

James  
Lind  
Alliance

Priority Setting Partnerships



BRITISH SOCIETY OF  
GASTROENTEROLOGY



# James Lind Alliance (JLA) Pancreatitis Priority Setting Partnership (PSP)



# Who is the James Lind Alliance (JLA)



- Non-profit making initiative, supported by the NIHR.
- Established in 2004, first PSP 2007 in Asthma
- Completed over 150 Priority Setting Partnerships (PSPs)
- JLA International PSPs - Canada, Germany, Netherlands, Uganda, Ethiopia
- To ensure that those who fund health research are aware of what matters to patients, carers and clinicians who need to use the research in their everyday lives.
- Transparency of process



- Transparency of the process
- Balanced inclusion of patient, carer and clinician interests and perspectives - equal voice
- Exclusion of groups or organisations that may have competing interests, e.g. pharmaceutical companies
- Using the existing evidence base to make sure questions are not already answered
- Maintained audit trail from original first survey, to final prioritised list



# What is a Priority Setting Partnership (PSP)?



- Bring patients, carers and clinicians on an equal footing - balanced inclusion
- Identify evidence uncertainties (questions which cannot be answered by existing research) which are important to all groups
- Work with all groups to jointly prioritise identified uncertainties
- Produce a Top Ten final list of jointly agreed research priorities, publicise them widely, and make sure that other uncertainties are recorded and available for researchers and research funders to access
- Provide a rare and valuable opportunity for patients and clinicians to shape the health research agenda.

# Why a JLA PSP in Pancreatitis



- Pancreatitis is underfunded and under researched
- No PSP has been undertaken previously in this condition
- Equal voice - patient/carers and healthcare professionals
- Those funding health research are aware of what matters to the people who need to use the research in their everyday lives.
- Recognised by the NIHR

# NOT POSSIBLE WITHOUT FUNDING + RESOURCES PROVIDED BY:



# Pancreatitis PSP steps and timeline



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PSP link with Partners



Form Steering Group & agree protocol

Launch website

Identify Evidence gaps

Consultation - 1st survey



Literature Reviews & guidelines



form summary questions from in-scope responses

Final summary questions	4 May 22
<b>TREATMENT</b>	
T1	Are there better ways to treat and manage acute and long-term pancreatitis pain, for example using non-opioid drugs?
T2	What causes fatigue in people with pancreatitis and how is this best treated and managed?
T3	What is the best form of follow-up for people with pancreatitis including routine monitoring and treatment review?
T4	Can gene therapy be used to treat people with pancreatitis?
T5	Are there better ways to treat and manage the gut problems linked to pancreatitis including malabsorption?
T6	Can treatments be developed to repair the damaged pancreas in people with pancreatitis?
T7	What factors determine the best times for endoscopy or surgery in people with pancreatitis? Which procedures benefit people the most?
T8	How can multiple organ failure be prevented and how can the care of people with pancreatitis with multiple organ failure be improved?
T9	Are there better ways to treat and manage flare-ups (when symptoms get worse) in people with chronic pancreatitis?
T10	Are there better ways to treat and manage diabetes type 3c in people with pancreatitis?



Launch of 2<sup>nd</sup> survey to reduce long list of summary questions to a short list

Agree Top 10 priorities - One day group workshop and then ....

<b>K</b> How can pancreatitis be diagnosed more quickly/accurately? ...?	<b>11-16</b> Middle priority for research	<b>17-23</b> Lower priority for research
<b>H</b> How can people be helped to manage their condition post diagnosis ...?	<b>A</b> What causes tiredness (fatigue) in pancreatitis ...?	<b>L</b> What would help health professionals to better understand & recognise pain ...?
<b>Q</b> How can multiple organ failure be prevented ...?	<b>T</b> What are the long term effects of pancreatitis and its treatment? ...?	<b>M</b> Are there better ways to treat & manage flare-ups ...?
<b>C</b> Are there better ways to treat and manage pancreatitis pain ...?	<b>G</b> Are there better ways to treat & manage gut problems in pancreatitis? ...?	<b>N</b> Can treatments be developed to repair the damaged pancreas ...?
<b>V</b> Why do some professionals have negative attitudes/behaviours ...?	<b>P</b> What is the best regime for tube feeding to ensure good nutrition? ...?	<b>B</b> Can PERT be improved by tailoring the treatment to the needs of the individual ...?
<b>D</b> Are there better ways to reduce inflammation in pancreatitis ...?	<b>N</b> What diet(s) benefit people with chronic pancreatitis ...?	<b>F</b> Can gene therapy ... be used to treat people with pancreatitis? ...?
<b>I</b> What is the best form of follow-up for pancreatitis ...?	<b>Q</b> What is the impact of pancreatitis on life expectancy? ...?	<b>E</b> What are the pathological (metabolic) impacts of pancreatitis ...?
<b>J</b> What is the best form of follow-up for pancreatitis ...?	<b>S</b> What are the pathological (metabolic) impacts of pancreatitis ...?	<b>E</b> When should damaged parts of the pancreas be removed? ...?



