

Pancreatitis



The UK's Top 10 Research Priorities

Your top 10 research priorities for pancreatitis
in the UK and Republic of Ireland.

Defining future pancreatitis research with
our Priority Setting Partnership.



The UK's Top 10 Research Priorities for Pancreatitis

Introduction



What is a Priority Setting Partnership (PSP)?

The James Lind Alliance (JLA) helps set up PSPs for a wide range of diseases. The purpose of a PSP is to identify and prioritise the unanswered questions for certain medical conditions, or areas of health.

PSPs bring together patients, carers, doctors, nurses, dietitians and other health professionals, all with an equal voice. Together, they decide the top ten research priorities for their condition.

Why did Guts UK choose to begin a PSP for pancreatitis?

A PSP has never before been completed into pancreatitis. It's time we change that. Guts UK is proud to initiate this huge step forward for this misunderstood condition.

What is pancreatitis?

Acute pancreatitis is a sudden inflammation of the pancreas gland. Chronic pancreatitis is long-standing inflammation of the pancreas (life-long).

How many people have pancreatitis and how does it affect people's lives?

30,000 people are affected by acute pancreatitis each year. There is little data on the amount of people living with chronic pancreatitis in the UK, but there are 12,000 hospital admissions per year for those living with chronic pancreatitis.

Sadly, acute pancreatitis can be fatal. Of those who will become severely unwell with severe acute pancreatitis requiring ICU care, 1 in 4 will die. Others may spend weeks to years recovering from their attack, depending on the severity and the time spent in hospital. Some people may have to learn to walk or speak again and some may also develop chronic pancreatitis.

Chronic pancreatitis for most is life changing. Many people live in pain and experience further complications such as developing type 3c diabetes. Those with chronic pancreatitis may struggle with losing too much weight. Many drugs are needed to treat this condition, such as multiple enzyme tablets with each meal. As with any chronic condition, sufferers may suffer psychological symptoms such as depression and relationship problems.

The process



1 Steering group

This was made up of 8 patients/carers and 8 healthcare professionals with direct experience of pancreatitis.

2

Protocol scope

This was where we decided what we would include in the PSP, and what we couldn't quite cover. This was defined by the steering group. We decided to include: causes, diagnosis, treatment, management, support for pancreatitis, in both adults and children.

3

First survey launch

This gathered research ideas from patients/carers and healthcare professionals. This was an opened answer survey, where we asked **'What research would you like to see into pancreatitis? What questions would you like research to answer'**. 751 people responded, asking a whopping 1717 questions!



4

Information process

Next, we categorised the questions and found that 894 were within the agreed protocol scope. These questions were summarised under 59 headings. The questions were then evidence checked to make sure that they hadn't already been answered by research.



5

Final survey

This was shared with patients, carers and healthcare professionals asking them to choose their top 10 research priorities from the 55 summary questions.

6

Final workshop

23 final questions were taken to the workshop. The workshop consisted of 13 patients, family members or carers (3 were ill/unable to attend on the day) and 16 healthcare professionals.

RESULTS!

7

The Top 10 Research Priorities for pancreatitis were agreed!



Priority 1

Are there better ways to treat and manage acute and long-term pancreatitis pain, for example using non-opioid (painkillers) drugs?



Oli's story



"Oli depended on opiate-based painkillers. Other painkillers wouldn't even touch his pancreatitis pain. Oli grew dependent on the painkillers. Opioids take the pain away but they alienate a person. The side effects and addictive nature of opioids have the capacity of creating a bigger struggle for the person than the illness they are meant to be treating.

For us as a family, we wouldn't want anyone else to go through the same struggles and loss as Oli did, and neither would Oli. Having alternative pain relief for pancreatitis would be a very positive step in ensuring this."

Sue, Stu, Ben & Danny - Oli's family

"Pain can be a feature of many different pancreatic conditions, so it is perhaps not surprising that it featured so highly in the priority setting partnership for pancreatitis. Pain can affect every part of a sufferer's life as well as those of their loved ones. Over recent years our understanding of the harms of certain painkillers, particularly opioids, has advanced but highly effective alternatives are few. This leaves sufferers in urgent need of new, effective and safer ways to manage pain."

