for contributing to the consultation process. We prioritised the use of prophylactic antibiotics in acute pancreatitis for review within this guideline owing to the variability in practice and uncertainty about the associated benefit and risks. We did not prioritise the use of antibiotics in the presence of infection or suspected infection as, based on the knowledge and experience of the guideline committee, it was agreed to be standard practice. As we did not review the evidence in this area we are unable to make recommendations for this.

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Faculty of Intensive Care Medicine / ICS Joint standards committee	Short	16	10	This statement does not reflect typical UK ICU practice: 'Current guidelines recommend aggressive fluid therapy during the first 24 hours of hospital admission guided by central venous pressure monitoring or the intrathoracic blood volume index'. Fluid resuscitation is generally guided by multifactorial clinical assessment rather than by one individual physiological measurement.	Thank you for your comment and for contributing to the consultation process. We have deleted this statement and corrected the text as follows: 'Current guidelines recommend using goal-directed therapy for fluid management, but do not recommend using a particular type of fluid.'
Faculty of Intensive Care Medicine / ICS Joint standards committee	Long	21	1 and 4	These are repetitions	Thank you for your comment and for contributing to the consultation process. We have corrected the repetition. One of the recommendations now refers to speed of administration of IV fluids and the other to type of IV fluid.
Faculty of Intensive Care Medicine / ICS Joint standards committee	Long	40		There is no mention of acute pain in pancreatitis	Thank you for your comment and for contributing to the consultation process. The management of acute pain in pancreatitis was not prioritised for inclusion in this guideline. We focussed on the areas considered to have the most variation in practice. The management of acute pain in pancreatitis would be in line with that for any acute abdominal condition and therefore was not included in the scope.
Faculty of Pain Management of the Royal	Full	General	General	Reference to NICE guidance for neuropathic pain should reflect the fact that evidence for these approaches is low in the chronic pancreatitis	Thank you for your comment and for contributing to the consultation process. We have updated our discussion of the evidence to highlight the fact that the NICE guideline on the management of neuropathic pain is not specific to chronic pancreatitis. However, as

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College of Anaesthetists				population. NICE neuropathic pain treatment guidelines are based on heterogeneous patient populations, and may not be effective in this patient group.	we did not find any evidence in a pancreatitis population, this remains the best available advice for management of all adults with neuropathic pain.
Faculty of Pain Management of the Royal College of Anaesthetists	Full	General	General	There is little discussion of nociceptive pain included in the review, but trials of opioids suggested.	Thank you for your comment and for contributing to the consultation process. We reviewed the pharmacological interventions used for the management of chronic pain in people with pancreatitis, which would include nociceptive pain. No evidence was identified for the use of opioids, which prompted the research recommendation. The included studies of other interventions did not specify if the pain was nociceptive, but often stated that the pain was of pancreatic origin.
Faculty of Pain Management of the Royal College of Anaesthetists	Full	General	General	There is insufficient reference to specialist pain services, pain management and conventional analgesic approaches.	Thank you for your comment and for contributing to the consultation process.  We looked at a range of interventions for pain management in chronic pancreatitis but did not find sufficient evidence to make any recommendations. We did not prioritise pain management for acute pancreatitis or conventional analgesic approaches as these are areas considered to be uncontroversial, and so were not included in the scope of the guideline. There is a NICE guideline currently in development on the assessment and management of chronic pain ( <a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10069">https://www.nice.org.uk/guidance/indevelopment/gid-ng10069</a> ) and this includes a review on pain management programmes. Any recommendations made as a result of this review would also apply to people with chronic pancreatitis.

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Faculty of Pain Management of the Royal College of Anaesthetists	Full	223	21	We are pleased to see reference to the Faculty of Pain Medicine's Opioids Aware initiative, but feel that there could be stronger warnings about the problems/limitations of strong opioid use in this population.	Thank you for your comment and for contributing to the consultation process. We state in our linking evidence to recommendations section that the rates of opioid-induced death are recognised as being high due to over-prescription of opioids and the high doses of opioids that are being prescribed. This is particularly important in people with chronic pancreatitis, as misuse of opioids may lead to a change in the perception of pain and, as a result of this, people with painful chronic pancreatitis may begin to fear oncoming pain and increase their opiate use. The committee also discussed the risk of increased tolerance and addiction, particularly in people who may have a history of alcohol misuse. However, in the absence of evidence we were unable to make a firm recommendation and agreed that a research recommendation would be appropriate to allow a strong, evidence-based recommendation in future updates of this guidance.
NHS England				<p>I have significant concerns about the balance of the content. Its content does not seem to match the title. It reads as if written by people expert in managing pancreatitis that has already been diagnosed (and expert group members confirm this).</p> <p>I think formatting could be improved - separate parts on acute and chronic pancreatitis. On acute pancreatitis I think should have more emphasis on</p>	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We have changed the structure of the guideline and split it into acute and chronic pancreatitis and have removed the word 'diagnosis' from the title.</p> <p>Not all clinical issues could be covered. Those issues where it was felt that current practice was satisfactory were not evaluated. There is less controversy in the diagnosis and treatment of acute pancreatitis and it was agreed to focus on areas where treatment was considered varied and in need of standardisation. More</p>