# Pancreatitis PSP: timeline (1)



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**7<sup>th</sup> September 2021**

Initial steering committee meeting. Preparing protocol  
8 lay members, 8 healthcare professionals

**Causes, Diagnosis, Treatment, Support,  
Management**

**March 2022- June 2022**

Sub-group set up, Filter questions, generated summary  
questions, checked against evidence

**59 summary questions** were evidence checked  
**55 unanswered questions remained**



**December 2021-February 2022**

Initial survey open, online/paper formats, promote  
via social media, target seldom heard groups, professional  
organisations

**751** people took part **1,717 questions** were asked  
**823 questions** were out of scope and **894** were in scope

This is the **FINAL pancreatitis survey**. There's still chance to have your say!

The Priority Setting Partnership (PSP) into pancreatitis is YOUR opportunity to help us identify the top 10 priorities for pancreatitis research. People submitted questions in our first survey that they wanted pancreatitis research to answer. The submitted questions have been sorted and categorised.

We would like you to choose the questions that are the **most important to you** from the list.

This survey is open to **ALL ages 11+**

The survey closes **Sunday 9th October 2022**.

Have your say here

[surveymonkey.co.uk/r/Pancreatitis\\_PSP\\_2](https://surveymonkey.co.uk/r/Pancreatitis_PSP_2)

Contact Helen West for a postal copy of the survey or further queries:  
[hwest@gutscharity.org.uk](mailto:hwest@gutscharity.org.uk) or call 0207 486 0341

# Pancreatitis PSP: timeline (2)



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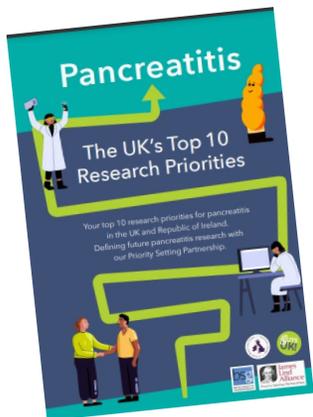


**August - October 2022**  
Second survey (prioritisation) opened.  
Young People 11+ - 28 Questions, Adult - 55  
questions  
**23 questions final questions**

## NEXT STEPS

Face-to-face meeting  
March 2023  
Started the PICO process  
Published the final report

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## July 2022

Steering group finalized and produced two surveys

## November 2022

Final zoom workshop

## TOP TEN



# First Survey (Dec'21-Feb'22)



- Designed by the Steering Group
- Open-ended question - asked people to respond with comments and questions based on their own experience
- Patients, carers and healthcare professionals
- Dissemination both digitally and poster - social media platforms, professional organisations, support groups, religious organisations, community notice boards  
+++

Have you ever asked a question about **pancreatitis**, that nobody was able to answer?

**We need your help.**

By taking part in a 5-minute survey, you will help us identify priorities for research in the diagnosis, treatment, management, and support for people with pancreatitis.

**Be part of deciding the top 10 priorities for future pancreatitis research by taking part in our survey**

The GUTS UK! logo is a green circle with the text 'GUTS UK!' in white, stylized font.

# Second (Prioritisation) Survey



- Move from a long list of unanswered questions, to a short list
- Long list is included within the second survey
- Ask patients, carers and healthcare professionals to vote on the most important questions in their experience
- Dissemination as per first survey + additional contacts



**This is the FINAL Irritable Bowel Syndrome (IBS) survey. There's still a chance to have your say!**

The Priority Setting Partnership (PSP) into IBS is YOUR opportunity to help us identify the top 10 priorities for IBS research. People submitted questions in our first survey that they wanted IBS research to answer. The submitted questions have been sorted and categorised.

