



NEWSLETTER

PUTTING PEOPLE WITH INFLAMMATORY BOWEL DISEASE (IBD) IN CONTROL OF THEIR CARE

LATEST NEWS

Welcome to the 2nd edition of the AWARE-IBD Study newsletter!

We would like to say a **BIG** thank you to everyone who has taken part so far – together, we are driving improvements to the Sheffield service and will ultimately improve outcomes & experiences of IBD care!

How are we doing so far?

408 “What Matters To you?” responses received (Tier 1)

343 people have agreed to be consulted about service improvement (Tier 2)

207 people have agreed to be part of the microsystem (Tier 3)

171 people have given consent to take part in the research study!

Keep your eyes peeled for letters inviting you to get involved in the project, your input is important to us and the future of IBD care at Sheffield.

Meet our patient coach **Samantha McCormick**

“Hi, I’m Sam, and I’m the Project Support Officer for the AWARE-IBD project.



I was diagnosed with Crohn’s in 2002 at 15, and know first hand how important Crohn’s & Colitis UK are in IBD research and raising awareness. My Crohn’s has been under control since 2014 thanks to self-injecting twice monthly with Adalimumab (Amgevita).

In 2021 I graduated with first-class honours BSc in Nutrition, Diet and Lifestyle with a particularly strong interest in how diet and exercise help to manage Crohn’s and Colitis. I will be further studying doing an MSc in Dietetics in January 2023.

Outside of my studies I am a Latin-American folkloric dancer, doing traditional dances from Mexico and Latin-America. I speak Spanish and recently started learning German. I also love to spend time with my partner and family, reading and exercise.”

Sam will be leading the work with the healthcare professionals to make improvements to the IBD service.

PUTTING PEOPLE WITH INFLAMMATORY BOWEL DISEASE (IBD) IN CONTROL OF THEIR CARE

Patient Oversight Committee (POC) a year in review

Both local and national and patient representatives were recruited to the POC to challenge and provide advice, particularly on patient involvement, reaching less heard voices and communicating what's important to patients. The POC hold the study team to account by ensuring the project is delivering benefits to patients with IBD. It's been a year since the POC for AWARE-IBD was formed. We want to give you an update on how they've been getting on.

"By getting involved with research, this is a chance to make a difference for those with IBD, improve care, medication, treatment, diet and so much more. By working on the AWARE-IBD project, it has given me the opportunity to hear other points of views, ideas, and opinions."

Vicky Buckley, POC member



"I am proud to be a part of this project and enabling patient to say 'What Matters' to them and communicate the type of care that they want to receive"

"As an ally, I am determined to do everything I can to ensure that LGBTQ+ voices are heard in the AWARE-IBD project. I am holding the project team accountable (in the nicest and most constructive way, obviously) for ensuring LGBTQ+ IBD patients participate in this project"

Paul Westlake, POC member



"It is important for us to get involved as we are able to provide a unique viewpoint and focus research on what is most important to those that it seeks to help."



"This sounds really obvious, but doctors, nurses and scientists can't fix some problems unless patients speak up and say what they are."

"It had taken me almost five years after I was diagnosed with Crohn's to get a real understanding of how I could best utilise the IBD services in my hospital to manage my IBD. Patient centred systems would mean optimised support for IBD patients sooner in their IBD journey. I am really optimistic that if we find the right framework, patient centered services could become the norm rather than the exception throughout hospitals in the UK"

Krupa Gupta, POC member

PUTTING PEOPLE WITH INFLAMMATORY BOWEL DISEASE (IBD) IN CONTROL OF THEIR CARE

What Matters to You survey findings

408 people receiving IBD care in Sheffield told us what matters to them most about their care. The infographic below provides a summary of what they said.

We sent a survey to everyone who receives Inflammatory Bowel Disease care at Sheffield Teaching Hospitals. The survey asked 'what matters to you' most about your care. 408 people replied.

The Top 3 Items were:

1. Accessibility



"To have rapid access to expert advice when problems arise"

2. Communication

"Being kept informed about what care I will receive, when I will receive this care, and why I am receiving this care"



3. Patient - centred care

"Treating me like a person and understanding that I am an expert in how I feel and how IBD effects me"



You have asked for:

1. Enhancements to the telephone advice line
2. Improved communication between hospital departments and GPs
3. More face-to-face appointments

PUTTING PEOPLE WITH INFLAMMATORY BOWEL DISEASE (IBD) IN CONTROL OF THEIR CARE

Can you solve the Easter Emoji challenge?



Easter Emoji

$$\begin{array}{r}
 \text{🐰} + \text{🐰} + \text{🐰} = 24 \\
 \text{🐣} + \text{🐰} + \text{🐰} = 19 \\
 \text{🐣} + \text{🔔} + \text{🔔} = 17 \\
 \text{🐣} \times \text{🐰} + \text{🔔} = 31
 \end{array}$$

$$\begin{array}{r}
 \text{🐰} = \\
 \text{🐣} = \\
 \text{🔔} =
 \end{array}$$

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](#)
- IBD UK Benchmarking Tool [Sheffield Report](#)

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

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



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