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			<p>the importance of distinguishing mild from severe cases, and how to do this, and that mild can turn into severe any time in the first 48 hours.</p> <p>As I read the exec summary it didnt specify how to diagnose acute pancreatitis, nor did it appear to state what needs to be done in the early management of acute pancreatitis due to a stone at the bottom of the common bile duct.</p> <p>So the guidance appears to be focussed on the specialist management of known pancreatitis (both acute and chronic).</p> <p>It will not provide the necessary guidance to the emergency general surgical (and general medical) teams that need to be able to rapidly and accurately distinguish acute pancreatitis from other causes of acute abdominal pain, and to identify the sub-group of patients with severe acute pancreatitis who need to have their immediate acute management in an ITU or HDU environment</p>	<p>information about the reasons for each point is listed in the following paragraphs.</p> <p>Scoring systems are in place for differentiating mild from moderately severe and severe cases of acute pancreatitis. If a patient deteriorates on a ward then the early warning score triggers escalation and a review by a senior doctor or ITU outreach team. In the guideline we specify that when referring to severity in acute pancreatitis the committee used the Revised Atlanta Classification.</p> <p>The diagnosis of acute pancreatitis is generally straightforward. Therefore, this was not prioritised for inclusion in the guideline and was excluded from the scope.</p> <p>A stone seen on imaging at the lower end of the bile duct is an indication for ERCP, sphincterotomy and stone extraction. This is a well-recognised pathway and therefore the evidence base for this topic was not prioritised for review.</p> <p>People admitted to hospital with acute abdominal pain will be assessed by emergency care protocols. These will include tests that help identify acute pancreatitis.</p>
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NHS England	Short		1.4.11- 1.4.12	<p>We are not sure the endoscopic approach can be stated as superior to percutaneous drainage or approach. Shouldn't the guideline state minimally invasive techniques of necrosectomy are preferred over open necrosectomy unless there is a clear indication for emergent surgery and that there may be benefits of endoscopic vs perc depending on situation?</p>	<p>Thank you for your comment. We agree that minimally invasive techniques are favoured over open necrosectomy, as reflected in the recommendation for endoscopic and percutaneous approaches. The committee had a very detailed debate about the evidence for an endoscopic compared with a percutaneous approach and concluded that the evidence of clinical benefit, combined with a very clear patient preference for the endoscopic approach, strongly supported offering this first line in those who are eligible for either approach. In summary, the evidence behind this was high and moderate quality evidence from a randomised trial of a clinical benefit of endoscopic approach for:</p> <ul style="list-style-type: none"> <li>- Length of stay (16 days less)</li> <li>- Pancreatic fistulae (269 fewer per 1000; compared with a baseline risk of 317 per 1000 with percutaneous approach)</li> <li>- Organ failure (139 fewer per 1000).</li> </ul> <p>The patient preference reported was based on the negative experience of having percutaneous drains for long periods that can leak and cause pain, as well as necessitate an extended hospital stay.</p> <p>However, our recommendations also acknowledge that endoscopic necrosectomy will not be possible in all people with infected necrosis requiring intervention and support the use of the percutaneous approach in the subgroup in whom endoscopic intervention is not anatomically possible.</p> <p>We highlight in the linking evidence to recommendations section of the full version of the guideline that approximately 60-70% of</p>
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					patients with infected pancreatic necrosis are more suitable for either percutaneous necrosectomy or endoscopic necrosectomy but not for both. We also note that this suitability for one or the other technique is governed by the anatomy of the necrosis and its relationship to the posterior wall of the stomach (for the endoscopic approach) or postero-lateral abdominal wall (for the percutaneous approach).
NHS England	Short		1.12	We would recommend adding a summary of the diagnostic criteria for CP here	<p>Thank you for your comment.</p> <p>We are unable to include a full summary of the diagnostic criteria here because we did not review or identify the evidence to provide the criteria. People with chronic pancreatitis usually present with chronic or recurrent abdominal pain. This guideline assumes that people with chronic abdominal pain will already have been investigated using CT scan, ultrasound scan or upper gastrointestinal endoscopy to determine a cause for their symptoms. Consequently we did not review this evidence. Following these tests we sought to answer the most appropriate diagnostic tools but did not identify any evidence. We have added the following recommendation: Think about chronic pancreatitis as a possible diagnosis for people presenting with chronic or recurrent episodes of upper abdominal pain and refer accordingly.</p> <p>We hope that by highlighting the main presenting symptom in this recommendation fewer diagnoses of chronic pancreatitis will be missed or delayed and appropriate tests will be requested. We have also added a discussion of the relative benefits of various</p>

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					tests to the recommendations and link to evidence section of this chapter in the full guideline.
NHS England	Short		1.1.11	Add advice to stop smoking and make it clear that there is a causal link between CP and smoking – many non-specialists and specialists may not be au fait with this data.	Thank you for your comment and for contributing to the consultation process. We agree that this is an established link and so have edited the recommendation as follows: Be aware of the link between smoking and chronic pancreatitis and advise people with chronic pancreatitis to stop smoking in line with NICE’s guidance on stop smoking interventions and services. .
NHS England	Short		1.4.14	We feel the guidance here should relate improvements in pain with correction of PEI and avoidance of aetiological factors such as alcohol and smoking	<p>Thank you for your comment.</p> <p>We reviewed the effectiveness of pancreatic enzyme replacement therapy (PERT) in improving pain and found 2 small studies comparing PERT with placebo for people with painful chronic pancreatitis. The evidence was of low quality and did not show a benefit of PERT for reducing pain. The committee agreed there was insufficient evidence to make a recommendation supporting PERT for pain management.</p> <p>We did not specifically look at the role of alcohol and smoking in reducing pain because alcohol and smoking are already known to be damaging in pancreatitis. We have provided recommendations advising people to stop smoking and drinking alcohol and referred to other NICE guidance on stopping smoking services and alcohol-use disorders</p>
NHS England	Short		1.4.9	We feel the guidance should explicitly mention PERT and need to assess diagnosis of PEI	Thank you for your comment and for contributing to the consultation process. PERT is already recognised as an important intervention and we believed it to be accepted practice in patients with chronic pancreatitis and for this reason, we did not prioritise the role of

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					<p>PERT for inclusion in this guideline other than its potential for reducing pain.</p> <p>We do recommend assessment to identify PEI in recommendation 1.3.20: Offer people with chronic pancreatitis monitoring by clinical and biochemical assessment, to be agreed with the specialist centre, for pancreatic exocrine insufficiency and malnutrition at least every 12 months (every 6 months in under 16s). Adjust treatment of vitamin and mineral deficiencies accordingly.</p>
NHS England	Short	2	1.1.1-1.1.7	<p>From a lay perspective we really welcome the comprehensive recommendations around the provision of information and support which should help people better cope with and manage the condition</p>	<p>Thank you for your comment and for contributing to the consultation process.</p>
NHS England	Short	4	12	<p>Considering key observations noted in the full version, it would be relevant to include recommendations about role of general practitioners/primary care services in supporting patients with pancreatitis particularly role of coordinated care to help address bio, psycho, social aspects of patients' illness and to facilitate primary care's role in meeting the Quality Standards outlined in NICE Guideline (CG138) about continuity of care.</p>	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We have amended the bullet point in this recommendation to read "pancreatitis services, including the role of specialist centres, and primary care services for people with acute, chronic or hereditary pancreatitis".</p> <p>Regarding the role of primary care we have also added a recommendation to highlight what information should be provided to GPs to promote coordinated care: Ensure that information passed to GPs includes all of the following, where applicable: detail on how the person should take their pancreatic enzyme replacement therapy (including dose escalation as necessary), that</p>

