


AWARE-IBD NEWSLETTER



WELCOME

This is issue 11 of the AWARE-IBD Newsletter.

RECRUITMENT

We have recruited 286  people with IBD to the study!

IN THIS ISSUE

- Page 2**– AWARE-IBD Project update
- Page 3**– What We Have Achieved
- Page 6**– Sharing Our Findings
- Page 7**– Ongoing Research
- Page 9**– IBD Patient Panel, Participant Update & Contact details

IBD NURSE HELPLINE

Did you know that you can get in touch with IBD team by calling **0114 2712209** on Mondays to Fridays 9-11 am. At other times you can leave a voicemail message which will be responded to within one working day! For more general information about the Sheffield IBD Centre, you can visit the website: **sheffield-ibd.sth.nhs.uk**

PROJECT UPDATE

Hello everyone!

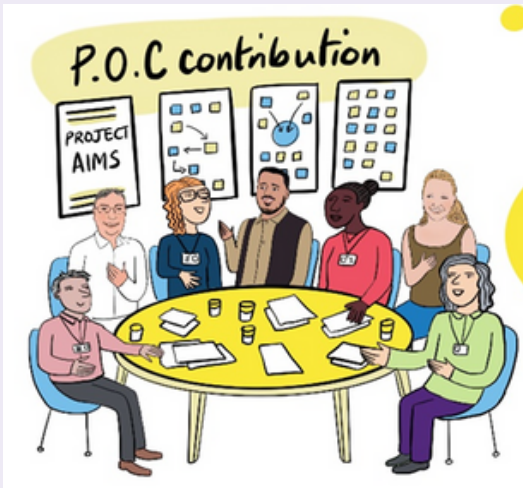
Welcome to the **final** AWARE-IBD newsletter!

First of all, we'd like to say thank you for your participation and engagement in the AWARE-IBD Project for the past three years. This project would not have been possible without your involvement.

We wanted to use this newsletter to look back at the project and celebrate what we have achieved together.



WHAT WE HAVE ACHIEVED



We implemented a Patient Oversight Committee (POC) to steer the project, and pioneering the first "patient coach" role to lead quality improvement training within an NHS Trust. Patients were embedded as leaders throughout-redesigning services, co-designing materials, and participating weekly in the IBD team microsystem implementing changes.

We launched a "What Matters To You?" survey which identified access, communication, and personalised care as top priorities for 613 patients.



We focused our co-designed service changes on these areas, trailing a rapid access clinic, nurse-led clinics, personalised care plans, a communication toolkit, and education program.



WHAT WE HAVE ACHIEVED

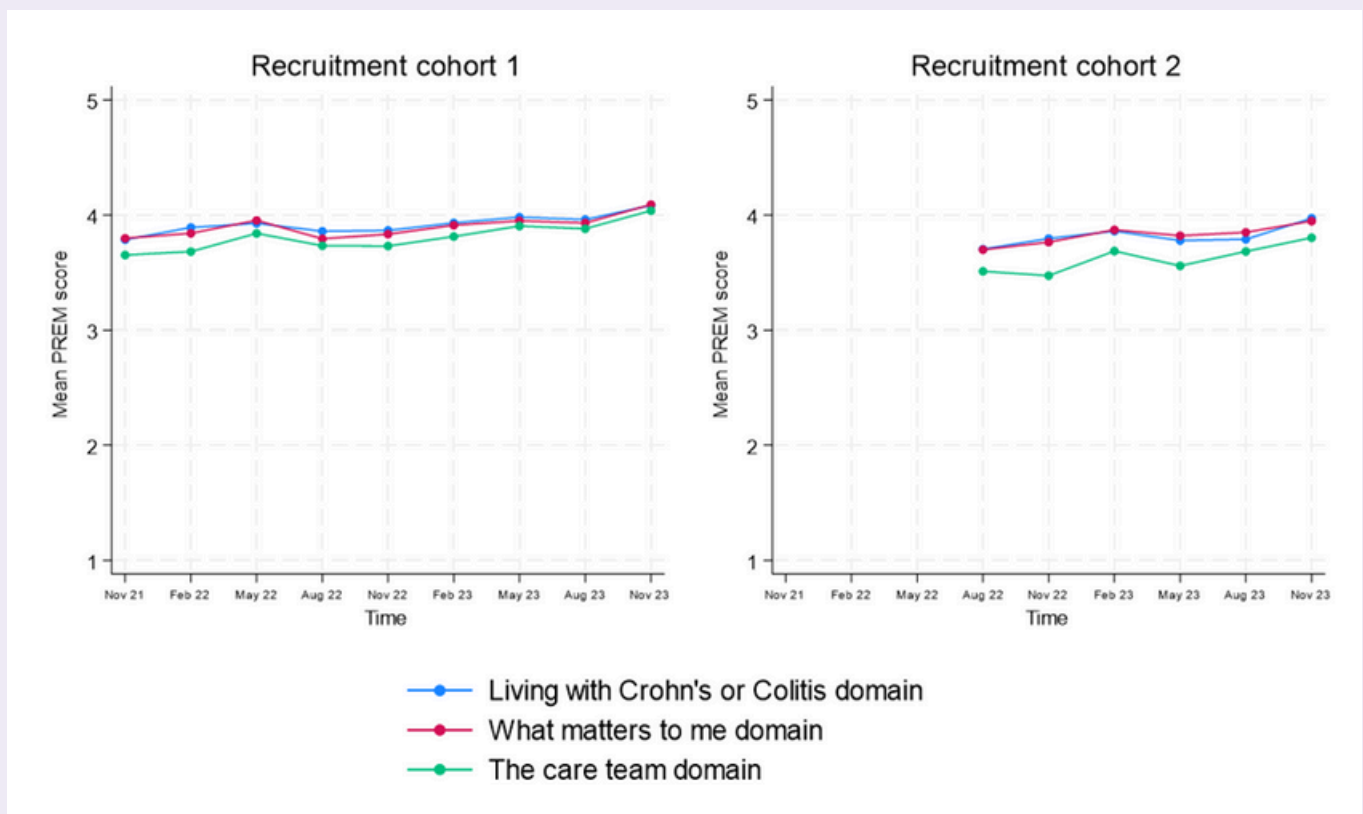
We built meaningful relationships with local community groups representing underserved populations based on deprivation, ethnicity, sexuality and disabilities. Their input shaped service improvements to better meet their needs and values.