Dr Graeme Fitzpatrick

Consultant in Anaesthesia and Pain Medicine



Priority 2

What can be done to prevent pancreatitis becoming worse, and to stop or reverse the damage to the pancreas?



"Pancreatitis is a disease which can either render a patient unwell for a few days, or can cause multi-organ failure, and even death. We have poor understanding why it affects different people in such different ways, and have little in the way of treatment to stop progression of the disease once it has been diagnosed. Breakthroughs in how we can stop pancreatitis worsening, or even reverse damage once it has occurred, would make a massive difference to the outcome of patients who would otherwise go on to develop life threatening disease."

Marianne Hollyman

Consultant Upper GI Surgeon



Katen's story



"It would mean a lot to find ways in preventing pancreatitis becoming worse. It could open me up to being able to eat properly, without having to worry about everything I eat. It could put my mind at rest. Continued research would give hope that pancreatitis is eradicated sooner rather than later, potentially improving my quality of life. I'd feel better overall, knowing there are wider options out there to help pancreatitis sufferers further."

Katen

Priority 3

Are there better ways to reduce inflammation in people with pancreatitis, both in the pancreas and the rest of the body?



Ray's story

"Through my whole eighteen-month journey with pancreatitis, I remained mainly inflamed and of course in lots of pain. Inflammation is still a problem for me and whilst I feel I manage it fairly well, I remain in fear that my condition will one day be serious again, and then I may not be so lucky. Inflammation scares me due to my past experiences. If this element of pancreatitis could be controlled more effectively, I hope we'd see more success in the recovery or prevention of acute and chronic pancreatitis."

Ray and wife, Jackie



"There are gaps in our understanding of the pathogenesis of pancreatitis, which is a major inflammatory disease of the gastrointestinal tract. There is no specific treatment for the inflammatory response which is responsible for the acute and chronic pancreatitis. Further research will lead to innovative new approaches to treating the inflammatory process and thus help manage both acute and chronic pancreatitis."

Mr Anil Agarwal

Consultant Surgeon

Priority 4

How can pancreatitis be diagnosed more quickly and accurately, especially on admission to hospital?



Jemma and James's story

"Early diagnosis is something that we would wish for every person with pancreatitis. We have two children with pancreatitis, Jemma and James. From the age of two, both Jemma and James were in and out of hospital regularly with abdominal pain and other complications. We were constantly doubted. James was accused of being an attention seeker, and Jemma even had a healthy appendix removed.

James received his diagnosis around his 14th birthday (12 years after his first symptoms), and Jemma was 23 years old (21 years after her first symptoms).

Early diagnosis is essential. Not having an accurate diagnosis affected how our children were perceived by medical professionals all those years. Early diagnosis can avoid unnecessary surgery, and improve long term physical and mental health."

**Katie, Paul and
the Ward family**



Priority 5

How can people with pancreatitis be helped to manage their condition post-diagnosis (after being diagnosed) e.g. by giving information about diet, medication and lifestyle changes?



"As healthcare professionals it's so important we better understand how best to help people with pancreatitis to manage their condition after diagnosis. So that they can be empowered to make changes and use available resources that may reduce the burden of the illness, improving symptoms and overall health and wellbeing. To achieve this, research to examine the different methods and value of strategies like providing specialist information and access to support for pancreatitis is required."

Stacey Munnelly

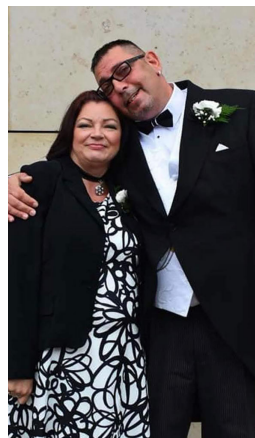
Advanced Gastroenterology Nurse Practitioner

Mandy's story

"I left hospital after my first attack without any information or advice. I was given no information on diet or lifestyle changes. No one explained malnutrition to me, that it could cause weight and hair loss. Even after my worst attack and five-month-stay in hospital, I left for home with no follow-up plan, no information or advice. I also left with no knowledge of what had happened to me and my body, during those five months in hospital.