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					the person should be offered HbA1c tested at least every 6 months and bone mineral density assessments every 2 years.
NHS England	Short	6	1.4.2-1.4.9	From a lay perspective we welcome the recommendations around nutritional support as coping with these symptoms can have a significant impact on the quality of life and it is critical that people can access a dietitian if they are having difficulty managing symptoms.	Thank you for your comment and for contributing to the consultation process.
NHS England	Full	63	1 (general)	We concerned that observations noted by patient members of the committee may be interpreted as lack of care provided in the community for patients who suffer from pancreatitis and encourage transfer of care for such patients to secondary care services. The importance of role of multidisciplinary team has further been highlighted on pages 308, 312 but it does not include highlighting the supporting role of supporting primary care teams to help contribute towards management of such cases – early referrals and coordination of care and delivery of services in the community. Particularly on page 321 when committee recognised that additional screening for diabetes to be carried out	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We fully acknowledge the important role of general practitioners in the management of chronic pancreatitis. The patient representatives on the committee all had roles supporting other patients with pancreatitis. They have on several occasions in the committee expressed their disappointment and concern regarding the lack of knowledge of pancreatitis in general practice and amongst non-specialist hospital consultants. It is hoped that this guideline will assist in correcting this.</p> <p>In this guideline there are specific recommendations on involving the specialist team. Other advice on networking can be found in the NHS England standard contract for hepatobiliary and pancreas services - A02/S/a (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>).</p>

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				every 6 months (to be carried out in general practice)	<p>Regarding specific involvement of primary care teams, we have added the following recommendation to highlight what information should be provided to GPs to promote coordinated care: Ensure that information passed to GPs includes all of the following, where applicable: detail on how the person should take their pancreatic enzyme replacement therapy (including dose escalation as necessary), that the person should be offered HbA1c tested at least every 6 months and bone mineral density assessments every 2 years.</p> <p>Also, the committee acknowledged in the guideline that more work could be done by specialist pancreatic centres to disseminate their expertise more effectively.</p>
NHS England	Full	223	30	The review questions do not seem to include questions related to interventions/strategies for pain control in the primary care.	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>Our review in section 23 in the full guideline covers pain management in any setting, including primary care. Unfortunately, we did not identify evidence specific to pancreatitis and so did not make recommendations in this area. NICE is currently developing a guideline in Chronic pain which covers all settings of the NHS including management in primary care (<a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10069">https://www.nice.org.uk/guidance/indevelopment/gid-ng10069</a>). The recommendations from this will cover patients with chronic pancreatitis.</p>

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NICE GP Reference Panel	Short	General	General	Three of the five respondents made specific comments on the lack of diagnostic guidance. I have reviewed the final scope (we didn't send this to the panel members) and it specifically excludes diagnosis – yet the title of this guideline is "Pancreatitis: diagnosis and management". I think Primary Care (like our panel members) will find this confusing!	Thank you for your comment and for contributing to the consultation process. The guideline covers issues related to diagnosis of chronic pancreatitis but excludes diagnosis of acute pancreatitis. We have removed any reference to diagnosis or management in the title of the guideline which has now been changed to 'Pancreatitis'. We have tried to make the section on diagnosis more prominent and have added a recommendation raising awareness of chronic pancreatitis as a possible diagnosis in patients with chronic or recurrent abdominal pain.
NICE GP Reference Panel	Short	General	General	<p><b><u>General points</u></b></p> <p>The guideline lacks primary care advice – this is most necessary in rural practice as there is poorer access to specialist care.</p> <p>The guideline confusingly switches between acute and chronic pancreatitis. Acute pancreatitis is largely managed by secondary care, whereas chronic pancreatitis is often managed in Primary Care, which is also responsible for providing chronic disease care, and spotting deterioration and deficiencies.</p>	<p>Thank you for your comment and for contributing to the consultation process. The areas prioritised in the scope as needing the most attention related to management in secondary care. We have made some recommendations directed towards primary care, and there are areas that future NICE guidelines will cover. The specific areas for GP involvement have been addressed as follows:</p> <ol style="list-style-type: none"> <li>1. We have added a recommendation raising awareness of chronic pancreatitis as a possible diagnosis in patients with chronic or recurrent abdominal pain</li> <li>2. The recommendations related to the follow-up of patients with chronic pancreatitis including type 3c diabetes</li> <li>3. Ensuring GPs are provided with information on using pancreatic enzyme replacement therapy.</li> <li>4. Pain control and opiate issues: There is further NICE guidance in development related to the management of chronic pain. The recommendations developed in that guideline will cover chronic pancreatitis and, if evidence</li> </ol>

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				It would be helpful to have more detailed directions to educational resources and support for patients.	permits, will provide guidance on pain management programmes.  We have changed the layout of the guideline separating acute and chronic pancreatitis into distinct sections to make the guideline clearer. There will be links on the guideline page directing people with pancreatitis to where they can find more information and support.
NICE GP Reference Panel	Short	General	General	<b><u>Chronic management and follow-up</u></b>  A general statement on follow-up frequency would be helpful  If symptom free does there need to be follow-up?	Thank you for your comment. We have made recommendations on the frequency of follow up and what should be done: follow up at least every 6 months for HbA1c, follow up at least every 12 months for pancreatic exocrine insufficiency and malnutrition, and follow up every 24 months for bone density assessment. This needs to be done even if symptom-free because pancreatic function is reduced and patients are at risk of diabetes and vitamin and nutritional deficiencies. This has been clarified in the linking evidence to recommendations section of the full guideline.
NICE GP Reference Panel	Short	General	General	<b><u>Deterioration</u></b>  How can acute-on-chronic pancreatitis be spotted early? What would trigger admission? Would tests help (lipase/amylase etc)?	Thank you for your comment and for contributing to the consultation process.  The scope does not include identification of “acute on chronic” pancreatitis, when people with chronic pancreatitis are suffering an attack of acute pain and so we were not able to make recommendations in this area. This was not prioritised for review as episodes of acute pancreatitis are relatively uncommon once chronic pancreatitis has become established and these cases can usually be managed following standard protocols for pain control

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					and general symptom management, with a focus on cessation of causative factors. Also, the diagnosis of acute pancreatitis is excluded from the scope of this guideline and so the accuracy of lipase or amylase has not been assessed. However, we have added a recommendation advising practitioners to consider chronic pancreatitis as a possible diagnosis for patients presenting with recurrent episodes of upper abdominal pain.
NICE GP Reference Panel	Short	General	General	<p><b><u>Prognosis</u></b></p> <p>Does early diagnosis improve prognosis?</p> <p>Does stopping drinking affect prognosis?</p>	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>These questions were not prioritised for review within the guideline and so we are unable to make specific recommendations in these areas.</p> <p>Regarding early diagnosis, it was agreed that there would be no reason to delay diagnosis if chronic pancreatitis was suspected and that, therefore, an evidence review would not be needed. However, the committee discussed the importance of raising awareness of chronic pancreatitis as a possible differential diagnosis in people who present with chronic or recurrent episodes of upper abdominal pain to ensure prompt diagnosis in these cases. Therefore, we have added the following recommendation: Think about chronic pancreatitis as a possible diagnosis for patients presenting with chronic or recurrent episodes of upper abdominal pain and refer accordingly.</p>

