

# AWARE-IBD NEWSLETTER



## WELCOME

This is issue 8 of the AWARE-IBD Newsletter.

## RECRUITMENT

We have recruited 286  people with IBD to the study!

**CROHN'S &  
COLITIS UK**

## IN THIS ISSUE

**Page 2** – Meet Rachael, our IBD representative!

**Pages 3 & 4** – Update on service changes

**Page 5** – IBD Toolkit

**Page 6** – Activity and contact details

Crohn's & Colitis UK's South Yorkshire Network are hosting their annual Educational Day! Come along on Saturday, 7th October 1-3pm at Northern General Education Centre – we'd love to see you there! This is a great opportunity to meet others affected by Crohn's and Colitis, as well as hearing about ongoing research projects involving IBD that benefit South Yorkshire patients. There will also be a Reiki and Reflexology session as well as a raffle prize draw!

# MEET RACHAEL

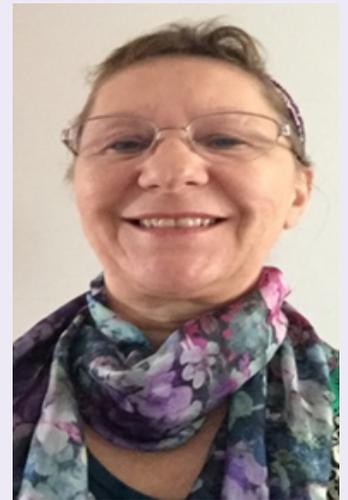
Hello

I'm Rachael and I'm a patient representative on the Aware-IBD project. I was diagnosed with Crohn's disease in 2015 and since then have been under the joint care of both the colorectal services and the IBD team at the Royal Hallamshire.

Since my Crohn's diagnosis I've participated in a number of national research projects, but most of them have been online. Being part of those 'online projects' meant I could remain in my 'safe space' but still feel that I was doing something positive! When I first heard about the call for patient reps on the AWARE-IBD project, I wasn't really sure if this was right for me. My battle with Crohn's had really knocked my confidence and meeting a room full of strangers did cause me a degree of anxiety!

Well... that was over two years ago and I'm so glad that I decided to step out of my 'safe space' and give it a go. It's been a real privilege to witness first-hand the dilemmas, pressures and the commitment of the IBD team, including those unsung heroes in admin! I've also been impressed by the amount of innovative ideas, forward thinking programmes and challenging discussions that's been raised during many of our meetings, and I'm confident that many of the topics we've discussed will go on to improve the IBD service for patients.

Being a patient rep has allowed me to share examples of my own lived experience with IBD, while also raising the subject of 'Hidden Disabilities.' Also, by highlighting some of the 'hidden' struggles many IBD patients face on a daily basis (but may not have shared with their care team) became a really positive experience. I know that many of the issues raised around this subject were later included into the design of the Personalised Care Plans. While being a patient rep has been both challenging and rewarding, it's also helped to build up my own confidence. I'm now part of the educational events team helping to design and present educational events (aimed specifically to support IBD patients) and I'm the Patient Lead working towards establishing a Patient Panel. However, one of the best things about becoming a rep on this project has to be that those 'strangers' I mentioned earlier have now become some lovely new friends!



# UPDATE ON SERVICE CHANGES

We are now into our final year of the AWARE-IBD project and we have tested a number of changes to the IBD service. The aim of the changes was to improve access to the service, improve communication and provide more patient-centred care. Below are updates on each of the service changes and what to expect over the next few months!

## 1 – Rapid access clinic

We completed two trials of this new clinic led by the IBD Consultants. The aim of the clinic was to provide rapid access to the service for patients who are:

- Newly diagnosed
- Have changed or started biologic treatments

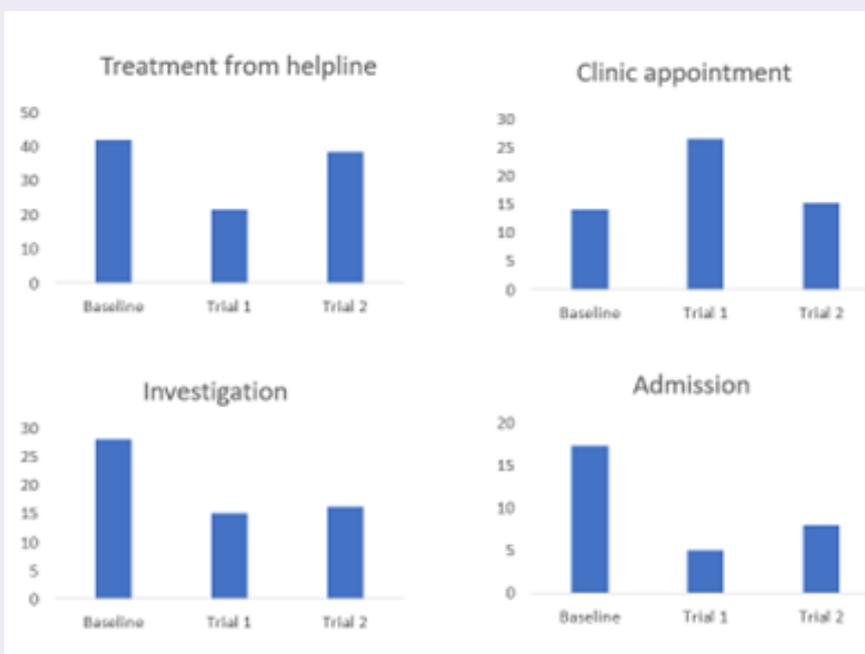
Or

- Require urgent clinical review for flare symptoms following a call to the helpline

We have been analysing the data and can share a first look at our findings!

