IBS

The UK's Top 10 Research Priorities

Your top 10 research priorities for Irritable Bowel Syndrome (IBS) in the UK. Defining future IBS research with our Priority Setting Partnership.

guts UK!

bsg BRITISH SOCIETY OF GASTROENTEROLOGY

James Lind Alliance
Priority Setting Partnerships

The UK's Top 10 Research Priorities for IBS
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 IBS?

A PSP has never before been completed into IBS. Guts UK is proud to initiate this huge step forward for this misunderstood condition.

What is IBS?

IBS is thought to be a disorder of the gut-brain interaction, with symptoms of abdominal pain, altered bowel habits and more. It is a chronic, long-term condition.

How many people have IBS, and how does IBS affect people's lives?

IBS affects approximately 1 in 20 of us, which means that millions of people are affected in the UK alone.

Those living with IBS are reported to have a worse health-related quality of life than other chronic, long-term conditions such as diabetes. People with IBS often report a reduction of confidence, and some are housebound because of symptoms. Those with IBS are also twice as likely to take sick leave, and 12% stop working altogether.

IBS is estimated to cost the NHS between 45 and 200 million pounds per year, which is thought to be high due to the inconsistent effectiveness of treatments.

The process

1 Steering group

This was made up of 7 patients/carers and 7 healthcare professionals with direct experience of IBS.

2 Protocol scope

Defined by the steering group who decided that the areas of inclusion would be: diagnosis, treatment and care of people with IBS. Causes of IBS was added after the first survey.

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 IBS? What questions would you like research to answer'**. Over 2,500 people responded, asking over 8,500 questions!

4 Information process

Next, we categorised the questions and found that 4,568 were within the agreed protocol scope. These questions were summarised 70 themed questions. The questions were then evidence checked to make sure that they hadn't already been answered by research. At this point, 5 questions were removed.

5 Final survey

This was shared with patients, carers and healthcare professionals. They chose their top 10 research priorities from the 65 summary questions.

6 Final workshop

24 final questions were taken to the workshop. The workshop consisted of 12 patients, family members or carers (2 were ill/unable to attend on the day) and 14 healthcare professionals.

7 RESULTS!

The Top 10 Research Priorities for IBS were agreed!

The IBS PSP was funded by the British Society of Gastroenterology (BSG) and Guts UK charity.

Priority 1

Are all forms of IBS the same condition, or are there different types of IBS with different causes and needing different treatments?

"As clinicians with a specialist interest in IBS we have learnt that a 'one-size fits all approach' to treatment is inefficient. Personalising care is therefore a top priority. This will allow professionals to recommend the right treatment, at the right time, for the right patient! There is exciting emerging evidence that there may be new, previously unrecognised, subtypes of IBS. There is therefore an urgent need for further research to find out if recognising the different types of IBS using these new approaches can help guide tailored treatment plans and improve the outcomes for IBS suffers."

Dr Dipesh Vasant,

Consultant Gastroenterologist, Manchester University NHS Foundation Trust.

"I think this is an excellent question as it may yield information which would be helpful to patients, carers and healthcare professionals alike going forward."

Miranda

Priority 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?

"One of the most distressing symptoms of IBS for my patients is bowel urgency. It has a huge impact on patients' lives and ability to leave the house due to fear of not making the toilet. Whether it is urgency with diarrhoea or following constipation, it affects most with IBS and has the biggest impact on their quality of life."

Sarah Alderson

Associate Professor of Primary Care and General Practitioner

"This question is important as it has the most significant impact on the sufferers of IBS. There were other research-based questions that were also interesting but from a patient point of view, sudden urgency is the feeling that stops us from living a full life and gives sufferers the biggest anxiety."

James

Priority 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?

"Abdominal pain is one of the core symptoms of IBS and can be debilitating. The impact on patients and their quality of life is often substantial. Unfortunately, pain in IBS can be challenging to treat effectively and existing approaches may not provide adequate relief. Further research to improve our understanding of what causes pain in IBS and to develop new treatments is, therefore, vital."

Dr Chris Black
Consultant Gastroenterologist

"This question is important to me because I experience gut hypersensitivity and experience pain daily from cramping caused by my IBS-D. I struggle every day to manage the cramps and it is linked to frequent and urgent bowel movements including diarrhoea. It's hard to manage. I've tried all sorts of treatments, but none work very well so this leaves me with very little pain management options.

I struggle to work, go about my daily life and rely on other people to help support me. My gut is sensitive to most foods and the pain is hard to manage sometimes. The pain caused from IBS isn't recognised widely either. Being able to have better treatment for the hypersensitivity and pain would mean I could live a more "normal" life which would be life changing. It is something extremely important to me as IBS has made my world so small it's almost non-existent."

Alexandra

Priority 4

Could a better understanding of the gut-brain connection in IBS lead to the development of new treatments?

"I have experienced a lot of anxiety with my IBS which I have noticed has a huge impact on my gut. The days where my anxiety is high (maybe because of an event where I don't want my IBS to hinder the experience) are always the days that it is as its worst. Which I think is no coincidence. It is a constant cycle of my anxiety being high because of my IBS but then my IBS flaring up because of my anxiety.