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					We did not prioritise a question on the effect of stopping drinking on prognosis. Instead, the committee focussed on interventions that assess the utility of structured programmes to help people stop or reduce drinking for reducing recurrent episodes of acute pancreatitis and improving quality of life.
NICE GP Reference Panel	Short	General	General	<b><u>Research priorities</u></b>  Agreement with priorities especially pain relief	Thank you for your comment and for contributing to the consultation process.
NICE GP Reference Panel	Short	General	General	This is a condition that is largely managed in secondary care, but often presents to primary care, and patients with chronic pancreatitis are seen often in primary care too.  The main area of diagnostic uncertainty that I struggle with is those patients who are suffering acute on chronic pancreatitis - at what point do they need admission and iv fluids etc? Are there any tests that will help me reach that decision? Is there anything that I can do in primary care to avoid an admission if their symptoms are starting to worsen? The guideline talks about moderate and severe episodes. What does this mean in practice?	Thank you for your comment. NICE guidelines try to focus on areas in which the NHS most needs advice. Therefore, the scope was limited to key clinical areas, such as areas where there is uncertainty on best practice, or a potential to improve health outcomes. The scope was finalised after public consultation.  The scope does not include when to admit people with chronic pancreatitis who are suffering an attack of acute pain and so we were not able to make recommendations in this area. This was not prioritised for review as episodes of acute pancreatitis are relatively uncommon once chronic pancreatitis has become established and these cases can usually be managed following standard protocols for pain control and general symptom management, with a focus on cessation of causative factors.  Moderately severe and severe acute pancreatitis refer to cases of diagnosed acute pancreatitis and are based on the Atlanta Classification, which was derived by international consensus and is

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				<p>It would also be helpful to have some guidance on follow up - how often should patients expect to be seen? There is mention of biannual DEXAs - whose responsibility is it to organise this? At what age should we start doing DEXAs for those with chronic pancreatitis? Does it differ between genders?</p> <p>Also some guidance on prognosis would be helpful - in those patients who have alcohol induced pancreatitis, for example, what benefit does stopping drinking have on survival? Can they expect to become symptom free? If they are symptom free can we stop DEXAs etc? If so, after what period of time?</p> <p>Sorry - lots of questions!</p>	<p>based on local complications, such as necrosis, and the presence of organ failure. It is defined in the glossary.</p> <p>Regarding follow-up, we have made recommendations for the frequency of assessment for pancreatic exocrine function, pancreatic cancer and diabetes (recommendations 1.3.20 - 1.3.25). Biennial DEXAs should happen for all people with chronic pancreatitis regardless of gender for the duration of the individual's life, even in the absence of symptoms, because pancreatic function is reduced and patients are at risk of diabetes and vitamin and nutritional deficiencies. This has been clarified in the discussion of the evidence in the full version of the guideline. The operational issue of who should organise DEXA scans is beyond the scope of this guideline.</p> <p>We did not prioritise a question on the effect of stopping drinking on prognosis in alcohol induced pancreatitis. Instead, the committee focused on the utility of structured programmes to help people stop or reduce drinking on reducing recurrent episodes of acute pancreatitis and improving quality of life.</p>
NICE GP Reference Panel	Short	General	General	<p>how do you diagnose pancreatitis in primary care ?- nil here on what tests should be done by GPs and which are specialist tests, there are no pancreatitis clinics locally, population too small and distance to travel</p>	<p>Thank you for your comment.</p> <p>Acute pancreatitis presents with acute abdominal pain and is suspected by the severity of the pain. It is therefore unlikely to be diagnosed in primary care. Chronic pancreatitis is to be suspected as part of the differential diagnosis of abdominal pain. This</p>

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			<p>elsewhere can be prohibitive, great if you live in London but not in rural areas</p> <p>lipase or amylase?</p> <p>there was obviously no GP involved in the guideline because of the lack of guidance for primary care - acute diagnosis and chronic management - because we end up looking after them long term - not hospital consultants</p> <p>no easy access for radiology as a GP</p> <p>chronic pain services current wait times can be up to a year and again rurally far away, not easy for patients to get too and a pain programme can take up a big commitment in time</p>	<p>overlaps with the diagnosis for cancer. We have added the following recommendation: Think about chronic pancreatitis as a possible diagnosis for people presenting with chronic or recurrent episodes of upper abdominal pain and refer accordingly.</p> <p>Regrettably, our efforts to recruit a GP for the committee were unsuccessful despite several attempts. We greatly appreciate the participation of the Royal College of General Practitioners and the NICE General Practitioners reference panel in the consultation process.</p> <p>We have not covered access to services in the guideline. The NHS England standard contract for hepatobiliary and pancreas services - A02/S/a (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>) suggests that pancreatic services are delivered by a multidisciplinary team through a regional network model. The multidisciplinary team includes radiologists.</p> <p>There is currently a NICE guideline in development on the assessment and management of chronic pain (<a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10069">https://www.nice.org.uk/guidance/indevelopment/gid-ng10069</a>) which will cover pain management programmes. Their review protocol includes programmes that do not require the patient to attend hospital in person.</p>
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NICE GP Reference Panel	Short	General	General	<p>This document is a little confusing in the way it switches from acute to chronic pancreatitis discussion in the text. As a GP i would want for some more detailed guidance on the clinical presentation of acute pancreatitis not least as presumably earlier diagnosis reduces the risk with the chronic condition [ although it would be useful to be presented with evidence here either way]. As GPs we would want to now how to recognize and suspect acute P earlier as well as acute exacerbations of chronic pancreatitis. It would also be helpful to have more detailed directions to educational resources and support for patients within the text and more detail as to exactly what exocrine bloods are expected to be checked including Vitamin/mineral levels as it does not specify</p> <p>I can see that much of this relates to specialist care but equally we have a role in the longer term aspects of Chronic pancreatitis and identifying</p>	<p>Thank you for your comment and for contributing to the consultation process. We have changed the structure of the guideline and split it into acute and chronic pancreatitis.</p> <p>The diagnosis of acute pancreatitis was excluded from the scope as it was thought to be relatively straight forward and dealt with in emergency room settings. Recognition of acute exacerbations of chronic pancreatitis was also not prioritised for review. Therefore, we are not able to make recommendations in these areas.</p> <p>There will be links on the guideline page directing people with pancreatitis to where they can find more information and support.</p> <p>Regarding which exocrine bloods should be checked, we have amended the recommendation to state that this should be agreed with the specialist centre. Please see recommendation 1.3.20. The specific tests will vary between individuals and we wish to leave this to clinical judgement.</p> <p>We agree that GPs have a role to play. Although most of the areas covered by the guideline relate to specialist care we have added a recommendation ensuring GPs are sent the relevant information related to a patient's condition to emphasise this point (recommendation 1.1.7).</p>
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				deficiencies and deterioration as well	
NICE GP Reference Panel	Short	General	General	In section 1.3, where it states that pancreatitis can be due to prescribed drugs-please could you consider listing the commonest drugs that can cause this? This would be helpful for non specialists. I wasn't aware of the need for 6 monthly HbA1c in people with chronic pancreatitis -this may need to be flagged up to GPs in discharge summaries.	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We have not provided a comprehensive list of prescription drugs that may cause acute pancreatitis because there are many that are potentially associated with the condition. The recommendation is to alert clinicians investigating the cause of a person's acute pancreatitis that it could be associated with their prescription drugs. We did not find the evidence to recommend anything more than this.</p> <p>We have also added the detail and frequency of follow up appointments to the recommendation on information to be passed onto to GPs (recommendation 1.1.7).</p>
NICE GP Reference Panel	Short	General	General	Agree with the research priorities particularly the pain relief question in chronic pancreatitis which is difficult and I think incorrectly diagnosed / poorly managed in primary and secondary care.	Thank you for your comment and for contributing to the consultation process.
NICE GP Reference Panel	Short	5	23	1.3. 2: Pancreatitis may be caused by drugs – which?	Thank you for your comment and for contributing to the consultation process. We have not provided a comprehensive list of prescription drugs that may cause acute pancreatitis because there are many that are potentially associated with the condition. The recommendation is to alert clinicians investigating the cause of a person's acute pancreatitis that it could be associated with their