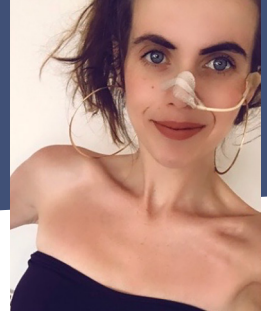
I want to see more support, advice and information, so people don't feel 'turfed' out of hospital, left to struggle on their own. I want to see people have the information that I never had."

Mandy



Priority 6

Are there better ways to treat and manage flare-ups (when symptoms get worse) in people with chronic pancreatitis?



Elise's story

"Since diagnosed, I've had many lengthy hospital admissions in which medical professionals had no plan. I've had complex surgeries, become dependent on a feeding tube and for many years was left on opioids as a way to 'manage' the pain. As a result, I have been diagnosed with complex PTSD and dissociation which worsens when in hospital settings.

18 years awaiting diagnosis, no curative treatment options and a lack of understanding on how best to manage flare ups of chronic pancreatitis has left me feeling lost and hopeless. This question is so important as it would provide the knowledge needed for health professionals including GPs to better support individuals both within the community and hospital settings. Each admission creates anxiety and a desperate hope that the Doctors have the knowledge and skills to provide the appropriate care you need."

Elise



"Chronic pancreatitis is a lifelong, often unremitting disease which is unpredictable. Flare-ups of pain can be particularly disabling for patients, hugely impacting upon their quality of life and often lands them in hospital to try to regain control. Finding better ways to identify and treat these flare up will have a massive positive effect for these patients. Even better would be prevention."

Dr John S Leeds,

Consultant Pancreaticobiliary Physician
Freeman Hospital, Newcastle Upon Tyne.



Priority 7

Can gene therapy (altering genes inside the body's cells) be used to treat people with pancreatitis?

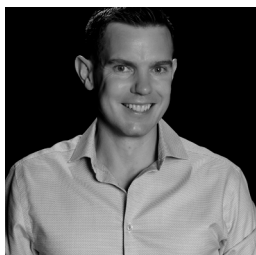


Zaki and Talia's story

"Both our children have genetic mutations that place them at higher risk of pancreatitis. Day-to-day we live with the anxiety of never knowing when another acute attack might occur. Seeing our children suffer and knowing there are very few treatment options available is heartbreaking. We are hopeful that research into gene therapy might find a way to treat or even cure those with genetic pancreatitis. This would mean our children could lead healthy and happier lives without the need for frequent hospital stays or medical interventions."



Claire and Mohamed, parents of Zaki and Talia



"We know that genetic susceptibility is a factor greater or small in most pancreatitis patients. We know the genetic mutations responsible for many attacks and are learning about new susceptibility genes every year. Excitingly, in the last few years we have developed the ability to use medications against a small number of specific mutations to help prevent recurrent acute pancreatitis. What we need to do is find more actionable mutations and develop medications against these, for the broader group of pancreatitis patients. This is why I am very pleased that the PSP has selected gene therapy as a top priority."

Dr Joe Geraghty

Consultant Gastroenterologist.



Priority 8

How can multiple organ failure be prevented in those people with pancreatitis who become seriously ill? How can the care of those people with multiple organ failure be improved?



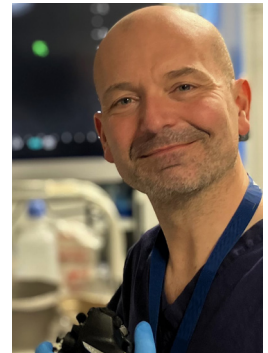
Steve's story



"My husband died in March 2020 after spending 3 months in intensive care with severe **acute pancreatitis** (SAP), so I have first hand experience of the effects of this terrible disease. Within 48 hours of being diagnosed he started suffering multiple organ failure. It was beyond heartbreaking to witness. Sadly, this is common in patients with SAP, drastically reducing their chances of survival. Being able to prevent and actively treat organ failure will significantly improve the outcome of patients with SAP."

