

The UK's Top 10

RESEARCH

PRIOR!TIES

for Diverticular Disease

Defining future diverticular disease research with our Priority Setting Partnership.



An introduction

The UK's top 10 research priorities for diverticular disease

What is a Priority Setting Partnership (PSP)?

Priority Setting Partnerships (PSPs) bring together patients, carers, doctors, nurses, dietitians and other healthcare professionals, all with an equal voice. Together, they identify and prioritise the unanswered questions for certain medical conditions or areas of health.

The James Lind Alliance (JLA) helps PSPs to find the unanswered questions and use them to decide the top 10 research priorities for a specific condition. This ensures that researchers and funders can make their research as meaningful as possible to the people who need it.

Why diverticular disease?

Diverticular disease is underfunded and under researched and this PSP is the first of its kind into the condition. By conducting a PSP into this condition, we can better understand what's most important to those affected.

Why did Guts UK and Bowel Research UK choose to collaborate on this PSP?

Guts UK is the national charity for the digestive system and Bowel Research

UK is the medical research charity for bowel cancer and bowel disease. Both charities are passionate about improving the lived experiences of patients and carers affected by conditions like diverticular disease and are committed to funding life-changing research into misunderstood and underfunded bowel conditions.

What does diverticular disease mean?

Diverticular disease and diverticulitis are conditions that affect the large bowel (colon) which cause small bulges or pouches in the wall of the large bowel called diverticula.

Many people have diverticula without symptoms. This is known as diverticulosis. But some develop diverticulitis, a condition that occurs when a single diverticulum (or several diverticula) become inflamed or infected, and this can cause symptoms like abdominal pain, bloating, or changes in bowel habits.

Most people will get some diverticula as they get older, but the majority of people will not get any symptoms.

For further information please visit www.gutscharity.org.uk

What do we know about diverticular disease already?



Between **1 in 2 and 1 in 3** people will be affected in their lifetime.



160,775 people were admitted into hospital with diverticulitis in England in 2020.



Around **half the population** aged 50+ in Western countries have diverticula in their large bowel. **By age 80, this rises to 70%.**



There are a **rising number of young people affected.** Understanding why is important.

Considering how many people are affected by it, little research has been done into the condition. There are many unknowns about how and why diverticular disease develops, and we need to identify and prioritise unanswered questions in this area.

The process

1

Steering group

This was made up of seven patients/carers and nine healthcare professionals (HCPs) with direct experience of diverticular disease.



2

Protocol scope

This was defined by the steering group, who decided that the areas covered would be: cause, diagnosis, treatment, management (including prevention), and support for people with diverticular disease.

3

First survey

This gathered research ideas from patients, carers, family members and healthcare professions. This was an open answer survey, where we asked, 'What research would you like to see into diverticular disease?' and 'What questions would you like research to answer?' Over 1,600 people responded, asking almost 3,400 questions.

4

Information process

Next, we categorised the questions and found that 1,811 of those submitted in the first survey were within the agreed protocol scope. These questions were summarised into 66 themed questions. The questions were then evidence checked to make sure that they hadn't already been answered by research. At this point, two questions were removed as they had already been answered by research.

Final survey

The second and final survey of the 64 themed questions was shared with patients, carers, family members and HCPs. They were each asked to choose their top 10 research questions from these 64 questions. The responses were collated and the top 25 questions were identified.

5

Final workshop

The top 25 questions were taken to the final workshop, where 12 patients and carers and 11 healthcare professionals discussed the questions and prioritised a top ten.

6



Results

The top 10 research priorities for diverticular disease were agreed.

7

PRIORITY 1

What are the best ways to manage diverticular disease over the long-term?

“ Living with diverticular disease makes many demands on people: knowledge, skills, adjustments and emotional strength, with support from those close to them and from their health care team. This question puts the focus on long term management, and how best to equip patients to meet those demands. As a clinical psychologist working on chronic pain, I appreciate the importance of patients feeling that they have what they need to manage their disease, practically and emotionally, and to know when to seek further medical help.”

