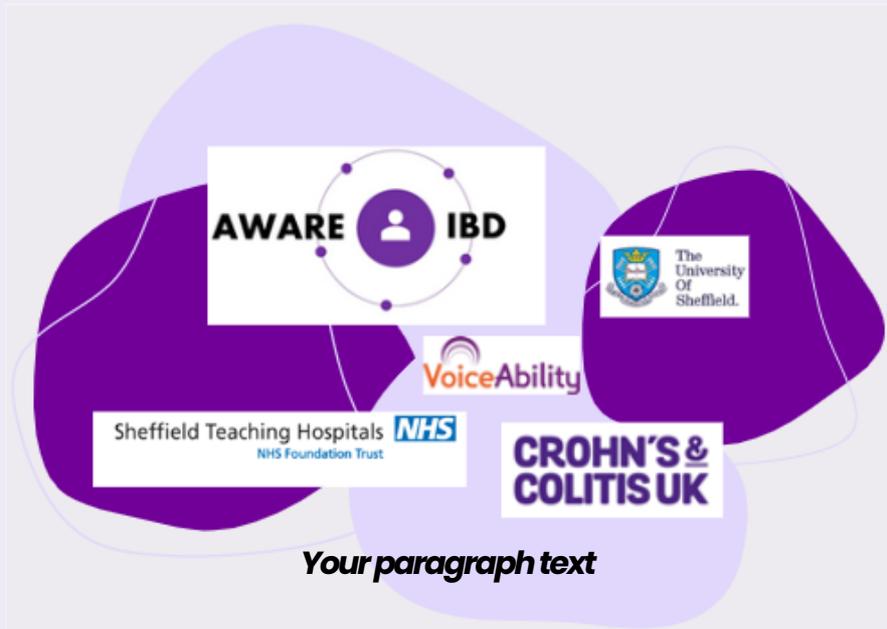


AWARE-IBD NEWSLETTER



WELCOME

This is issue 4 of the AWARE-IBD Newsletter.

RECRUITMENT

We have recruited **249 patients to the study!**

IN THIS ISSUE

- Page 2** – Meet Kerry, IBD Nurse
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- Page 5** – What Matters to You
- Page 6** – Autumnal Colouring

But we still need **your help!** If you identify as **LGBTQ+ and have IBD** we'd like to talk to you about your experiences and views of the service.

Please do get in touch:
aware-ibd@sheffield.ac.uk

MEET KERRY

Hi, I am Kerry, I have been an IBD nurse in Sheffield since 2003.

Since then, the IBD service has grown hugely, and we now have a team of eight IBD nurses. Before I became an IBD nurse I worked on a colorectal surgical ward, and then as a stoma care nurse and it was during that time that I developed an interest in IBD.



I am currently doing an MSc in advanced practice as part of the Crohn's and Colitis UK Nurse specialist programme which supports and helps IBD nurses to develop through study and by developing strong links with other IBD nurses throughout the country.

I am really enjoying the programme and getting to know other IBD nurses and sharing best practice and am finding the modules interesting.

The best thing about being an IBD nurse for me is getting to know people living with IBD over many years and developing a trusting relationship with them.

I am really excited about the AWARE-IBD project as it is an opportunity to work together with people who use our service and to make changes to the service based on their feedback about what matters most to them.

UPDATES

PERSONALISED CARE PLAN

As part of the AWARE-IBD Project, we would like to introduce written personalised care plan to improve the IBD service.

We recently sent you a survey to find out what you would like a care plan to look like, what content we should include and what would be most beneficial to you. Thank you to everyone who has responded so far! We have put together a summary of what we've found on Page 4 of the newsletter. These findings will be discussed at a workshop to start designing the care plan (see below for more details).

The aim of this work is to contribute to improving the service in Sheffield. However, we think the information will also be very valuable for other IBD centres. The survey captures your views and experiences. These may be used in publication and presentations that we make to other professionals and patient groups. You would not be identifiable in any way and no views you expressed would affect your personal care.

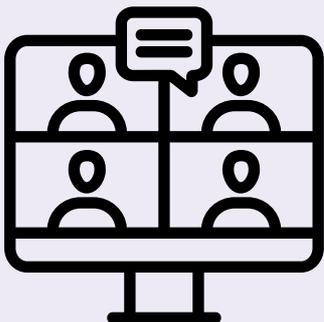
If you haven't yet completed our survey then the link is [here](https://forms.gle/317XD68j8snUgj4z9):

<https://forms.gle/317XD68j8snUgj4z9>



WORKSHOP

There will be an **online** workshop on **Tuesday 20th September 5.30-7.30pm**



This will be used to discuss with patients and the IBD team what should go in the care plan, who completes it and how it will be completed. If you'd like to come along, please let a member of the team know by e-mailing: aware-ibd@sheffield.ac.uk