David, remembering his husband Steve

"The effects of severe acute pancreatitis are devastating and can affect patients of any age, background or cause. Once multi-organ failure develops from severe pancreatitis, the risk of death rapidly increases. In those that do survive it, is after a prolonged stay on intensive care units, which can be months. I see first-hand the multiple procedures to support organ failure which results in massive physical and psychological distress, which has long lasting effects on patients and families. Despite the best efforts of our intensive care units, preventing or reversing the underlying inflammatory cascade to avoid these life-shattering consequences is greatly needed, as it's one I see too often."



Professor Andrew Hopper

Honorary Professor and Consultant Gastroenterologist.

Priority 9

How can pancreatic cancer be diagnosed earlier in people with pancreatitis?



“Pancreatitis is a known risk factor for the development of pancreatic cancer. This risk is increased further when the pancreatitis is due to hereditary causes, or in patients who smoke or drink alcohol to excess. Pancreatic cancer is only curable when caught early and unfortunately it can be harder to diagnose in patients who have pancreatitis. The aim of this research will be to help develop tests to allow for screening and for earlier diagnosis so that we can successfully treat patients with pancreatitis who unfortunately develop pancreatic cancer.”

Dr Matthew Huggett,

Consultant Gastroenterologist and HPB Physician.



Priority 10

What are the psychological (mental and emotional) impacts of pancreatitis? What are the best ways to treat and support people (both young people and adults) with pancreatitis who experience mental health problems?



Amy's story

"This question was important to me, as a patient is physically examined and observed throughout their illness, but their mental health is either not looked at or not considered. There is little research and awareness on pancreatitis, so when you are a patient it is a very lonely place to be. There are times that patients are unable to work, go out and do the basic things we take for granted. If research was done on improving this I feel it will empower patients and give them hope that they are being listened to and they aren't on their own. I wasn't listened to so let's make sure that others are."

Amy



"There have been strong associations reported between chronic illness and patients' mental health, but not so for pancreatic diseases. Especially for children and young people with pancreatitis, in whom their unique mental health needs can be overlooked, by focussing on other equally important aspects of their care. Attempting to identify the impact of pancreatitis in mental health means healthcare professionals caring for these patients can better understand their needs, and shape the development of services to address those issues in a meaningful way."

Dr Tassos Grammatikopoulos

Consultant in Paediatric Hepatology and Honorary Senior Lecturer.

Question 11-23

These questions were also discussed and put in order of priority at the final workshop. They are important and not forgotten questions, with all information available and open for research.



11. Can treatments be developed to repair the damaged pancreas in people with pancreatitis?
12. What diet(s) benefit people with different types of pancreatitis and at different stages of the illness?
13. What causes tiredness (fatigue) in people with pancreatitis and how is this best treated and managed?
14. What is the best regime for tube feeding to ensure good nutrition and hydration for people with pancreatitis?
15. What is the best form of follow-up for people with pancreatitis including routine monitoring and treatment review?
16. Are there better ways to treat and manage the gut problems linked to pancreatitis including not being able to absorb food (malabsorption)?
17. Why do some health professionals have negative attitudes and behaviours towards people with pancreatitis? How can this be improved?
18. When should damaged parts of the pancreas be removed in people with pancreatitis? Which procedures benefit people the most?
19. What are the long term effects of pancreatitis and its treatment? How likely are people to recover or become worse over time?

20. What would help health care professionals to better understand and recognise pain in people with pancreatitis?
21. Can pancreatic **enzyme replacement therapy (PERT)** be improved by tailoring the treatment to the needs of the individual? Does this treatment need to be life-long?
22. What is the link between pancreatitis and other health conditions (for example **irritable bowel syndrome**, autoimmune conditions)? Do they have a common cause or does one cause the other?
23. What is the impact of pancreatitis on life expectancy?

For more information on the PSP, the protocol and the questions (including out of scope ones), go to:
gutscharity.org.uk/Pancreatitis-Top-10



The future looks brighter

This is the first time you have been asked what research you'd like to see into your condition. Now, Guts UK is promoting these questions and putting them into 'researchable' format. We're dedicated to researching causes, diagnosis, treatment, management and support for pancreatitis.

The National Institution of Health & Research (NIHR) welcome research applications for conditions with PSPs, which we're delighted to say that pancreatitis now has!

We finally have a direction for pancreatitis research in the UK, a condition that has been neglected and misunderstood for too long. Together, we're changing that.