Amanda C de C Williams
Professor of Clinical
Health Psychology



“ I wanted to be involved in this PSP as I thought it was important that the patients give a view on the subject. From my complex medical history of over 50 years, I think I have a pretty good practical knowledge. Through a combination of diet and exercise, I have my diverticulitis under control. I have not suffered for over three years, and I only take medication as a last resort. I have an endoscopy and colonoscopy every two years. I know not everyone is in the same situation as me and there needs to be more research, so that more guidance can be provided about how patients can best manage this

disease over the long-term. Living with a chronic condition is not easy so it is so important that people are offered the best advice to make their condition manageable.”

Michael
Patient



PRIORITY 2

What are the best ways to identify, treat and manage flare-ups of diverticular disease?

“ During my rotations, I've seen how common diverticular disease is and how difficult flare-ups can be for both individuals and healthcare professionals to manage. These episodes can significantly affect quality of life and often lead to hospital admissions. That's why I believe this is such an important research priority. There's a real need for stronger evidence and clearer guidance on how to identify, treat, and manage flare-ups more effectively. I'd love to see research that gives both patients and clinicians the tools they need to feel more confident in managing this condition.”

Pippa Slater
Foundation Year 2 Doctor



“ I found out by personal experience that although this is a very common condition, there is very little guidance to help clinicians provide the best care possible for patients like me. Despite seeking help, I ended up needing an emergency operation that has been life changing. This is why I was very keen to be involved in this important work, to ensure that future research leads to those evidence-based practice guidelines that are so desperately needed. If we can find out what are the best ways to identify, treat and manage flare ups this will hopefully reduce the number of people like me who end up needing emergency surgery.”

Linda
Patient



PRIORITY How and why do pouches (diverticula) form? Can this be prevented?

3

“ The formation of pouches remains a fundamental question that underpins the disease. We need to better understand whether the cause is genetic or related to diet, and whether interventions such as endoscopic clipping could help. Knowing what truly causes the pouches to form will help us best design treatments that prevent, eradicate, or reduce the complications patients experience from them. Thus, more research is required to understand the underpinning biology behind pouch formation.”



Dale Vimalachandran
Consultant General and
Colorectal Surgeon

“ Several years ago, I underwent lifesaving surgery and lost 95% of my bowel. I wanted to be involved in this project to share the perspective of someone who has experienced the condition firsthand. I personally think pouches form due to poor diet, stress, and the overuse of anti-inflammatory medications but we need proper research to be completed to confirm this and other reasons, and then we must work on whether we can stop it from happening.”

Darren
Patient



PRIORITY Is there a way to identify which people will develop complications with diverticular disease?

4

Liz is a patient in her 60s. She has had diverticular disease for around 15 years, during which time she has had several nasty episodes of diverticulitis.

“ Although only a small number of people with diverticular disease develop life-threatening complications, there is currently no way of predicting who those people are. Recent tests have confirmed that I now have severe diverticular disease which has caused significant anxiety about potential complications. If there was a way of predicting who will develop complications then a lot of pain, heartache and anxiety could be prevented, not to mention reducing the huge cost to the healthcare system of treating them.”



Sophie Williams, Gastroenterology Research Fellow and Senior Colorectal Trainee, managed a diverticular disease clinic receiving secondary and tertiary referrals.

“ As clinicians with a specialist interest in diverticular disease, we see many patients with complications related to diverticular disease, which are often debilitating, as well as many patients with incidentally discovered diverticular disease who may or may not have future problems. There is a need, therefore, to identify those patients who are more likely to develop complications in order to better advise and offer targeted treatments to our patients.”



PRIORITY

5

When is surgery the best option for people with diverticular disease, outside of emergencies?

Amanda, a patient, had major colorectal surgery due to a complicated case of diverticulitis. Amanda was keen to take part in the final workshop to prioritise the diverticular disease research questions and to help ensure that the most relevant research is carried out to improve the overall experience of those living with diverticular disease.

“ I feel that when medical professionals treating those with diverticular disease know when to advise patients that surgery is their best option backed up by research, it can allow patients to prepare mentally and physically for the surgery which will hopefully lead to a better outcome and prevent emergency surgery.”