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					prescription drugs. We did not find the evidence to recommend anything more than this.
NICE GP Reference Panel	Short	7	22	<p><u>Chronic disease management:</u></p> <p>1.4.14 Pancreatic pain is poorly diagnosed and managed in primary and secondary care Chronic pain services are poorly accessible and have long waiting times – so specific advice for primary care would be helpful (I note that there is a link to neuropathic pain in pancreatitis – but is this the predominant pain syndrome, and how should GPs manage non-neuropathic pain?).</p>	<p>Thank you for your comment and for contributing to the consultation process. We looked for studies specific to pain management in pancreatitis but did not find sufficient evidence to make a recommendation. Therefore, we have made a research recommendation about the long-term use of opioids in chronic pancreatitis as the guideline committee agreed that this was the most critical area where evidence is required.</p> <p>There is a NICE guideline currently in development on the assessment and management of chronic pain (<a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10069">https://www.nice.org.uk/guidance/indevelopment/gid-ng10069</a>) which we hope will address this issue.</p>
NICE GP Reference Panel	Short	9	6	<p>1.6.1 What exocrine and malnutrition tests are expected? Which mineral and vitamin levels should be monitored (and what is the evidence for this)?</p>	<p>Thank you for your comment and for contributing to the consultation process. We focused on how often to monitor and left the specific tests to clinical judgement.. However, we have amended the recommendation to state that the methods of assessment should be agreed with the specialist centre.</p>
NICE GP Reference Panel	Short	9	10	<p>1.6.2 DEXA – who should organize? This may depend on access to radiology Should the recommendation vary with age or gender?</p>	<p>Thank you for your comments and for contributing to the consultation process. Our review concerned how often to monitor. The service delivery question of who should organise DEXA scans is beyond the scope of this guideline.</p>

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					Biennial DEXAs should happen for all people with chronic pancreatitis regardless of gender for the duration of the individual's life. This has been clarified in the discussion of the evidence in the full version of the guideline.
NICE GP Reference Panel	Short	9	19	1.6.5 HbA1c six-monthly (minimum) - it would be beneficial to flag this up in discharge letters	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>The committee anticipated that patients who have been discharged from hospital care would have specific information provided to their GP regarding follow-up. We have added the following recommendation to ensure this is followed as standard practice: Ensure that information passed to GPs includes all of the following, where applicable: detail on how the person should take their pancreatic enzyme replacement therapy (including dose escalation as necessary), that the person should be offered HbA1c tested at least every 6 months and bone mineral density assessments every 2 years.</p>
Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS)	Full	general	general	We are pleased nutrition has been considered in many areas of this guideline as we are aware of the impact good quality nutritional management can have on people with pancreatitis. We feel that adherence to this guideline will have significant benefit to people with this condition.	Thank you for your comment and for contributing to the consultation process. The committee hopes this will have significant benefit to people with pancreatitis.
Nutrition Interest Group of the	Full	18	14-24	We welcome this recommendation; however the implementation will be difficult due the lack of specialist	Thank you for your comment and for contributing to the consultation process.

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Pancreatic Society of Great Britain and Ireland (NIGPS)				<p>dietetic resourcing. It would be useful for these recommendations to include guidance on resourcing for dietetics.</p>	<p>Resourcing is outside the scope of the guideline. In the ‘putting the guideline into practice’ section of the short version we have highlighted that networks of dietitians and specialist dietitians need to be established to support the production and dissemination of protocols to identify when advice from a specialist dietitian is needed.</p> <p>We also discuss the implementation challenges in the linking evidence to recommendations section of the full version of the guideline. The recommendation is based on the available evidence and consensus of the committee, including a specialist dietitian.</p> <p>We also note that the NHS England standard contract for hepatobiliary and pancreas services (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>) recommends multidisciplinary teams with members, which include dietitians, who must hold specific and relevant training, experience and resources.</p>
Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS)	Full	18	5-12	<p>This may be difficult for non-specialist centres to adopt. Despite clear evidence to avoid the first line use of parenteral nutrition in the nutritional support of patients with acute pancreatitis, many non-HPB surgeons still routinely initiate this. While these recommendations will clearly help to address, liaison with surgical education bodies would be useful to address this.</p>	<p>Thank you for your comment and for contributing to the consultation process. The intention of this recommendation is to standardise practice. We hope that all clinicians treating people with pancreatitis will read the guideline and follow the recommendations. We have recommended parenteral nutrition for those who cannot tolerate enteral nutrition but enteral is the priority. However, it is beyond the scope of the guideline to recommend liaison with surgical education bodies.</p>

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Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS)	Full	19	38-43	As per comment 2 – these recommendations are very welcome but implementation will be challenging due to lack of specialist dietetic resourcing. Annual assessment of nutritional status has been adopted in Cystic Fibrosis and the need to include at least one dietitian as member of the specialist MDT was included in the NICE guidance for CF. Could this be mirrored in the guidance for Pancreatitis? These groups have similar complex, often evolving, nutritional needs, and require regular assessment and monitoring.	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>Resourcing is outside the scope of the guideline. We have highlighted in the ‘putting the guideline into practice’ section of the short version that networks of dietitians and specialist dietitians need to be established to support the production and dissemination of protocols to identify when advice from a specialist dietitian is needed.</p> <p>We also discuss the implementation challenges in the linking evidence to recommendations section of the full version of the guideline. The recommendation is based on the available evidence and consensus of the committee, including a specialist dietitian.</p> <p>We also note that the NHS England standard contract for hepatobiliary and pancreas services (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>) recommends multidisciplinary teams with members, which include dieticians, who must hold specific and relevant training, experience and resources. However, as we did not review the evidence for the optimal MDT composition we cannot make a specific recommendation about this.</p>
Nutrition Interest Group of the Pancreatic	Full	19	38-41	Could this say ‘at least every 12 months’ or ‘a minimum of once every 12 months’? Many people will need monitoring more frequently than once a	Thank you for your comment and for contributing to the consultation process. We agree and have changed this to ‘at least every 12 months’ and have added some detail to the linking evidence to recommendations section.

