

**AWARE-IBD: Putting people with inflammatory bowel disease (IBD) in control of their care**

The Sheffield IBD Centre

*Introducing personalised written care plans as part of your ongoing IBD care*

1. **What is the AWARE-IBD Project about?**

Sheffield Teaching Hospitals (STH) are running a project called AWARE-IBD to improve the Inflammatory Bowel Disease (IBD) service. The aim of the project is to empower people with Crohn’s Disease and Ulcerative Colitis, the two main forms of IBD, to shape improvements to your care based on what matters to you.

We are working with the Sheffield Microsystems Coaching Academy (MCA) to introduce new ideas. We have trained a patient from the Sheffield IBD service as an MCA coach to leading the microsystem with others who use the service contributing alongside healthcare professionals.

1. **What have we done so far?**

To identify areas for improvement, we have collected survey data from over 600 patients from the Trust asking what matters most to them. Patients told us that accessing the service, communication and patient-centred care are most important.

We have also been collecting data from 279 research participants asking about their experience of the service and their symptoms to identify areas for improvement. So far, the survey findings show that people with IBD do not have a personalised written care plan.

1. **What is a personalised written care plan?**

IBD UK’s national standards say what high quality care should look like at every point of a patient’s journey – from first symptoms, to diagnosis, treatment and ongoing care. They are designed to ensure that people with IBD receive safe, consistent, high quality, personalised care. One of the standards states that ‘a personalised care plan should be in place for every IBD patient, with access to an IBD Nurse Specialist and telephone/email advice line’.

The plan can help prepare patients for appointments by giving prompts and questions that will help them focus on what matters to them. It also supports clinicians to open up conversations to include aspects of daily living, including mental wellbeing. This way, they can find out how someone’s IBD affects their mood, relationships, employment and sexual health.

Following the conversation, the care plan provides a record of what was discussed, shared decisions about treatment and investigations, goal-setting or next steps. It also includes contact details for an IBD Nurse Specialist and telephone/email advice.

1. **What does the care plan involve? How and when will it be completed?**

As part of the AWARE-IBD Project, we aim to improve the IBD service by introducing a personalised written care plan for everyone who uses the service in Sheffield. So far, we have developed a care plan template based on surveys and workshops with people who agreed to give their feedback at the start of the project.

To trial this new care plan, we are asking some people on the research study to complete the care plan before their next consultation. You may not currently have an appointment booked, but one will be arranged in due course by the IBD team as part of your ongoing care.

During your next consultation, the IBD Consultant or IBD Nurse Specialist will go through the care plan with you. We have enclosed a copy of the care plan with this information sheet so you can see what the care plan looks like. We have included a summary of what’s included on the different pages below. If you want to, you can make some notes on this paper copy ready for your appointment. After your appointment, the consultant will include the up to date care plan with your clinic letter to your GP, which you’ll receive a copy of.

*PAGE 1: The IBD Care Team will complete Page 1 before your appointment,* including the sections on Diagnosis, Background and Support and Contact.

*PAGE 2: Please can* ***you*** *complete the following sections* ***before*** *your appointment:*‘What Matters To Me?’, ‘Managing my diet, lifestyle and other health-related conditions’ and ‘How have things been going for me?’. We have provided a summary of what these sections mean below.

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| **Section of the care plan** | **Explanation** |
| What Matters To Me? | Please tell us what is important to you. This may include, but is not limited to, your values and needs, your sexuality, gender or identity, goals for your IBD, your hopes and aspirations, future plans and support |
| Managing my diet, lifestyle and other health-related conditions | Please record any diet, lifestyle or other health related conditions considerations that are important to you. What would you like to discuss or receive more information on? |
| How have things been going for me? | Please note any issues or concerns you have about your day-to-day life and managing your IBD overall (work, home, feelings, psychological difficulties, symptoms). Please feel free to include issues that you think you might find difficult to raise otherwise. |

**The final section ‘Current treatment, next steps and review date’ will be completed at the appointment.**

At times, it may feel like there is a lot to talk about during your consultation. It’s important to explain what matters to you and find ways to achieve that, or to get as close as possible to it. Your personalised care plan has been designed to help you do that, so we encourage you to ask your IBD Consultant or Nurse to take the time to go through this with you - it’s really important to work together.

1. **How can I give my feedback?**

It’s important that the service improvements we make are acceptable to you as a user of the IBD service. We would therefore like to ask for your feedback on the personalised written care plan and whether or not your experience of care improved by its use. The IBD Team may be in touch to ask for your feedback on this.

1. **Do I have to take part?**

No, it is up to decide whether or not you want to complete a care plan with the IBD Nurse or Consultant at your appointment. There is an opt in / opt out slip at the bottom of this information sheet. Please fill this in to tell us whether or not you would like to complete a care plan and bring this with you to your appointment.

1. **Who is organising and funding the AWARE-IBD Project?**

The AWARE-IBD Project is funded by the Health Foundation (project number FR-000002444) under the Common Ambition Programme. The project is led by Crohn’s and Colitis UK and the research study is organised by the University of Sheffield and Sheffield Teaching Hospitals. For more information about the study, please see the AWARE-IBD webpage at Crohn’s and Colitis UK under our work - campaigns section.

# Who has reviewed the study?

The project has been reviewed and approved by an independent Health Foundation scientific panel, the Health Research Authority (HRA) and Wales Research Ethics Committee 3 (an independent group of people who protect your rights, wellbeing and dignity).

**Contact details:** If you have a concern about any aspect of this project, please contact Project Manager, our Patient Coach or talk to a member of your IBD care team.

**Patient Coach:** Samantha McCormick. Email: samantha.mccormick5@nhs.net

**Study manager:** Elena Sheldon. Email: aware-ibd@sheffield.ac.uk

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Yes I would like to complete the care plan as part of my appointment

No I do not want to complete the care plan as part of my appointment