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Public involvement insight report

Investigating fatigue among patients with Inflammatory Bowel Disease (IBD) using GP records

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Contents

Background 3
Imperial Biomedical Research Centre 3
The Patient Experience Research Centre 3
Public involvement and engagement in research 3
The project: Investigating fatigue among patients with Inflammatory Bowel Disease (IBD) using GP records 3
Lay summary 3
Approach and purpose 4
Session overview 4
Attendees 4
Session feedback 4
Feedback and summary of actions 5
Appendices 7
Appendix A: Demographics of attendees 7
Appendix B: Final Lay Summary 8
Appendix C: Responses to feedback form questions 9

Background

Imperial Biomedical Research Centre

The Imperial Biomedical Research Centre (BRC) is a collaboration between Imperial College London (Imperial) and Imperial College Healthcare NHS Trust, which is funded by a five-year infrastructure grant from the National Institute for Health and Care Research (NIHR) until November 2027. The Imperial BRC supports 14 areas of research focus, including a Digestive Diseases research theme, as well as a number of core facilities.

The Patient Experience Research Centre

The Patient Experience Research Centre (PERC) is a core facility of the Imperial BRC, which undertakes research on involvement in and engagement with translational research and leads on implementing the Imperial BRC Patient, Public, Involvement, Engagement and Participation (PPIEP) in research Strategy.

Public involvement and engagement in research

The NIHR defines public involvement in research as "research being carried out 'with' or 'by' members of the public, rather than 'to', 'about', or 'for' them."

The NIHR defines public engagement in research as where information and knowledge about research is provided and disseminated.

Public includes patients, carers, people from underserved communities, and individuals with lived experience of health conditions, whether they are current patients or not.[1]

The project: Investigating fatigue among patients with Inflammatory Bowel Disease (IBD) using GP records

An Imperial researcher Rohan Sundramoorthi, Research Postgraduate at Imperial's Department of Metabolism, Digestion and Reproduction, was applying for funding from the Crohn's and Colitis UK (Targeted Call Research Awards 2026 - spotlighting priority areas identified by people living with Crohn's Disease and Ulcerative Colitis in the Top 10 Impacts of Crohn's and Colitis report) to support a proposed project which aims to understand when fatigue starts and who is most affected of people living with inflammatory bowel disease (IBD). A lay summary is set out below:

Lay summary

Fatigue is one of the most common and difficult symptoms experienced by people with inflammatory bowel disease (IBD). It can have a major impact on quality of life. Fatigue can affect work, daily activities, and mental wellbeing. Despite its importance, fatigue in IBD is still poorly understood. We do not yet know how often it occurs, when it starts, or why some people experience it more severely than others.

This study will use information from general practice (GP) records to better understand fatigue in people with IBD. We will analyse a large UK database of anonymised GP records covering over 37 million patients. Using this data, we will study how common fatigue is and how it develops over time. We will examine different groups of people with IBD. This includes people with Crohn's disease, ulcerative colitis, and those who have had surgery for their condition. We will also explore whether fatigue affects some groups more than others. This includes older adults and people from ethnic minority backgrounds who are often underrepresented in research.

This database has previously been used to study how IBD develops. Most earlier studies focused on digestive symptoms. However, fatigue may occur before bowel symptoms appear. The database has also been used to study fatigue in the

[1] https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#definitions-of-involvement-engagement-and-participation

general population. These studies show that fatigue is not always a harmless symptom. In some groups, it can be linked to serious health conditions.

In people with IBD, fatigue can occur during disease flares. It can also occur when bowel inflammation is otherwise well controlled. Research suggests that fatigue may be linked to several factors. These include inflammation, mental health, nutrition, and changes in gut bacteria. However, the exact causes remain unclear. In this project, we will investigate possible contributors to fatigue. These include mental health conditions, previous infections, and certain medications such as antibiotics or steroids. We will also examine nutritional markers and blood or stool test results recorded by GPs. Modern data analysis techniques, including artificial intelligence, will allow us to analyse large amounts of health data and identify patterns or risk factors that may not otherwise be obvious.

By understanding when fatigue starts and who is most affected, this research will provide new insights into one of the most challenging symptoms of IBD. It will also help identify factors that increase the risk of fatigue. This knowledge could guide future research into the biological causes of fatigue. In the long term, it may help doctors predict fatigue earlier and improve how it is managed.

Approach and purpose

To ensure the research design reflected what matters most to people with lived experience, PERC facilitated an online discussion with those with lived experience of IBD. The aims of the session were as follows:

1. To outline the research background, why the project is needed, and how the proposed project would be designed.
2. To request feedback on the following aspects of the proposed project:
    a. Possible concerns
    b. Data variables
    c. Outcome measures
    d. Equality, Diversity and Inclusion
    e. Project impact

Session overview

The online discussion was held on 23 March 2026 from 5.30pm to 7pm via Zoom, as part of the Imperial IBD Patient Network meeting. The meeting was attended by five people with lived experience of Ulcerative Colitis and IBD. In advance of the session, all attendees were provided with the above lay summary with an invitation to express interest in the discussion.