“ As a surgical trainee, this question is important to me because surgery carries significant risks and long-term implications for patients. Determining the optimal timing allows us to intervene before complications arise, improve quality of life, and potentially avoid an emergency situation where outcomes can be worse. Balancing the benefits of elective surgery against its risks—and doing so in a way that is tailored to each patient—remains an important, yet still unresolved, aspect of managing this complex disease.”

George Fowler

Honorary Research Fellow and
Colorectal Surgical Trainee



PRIORITY

6

What is the best long-term diet for people with diverticular disease to maintain good health?

Sue, a patient was keen to be involved in the PSP to help ensure patients are given more support to take ownership of their own condition. Key to this day-to-day ownership is understanding how to manage diet and what is best to eat to stay healthy and to manage the condition.

“ It is so important that research is carried out to better guide patients on what they should eat, how often they should eat and the optimal size of meals. At the moment there is no data available and so information is inconsistent and only available from specialist dietitians when it should be readily available to all.”



Julie Thompson, a gastroenterology dietitian and Information Manager at Guts UK, agrees that information about diet is not available and will make a big difference.

“ Most people who contact Guts UK with lived experience of diverticular disease ask what the best diet is that they should follow over the long term. We don't have enough research into diet and diverticular disease now to confidently answer that question, so further work is essential to be able to support people living with this condition.”



PRIORITY

7

What are the best ways to treat and manage pain in people with diverticular disease?

" I have had diverticular disease for at least 10 years and while I have no severe complications and am currently symptom free, I live with occasional pain and both my mother and mother-in-law have also been impacted by diverticular disease. Living with pain can be debilitating for people and everyone experiences it differently. If we understand more about the best options for managing and treating pain, then people living with diverticular disease will find it easier to manage their day-to-day life and flare-ups and the associated pain will be easier to handle and live with."

Heather
Patient



Peter Paine, Consultant Gastroenterologist and Honorary Clinical Professor, has been involved in the diagnosis and the medical management of diverticular disease for over 20 years.

" There is so much we don't really understand about the causes of symptoms in diverticular disease and even less how best to manage them. Despite it being one of the most common conditions affecting the colon, it is also one of the most neglected in terms of research. Chronic pain is one of the biggest areas of unmet need for clinical medicine for which we have very few effective treatments and we can't assume that what might work for other conditions like irritable bowel syndrome will be equally effective for diverticular disease. There is a definite need for specific trials in diverticular disease of medications like gut-brain neuromodulators (a substance that inhibits the transmission of a nerve impulse), to see if they can help chronic symptoms including pain."



PRIORITY

8

What are the safest and most effective ways to treat diverticular disease using antibiotics?

" This question was significant to me because I have other medical conditions as well as diverticulitis. In the past, I've been given numerous courses of antibiotics, which might have been unnecessary. I believe the overuse of antibiotics is why my body doesn't respond as well to them now. This is extremely worrying for me when my diverticulitis flares up.

Further research is important because antibiotics play a vital role in preventing infections from escalating and if we know which ones to use and when to use them, hopefully they would be more effective and would prevent people like me from being admitted to hospital."

Sarah
Patient



David Humes has first-hand experience of operating on patients with diverticular disease as a colorectal surgeon and Associate Professor of Surgery at the University of Nottingham:

" Antibiotics are often prescribed to patients with diverticular disease so it is essential that we know that patients who are prescribed these medications will benefit from them and not suffer any harm as a result. Further understanding of which patients with diverticular disease would benefit from treatment with antibiotics across all healthcare settings is vital to improve the treatment of these patients and ensure antibiotics are only prescribed to those patients who will benefit from them."



PRIORITY Does having a poor quality microbiome (bad gut bacteria) increase the risk of developing diverticular disease? Could treating the microbiome reduce the risk?