Based on our initial analysis, we have found that the new clinic resulted in:

1. Reduced the number of admissions to hospital
2. Reduced the number of patients needing further investigation
3. Increased the number of patients being treated from the helpline by an appropriate IBD Nurse Specialist
4. Reduced the number of clinic appointments being requested
5. Where requested, clinic appointments were more rapidly obtained and booked in



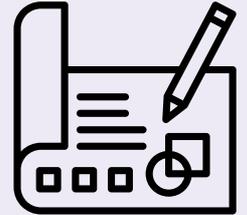
The IBD team are continuing to review and analyse the data and are thinking of ways to make this 'rapid access clinic' a standard procedure for the IBD service!

Please note that these findings now need to be confirmed by a Statistician who is working on the project at the University of Sheffield. Research data on the IBD Control and Patient-Reported Experience Measure will be analysed later in 2023.

## 2 – Personalised care plans

We are currently doing our second trial of the personalised written care plans. The care plan template was designed by people with IBD and you can view a copy by clicking [here](#).

The aim of this trial is to use the template with as many research participants as possible to see whether you think it is acceptable and improves your experience of the service. If you have an upcoming clinic appointment with the IBD service and would like to try the care plan, please let the IBD Team know.



## 3 – Education sessions

We are planning a series of free education sessions for people living with IBD in Sheffield. The sessions will aim to provide information about a range of topics including:

Session 1: *What is IBD and how does it affect me physically?*

Session 2: *Care and treatment options*

Session 3: *Mental health and IBD*

Session 4: *Self-management and IBD (What to do when...)*

Session 5: *Diet and Nutrition in IBD*

Session 6: *Living with a hidden disability (Employment and education, Benefits and finances, Disability recognition, Social challenges)*



The sessions will be held throughout September and October 2023 at a venue close to Sheffield City centre. Our chosen venues have free disabled parking, can be easily accessed by public transport and will have clean and accessible toilet facilities. Tea and coffee will also be provided!

There will be an IBD Consultant, an IBD Nurse Specialist and patient representative at each of the sessions. Some of the sessions, such as ‘Mental Health and IBD’ will also be delivered by specialists on that particular topic. This is a great opportunity to meet other people living with IBD and hear from the professionals about different topics.

Sessions will be open on a first come first served basis. If you are interested in attending one of these sessions, please get in touch with the AWARE-IBD team on [aware-ibd@sheffield.ac.uk](mailto:aware-ibd@sheffield.ac.uk) or complete the Google form here: <https://forms.gle/6ur9HJav5UtfzwNAA>



# IBD TOOLKIT - NOW WITH A VIDEO!

We've been working with Neck of the Woods Films to produce an animated video about our IBD Toolkit!

You can watch the video on YouTube here:  
[https://www.youtube.com/watch?v=3psvli17\\_SU](https://www.youtube.com/watch?v=3psvli17_SU)

The toolkit was co-designed by people with IBD, Sheffield IBD Centre and VoiceAbility as part of the AWARE-IBD Project with the aim to help people to express themselves fully with the service.

Nick, whose role on the AWARE-IBD Patient Oversight Committee is to represent the views of patients across the UK, said: "The AWARE-IBD toolkit is very exciting and I only wish that it had been available when I was diagnosed. The toolkit helps you think about how you feel and how to express that effectively to your healthcare team. It also has pointers and signposts to sources of help and information, giving you the knowledge to work with your IBD team.



Oh, how I wish I'd known where the answers were to the questions I had and the many more questions I didn't know I had! So please – anyone with an IBD condition – do access the toolkit and let it help you to help yourself and more effectively access the healthcare services you need, want and deserve."

Since our last edition, we have had significant press coverage by local and national newspapers including:

[The Sheffield Star](#)  
[Yorkshire Bylines](#)

[The North Wales Pioneer](#)  
[The Wrexham Leader](#)

Download your copy of the IBD Toolkit by clicking here:

<https://www.voiceability.org/assets/download/VA74-IBD-Toolkit-v4.pdf>

This toolkit about IBD is also available online at [voiceability.org/aware-ibd](https://www.voiceability.org/aware-ibd)

You can use the website's toolbar to read the text aloud, show simplified information, or translate the words into your language.

## ACTIVITY - AUTUMN WORD SEARCH



ACORN  
APPLE  
AUTUMN  
CHESTNUTS  
CHILLY

COBWEB  
COOL  
CRISP  
HARVEST  
HAYSTACK

LEAVES  
NUTS  
PUMPKIN  
RAINCOAT  
SCARECROW

SEASON  
SQUASH  
SQUIRREL  
WEATHER  
WINDY



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 :

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