Following the session two of the attendees provided detailed comments on the lay summary which comments were incorporated into the final lay summary (see **Appendix B**).

Attendees

Attendees were recruited through Imperial's IBD Patient Network, that was set up by PERC to support the Imperial BRC research on IBD, ensuring that all attendees had lived experience of Ulcerative Colitis.

Attendees have provided their demographic details (voluntarily) as part of the Imperial IBD Patient Network expression of interest form (see details of attendee demographics at **Appendix A**). In accordance with NIHR payment guidelines, attendees were reimbursed £42.50 for their time for contributing to the 1.5-hour session including £5 for Wi-Fi/data expenses.

Session feedback

Following the session, attendees were sent an online feedback form to comment anonymously on ways the session could be improved and to give any additional views on the topics covered in the session. Comments received relating to the questions posed in the discussion session were integrated into the 'Feedback and summary of actions' section of this report. Attendees were also given the opportunity to sign up for future public involvement, engagement, and participation opportunities. General feedback on the session is summarised at **Appendix C.**

Feedback and summary of actions

The following responses and actions were provided by Rohan Sundramoorthi in relation to the comments made during the public involvement session on the project design.

Topics/issues raised and discussed	Response/details	Actions & changes to the project
Project background and outcome measures		
Concerns about the **quality of primary care data**, particularly the accuracy of coding symptoms and how representative these data might be. For example, in cancer cases there might be more physical symptoms and perhaps easier for GPs to code. Usually, IBD patients approach their IBD nurses and not GPs for their fatigue/symptoms and also GP availability is dependent.	It will not be perfectly representative. However, previous groups have investigated fatigue in the general population using GP records and have had positive results using an extensive list of codes that will help us pick up whenever a patient presents to their GP with the complaint of fatigue.	I have mentioned this key limitation in the outline methodology.
Need to talk to patients as well, face to face, because not every patient is registered with fatigue which is attributed to ulcerative colitis. For example, GPs might assume that patients have fatigue because they had COVID, but not because of ulcerative colitis.	We aim to capture all patients that present with fatigue even if it has not been formally attributed to IBD.	
Plan on measuring the different components of fatigue, not just the fatigue, e.g. brain fog, shut down and fall asleep with overstimulation.	The list of 43 codes includes varied presentations of fatigue.	I have mentioned this in our outline methodology
Session attendees suggested that the project should be also measuring/looking into diet		No action taken

Linking up GP referrals: How will the research study and data link up the GP referrals which might be months away but refer to the same underlying issue? What if fatigue is attributed in two separate referrals? How these will be linked up to the condition?	I really would like to look at all referrals as an outcome measure in what we're doing with this project and compare it to the number and type of referrals among patients without fatigue.	
How will the new GP referral practices, that will be implemented in April, could potentially affect your work in the study?	Referral practices have shifted to advice and guidance, which will hopefully reduce unnecessary referrals and allow us to study the most important referral practices.	
Equality, Diversity and Inclusion		
Targeted recruitment and sample collection from various places where they might have GPs that are of a greater volume of people, including lower income areas to address less trust in GPs, backlog and even out representation.	We would want to ensure we look at lots of different types of groups of patients including patients of different ethnic groups, different ages and different types of IBD. We will also have data on socio-economic status through another measure called the Deprivation Index.	
When pulling the data from the primary care database, if we can just include, if possible, how many of those GP consultations happened using an interpreter or family member who could interpret. This could help capture people those whom English isn't their first language.	Yes	This will be included in our methodology for the formal application.
The participants who are in the study, they will have to come from different backgrounds every background is different… every person is a world.	I agree	No action needed
Project impact		
Fatigue is under recognised symptom of living with IBD. If there's correlation with dietary deficiencies or gut microbiome would highlight a potential patient impact. It needs to be showcased on what this research will change for patients.	I agree	This has been added to the outcomes in my application.
Need to communicate that the project will look more into the mechanisms in a molecular level and algorithms and how to manage it.		This has been included in the outcomes of the project proposal.

Appendices

Appendix A: Demographics of attendees

The demographics were taken from the expression of interest forms for Imperial's IBD Patient Network, where completed and provided (n=5/5).

Characteristics	**n**
Age groups (in years)	
25 or under	0
26 – 35	1
36 – 45	1
46 – 55	2
56 – 65	0
66 – 75	0
76 – 85	0
86+	0
Prefer not to say	1

Ethnic group (self-reported)

Characteristics	**n**
Any other White background	3
Any other Mixed / Multiple ethnic background	1
Any other ethnic group, please specify below: Afro Arab	1

Appendix B: Final Lay Summary

Fatigue is one of the most common and challenging symptoms experienced by patients with inflammatory bowel disease (IBD), affecting around half of all patients. It has a major impact on quality of life and is ranked as the most burdensome symptom in the Top 10 Impacts Report by Crohn's & Colitis UK. Fatigue can interfere with work, daily activities, and mental wellbeing. Despite its importance, it remains poorly understood.

