



IBS Priority Setting Partnership Prioritisation Survey

Have YOUR say on the future of IBS research

In a recent national survey, we asked patients, their families, and healthcare professionals to say what questions they would like to see answered by future irritable bowel syndrome (IBS) research. These questions related to the diagnosis (including risk factors), treatment and care of people with IBS in the UK.

Thank you to all of those who submitted questions!

Guts UK and the British Society of Gastroenterology are supporting this project to help ensure that all voices are heard.

The submitted questions have been sorted, categorised and evidence-checked against already published research, and organised into **65 questions**. The questions are under the three headings: diagnosis (including risk factors), treatment and care of people with IBS.

Questions that have already been answered by research are not included here.

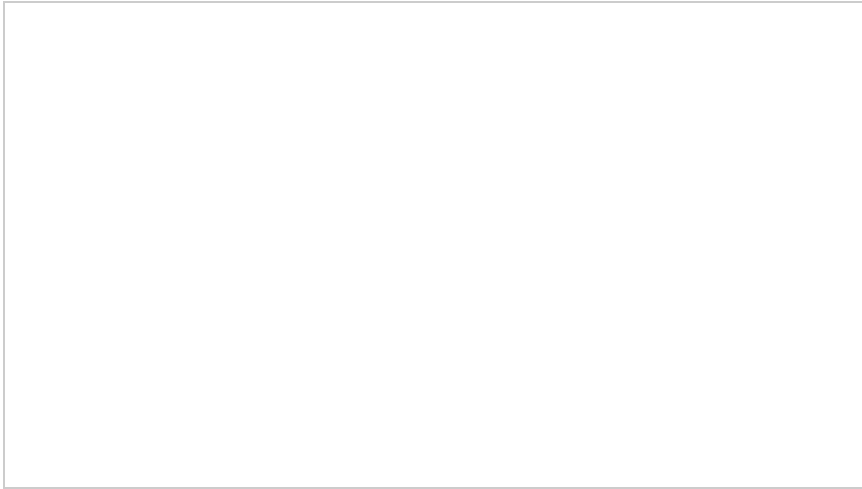
Now is your chance to choose the questions that are most important to you. This survey is open to people 16 years plus with IBS, carers, families, healthcare professionals, charities, and anyone else affected by this condition.

This is your chance to have your say – so we want to hear from you!

The survey is now open and will close on the **6th of February**. It will take approximately **5 minutes** to complete and with your help, the findings will determine the direction of future IBS research in the UK.

If you require this survey in another language, please contact Helen West at Guts UK Charity – hwest@gutscharity.org.uk

For more information about the IBS Priority Setting Partnership (PSP) please contact Helen West at Guts UK Charity – hwest@gutscharity.org.uk



We are unable to provide medical advice for specific and personal medical queries, but can offer general information on digestive diseases and symptoms. For support with any issues raised by filling out this survey, go to: www.gutscharity.org.uk



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Section One:

First, please tell us a little bit of information about you. Please note: ALL responses will be anonymised (no one will know your personal details).

Which one of the following BEST describes you?

- Patient who currently has or previously had IBS (16+ years old)
- Family member or carer of somebody with IBS (16+ years old)
- Healthcare professional with experience of caring for or treating patients with IBS

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- Other (please specify)



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You selected healthcare professional. Which one of the following BEST describes you?

- General Practitioner
- Pharmacist
- Gastroenterologist
- Surgeon
- Dietitian
- Nurse
- Physiotherapist
- Occupational Therapist
- Psychologist
- Pain specialist

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- Other (please specify)



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Which one of the following **BEST** describes the type of IBS that you (or your relative/friend) have experienced most recently?

- IBS-C (IBS with constipation)
- IBS-D (IBS with diarrhoea)
- IBS-M (mix of constipation and diarrhoea)
- Post-infectious IBS (caused after food poisoning/gastroenteritis)
- IBS type unknown by healthcare professional
- I don't know what type of IBS I have
- I don't currently have IBS, but have previously
- Not applicable / I'm a healthcare professional

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- Other (please specify)

Are you (or your relative/friend)?