Message from Julie Harrington CEO, Guts UK Charity

"Within weeks of joining Guts UK as CEO in 2016, the pancreatitis community came knocking on our door. It became clear that those with pancreatitis had no support, no information and nowhere to turn for help. Pancreatitis is underfunded, under-researched and misunderstood. It has been for decades.



We have since created further information for patients, and our **Kranky Panky Awareness Campaign** creates a community for those affected by pancreatitis. **But we knew we needed to do more.**

We made a commitment to the pancreatitis community that we would undertake a Priority Setting Partnership with the James Lind Alliance to decide the top 10 research priorities for pancreatitis. **It fills me with pride to say we finally achieved this**, alongside the British Society of Gastroenterology and the Pancreatic Society of Great Britain and Ireland.

The strength and passion of the pancreatitis community drove this project forward, creating true and lasting change. Thank you to everyone involved."

Message from Vikramjit Mitra

PSP Clinical Lead, Consultant Gastroenterologist and Honorary Senior Clinical Lecturer, University Hospital of North Tees. Chair of Pancreas Clinical Research Group, British Society of Gastroenterology (BSG)

"When I first started working as a Consultant Gastroenterologist in 2014, it became clear to me that expertise in the management of pancreatitis was limited and services needed to improve to achieve better patient outcomes in the UK. It became evident that pancreatitis has been under-researched and underfunded for decades and services would only improve through extensive research in this area.

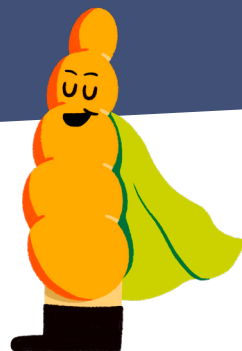


I am delighted to announce that we have now been successful in identifying the top 10 research priorities in pancreatitis in the UK. This would not have been possible without the unwavering support, passion and dedication from the entire pancreatitis community in the UK. On behalf of the whole team, I would like to thank everyone who has been involved in this journey."

You made it possible

We'd like to give our most sincere thanks to our wonderful steering group for leading this process so beautifully. Thank you for giving up so much of your time to ensure this PSP was done to the best standard possible.

Amy Lucas, Andrew Hopper, Barbara Ryan, Damian Mole, David Hawkins, George Rawlins, Ian Scott, John Leeds, Katie Ward, Kirsty Donaldson, Mark Batey, Mary Phillips, Stacey Munnelly, Tassos Grammatikopoulos, Vishnu Aggarwal. Vikramjit Mitra (PSP Clinical Lead), Julie Harrington (PSP Lead), Helen West (PSP Co-ordinator) Maryrose Tarpey (James Lind Alliance Facilitator) Kristina Staley (Information Specialist).



Thank you to everyone who submitted their questions and thoughts. You can say with confidence that you helped shape the future of pancreatitis research!

We'd also like to thank those who attended the final workshop for the PSP, for giving up a full day of your time and being so open and honest with your personal research priorities.

Amy Lucas, Andrew Hopper, Anil Agarwal, Bilal Khan, Claire Bendjillali, Damian Mole, David Hawkins, Debasis Majumdar, George Rawlins, Graeme Fitzpatrick, Ian Scott, Jayne Fairburn, Joe Geraghty, John Leeds, John Tuite, Julia Larmer, Katie Ward, Kirsty Donaldson, Lola Tuite, Leuan Davies, Marianne Hollyman, Mary Phillips, Matthew Huggett, Sharan Shetty, Shiran Esmaily, Stacey Munnelly, Tassos Grammatikopoulos, Vikramjit Mitra, Vishnu Aggarwal.

Observers:

Arjun Kattakayam, Esther Southey, Francis Robertson, Helen West, Jenny Holdsworth, Julie Harrington.

James Lind Alliance Facilitators:

Beccy Maeso, Katherine Cowan, Louise Dunford, Maryrose Tarpey, Patricia Ellis.

Thank you to the British Society of Gastroenterology and the Pancreatic Society of Great Britain and Ireland for co-funding the pancreatitis PSP. **Your expertise and crucial connections opened doors throughout the process, ensuring the outcome was a success for all.**