While healthcare professionals know about the gut-brain connection in IBS I believe that if further research is done into its link we would find a whole host of new ways to approach this and in turn hopefully develop new treatments."

Tiegan

"What is going on in someone's head can affect their tummy and vice versa. Identifying the pathways involved and how they can be modified, could help us develop better ways of treating conditions like IBS where these pathways don't seem to function normally."

Professor Peter Whorwell

Professor of Medicine and Gastroenterology

Priority 5

Do hormonal changes during the menstrual cycle, pregnancy and menopause affect IBS symptoms? If yes, could this understanding lead to new treatments?

"Women are 1.5 x more likely to suffer from IBS than men. The hormonal changes a woman undergoes across her lifetime are vast and yet few clinical studies have concluded upon the precise role of female hormones in IBS. As it stands, women are left in the dark as to the impact of their menstrual cycle, pregnancy and menopause on their IBS symptoms. From contraception choice to postmenopausal hormone replacement therapy – women lack the information they require to make informed choices. This is an exciting, intriguing and crucial area of research because it cross pollinates two specialist areas which have long been uncoupled."

Dr Rabia Topan
Gastroenterologist

"This question is important for several reasons. Although there is evidence to suggest that hormonal changes do affect the bowel during menstruation, pregnancy and menopause, there isn't enough. Research needs to be done to demonstrate the connection further. As a woman who has suffered many symptoms of IBS during menstruation as well as being diagnosed with endometriosis, I find this question particularly important.

I hope research into this area will lead us to a greater understanding of the bowel and its connection between hormonal changes, which in turn will hopefully lead to faster diagnoses. As well I hope it encourages working partnerships with different healthcare professionals and practitioners within different specialities, in order to get the best outcome for patients."

Angelina

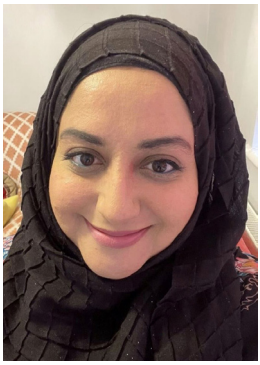
Priority 6

How does mental health, particularly anxiety and depression, affect IBS? Do treatments for anxiety/depression reduce or stop IBS symptoms?

"The brain and gut communicate through the nervous system and that communication travels in both directions, from the brain to the gut and vice versa. This communication system can influence many gut disorders, including irritable bowel syndrome (IBS). We know that in some people IBS can trigger the new onset of anxiety or depression, and in other people a history of anxiety or depression can be a risk factor for developing IBS in the future. How all these different factors act together in people with IBS to influence prognosis is not clear though. In addition, some drugs that are viewed as treatments for anxiety or depression may be beneficial in IBS. However, often these drugs are used in IBS at a much lower dose than is used to treat anxiety or depression, so whether these drugs are having a benefit because of their actions on the bowel or their actions on the brain is unclear."

Professor Alexander C. Ford

Professor of Gastroenterology and Honorary Consultant Gastroenterologist



"I know that my IBS and my mental health is completely exacerbated by each other. For me, my mental health and particularly IBS has ruined my life. Not just myself but many others too. It's actually heart-breaking you have to learn a whole new way of life. It's tough to have that battle with your mind and it's almost like you have to learn a whole new normal. I hope that one day that there is treatment that will help people like myself because everyone deserves to live the best life they possibly can."

Sofie

Priority 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?

"It is important to continue to develop new ways of helping patients manage symptoms that they identify as impacting their quality of life, such as pain, bloating and urgency."

Rebecca Embleton
Bowel Dysfunction Clinical Nurse Specialist at County Durham and Darlington NHS FT

"Initially I was sceptical about this question as I couldn't believe that I could learn to manage my own pain and bowel movements. However, after learning more, I now see this as an exciting development. Other treatments, such as biofeedback, could mean that IBS sufferers would actually have an element of control over their symptoms rather than simply tolerating them. There is so much we don't know about IBS – the many different symptoms, how it develops and how it can be tested for, all of which are vital research areas. But it is also vital from a quality-of-life point of view to focus on positive and practical ways to help manage symptoms, many of which can have such a debilitating effect on the day-to-day life of the sufferer."

Sarah

Priority 8

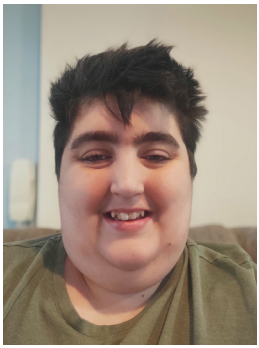
How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?

"Many patients are distrustful of a clinical diagnosis of IBS, and many doctors investigate patients to help support the diagnosis by 'ruling out' other diseases. A test that will help make a positive diagnosis should hasten the diagnosis, reassure patients (and clinicians) and ultimate improve the management of people with IBS."