- Female
- Male
- Prefer not to say

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- Other (please specify)

What is your (or your relative/friend's) age?

Where do you (or your relative/friend) live?

- England
- Northern Ireland
- Scotland
- Wales
- Prefer not to say

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Other country (please specify):

What is your (or your relative/friends) ethnic background? (If you do not wish to answer, please enter: 'prefer not to say').

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First stage of prioritisation

Please select from the 65 questions listed below those which are the most important to you.

Please choose as many questions that are important to you from the list below.

On the next page, you will be asked to choose the 10 most important questions from those you have selected.

Questions have been broken down into three categories: Diagnosis (including risk factors), Treatment, and Care of people with IBS. The category headings are in blue.

Please select all questions that are important to you

- DIAGNOSIS (INCLUDING RISK FACTORS) (THIS IS A HEADING - PLEASE DO NOT SELECT)**
- How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?
- Can accurate and reliable tests be developed to identify which foods are triggers for a person with IBS?
- Do IBS symptoms change as people get older?
- Does IBS and/ or its treatment have an effect on people's health in the long term?
- Do conditions commonly linked with IBS e.g. Ehlers-Danlos Syndromes (EDS) or endometriosis have the same cause as IBS or does one lead to the other?
- Does IBS affect other parts of the body other than the gut e.g. the skin or heart?
- How does mental health, particularly anxiety and depression, affect IBS? Do treatments for anxiety/depression reduce or stop IBS symptoms?
- Are all forms of IBS the same condition, or are there different types of IBS with different causes and needing different treatments?

- Do hormonal changes during the menstrual cycle, pregnancy and menopause affect IBS symptoms? If yes, could this understanding lead to new treatments?
- Why is IBS so variable? Why does it affect different people in different ways? Why do symptoms vary over time?
- Does having IBS have an impact on fertility or pregnancy? How is IBS best treated during pregnancy?
- Is there a genetic link to IBS? If yes, how does this affect the risk of IBS in families?
- Is the presence of certain gut bacteria a risk factor for IBS e.g. following the use of antibiotics?
- Is stress or an emotional or physical trauma, either in childhood or in later life, a risk factor for IBS?
- Are certain foods or a lack of vitamins/ minerals risk factors for IBS?
- Is an autoimmune disease (where the body reacts against its own tissues) a root cause of IBS?
- Are toxins a risk factor for IBS (e.g. chemicals used in food production or some medicines)?
- Is pregnancy or giving birth a risk factor for the start of IBS?
- Why do some people develop IBS at a late age?
- Are any particular groups of people at higher risk of developing IBS (for example women or specific ethnic groups)? Can these risks be reduced?
- Is more than one risk factor (e.g. diet and stress) required for IBS to start?
- TREATMENT (THIS IS A HEADING - PLEASE DO NOT SELECT)**
- What causes fatigue in people with IBS and how is this best treated and managed?
- Are treatments which change the gut bacteria (microbiome) effective for people with IBS for example including faecal (poo) transplants, prebiotics (food for gut bacteria), probiotics (live bacteria products)? Which are most effective?
- What is the best form of follow-up care for people diagnosed with IBS including ongoing monitoring, treatment and support?
- Do complementary and alternative therapies (including herbal/ natural remedies) benefit people with IBS?