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Society of Great Britain and Ireland (NIGPS)				year to identify deterioration in their pancreatic function or nutritional status.	
Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS)	Full	20	27-36	We welcome the inclusion of the type 3c diabetes section, and acknowledgment of the differences between it and types 1 and 2. It is recommend that people have access to the type 1 and type 2 NICE booklets for DM. Are recommendations only for NICE information? We have produced an information booklet on type 3c Diabetes. If not able to mention non-NICE documents, could it be said that a type 3c-specific booklet is warranted?	Thank you for your comment and for contributing to the consultation process. The pathway for the guideline will be further highlighted and explanations provided on how our recommendations link to other NICE guidelines in the electronic pathways available for public access online. The committee would welcome a well written booklet on type 3c diabetes but we are unable to refer to non-NICE guidelines or documents in our recommendations. This ensures consistency in the assessment of evidence across our body of work.
Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS)	Full	20 and 21	39-43 1-21	It appears that recommendation 2 and 3 are the same. The guidelines highlight a lack of high quality nutritional studies, for some questions there were no studies to review. This limits their scope for recommendation. It would be useful to include nutritional priorities for research to address these. This would focus and prioritise future research, and aid research funding sourcing.	Thank you for highlighting this and for contributing to the consultation process. We have corrected the text to reflect the committee's decision to include one research recommendation on the type of IV fluid and one on the speed of administration for IV fluids used for resuscitation.  Regarding nutritional evidence, the committee believed the evidence was sufficient to make strong recommendations for the enteral route of feeding in severe and moderately severe acute pancreatitis. Regarding the timing of nutritional intervention and specialist nutritional assessment in chronic pancreatitis, although no studies were identified, the committee agreed that it would be in

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					<p>the best interest of patients to make active recommendations rather than research recommendations.</p> <p>For the timing of nutrition intervention, as enteral nutrition in severe and moderately severe acute pancreatitis is recommended, the committee also agreed that it was important to specify that the aim should be to meet nutritional requirements as soon as possible, to avoid underfeeding in this population which is known to occur in current practice.</p> <p>For specialist nutritional assessment the committee agreed that chronic pancreatitis is a complex condition, and the potential consequences of not receiving involvement from a dietitian specialising in pancreatitis includes deterioration in quality of life. More detail is provided in the discussion of the full version of the guideline.</p>
Pancreas North	Short	General	General	<p><b>Enzyme replacement guidelines</b> Guidelines relating to the taking of enzyme replacement should be included as this is a common subject query when Pancreas North visit patients. Patients feedback is that they are released from hospital without guidance GPs struggle to properly prescribe. We've have one lady whose GP had to ring up the Pancreatitis specialist nurse</p>	<p>Thank you for your comment and for contributing to the consultation process. We have included a recommendation advising clinicians to give written and verbal information on how to take pancreatic enzyme replacement therapy (recommendation 1.1.3). We have also added the following recommendation to highlight what information should be provided to GPs to promote coordinated care: (recommendation 1.1.7) states: Ensure that information passed to GPs includes all of the following, where applicable:</p> <ul style="list-style-type: none"> <li>• detail on how the person should take their pancreatic enzyme replacement therapy (including dose escalation as necessary)</li> </ul>

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				<p>asking if she could increase her dose from 1 tablet to 2 with each meal.</p> <p><b>Suggested Topics</b> When to take, before, during and after a meal How to take we've had instances of some people were chewing and releasing enzymes into their mouth How many to take in relation to snacks and full meals In Chronic cases advice about increase enzymes as the Pancreas degrades There is an assumption that people understand why enzymes are necessary and how to take, this in practice isn't the case.</p>	<ul style="list-style-type: none"> <li>that the person should be offered HbA1c tested at least every 6 months and bone mineral density assessments every 2 years.</li> </ul> <p>The committee also noted that there is a recommendation in the patient experience guideline (CG138, rec 1.4.3) which states "Ensure clear and timely exchange of patient information: between healthcare professionals (particularly at the point of any transitions in care)."</p>
Pancreas North	Short	General	General	<p><b>Information for GPs post hospitalisation</b> <b>Acute</b> It would be beneficial if patients who have been hospitalised with <b>Acute Pancreatitis</b> had a discharge pack they could hand to their GP which covers what has happened to them during their hospital stay and what the GP should look out for going forward, this would deliver the necessary and precise information directly rather than the GP</p>	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>We could not cover discharge packs in the guideline as it is outside the agreed scope. However, while it is not possible for us to recommend a specific discharge pack that patients pass to GPs, we have added the following recommendation to promote appropriate follow-on care in the community, (recommendation 1.1.7) states: Ensure that information passed to GPs includes all of the following, where applicable:</p>

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				<p>having to look up the condition and speed up the process if the patient is ill and needs to be readmitted.</p> <p><b>Chronic</b> GP pack for patients with Chronic including bone scans, diabetes. Type 3c diabetes seems to be referred back to hospitals.</p> <p><b>Information For Patients</b> Including Enzyme replacement, alcohol consumption, diet, anticipated time to full recover.</p>	<ul style="list-style-type: none"> <li>• detail on how the person should take their pancreatic enzyme replacement therapy (including dose escalation as necessary)</li> <li>• that the person should be offered HbA1c tested at least every 6 months and bone mineral density assessments every 2 years.</li> </ul> <p>Information for GPs post-hospitalisation is also covered in the patient experience guideline (CG138), rec 1.4.3 which states “Ensure clear and timely exchange of patient information: between healthcare professionals (particularly at the point of any transitions in care)”.</p> <p>Regarding information for patients, enzyme replacement, alcohol consumption and diet are already addressed within the guideline. We have also added the following to recommendation 1.1.5: for people who achieve full recovery, time to recovery may take at least 3 times as long as their hospital stay.</p>
Pancreas North	Short	General	General	<p>Scope doesn't cover resectional surgery or total Pancreatectomy – was this excluded from scope?</p>	<p>Thank you for your comment.</p> <p>Although not mentioned in the scope these interventions were included in the protocols for the following reviews: pseudocysts, pancreatic duct obstruction, small duct disease (including total pancreatectomy), ascites and pleural effusion and biliary obstruction. Evidence on these procedures, was therefore reviewed within the guideline and formed part of the basis for the following recommendation:</p>