9

" I unknowingly had diverticular disease until my bowel ruptured. I now have my condition under control but am no wiser about why I have this disease. There is much in the press and media about the microbiome and how managing it can help your digestive health, but it can be hard to know whether a particular suggestion is a trendy topic or fad, driven by commercial interests, or is based on some serious scientific evidence. So, I am delighted that this question about gut bacteria has come out as a priority, and I am hopeful that future research will shed some proper light on the topic."

Frances
Patient



PRIORITY Why is diverticular disease becoming more common in younger people?

10

" This question was so important to me as when I was diagnosed at the age of 21, I felt very disheartened as it is generally labelled as a disease people get later in life, so I found myself wondering, 'Why me?' I feared it would have a life-long worsening impact on me, particularly in my ability to have children. I wanted to be part of this PSP so that I could be part of the change for patients with diverticular disease, making a start in finding answers and getting a better understanding of the condition so when people are diagnosed younger, like me, they have great support straight away."

Sophie
Patient



" The gut microbiome - the community of microorganisms living in the large bowel - may play a role in the development and progression of diverticular disease. Imbalances in the gut microbiome (called dysbiosis) may contribute to the development of diverticula, inflammation and complications, for example, diverticulitis. Currently there is no clear evidence that diverticular disease can be attributed to changes in microbial relative abundance or whether treatments based on the microbiome reduce the risk. Much more research is needed in this area to explore the potential of the microbiome and understand more about this neglected area of digestive disease.

Julie Thompson
Information Manager at Guts UK



" Diverticular disease has often been thought of as an older person's disease. However, we are seeing more and more people diagnosed with it at an earlier stage. We simply don't know why that is and whether it's an evolution of the disease or just people seeking help earlier. Better understanding of this earlier emergence could help us unlock the causes and therefore improve treatment and diagnostic pathways for people of all ages."

Jonathon Simpson
General Practitioner (GP)



PRIORITIES 11-25

The remaining questions were also listed in order of priority during the final workshop. They are important questions that many people would like answered by research in the future. All information will remain available, and these questions will be open for research.

- 11 How can the **risk of developing** diverticular disease be reduced or avoided?
- 12 What are the best ways to **recognise triggers** and **prevent flare-ups** of diverticular disease?
- 13 Is **treatment of the gut microbiome** (gut bacteria) effective for diverticular disease (e.g. with probiotics or prebiotics)?
- 14 Is there a **link between diverticular disease and other gut conditions** e.g. irritable bowel syndrome (IBS) or colitis?
- 15 Are there ways to **repair or close** the pouches (diverticula)?
- 16 Why is diverticular disease not always taken seriously? What would help health professionals to better **understand and respond to people's symptoms**?
- 17 Are there ways to **prevent the pouches** (diverticula) from becoming **inflamed or infected**?
- 18 What **lifestyle changes** (e.g. exercise, reducing stress) help **manage the symptoms** of diverticular disease?
- 19 Does **diet affect the risk** of developing diverticular disease?
- 20 Why do diverticular disease **symptoms repeatedly flare up, even after months** without any symptoms?
- 21 Why do people with diverticular disease **experience bowel problems** (e.g. constipation, diarrhoea or wind)? What are the best **ways to treat and manage** these symptoms?

22

Is there a **less invasive way** of diagnosing diverticular disease **avoiding colonoscopy**?

23

How do **certain foods** make diverticular disease **worse**?

24

Do **environmental factors** increase the **risk** of developing diverticular disease e.g. toxins, trauma or stress?

25

Are any **alternative treatments or supplements** effective treatments for people with diverticular disease? (e.g. complementary therapies)

The future looks brighter

Guts UK and Bowel Research UK are proud to have delivered this PSP. This is the first time that people with experience of diverticular disease have been asked what research they'd like to see into the condition.

We're committed to supporting research into the causes, diagnosis, treatment and management of diverticular disease and we will now promote these questions into a researchable format.

The National Institute for Health and Care Research (NIHR) welcomes research applications for conditions with PSPs and offers research awards dedicated to PSPs facilitated by the JLA.

Finally, we have a direction for diverticular disease research in the UK and we're excited by the prospect of learning and discovering more about this misunderstood digestive condition.