Fatigue in IBD can occur during disease flares, but it is also common when bowel inflammation is well controlled. Previous research suggests that fatigue may be linked to several factors, including ongoing inflammation, mental health, nutrition, and changes in gut bacteria. However, the exact causes and risk factors are still unclear.

This study will use anonymised data from general practice (GP) records to better understand fatigue among people with IBD. We will analyse a large UK database covering over 37 million patients. This resource has previously been used to study digestive symptoms among patients with IBD and fatigue in the general population. Using this data, we will identify patients who have reported fatigue either before or after being diagnosed with IBD. We will examine how common fatigue is across different groups, including patients with Crohn's disease, ulcerative colitis, and those who have undergone surgery. We will explore whether fatigue affects certain groups more than others, such as older adults and patients from minority ethnic backgrounds, who are often underrepresented in research.

This project will investigate risk factors for fatigue, including mental health conditions, previous infections, and medications such as antibiotics or steroids. We will also analyse nutritional markers and results from blood or stool tests recorded in GP data. By applying advanced data analysis methods, including artificial intelligence, we aim to identify patterns and relationships within this large database that may not be visible in smaller studies. All findings will be carefully reviewed by researchers and validated to ensure they are reliable and clinically meaningful. In addition, we will examine the impact of fatigue on clinical outcomes, such as the need for medication, hospitalisation, or surgery.

By improving our understanding of when fatigue develops and who is most affected, this research will provide important insights into one of the most challenging symptoms of IBD. It will identify factors that increase the risk of fatigue and help doctors better predict who is most likely to be affected, enabling more timely access to treatment. Importantly, by uncovering the factors that drive fatigue, this work will inform future research into biological causes and support the development of more effective treatments.

Appendix C: Responses to feedback form questions

4/5 attendees completed feedback forms, and their complete responses are set out below:

Q1. Overall, how would you rate the session?

No response	Very bad	Bad	Average	Good	Very good
0	0	0	0	1	3

Q2. Please tell us why you chose the above rating:

- It was very relevant, very engaging and it actually required some specific and constructive input from the patients. A true representation of why Community Partners exist. It was also not lengthy which kept it interesting.
- Well planned session, but the ending was rushed
- Both John and Rohan presented their grant applications in an appropriate and clear manner. They were also very receptive to the comments of the CPs attending, including where CPs had concerns that an element of the research could be problematic

Q3. Do you think you were provided with sufficient information about the session prior to attending?

Yes	No
4	0

Q4. Did you find the presentations easy to understand?

Yes	No
4	0

Q5. How informative did you find this session?

No response	Not at all	Slightly	Moderately	Very	Extremely
0	0	0	0	0	4

Q6. How likely are you to attend a session like this again?

No response	Not at all	Slightly	Moderately	Very	Extremely
0	0	0	0	0	4

Q7. What did you learn, if any, during the session?

- All kinds of scenarios not just mine
- The two research studies were very different and proposing to use different approaches (the one will focus on smaller sample and more depth and the other in bigger population). One thing I remember that I learned was on Dr Rohan's presentation after one of the questions that the GPs can only assess one reason of visit at a time, even if you mention that you might have different symptoms and different diseases.
- I learnt a lot about what is happening in the community along with the growing interests of the topics discussed. It was interesting learning about how people
- It was really interesting to hear about what John and Rohan's proposed research projects hope to achieve and the different methods they would use for achieving this. I found out more about access to GP records and gained a better understanding of how that data can be interrogated for research purposes. It is also interesting to see how research in one area has the potential to have multiple benefits, some of which may only evolve once the research is underway or completed.

Q8. From your lived experience, which priority areas should Imperial's IBD research focus on?
• To support the patient in every and any way possible. • I think that there should more in depth research to a more wholistic approach to IBD, covering not only medications but also supporting it from relevant research in nutrition, mental health and fitness, given that all of them are impacting the autoimmune diseases to an extent. • Holistic care, this includes investigatory care that helps prevent disease progression and help individuals reduce/limit flare ups. • Prevention - gaining a better understanding of the specific triggers for IBD - what makes one person develop it and another, with similar health, genetics, environment etc, not. - Deeper understanding of what factors increase the chance of a flare (eg diet, stress, other conditions etc) and whether a more holistic approach to care can reduce relapses/severity - patients want to know if there is anything they can do/not do to help themselves - less invasive methods for monitoring disease activity - better treatments with safer long term profiles - many patients will be on eg biologics for years - research into the role of hormones on disease activity especially relating to women and bone health - a cure - understanding how to 'switch off' the inflammation
Q9. If there is anything else you would like to share about the projects, or any additional comments that weren't covered during the session, please add them below:
• Nothing more to add. The lay summaries were also really good. I would usually add some comments, but they were to the point. Thanks for organising this session. Looking forward to more. • Both projects seemed really good and interesting. Whilst the one focussing on fatigue primarily is very interesting and could be extremely beneficial, it's very disappointing that the method is so flawed that it could miss a large part of the IBD community. It's sad that there were on options for amending this. • I felt that one of the research grant applications slightly lacked focus - the potential for the study is great as GP records are a huge resource/big data, but the specific scope/aims/limitations of his study could be clearer