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					<ul style="list-style-type: none"> <li>Consider surgery (open or minimally invasive) as first-line treatment in adults with painful chronic pancreatitis that is causing obstruction of the main pancreatic duct</li> </ul>
Pancreas North	Short	General	General	The guidelines are fantastic and a positive and huge step towards treating Pancreatitis in a consistent way across the country, thank you.	Thank you for your comment and for contributing to the consultation process.
Pancreas North	Short		9	<p><b>Type 3c Diabetes.</b> Advice should be provided to diabetic special staff in the community who treat Hereditary Pancreatitis patients about the altering levels over time due to deteriorating insulin production in the pancreas caused by Pancreatitis.</p>	Thank you for your comment and for contributing to the consultation process. We believe that the recommendations need to focus on all patients with type 3c diabetes and those who may develop type 3c diabetes including those with hereditary pancreatitis. Our follow-up recommendations are designed to pick up all patients with deteriorating insulin production.
Pancreas North	Short	4	1.1.5	An explanation is needed for patients and family as why the transfer to a specialist unit could take 4-6 week due to the condition needing to develop before treatment can start	<p>Thank you for your comment and for contributing to the consultation process. We have added a bullet point to the recommendation stating that it may be safer to delay intervention (for instance to allow a fluid collection to mature). Please see recommendation 1.1.5</p> <p>We have also amended the discussion of the recommendation in the full version of the guideline to explain the following: In the management of acute pancreatitis transfer is only usually required for an intervention, that is a procedure, usually for extensive or infected necrosis. Intervention for necrosis is rarely done in the first 4 weeks and may be undertaken later. As the patient's necrosis deteriorates the patient may be transferred at an appropriate time for direct specialist care. However, many patients</p>

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					with necrosis do not need transfer and can be managed closer to home at their local hospitals. In the early stages the local hospital will often contact the specialist centre for advice. The specialist centre will review the laboratory results and scans and then advise the local hospital on the person's management, including whether transfer is required.
Pancreas North	Short	6	General	<p>Nutrition support for both Chronic and Acute pancreatitis</p> <p>Question 1: The recommendation does not reference that there may be a need for enzyme replacements, experience from visiting patients by Pancreas North, patients not in specialist centres are often not prescribed enzyme replacements.</p>	<p>Thank you for your comment and for contributing to the consultation process. We have made reference to pancreatic enzyme replacement therapy in our recommendations for nutrition support in chronic pancreatitis. We did not review the effectiveness of enzyme replacement in acute pancreatitis because we believed it was common practice in those in whom it is needed (those with severe acute pancreatitis), consequently we have not made a recommendation. We have added a comment in our discussion of the evidence to highlight the importance of using enzyme replacement therapy in patients recovering from severe acute pancreatitis.</p> <p>We have also made reference to its use in the patient information recommendations and in a new recommendation on passing information to GPs.</p>
Pancreas North	Short	9	1.6.5	<p><b>Hereditary Pancreatitis</b></p> <p>If a patient is identified as having hereditary pancreatitis then can this be flagged so that GPs are aware that other members of the family/relatives may need to be screened for the condition?</p>	<p>Thank you for your comment and for contributing to the consultation process. Screening of patients for hereditary pancreatitis was not within the scope of this guideline and so we are not able to make a recommendation on this.</p>

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Pancreas North	Short	11		<b>Putting this guideline into practice</b> It would be beneficial if each referral centre has a member of staff identified as an interested party in Pancreatitis, this would form a stronger referral path. (page 12 recommends identify a lead to champion the rollout of the guidelines but this needs to be ongoing and long term)	Thank you for your comment and for contributing to the consultation process. The committee noted that this was in line with the NCEPOD report on acute pancreatitis ( <a href="http://www.ncepod.org.uk/2016report1/downloads/TreatTheCause_fullReport.pdf">http://www.ncepod.org.uk/2016report1/downloads/TreatTheCause_fullReport.pdf</a> ). It is included as a pointer in the section of guideline on “Putting this guideline into practice” that appears on NICE’s web pages for this guideline. However, service delivery is beyond the scope of this guideline and we cannot make a recommendation in this area.
Royal College of General Practitioners	Full and short			This are generally excellent guidelines	Thank you for your comment and for contributing to the consultation process.
Royal College of General Practitioners	Full and short			Consider changing the title to Pancreatitis: diagnosis and management including Type 3c Diabetes.	Thank you for your comment and for contributing to the consultation process. Type 3C diabetes only forms a small part of the guidance so has not been added to the title.
Royal College of General Practitioners	Full and short			The American Gastroenterological Association Institute guideline on Initial Management of Acute Pancreatitis has recently publishes 8 recommendations which are broadly consistent with NICE recommendations. There is no mention in the NICE full or short guideline re recommendation 7 ie in acute biliary pancreatitis there is no mention of when cholecystectomy should be carried out	Thank you for your comment and for contributing to the consultation process. We did not prioritise the use of cholecystectomies for acute biliary pancreatitis for inclusion in the guideline as it was considered to be adopted current practice. The timing of a cholecystectomy is addressed in detail in the NCEPOD report Acute Pancreatitis: Treat the Cause (2016) ( <a href="http://www.ncepod.org.uk/2016ap.html">http://www.ncepod.org.uk/2016ap.html</a> ) therefore we did not include the management of pancreatitis with cholecystectomies in this guideline.

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				<p>1A. In patients with AP, the AGA suggests using goal-directed therapy for fluid management. Comment: The AGA makes no recommendation whether normal saline or Ringer’s lactate is used.</p> <p>1B. In patients with AP, the AGA suggests against the use of HES fluids.</p> <p>2. In patients with predicted severe AP and necrotizing AP, the AGA suggests against the use of prophylactic antibiotics.</p> <p>3. In patients with acute biliary pancreatitis and no cholangitis, the AGA suggests against the routine use of urgent ERCP.</p> <p>4. In patients with AP, the AGA recommends early (within 24 h) oral feeding as tolerated, rather than keeping the patient nil per os.</p> <p>5. In patients with AP and inability to feed orally, the AGA recommends enteral rather than parenteral nutrition.</p> <p>6. In patients with predicted severe or necrotizing pancreatitis requiring enteral tube feeding, the AGA suggest either NG or NJ route.</p>	
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			<p>7. In patients with acute biliary pancreatitis, the AGA recommends cholecystectomy during the initial admission rather than after discharge.</p> <p>8. In patients with acute alcoholic pancreatitis, the AGA recommends brief alcohol intervention during admission</p> <p>American Gastroenterological Association Institute Guideline on Initial Management of Acute Pancreatitis Crockett, Seth D.Crockett, Seth et al. Gastroenterology, Volume 154, Issue 4 , 1096 - 1101</p> <p><a href="http://www.gastrojournal.org/article/S0016-5085(18)30076-3/pdf">http://www.gastrojournal.org/article/S0016-5085(18)30076-3/pdf</a></p>	
Royal College of General Practitioners	Full and short		<p>Diagnosis and coding of Type 3c diabetes</p> <p>Type 3c diabetes, or diabetes of the exocrine pancreas, is currently misdiagnosed as type 2 diabetes in most patients, a large UK primary care study has reported in late 2017 using the RCGP Research Surveillance Centre</p>	<p>Thank you for your comment and for contributing to the consultation process. The committee hopes this guideline will raise awareness of type 3c diabetes and help reduce its misdiagnosis. The committee agreed that correctly coding type 3c diabetes would be beneficial as it can be rapidly progressive. However, the creation and use of disease codes for the NHS is outside the remit of NICE guidance.</p>