A message from Suzanne Hudson, Chief Executive at Guts UK



“Currently, 1 in 3 people will be affected by diverticular disease in their lifetime and that number is rising, particularly in younger people. Despite being a common condition, it has been unresearched and there are many unanswered questions surrounding this disease.

We hear from many people affected by the condition, especially those at the earliest stages of their journey who are seeking a diagnosis and want to better understand their symptoms, their treatment options, and how the condition will impact their daily life.

This PSP is a fantastic first step in ensuring that diverticular disease

gets the attention it deserves, from better understanding amongst the healthcare professionals involved directly in patient care, to discovering kinder, better treatments for those living with the condition.

Thank you to everyone who contributed to this PSP and shared their views and personal experiences. Your dedication to improving outcomes for others affected by diverticular disease is highly valued and will drive much-needed change when it comes to prioritising dedicated research into the condition.”



A message from Lindsay Easton, Chief Executive at Bowel Research UK



“Diverticular disease affects millions of people worldwide, yet remains one of the most overlooked conditions in medical research. It is crucial that we address the significant knowledge gaps that exist around diagnosis, treatment, and long-term management, especially as incidence is on the rise, particularly among younger people.

Through this Priority Setting Partnership, we have witnessed the power of bringing together diverse voices – patients navigating uncertainty about their condition, carers providing essential support, and clinicians striving to deliver the best possible care despite limited evidence-based guidance.

The viewpoints from patients, carers and clinicians shared in this report say it all – despite diverticular disease being a common condition, it has a huge, often overlooked, impact on

people’s lives. It’s clear that the uncertainty in how best to manage and treat the disease creates anxiety and adds to the burden of living with or treating the condition. This needs to be urgently addressed through research.

Bowel Research UK has been delighted to work with our colleagues at Guts UK on this ground-breaking initiative, developing close ties which I hope will evolve and develop further to the ultimate benefit of all those affected by diverticular disease and bowel disease in general.

I am so grateful to everyone who participated in this Priority Setting Partnership. This work marks the beginning of a new chapter in diverticular disease research – one driven by genuine partnership and focused on the priorities that truly matter.”

**A message from
Dale Vimalachandran,**
PSP Clinical Lead,
Consultant General
and Colorectal
Surgeon at Countess
of Chester Hospital



“As a clinician, it’s really important to understand what patients want, what they need, and what their priorities are, otherwise we’ll ask the wrong questions. Having all the stakeholders involved - not only patients and clinicians but the people that manage healthcare services - in priority setting partnerships like this one is important across primary care, secondary care and tertiary care. The insight that partnerships like this provide is invaluable.

It’s vital that everyone’s voice is heard as it allows us to understand the reasons behind the questions that are being asked by patients and ensures that future research into the condition is impactful for people living with and affected by diverticular disease.”

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You made it possible

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

Steering group and workshop participants:

Amada Williams, Dale Vimalachandran (Clinical Lead), Darren Gulston, David Humes, Gabby Thorpe, Helen Lorentsen, Jamie Catlow, Jo Martin, Jonathon Simpson, Julie Thompson, Linda Griffiths, Lisa Hawke, Neil Smart, Penny Flavell, Sophie Miller and Sue Hoolahan.

Helen West

PSP Lead, Guts UK

Sam Alexandra Rose

PSP Co-ordinator, Bowel Research UK

Maryrose Tarpey

James Lind Alliance Facilitator

Kristina Staley

Information Specialist

Thank you to everyone who submitted their questions and thoughts as part of this process. You can say with confidence that you helped shape the future of diverticular disease 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 research priorities.

Additional workshop participants:

Amanda Sarosi, Angela Dickerson, Brett Barnard, Frances Clegg, George Fowler, Jack Dowell, Liz Pinney, Michael Blaise, Peter Paine, Pippa Slater, Sarah Gaiger, Sarah Townshend, Savvas Papagrigoriadis, Shawn Casini, Sophie Williams, Sue Hoolahan and Vaishnav Potti- Dhananjaya

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THANK

YOU



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