**We would like you to choose the questions that are the most important to you from the list.**

**This survey is open to ALL ages 16+**

**The survey closes TBC**

Have your say here 

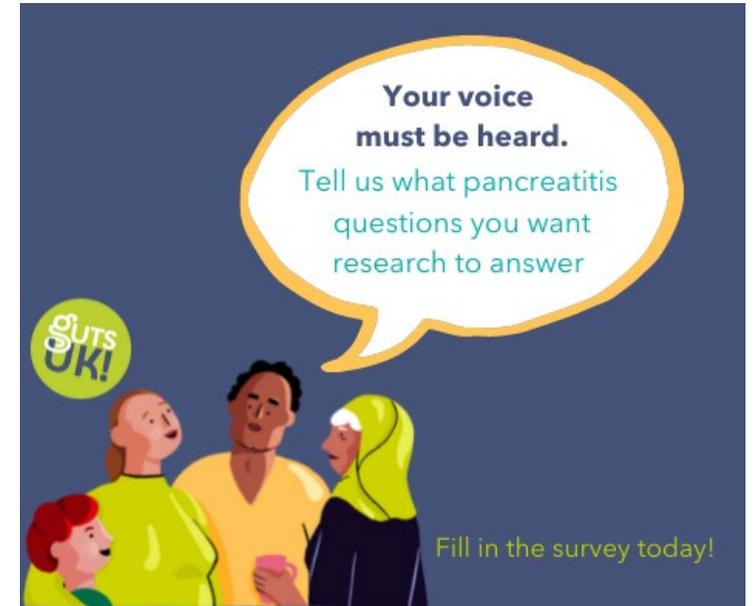
<https://www.surveymonkey.co.uk/r/73B9M6N>

Contact Helen West for a postal copy of the survey or further queries:  
hwest@gutscharity.org.uk or call 0207 486 0341



# Second Survey (Aug -Oct'22)

- 55 evidence checked questions
- **Two versions of the survey:**



- **11-18 years (Young Person)** 28 questions taken from the list of 55 - no changes to wording, questions that were age appropriate.....83 responses
- **18+ years (Adult)** 55 questions.....682 responses

# Questions taken to final workshop



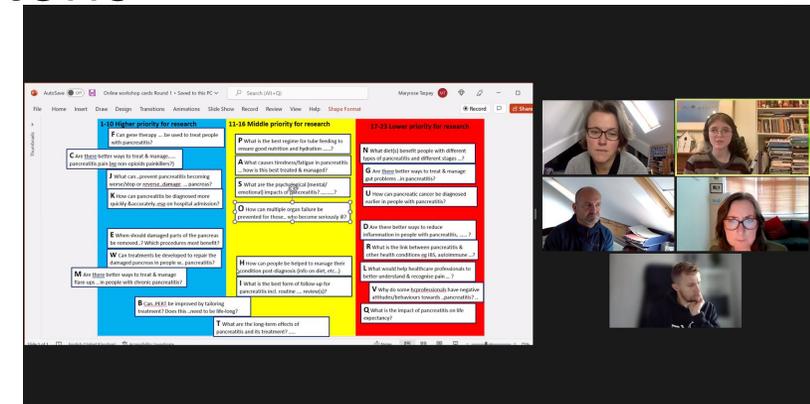
## Calculating what questions went to the final workshop:

Top ten questions asked by Young Person from the survey  
Adult survey:

- Top ten questions asked from the patient/carer/family/friend
- Top ten questions asked from the Healthcare professionals

