


AWARE-IBD NEWSLETTER



WELCOME

This is issue 9 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 ongoing participation and engagement in the AWARE-IBD Project for the past two years. This project would not have been possible without your involvement. As the project draws to a close, there are a few things happening that we would like to update you about.

Data collection

We have been collecting data from 286 research participants since November 2021. This data included a questionnaire about IBD symptoms (called the IBD-Control questionnaire) and our very own Patient Reported Experience Measure (PREM) to measure peoples' experiences of the service. We collected this data to understand whether the service changes that we trialled as part of the AWARE-IBD Project improved outcomes and experience.

We sent the final follow up questionnaires at the beginning of November 2023 to all of our active research participants. This is the last time we will be collecting this data for the research study. A final reminder will be sent to those who have not completed the questionnaires at the end of December (just before Christmas!).

In the New Year, our statisticians will be working hard to analyse the data and provide the results for the study. We will share these with you in due course.

PROJECT UPDATE

Staff changes

Our Project Manager, Elena, will be leaving the University on 18th December to start a new role at Sheffield Children's Hospital!

Taking her place will be Naseeb, who has worked as a Research Assistant on the project since March 2023. We are sad to see Elena go but we know that Naseeb will do an amazing job!



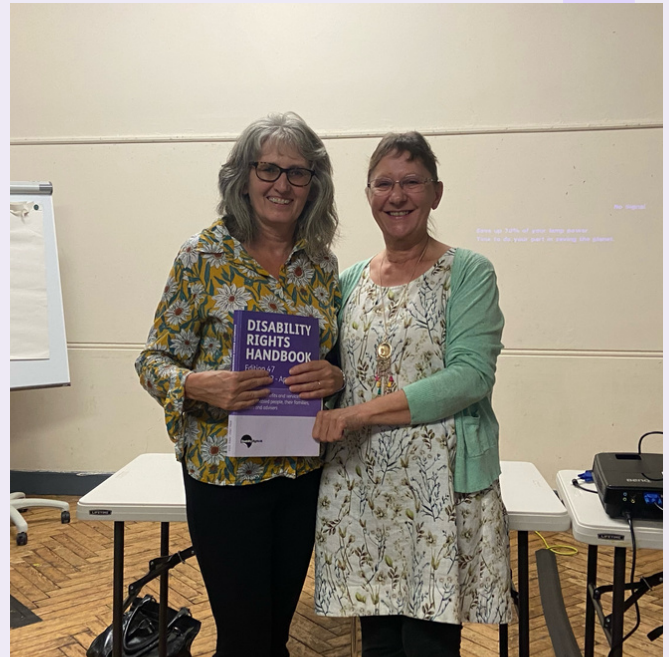
SERVICE CHANGES UPDATE

Update on service changes

We have now finished trialling our service changes as part of the AWARE-IBD Project! The aim of the changes was to improve access to the service, improve communication and provide more patient-centred care. The service changes included:

- An IBD Nurse Specialist clinic on the infusions unit
- An IBD Consultant 'rapid access' clinic for people with IBD who are newly diagnosed, starting or changing a biologic treatment or require urgent clinical review following a call to the IBD Helpline for flare symptoms

- An IBD Education Programme, including eight sessions on a range of topics including what is IBD, care and treatment options, self-management, mental health, diet and nutrition, employment and benefits and finances. If you missed any of our education sessions, you can view the content for each session as well as additional online resources by clicking [here](#).



- Introducing a personalised written care plan template, designed by you (view [here](#))
- Our IBD Toolkit, designed by people with IBD (view on VoiceAbility's website [here](#))