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			<p>Woodmansey C, McGovern AP, McCullough KA, et al. Incidence, demographics, and clinical characteristics of diabetes of the exocrine pancreas (type 3c): a retrospective cohort study. <i>Diabetes Care</i> 2017;dc170542. doi:10.2337/dc17- There is currently no code in use in UK primary care which uses the nomenclature 'type 3c' diabetes. On the 09 November 2017 in BMJ rapid response Andrew P McGovern Clinical Researcher and Professor Simon de Lusignan University of Surrey recommended the use of the following codes to clearly label this type of diabetes.</p> <p>Read Version 2: • C10G. Secondary pancreatic diabetes mellitus Read CTv3: • X40JB Secondary pancreatic diabetes mellitus SNOMED CT: • SCTID: 51002006 Diabetes mellitus associated with pancreatic disease (disorder)</p>	
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				The use of these codes will ensure that patients will remain on the QoF diabetes registers and therefore be flagged for appropriate diabetes reviews and monitoring.	
Royal College of Nursing				This is to inform you that there are no comments to submit on behalf of the Royal College of Nursing to inform on the Pancreatitis: diagnosis and management Draft guidance consultation.	Thank you for your comment and for contributing to the consultation process.
Royal College of Physicians and Surgeons of Glasgow	Full	general	general	<p>The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow represents Fellows and Members throughout the United Kingdom. While NICE has a remit for England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments.</p> <p>The College welcomes this Quality Standard in an important area. Acute and Chronic pancreatitis are significant causes of mortality and morbidity. The acute situation requires admission to</p>	<p>Thank you for your comment and for contributing to the consultation process.</p> <p>NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.</p> <p>The committee agreed that there was a lack of evidence in this area and that it is a difficult area for research. The guideline has been developed following NICE processes to make it as transparent and as free of bias as possible. This is reflected in strength of recommendations or the research recommendations generated. In an area without much evidence to support it, it is likely that there will be a difference in opinion. The committee welcomes debate and hope that it helps towards improving care for people with pancreatitis.</p>

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			<p>hospital often requiring critical care support. It is in its chronic form, patients will require continuing use of primary and secondary care.</p> <p>The College welcomes the philosophy of working with patients, their families and carers providing information so they can give informed discussion regarding their health care in a difficult area.</p> <p>The College notes that the lack of evidence or very low quality evidence supporting these guidelines effectively means that the recommendations are largely consensus based. It is noted that this is a difficult area for research.</p> <p>However our reviewer reasonably questions the validity of the recommendations with such a limited panel, some of whom are not recognised experts in the field. The recommendations may not reflect the breadth of opinion in this clinical area. The leading experts may have therefore introduced a bias towards</p>	<p>The guideline committee encompassed all specialities of clinicians working with pancreatitis patients, acute and chronic, including a general surgeon and general gastroenterologist who work with these patients in their district general hospitals. The specialists are recognised experts in their field. The number of people on NICE guideline committees is set to ensure that the committee is able to operate effectively. They contribute to the development of the guideline within a process that includes a formal consultation at scoping and after development. The reason for undertaking stakeholder consultation is to gain the opinions of the wider community and not just those on the committee, and recommendations do change in light of stakeholder comments where there is significant feedback of disagreement that has a sound rationale underpinning it.</p>
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				their views in drafting the guidelines. While the reviewer has few arguments about the conclusions, there is ample room for debate over some of these issues.	
Royal College of Physicians and Surgeons of Glasgow	Full	19/20	L38-12 37-42	Follow up for chronic pancreatitis would require development of new services in most parts of UK. Screening for pancreatic cancer in patients with hereditary pancreatitis is currently within research protocol only.	<p>Thank you for your comment and for contributing to the consultation process. The recommendations for the follow up of people with chronic pancreatitis were written to address the current variation in practice and to improve the level of care received. The committee anticipated that the need for new services may be minimised by the use of regional networks.</p> <p>This network model approach is also recommended in the NHS standard contract for hepatobiliary and pancreas services (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>).</p> <p>The committee was aware that pancreatic cancer screening in people with hereditary pancreatitis is currently only in research, but agreed that it was important to recommend monitoring for cancer in patients with hereditary pancreatitis because of the very high incidence in this group and the benefits of identifying the condition early. This is also in line with other international guidelines.</p>
Royal College of Physicians and Surgeons of Glasgow	Full	18	L3 Rec 25	Few general hospitals have access to endoscopic drainage of pancreatic collections which requires expert endoscopic ultrasound. The implementation of this guideline will	<p>Thank you for your comment and for contributing to the consultation process. Regional networking is part of the NHS England standard contract for hepatobiliary and pancreas services – A02/S/a (<a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a>). In the ‘putting the guideline into practice’</p>

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				require a regional networking arrangement so that patients can be discussed with and transferred to sites with available expertise.	section of the short version we have highlighted that models where local centres interact and collaborate with a regional specialist centre for acute pancreatitis are only currently established in some regions. Therefore, this model will need to be implemented across the country to enable the recommendations on specialist referral to be followed.
Royal College of Physicians and Surgeons of Glasgow	Full	19	L22 Rec 34	The implication is that other problems described can be safely managed in a non-specialist centre which is clearly not the intention.	Thank you for your comment and for contributing to the consultation process. It is expected that regional pancreatitis networks will use these guidelines to manage patients and use advice from and transfer to the specialist centre when necessary. In this guideline there are specific recommendations on involving the specialist team. Other advice on networking can be found in the NHS England standard contract for hepatobiliary and pancreas services - A02/S/a ( <a href="https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf">https://www.england.nhs.uk/wp-content/uploads/2013/06/a02-hepto-pancreas-adult.pdf</a> ). In the case of ascites and pleural effusion, no evidence was found; but due to the complex nature of the condition, the input of a specialist centre has been recommended.

*\*None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

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