

AWARE-IBD NEWSLETTER



WELCOME

This is issue 7 of the AWARE-IBD Newsletter.

RECRUITMENT

We have recruited 286  people with IBD to the study!

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Ship Shape Community Hub is hosting a FREE Health and Wellbeing Open day this **Friday (23rd June) 12:30–3:30pm** at **Madina Mosque in Sheffield**.

Come find our AWARE-IBD stall! There will also be stalls on mental health, blood pressure and pulse checks, dementia awareness and oral health.

MEET NASEEB & SIENNA

Hi everyone,

I'm Naseeb, one of the research assistants on AWARE-IBD. I have worked as a researcher at The University of Sheffield since 2020 and have recently joined the AWARE-IBD project. I studied a master's degree in public health and have an interest in co-production.



My work on AWARE-IBD will be focused on assisting with project management and ensuring patient voices are heard through community outreach sessions. I'm looking forward to learning more about patient experiences and facilitating meaningful service changes that matter to you.

I'm Sienna, I am also a Research Assistant working on the AWARE-IBD project. I joined the Sheffield Clinical Trials Research Unit in 2021 after completing my MSc in Nutrition and Public Health Management. I have an interest in clinical trials and research into health behaviour change, as well as service improvement.



On AWARE-IBD, I am involved in the analysis of the qualitative interviews, hearing first hand how the service changes are impacting both the patients and professionals, and providing feedback to the project management team to help further improve the services.

IBD TOOLKIT

Introducing our new IBD Toolkit!

People with Inflammatory Bowel Disease (IBD) have worked with Sheffield IBD Centre and VoiceAbility to create a toolkit to help you communicate with confidence and prepare for your appointments, to make sure you get the best results for you. The toolkit has been developed in collaboration with and with the support of the Sheffield IBD team. It's important to the IBD team that people feel comfortable to express themselves fully within the service, to communicate effectively and are satisfied with their consultations.

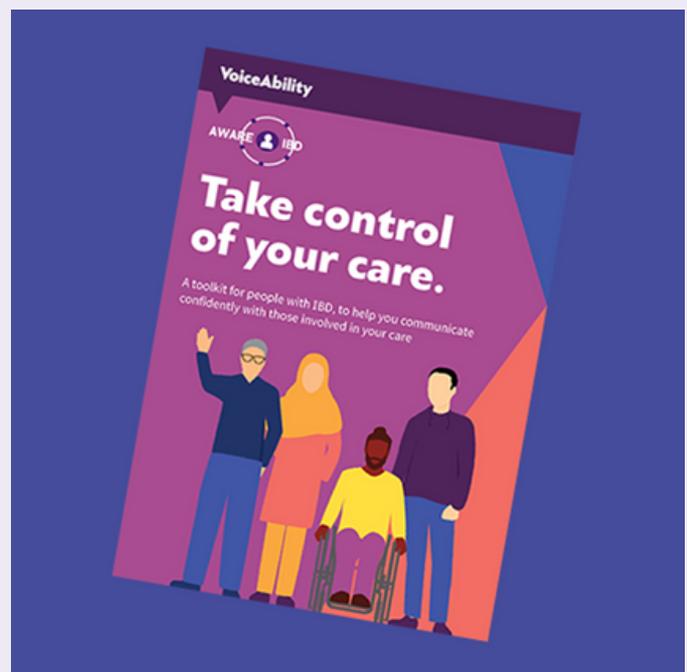
Download your copy of the IBD Toolkit by clicking here:

<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.

If you'd like a physical paper copy of the toolkit, you can request one to be posted to you by e-mailing the AWARE-IBD team: aware-ibd@sheffield.ac.uk



GET INVOLVED - PATIENT PANELS

What is a Patient Panel?

A Patient Panel is a forum for patients who use the local services to provide the hospital team with feedback and suggestions for improvements. IBD Patient Panels normally meet regularly to discuss topics of care within the local area.



Patient panels give the IBD service an opportunity to listen, understand and respond to the needs of the patients and carers, their perceptions and also their expectations. This allows for continuous improvement and transformation within the service. The key to these improvements is communication and understanding.

How can I get involved?

Sheffield IBD Centre would like to start up a new Patient Panel. So far, we've put together a small working group of people (including IBD Consultants, IBD Nurse Specialists and a person with IBD) who are working with the Sheffield IBD team to talk about what would be involved.



We are looking to recruit IBD patients to the Panel. If you're interested in being involved or would like to find out more info, please contact the AWARE-IBD Team: aware-ibd@sheffield.ac.uk

Please note, the Panel is not a platform for making complaints about the IBD service, rather it is about sharing experiences to bring about positive change. Should patients or carers have complaints about the Trust's services, these should be directed to PALS. (Patient Advice and Liaison Service)

Tel: 0114 271 2400 Email: sth.pals@nhs.net

UPDATE ON SERVICE CHANGES

We're 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!



Rapid Access Clinic

We have just completed our second 6-week trial of the new clinic led by IBD Consultants. The aim of the new clinic is to provide rapid access to 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 are now looking at the data to see whether we think the service change improved patients' experiences of the service and their IBD outcomes. We will also discuss whether or not the service change should be sustained long-term.

PERSONALISED WRITTEN CARE PLANS

We are planning our second trial of our new, personalised written care plan. The care plan template was designed by people with IBD and you can view a copy by clicking [here](#). We want to trial this template with as many patients as possible to see whether it's 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.



IBD EDUCATION PROGRAMME

We are working with the IBD Consultants and IBD Nurse Specialists to plan 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)

Based on recent survey feedback, we are planning a mixture of face to face and online sessions, and we will be making some online videos and resources to accompany the sessions.

We will be in touch by email to advertise the sessions and provide a sign up link, so keep your eyes peeled for more information!



ACTIVITY



Summer

Find and circle all of the summer words that are hidden in the grid. The remaining letters spell an additional summer item.

J U N E S T S S S S Y K S E U L B M
 U S M E A U Y E O U H I K I N G S A
 S M W E E A N L U B N W A S E Y R E
 U T W I R R S G I C A B L N A R E R
 N S H V M T C C L T E A U D T V L C
 T Y U G I M Y S E A D B I R S S K E
 A G L C I C I R N N S L R R N D N C
 N R E U L F M N A U O S E A R G I I
 O E A E J E R S G H S W E A B N R C
 S E D A L B R E L L O R O S R I P R
 C N A O F L O G T L T B T E E T S E
 H G N I H S I F F A E O A E E A H C
 O R C A M P I N G T W T H B Z O C C
 O A C I N C I P A W A S P S E B A O
 L S F L I E S K M O S Q U I T O E S
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 G N I N E D R A G S U N S H I N E N

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|----------|-------------|---------------|--------------|
| ANTS | FISHING | JULY | SUNBURN |
| AUGUST | FLIES | JUNE | SUNGLASSES |
| BARBECUE | FLOWERS | MOSQUITOES | SUNSCREEN |
| BASEBALL | GARDENING | NO SCHOOL | SUNSHINE |
| BEACH | GOLF | PICNIC | SUNTAN |
| BEEES | GREEN GRASS | ROLLER BLADES | SWEAT |
| BICYCLE | HAT | SANDALS | SWIMMING |
| BLUE SKY | HIKING | SKATEBOARD | U V RAYS |
| BOATING | HOLIDAYS | SOCCER | WASPS |
| BREEZE | HOT | SOLSTICE | WATER FIGHTS |
| CAMPING | ICE CREAM | SPRINKLERS | WATERMELON |



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!