


# AWARE-IBD NEWSLETTER



## WELCOME

This is issue 10 of the AWARE-IBD Newsletter.

## RECRUITMENT

We have recruited 286  people with IBD to the study!

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## 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!

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.

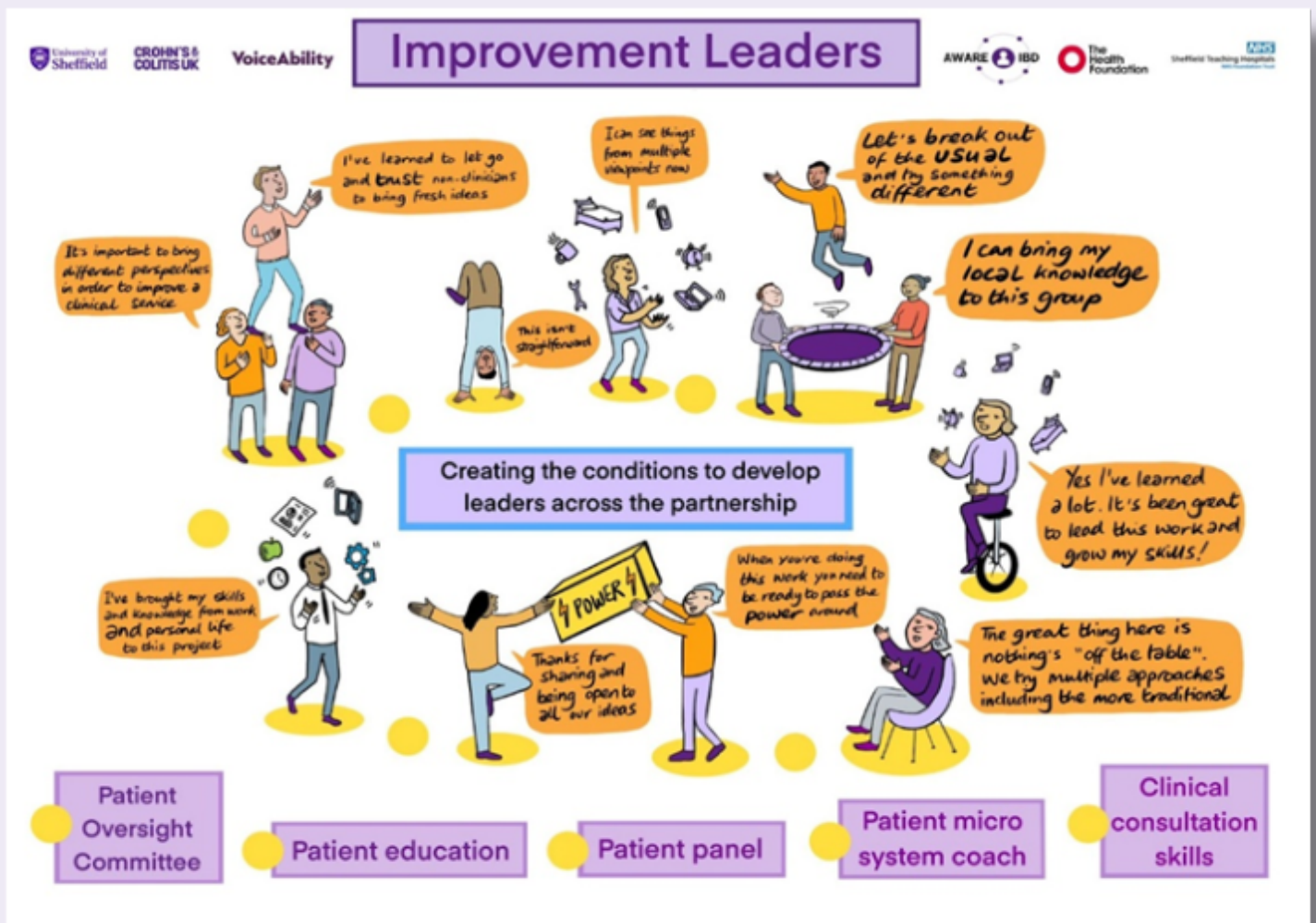
We are now heading towards the end of the project, and our focus has turned to reflecting on what we have achieved and how we can spread our learnings from the project. The next few months will be focused on analysing the data we have collected and sharing our findings with key audiences.





# WHAT WE HAVE ACHIEVED

1. **You told us** that patient leadership and partnership is essential for improving IBD care services.



**We acted** by establishing a Patient Oversight Committee 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.

# WHAT WE HAVE ACHIEVED

2. **You told us** that understanding and addressing what matters most to IBD patients is crucial.



**We acted** by launching 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, trialing a rapid access clinic, nurse-led clinics, personalised care plans, a [communication toolkit](#), and education program.



# WHAT WE HAVE ACHIEVED

3. **You told us** that underserved communities face barriers accessing quality IBD care.



**We acted** by building 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.

# WHAT WE HAVE ACHIEVED

4. **You told us** that patient-reported outcomes are vital for measuring quality of care.

**We acted** by co-designing, validating and using a new inflammatory bowel disease patient-reported experience measure ([IBD PREM](#)) to collect data throughout the project. It allows the measurement and comparison of experience over time and across centres.

## SHARING OUR FINDINGS

Our longitudinal PREM data is currently being analysed by our statisticians and will be shared in due course.

**In February** Prof Alan Lobo (Chief Investigator) and Naseeb Ezaydi (Project Manager) attended the European Crohn's and Colitis Organisation (ECCO) congress in Stockholm.



They presented posters on the validation of the PREM and health care inequalities in IBD.



We have just published [our paper](#) on engagement of underserved populations in AWARE-IBD. This has been published in Health Expectations!

Our scoping review on inequalities has been accepted for publication in Inflammatory Bowel Disease.

We have also just published a [scoping review](#) on quality improvement exercises in Inflammatory Bowel Disease (IBD) services in PLOS ONE!

# SHARING OUR FINDINGS



Prof Alan Lobo and Prof Ailsa Hart met with Lord Hunt of King's Heath at the House of Lords on **March 5th** to discuss standards of care for people with IBD and give examples of patient centred care including the AWARE-IBD project.

## ONGOING RESEARCH

**Rachel Hawkins** is completing her PhD at The University of Sheffield with the IBD team looking at avoidable unplanned emergency admissions.

This will form a sub-study of AWARE-IBD, and will include several opportunities for involvement over the next 12-15 months. .

She has had over 100 responses to her survey asking about views on admissions. She will soon be completing interviews with clinicians to gain further insight on admissions.

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





# ONGOING RESEARCH

## 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](mailto:Rhawkins4@sheffield.ac.uk)



# ONGOING RESEARCH

## 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](mailto:ibdpatientpanelsheff@gmail.com)**



Our brilliant patient representative Rachael recently took part in a film by Crohns and Colitis UK outlining the different symptoms that some people may experience when living with Crohn's or Colitis.

You can watch it here: <https://youtube.com/watch?v=jl0NRovOAPw>



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](mailto:aware-ibd@sheffield.ac.uk)**

### Useful Links:

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

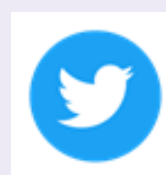
AWARE-IBD [Launch Webinar on YouTube](#)

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 :**

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