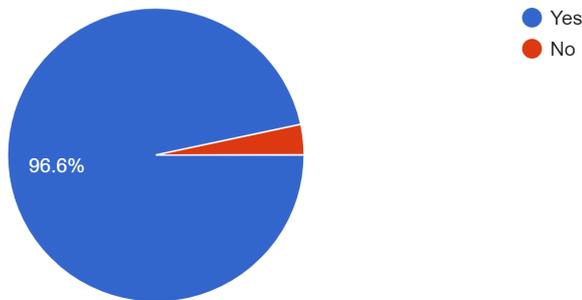
PERSONALISED CARE PLAN – RESULTS FROM SURVEY

Thank you to everyone who has completed the survey so far! Here are some of our findings:

- 96% of respondents said they would like to have a personalised written care plan as part of their IBD care
- 91% of respondents said they would like the care plan to include an open text box to write about what matters to you at a particular point in time
- 99% of respondents said they would be happy to complete sections of their care plan before each consultation

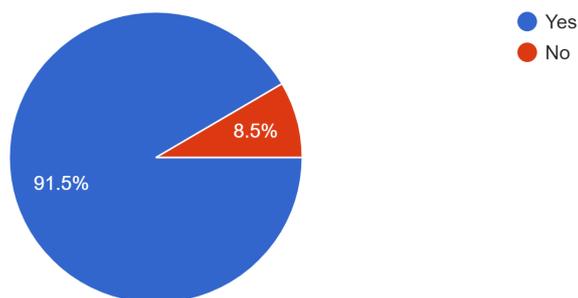
I would like to have a personalised written care plan as part of my IBD care

119 responses



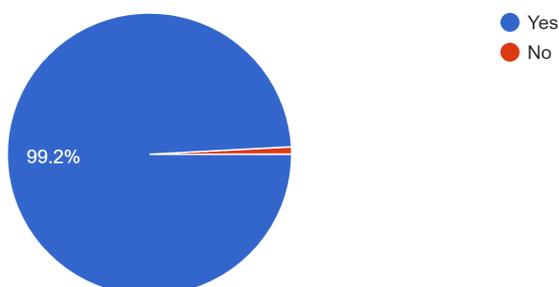
Would you like the care plan to include an open text box to write about what matters to you at a particular point in time?

118 responses



I would be happy to complete relevant sections of my care plan before each consultation (e.g. my goals)

119 responses



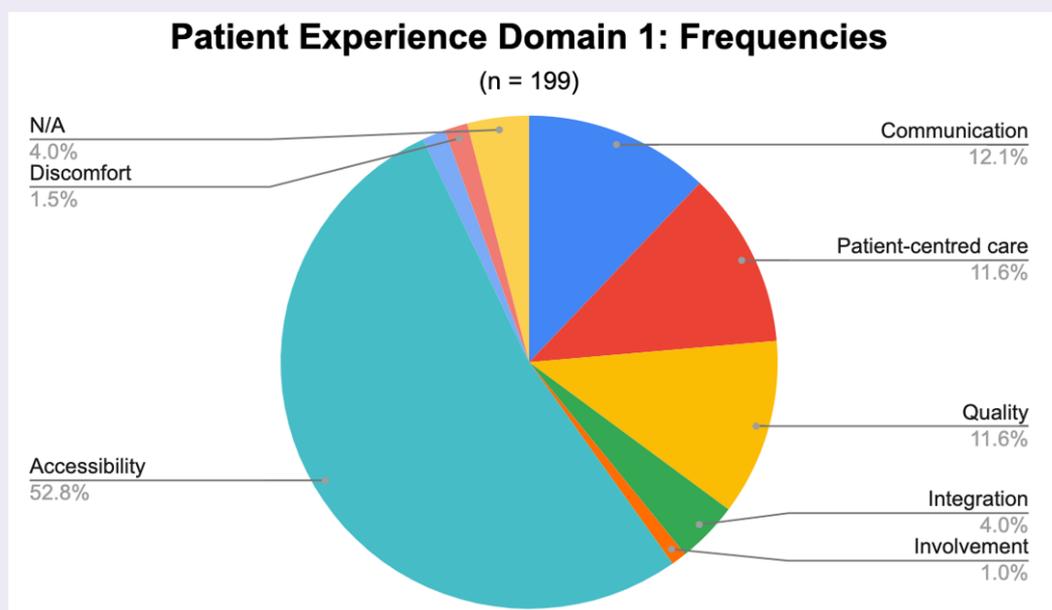
WHAT MATTERS TO YOU

We sent out some more letters recently, asking What Matters to You, and collect 199 responses.

Much like the first round, the themes that mattered most to people were:-

- Accessibility (52.8%)
- Communication (12.1%)
- Patient Centred Care (11.6%)

But this second round Quality (11.6%) was third most important.



We will be using these results to inform the changes we are making to the IBD services, thinking about areas such as:

- Improved IBD Nurse helplines
- Personalised care plans
- Increased awareness for Mental Health care
- whether appointments are face to face or over the telephone

AUTUMNAL COLOURING PAGE



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 :

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



@Awareibd

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