Professor Chris Probert
Professor of Gastroenterology

"A fast diagnostic test would help people to begin the process of understanding and treating their condition sooner. It also helps track how many people are living with IBS and enable access to the treatments that already exist and will hopefully come out research."

Morgan



Priority 9

What changes in diet benefit people with IBS? Which diet is best for the long-term?

"IBS is not nice. From the pain and bloating brought on by constipation, to the feelings of humiliation and loss of control caused by incontinence. IBS is a physical and a mental affliction. I'm so glad this question about diet and dietary changes is being prioritised, because food and drink can have such a big impact on IBS.

Further research is needed as a priority to identify trigger foods that may affect the patient causing symptoms, and how changes to their diet will improve their health and wellbeing."

Sandy

"Approximately 8 out of 10 IBS patients believe that food impacts their gut symptoms. Answering this top research priority question for people with IBS would optimise the long-term effects of dietary change including its safety, minimising food-related anxieties, improving quality of everyday life, and reducing healthcare utilisation."

Yvonne McKenzie

Clinical Gastroenterology Dietitian. First author of the British Dietetic Association's evidence-based practice guidelines for the dietary management of IBS in adults (2016 update)

Priority 10

Are treatments which balance the gut bacteria effective for people with IBS, including faecal transplants? Which prebiotics and probiotics are most effective?

"There is a bewildering amount of information on the web when it comes to the microbiome, including probiotics/prebiotics and other solutions available to correct a perceived imbalance in gut bacteria for the IBS sufferer. My wife has fought IBS for nearly 40 years and has tried many remedies. We need to better understand the microbiome and its relationship to IBS, and specifically which probiotics, prebiotics and other remedies are most effective when it comes to treating this condition."

Peter

"IBS is associated with alterations in gut bacteria. Modulating the gut bacteria (e.g. through the use of prebiotics, probiotics or faecal transplant) might improve the symptoms of IBS, but the evidence is limited and conflicting. Hence, high-quality studies evaluating these approaches in IBS are needed."

Dr Imran Aziz

Honorary Consultant Gastroenterologist & Senior Clinical 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. 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 (GP 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?

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

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

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

Message from Julie Thompson

PSP Lead and Information Manager at Guts UK Charity

"When I joined Guts UK it became clear that there were millions of people living with IBS in the UK with little support, often ineffective treatment options and didn't know where to turn to get help.

IBS is underfunded, under-researched and misunderstood. It has been for too long.

We knew we needed clear direction for IBS research, decided by patients and healthcare professionals. We made a commitment to our IBS community that we would undertake a Priority Setting Partnership with the James Lind Alliance to decide the top 10 research priorities for IBS. People with IBS and their carers responded to the surveys in large numbers, making it clear that they wanted to voice their opinion about research. In a health condition where people have few opportunities of being heard, being part of this process was essential. The dedication and drive for change from the IBS community is what pushed this project forward, creating true and lasting change. It has been incredible to be part of such vital work. Thank you to everyone involved."

Message from Alexander Ford

PSP Clinical Lead, Professor of Gastroenterology and Honorary Consultant Gastroenterologist. Leeds Institute of Medical Research, Leeds Teaching Hospitals Trust.

"It was a great privilege for me to serve as the medical lead for this James Lind Alliance Priority Setting Partnership for IBS, which I know has a huge impact on people living with the condition.

We were delighted by the huge interest the process generated. The active participation of so many people with IBS, their carers, and healthcare professionals helped us to identify a list of research priorities for the condition, as well as in formulating a "top 10" list.

We are hopeful that this will serve both as a way of highlighting the difficulties that people living with IBS experience on a daily basis, as well as a means of recognising that IBS should be a priority for future research funding."

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.

Alex Ford (Clinical Lead), Christine Pollard, Christopher Black, David Greenwood, Hazel Everitt, Lesley Kirkpatrick, Margaret Surginor, Maura Corsetti, Morgan Scofield-Marlowe, Pauline Hunt, Peter Setter, Rona Moss-Morris, Yvonne McKenzie.

Julie Thompson (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 IBS 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.

Angelina Norton, Chris Probert, Christopher Black, Dipesh Vasant, Gillian Goddard, Imran Aziz, James Catton, Joanna Grant, John Lidell, Lee Martin, Miranda Lane, Morgan Scofield-Marlowe, Nelly Gonzalez Canete, Peter Setter, Peter Whorwell, Qasim Aziz, Rabia Topan, Rachel Hill, Rebecca Embleton, Sandy Joyce, Sarah Alderson, Sarah Cox, Tiegan Hill, Tor Mexted, Yvonne McKenzie.

Observers:
Alex Ford, Charlotte Gallagher, Chloe Lane, Esther Southey, Helen West, Julie Thompson, Samantha Burke.

James Lind Alliance Facilitators:
Jonathan Gower, Katherine Cowan, Maryrose Tarpey.

Thank you to the British Society of Gastroenterology for co-funding the IBS PSP with us. Your expertise and crucial connections opened doors throughout the process, ensuring the outcome was a success for all.


THANK YOU