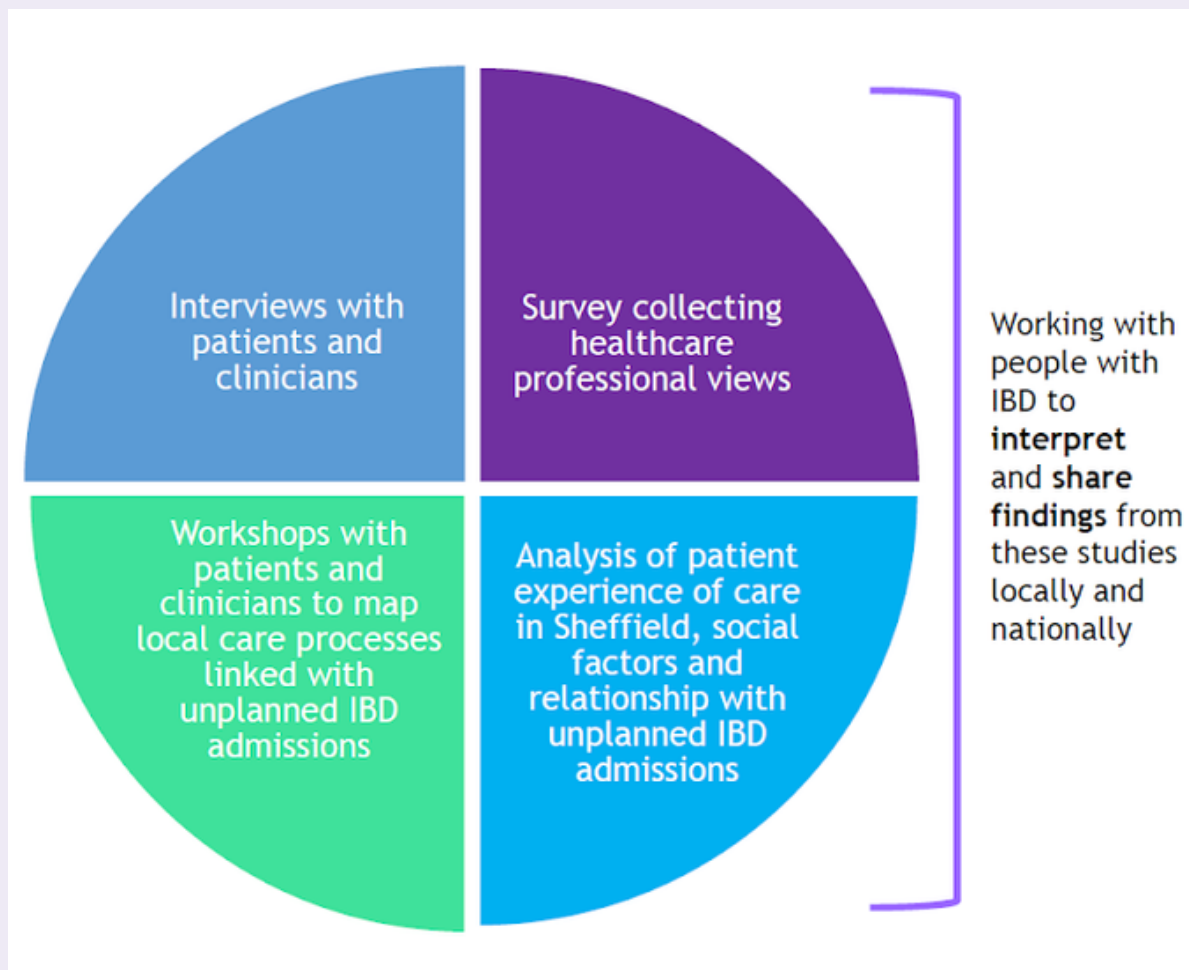
We are now analysing data to evaluate the service changes. The IBD team will use these findings to decide how to take forward these service changes beyond the AWARE-IBD Project.

We are also establishing a **Patient Panel** for the Sheffield IBD Service. The Patient Panel meet regularly to discuss topics of care within the hospital. The IBD Patient Panel is run by patients for patients and is a forum for people who use the services within the hospital to provide the team with feedback and suggestions for improvements.

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

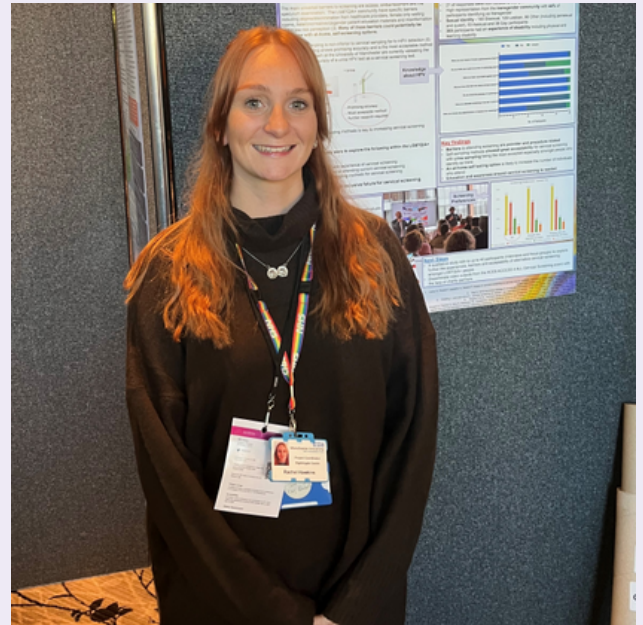
NEW RESEARCH OPPORTUNITY

Rachel Hawkins is completing her PhD at The University of Sheffield with the IBD team looking at investigating avoidable unplanned admissions. This research aims to investigate if some unplanned admissions in IBD could be avoided or prevented through improvements in the healthcare system.



Between October 2023 to April 2025 there will be opportunities for people with IBD to get involved in this research. This includes opportunities to take part in research studies and/or to be involved in shaping this work.

If you have experienced an unplanned hospital admission for your IBD then there will be an opportunity to take part in an interview with Rachel in the summer/autumn next year.



If you would like more information about involvement in this research please contact Rachel Hawkins: **Rhawkins4@sheffield.ac.uk**



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 :

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