

# AWARE-IBD NEWSLETTER



## WELCOME

This is issue 3 of the AWARE-IBD Newsletter - with a new and improved format

## RECRUITMENT

So far **173** people have given consent to take part in the research study!

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*Thank  
you!*

# UPDATES

## MICROSYSTEM

Sam McCormick, our patient coach, has started the Microsystem in Sheffield.

Microsystems are the building blocks of healthcare where patients and carers meet. The healthcare system is made up of Macrosystems (Sheffield Teaching Hospitals), Mesosystems (Gastroenterology department) and Microsystems (IBD service).

A microsystem is not just the clinical staff, but also the supporting staff (i.e. clerical and ancillary), patients and their families. This allows to provide services that are more personalised to the individual.

## PURPOSE STATEMENT

The Microsystem team have written a Purpose Statement for the project.....

**Working in partnership with people living with IBD to improve their quality of life, by developing an innovative person-centred service, which provides a blueprint for other services**

## INSIGHTS – SO FAR

### What insights have we gathered so far?

We have now collected information from 151 people with IBD through our Patient-Reported Experience Measure (PREM) questionnaire.

We have been monitoring the responses and are discussing them as a team. So far, the area that stands out is that most people have reported that they don't have a written personalised care plan.

A care plan is a document that sets out how Crohn's or Colitis will be treated, managed and monitored. It should take into consideration hopes and life aspirations. It is an agreement or plan with healthcare professionals to help meet those goals. This is different to letters or correspondence that a doctor may send after each appointment. The format of which can either be paper or electronic.

We will be feeding this insight into the weekly meetings, so that the collective group of clinicians and people with IBD can consider what changes could be made to the service. Throughout the project we will continue to monitor these responses, and hope that we will see positive changes in them over time.

We will share the improvements that are made throughout the project through these newsletters and hope that this has given you an insight into how we are using your questionnaire responses, and how important they are to the changes being made.

## MEET GEMMA

Hi everyone,

I'm Gemma Research and Quality Improvement Lead at Crohn's & Colitis UK, and I work on the AWARE-IBD project alongside Rachel Ainley our Head of Research and Evidence and Ruth Wakeman our Director of Services, Advocacy and Evidence.



Since 1979, Crohn's & Colitis UK has been there for everyone affected by Crohn's and Colitis. Over the next three years we are making it our mission to understand the experiences of everyone living with Crohn's and Colitis. We are working to provide a wealth of information and support, to speak up for our community on issues such as healthcare, employment, and education and to drive long-term solutions through pioneering research.

AWARE-IBD is a flagship project for us. We are proud to work with partners in Sheffield to put people with Crohn's and Colitis at the centre of their care.

Involving people with Crohn's and Colitis throughout the project is really important to us. It has been great to work with the Patient Oversight Committee to ensure the project really delivers and remains focused. We have also worked with a group of people with the conditions to develop a questionnaire to measure experiences of using an IBD service and been involved in recruiting and inducting our patient coach Sam. We are very grateful for all the input and are already using all the information gathered through the various workshops and questionnaires.

We want to use the learning from this project across the UK and have already been sharing updates with a wide range of stakeholders, including our partners in IBD UK.

We are excited to start making improvements to the Sheffield IBD service and would encourage you to get involved, if you haven't already, and make a difference to your care and to that of others across the UK.

# VOICEABILITY

The following infographic outlines our partnership with VoiceAbility on the project.



## Our partnership with VoiceAbility

### The AWARE-IBD Project

AWARE-IBD is a 3-year project funded by The Health Foundation. The aim is to bring together people with Crohn's and Colitis and healthcare professionals to design and deliver improvements to the Inflammatory Bowel Disease (IBD) service in Sheffield. Our ultimate goal is to empower people with Crohn's and Colitis and improve their care based on what matters to them.

We are working in partnership with VoiceAbility to make sure that all people living with IBD, their families, and carers are heard and are at the centre of this project. Find out more about how VoiceAbility are working together with people in Sheffield with IBD and how you can get involved below.

### Upskilling toolkit

VoiceAbility are working in partnership with people in Sheffield with IBD to design an upskilling toolkit. The toolkit aims to give people the information, confidence and skills to get the most out of appointments. It will support people to take control and take an active role in decisions, as experts in their own care. VoiceAbility will run workshops to design and produce the toolkit to ensure it's useful and accessible to everyone who receives IBD care in Sheffield.



# VOICEABILITY

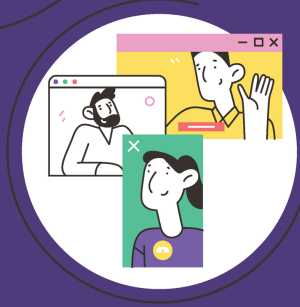


## Peer Led Evaluation

In a series of workshops, VoiceAbility will ask people with IBD 'What Matters To You?'. Findings from the workshop will help us to evaluate the quality of the IBD service in Sheffield and how this changes over time. VoiceAbility will distribute the survey to people who receive IBD care in Sheffield. The results will inform what service changes we make in the AWARE-IBD Project.

## Service improvement

As part of the AWARE-IBD project there will be weekly meetings that bring together people with IBD and healthcare professionals to design and implement service changes. We want to make sure that improvements to the IBD service are important to a wide range of people; however, we only have space for 2-3 people with IBD to be involved in our weekly meetings. VoiceAbility are therefore running separate workshops with wider group of people with IBD to sense check service changes ideas.



## Community outreach

VoiceAbility want to talk to people from a wide variety of community groups in Sheffield to understand any barriers or challenges they experience to accessing the IBD service. It's important we hear from the entire community of people with IBD, including those affected by IBD, to ensure service changes will be a positive change for all. Findings from the workshops will also inform changes to the service that can remove or overcome any barriers.

## Get Involved!

VoiceAbility want to hear from as many people with IBD as possible! If you want to have your say on what matters to you, what changes you think we should make to the IBD service or you'd like to attend a workshop with VoiceAbility, then please get in touch!

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