Many questions asked were in all three of the top tens

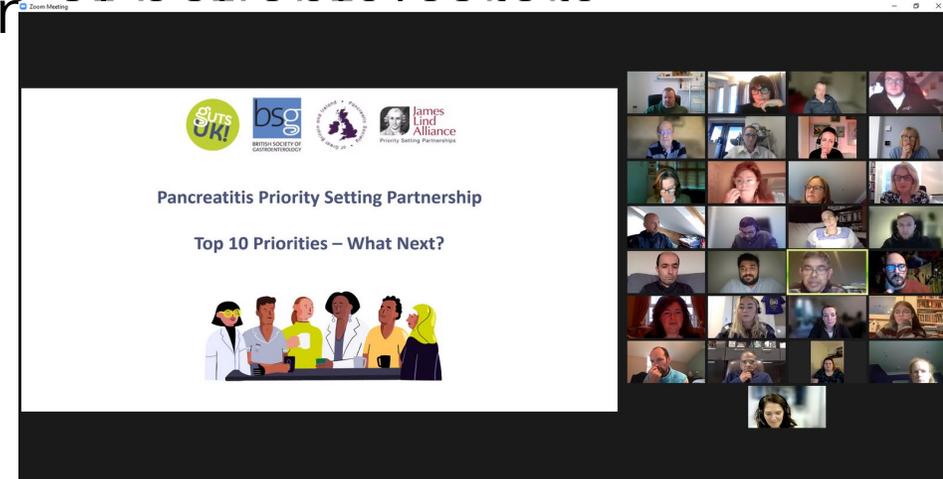
TOTAL: 23 QUESTION FOR FINAL WORKSHOP



# FINAL WORKSHOP (Nov 2022)



- Flipped online last minute due to train strikes
- 31 people attended with 5 observers
- Chaired by the JLA Adviser and supported by JLA facilitators
- 5 groups of 6 made up of equal representation of patients / carers and healthcare professionals
- Ranking of the Top 23 questions





## TOP 10 PRIORITIES FROM FINAL WORKSHOP

1	Are there better ways to treat and manage acute and long-term pancreatitis pain, for example using non-opioid (painkillers) drugs?
2	What can be done to prevent pancreatitis becoming worse, and to stop or reverse the damage to the pancreas?
3	Are there better ways to reduce inflammation in people with pancreatitis, both in the pancreas and the rest of the body?
4	How can pancreatitis be diagnosed more quickly and accurately, especially on admission to hospital?
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?
6	Are there better ways to treat and manage flare-ups (when symptoms get worse) in people with chronic pancreatitis?
7	Can gene therapy (altering genes inside the body's cells) be used to treat people with pancreatitis?
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?
9	How can pancreatic cancer be diagnosed earlier in people with pancreatitis?
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?

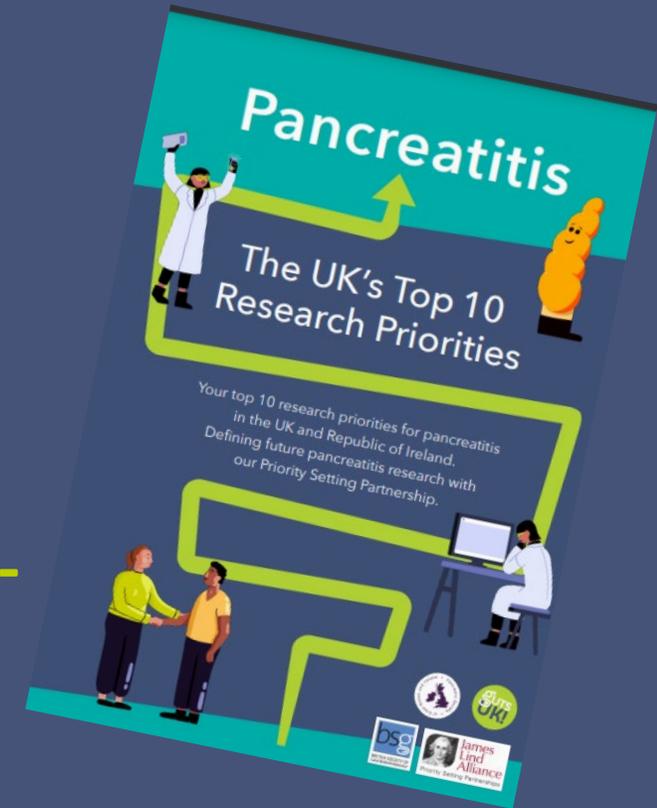


For more information on the Pancreatitis PSP and next steps .....

See GutsUK webpage & reports: [gutscharity.org.uk/research/pssp/shape-the-future-of-pancreatitis-research/](https://gutscharity.org.uk/research/pssp/shape-the-future-of-pancreatitis-research/)

or James Lind Alliance link:

[www.jla.nihr.ac.uk/priority-setting-partnerships/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/)



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The top 10 research priorities for pancreatitis: findings from a James Lind Alliance priority setting partnership  
Vikramjit Mitra • Stacey Munnelly • Tassos Grammatikopoulos • Damian Mole • Andrew Hopper • Barbara Ryan • et al. [Show all authors](#) • [Show footnotes](#)  
Published: June 22, 2023 • DOI: [https://doi.org/10.1016/S2468-1253\(23\)00151-6](https://doi.org/10.1016/S2468-1253(23)00151-6) • [Check for updates](#)