- What causes pain and/or gut hypersensitivity in people with IBS, including spasms and cramps? Are there better ways to treat and manage these?
- What causes bloating in people with IBS and how is this best treated and managed?
- What causes diarrhoea in people with IBS and how is this best treated and managed?
- What causes constipation in people with IBS and how is this best treated and managed?
- What causes the cycle of diarrhoea and constipation in some people with IBS and how is this best treated and managed?
- Could a better understanding of the gut-brain connection in IBS lead to the development of new treatments?
- What causes bowel urgency (a sudden urgent need to go to the toilet) in people with IBS? How is this best treated and managed?
- Is there a daily rhythm to IBS symptoms and is IBS linked to disrupted sleep patterns? Could this understanding lead to new treatments?
- What causes wind in people with IBS and how is this best treated and managed?
- What role does the immune system play in IBS? Could a better understanding of this lead to new treatments?
- Are there any medications used for other conditions that might be effective for people with IBS?
- Would gene therapy (altering genes inside the body's cells) be an effective treatment for people with IBS?
- What causes excess mucus production in people with IBS? How is this best treated and managed?
- Could a better understanding of gut motility (the movement of food and fluid through the gut) in people with IBS lead to new treatments?
- Do IBS symptoms vary with the seasons? If yes, why is this?
- Does intestinal permeability (a leaky gut) cause IBS symptoms? If yes, how is this best managed and treated?
- How is incontinence in people with IBS best treated and managed?
- How can IBS be prevented?
- CARE OF PEOPLE WITH IBS (THIS IS A HEADING - PLEASE DO NOT SELECT)**

- What are the psychological impacts of IBS? How are these best treated and managed?
- What are the impacts of IBS on people's quality of life, including work, finances, relationships, family and social life? What kinds of support would be of benefit?
- What is the impact of caring for someone with IBS on family and friends? How can they be supported? How can they best help their loved one?
- What changes in diet benefit people with IBS? Which diet is best for the long-term?
- Why does stress cause a flare-up of IBS symptoms? How can this be reduced or avoided?
- What is happening in the gut during an IBS flare-up? Can this understanding lead to new treatments to stop or shorten a flare-up?
- What triggers (other than diet and stress) cause a flare-up of IBS? How can people with IBS be helped to identify these triggers to avoid further attacks?
- What lifestyle changes (e.g. changing job) benefit people with IBS?
- What affect does exercise have on people with IBS? If beneficial, what is the best form of exercise for people with IBS?
- Why do certain foods trigger IBS symptoms? Why does this vary from person to person and change over time?
- 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?
- What are the best ways for people with IBS to maintain a healthy weight?
- Can treatments be developed to overcome food sensitivities so that people with IBS can eat a normal diet?
- Are there ways for people with IBS to learn to be less sensitive to feelings in the bowel and/or have better control of their bowels e.g. through training with biofeedback (a technique used to help learn to control some of the body's functions)?
- What do people with IBS feel is a successful outcome from treatment /management of their condition? How can this be measured?
- Why don't some health professionals take IBS seriously? What would help them to respond appropriately to people's symptoms?
- How can people with IBS be treated holistically to improve all aspects of their physical and mental health within one service?

- 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?
- Do people with IBS benefit from specialist care? If yes, how can this be improved?
- What are the best ways to support people with IBS in managing their condition? How can health professionals best help with this?
- How can treatment and care of people with IBS be tailored to the individual, particularly if they have other health issues?
- How can the disadvantages that people with IBS from ethnically diverse groups experience in their treatment and care be addressed?



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Final stage of prioritisation

Now please choose up to 10 of the most important questions from those you selected on the previous page.

Please note, if you pick more than 10 questions, it will not let you continue.

- How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?
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- Does IBS and/ or its treatment have an effect on people's health in the long term?
- Do conditions commonly linked with IBS e.g. Ehlers-Danlos Syndromes (EDS) or endometriosis have the same cause as IBS or does one lead to the other?
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Thank you for helping improve the outcome for IBS patients, carers and families across the UK.

Please feel free to share this survey with friends, family, and colleagues:

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

Next Steps

If you would like the opportunity to take part in the all-day final workshop on **Thursday 2nd March** in central London, please contact Helen West - hwest@gutscharity.org.uk

The aim of the workshop is to decide the top 10 priorities for future research on IBS. We need people to join the workshop who are prepared listen and to share their experiences and opinions as part of a group discussion. This is a full day workshop.

The outcome of this survey, which will result in the top 10 priorities for research, will be available in spring 2023. If you would like to be kept up to date, please enter your details below, or link onto our [website](#)

Name

Email Address

Your name & email address above will be separated from the survey before it comes to reviewing results, so your questions and details will remain completely anonymous.