



James Lind Alliance (JLA) IRRITABLE BOWEL SYNDROME (IBS) Priority Setting Partnership





Who is the James Lind Alliance (JLA)

- Non-profit making initiative, funded by the NIHR.
- Established in 2004, first PSP 2007 in Asthma
- Completed over 150 Priority Setting Partnerships (PSPs) for research to address
- 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

JLA Principles

- 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 James Lind Alliance Priority Setting Partnership (PSP)?

- Brings patients, carers and clinicians on an equal footing - balanced inclusion
- Identifies evidence uncertainties (questions which cannot be answered by existing research) which are important to all groups
- Works with all groups to jointly prioritise identified uncertainties
- Produces 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
- Provides a rare and valuable opportunity for patients and clinicians to shape the health research agenda.

Why a JLA PSP in IBS



- Irritable Bowel Syndrome 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:**



IBS PSP steps and timeline



James Lind Alliance

Priority Setting Partnerships



BRITISH SOCIETY OF GASTROENTEROLOGY

Setting Up

(June-Dec'21)

PSP link with JLA Adviser & Partners

Form Steering Group & agree protocol



Launch website

Gathering uncertainties

(Jan – April'22)

Identify Evidence gaps

Consultation survey



Literature Reviews & guidelines



Analyse responses & evidence check

(May - Sept'22)



form summary questions from responses

Prioritise questions

(Oct – Nov'22)



Reduce long list of summary questions to short list

Final priority setting workshop

(Dec'22-Feb'23)

Agree Top 10 - One day group workshop



Irritable Bowel Syndrome (IBS) PSP: timeline (1)



BRITISH SOCIETY OF GASTROENTEROLOGY

20th October 2021

Initial steering committee meeting. Preparing protocol
7 lay members, 7 healthcare professionals

**Diagnosis, Treatment, Care of people with IBS
Cause - included after first survey**

April 2022- June 2022

Subgroup set up, Filter questions, generated summary
questions, checked against evidence
70 questions

symptoms
constipation specialist CARE
OBSTACLES DIARRHOEA QUESTIONS
bowel therapy Bloating habit sensitivity Straining
outcomes urgency habit behaviour
research IBS pain Gut INFORMATION
faeces affect life EMPATHY
healthcare intractable abdominal support
family carers healthcare
awareness long-term friends
PRIORITIES

WordItOut

February 2022-April 2022

Initial survey open, online/paper formats, promote
via social media, disseminated to over 52 professional
Organisations, focus on unheard communities

3,639 people took part,
8,638 questions were asked,
4,568 In scope, questions,
4,070 out of scope questions



Irritable Bowel Syndrome (IBS) PSP: timeline (2)



December 2022 - February 2023

Second (Prioritisation) Survey - 65 questions

March 2023

Final workshops, face-to-face, **24 Questions,**
26 participants

IBS PSP workshop: final scores (change of wording to Q7)	
1	Are all forms of IBS the same condition, or are there different types of IBS with different causes and needing different treatments?
2	What causes bowel urgency (a sudden urgent need to go to the toilet) in people with IBS? How is this best treated and managed?
3	What causes pain and/or gut hypersensitivity in people with IBS, including spasms and cramps? Are there better ways to treat and manage these?
4	Could a better understanding of the gut-brain connection in IBS lead to the development of new treatments?
5	Do hormonal changes during the menstrual cycle, pregnancy and menopause affect IBS symptoms? If yes, could this understanding lead to new treatments?
6	How does mental health, particularly anxiety and depression, affect IBS? Do treatments for anxiety/depression reduce or stop IBS symptoms?
7	Are there ways for people with IBS to improve sensitivity in the bowel and/or improve control of their bowels e.g. through training with biofeedback?
8	How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?
9	What changes in diet benefit people with IBS? Which diet is best for the long-term?
10	Are treatments which balance the gut bacteria effective for people with IBS, including faecal transplants? Which prebiotics and probiotics are most effective?
11	What causes bloating in people with IBS and how is this best treated and managed?
12	What are the best ways to support people with IBS in managing their condition? How can health professionals best help with this?
13	Can accurate and reliable tests be developed to identify which foods are triggers for a person with IBS?
14	What causes diarrhoea in people with IBS and how is this best treated and managed?
15	Why don't some health professionals take IBS seriously? What would help them to respond appropriately to people's symptoms?
16	What causes fatigue in people with IBS and how is this best treated and managed?
17	What is the best form of follow-up care for people diagnosed with IBS including ongoing monitoring, treatment and support?
18	Does IBS affect other parts of the body other than the gut e.g. the skin or heart?
19	What is the best way to work out which foods trigger IBS symptoms? How can people with IBS best be supported to do this and to change their diet?
20	Is the presence of certain gut bacteria a risk factor for IBS e.g. following the use of antibiotics?
21	Is IBS an autoimmune disease?
22	Which aspects of IBS treatment and care are best provided in primary (GPs and community services) and secondary care (hospitals)? How can improvements be made?
23	Is stress or an emotional or physical trauma, either in childhood or in later life, a risk factor for IBS?
24	What do people with IBS feel is a successful outcome from treatment /management of their condition? How can this be measured?



Next Steps



NIHR | National Institute for Health Research

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

THE LANCET
Gastroenterology & Hepatology



Priority Setting Partnerships

First Survey (Feb - Apr '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
+++

Irritable Bowel Syndrome (IBS)

Tell us what IBS questions you want research to answer!

We need your help to identify priorities for research in the diagnosis, treatment and care of people with IBS.

Guts UK is working on a 'Priority Setting Partnership' (PSP). This has never been done for IBS before and will ignite true, lasting change.

With input from patients, carers, family and healthcare professionals, we will identify the top 10 priorities for future UK research into IBS.

Deadline: 22nd April 2021

Complete the survey and have your say today:

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

An illustration of six diverse people (three men and three women) of various ethnicities and ages, dressed in professional attire, standing around a table and talking.

James Lind Alliance
Priority Setting Partnership

guts UK!

bsg

Second Survey (Dec'22 - Feb'23)



- 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



Final Workshop (March 2023)



- Face to Face
- 26 people attended - 12 Patient/carers and 14 Healthcare Professionals
- Chaired by the JLA Adviser
- 4 Observers
- Ranking of the Top 24 questions



IBS PSP workshop: final Top 10 questions

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For more information on the IBS PSP & Top 10 Priorities

See GutsUK's report:

<https://gutscharity.org.uk/wp-content/uploads/2023/06/IBS-The-UKs-Top-10-Research-Priorities-FINAL.pdf>

OR

James Lind Alliance webpage:

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/irritable-bowel-syndrome/>



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Top 10 research priorities for irritable bowel syndrome: results of a James Lind Alliance priority setting partnership

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