We co-designed, validated and used a new inflammatory bowel disease patient-reported experience measure (IBD PREM) to collect data throughout the project.

WHAT WE FOUND

After analysing the PREM results, we found that the experience of people attending the service improved – although the improvement was small.



The small increase in PREM scores may be due to high baseline scores – i.e. most people had a better experience. Therefore, given this high baseline, it's harder to show a difference as highlighted by the small improvement in PREM. This may also be a biased sample of people who already had a good experience.

Our full findings and analysis will be published in due course – keep an eye on our twitter page for updates.



HIGHLIGHTS

In June Prof Alan Lobo (Chief Investigator), Naseeb Ezaydi (Project Manager) and Sam McCormick (Patient Coach) attended the British Society of Gastroenterology (BSG) conference in Birmingham.



They presented posters on engagement of underserved voices and evaluation of our personalised care plan!



The AWARE-IBD project was also awarded 3rd place for the BSG CSSC Service Development Prize! Alan and team accepted the award at the BSG conference.

We have also published our paper on how patients, GPs and hospital services can all contribute to delay in diagnosis for IBD.

ONGOING RESEARCH

Rachel Hawkins is completing her PhD at The University of Sheffield with the IBD team looking at reducing avoidable admissions in Inflammatory Bowel Disease.

This will form a sub-study of AWARE-IBD, and will include opportunities for people with IBD to take part in research over the next six to eight months.

Recruiting NOW!

If you have or have not experienced an unplanned admission for your IBD over the past two years, we are interested in hearing about your experience of accessing IBD care leading up to, and during a flare for your IBD.

There is an opportunity to take part in an interview which will ask about your experience.

Recruiting from 2025

Interactive workshops (online and in person) which aim to create a visual map of the Sheffield IBD service in order to understand key points across the patient journey where intervention could prevent an IBD admission. This output will aim to inform service improvement to reduce admissions locally in Sheffield and will be shared nationally to support other services.

You can take part in **one or both** of these opportunities. You will be reimbursed for your time taking part in this research.

For more information about involvement in this research please contact Rachel Hawkins:
Rhawkins4@sheffield.ac.uk

A summary of Rachel's review into inequalities in healthcare access is shown **on the following page:**





Inequalities in healthcare access, experience and outcomes in adults with Inflammatory Bowel Disease: A review of published research



Purpose of the research

To summarise research investigating inequalities in Inflammatory Bowel Disease healthcare in terms of access, experience and outcomes of care.



How?

The researchers systematically searched research databases to find published studies until September 2023.

Key findings -> 51 studies across 7 countries



Inequalities in **health outcomes (42/51)** was prominently investigated, followed by **accessing care (24/51)**. Much fewer explored inequalities in **experience of care (8/51)**



Unequal access, experience and outcomes of care was found in patients from Black, Asian and other ethnic minority backgrounds. These individuals showed greater rates of IBD complications, emergency admissions, reduced access to treatments, to accessible information, and specialist IBD care.



Patients living in rural areas had insufficient access to manage their condition. They experienced delayed referrals and access to gastroenterologists. This meant they had greater hospital admissions and need for surgery. Patients described "falling through the cracks".



People from deprived backgrounds had greater emergency admissions and visits to A&E. In the US, many went without treatment to avoid the financial costs associated with treatment.



South Asian IBD patients experienced a lack of cultural sensitivity of health professionals during appointments. One study of LGBT+ people with IBD described feeling as though they were treated differently to other patients.

What next?

Future research is needed to focus on inequalities in experience of IBD healthcare. Cultural humility in IBD care is required to support patients from all ethnic and religious backgrounds. More research is needed in people from LGBT+ backgrounds and with physical and learning disabilities.



For more information about involvement in this research please contact Rachel Hawkins:

Rhawkins4@sheffield.ac.uk



PATIENT PANEL FOR THE SHEFFIELD IBD SERVICE

The patient panel are a newly formed group that work alongside clinicians for the Sheffield IBD service to provide the team with feedback and suggestions for improvements.

Their role is to assist in the development and implementation of Sheffield's IBD service, including being part of STH's patient and public partnership strategy.

They also advise and participate in the development and provision of education for staff, appraise information for patients produced by the Trust and also advise the Trust on issues/items of concern regarding the service.

If you would like to contribute to the IBD Patient Panel by highlighting a particular area you would like to see the panel address, please don't hesitate to get in touch:

ibdpatientpanelsheff@gmail.com



If there are any changes to your contact details, please let the study team know by sending an email to aware-ibd@sheffield.ac.uk

Useful Links:

Crohn's & Colitis UK [AWARE-IBD](#) webpage

AWARE-IBD [Launch Webinar on YouTube](#)

IBD UK [IBD Standards](#)

IBD UK report [Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change](#)

If you have any questions about the project, you can contact :

Naseeb Ezaydi
AWARE-IBD Project Manager
Tel: +44 (0)114 222 4307
Email: aware-ibd@sheffield.ac.uk



Finally, don't forget to follow us on twitter to stay up to date with the project in between newsletters!