

AWARE-IBD NEWSLETTER



WELCOME

This is issue 5 of the AWARE-IBD Newsletter.

RECRUITMENT

We have recruited **277** patients to the study!

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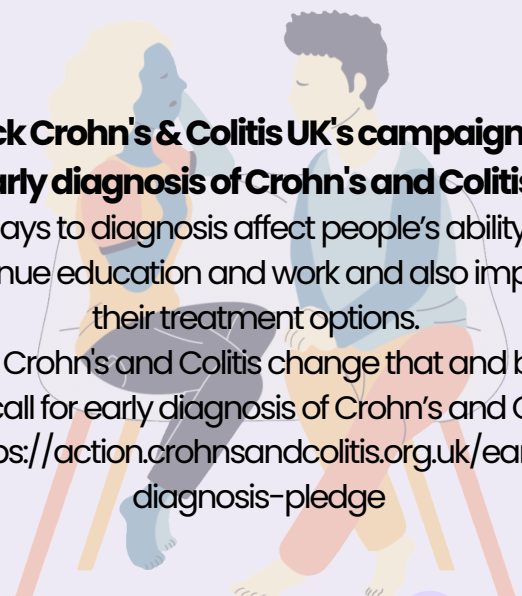
Page 6 – Christmas themed activity and contact details

Back Crohn's & Colitis UK's campaign for early diagnosis of Crohn's and Colitis!

Delays to diagnosis affect people's ability to continue education and work and also impacts their treatment options.

Help Crohn's and Colitis change that and back their call for early diagnosis of Crohn's and Colitis.

<https://action.crohnsandcolitis.org.uk/early-diagnosis-pledge>





MEET ELENA

Hi everyone,

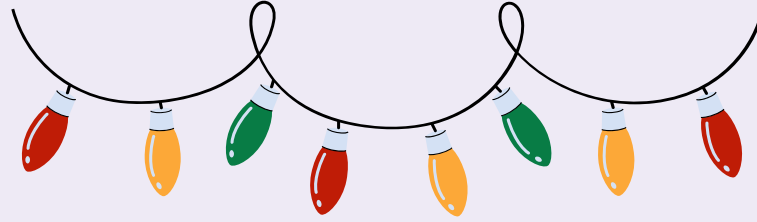
I'm Elena, the Project Manager of AWARE-IBD. I have worked as a researcher at The University of Sheffield for almost four years, and have managed the AWARE-IBD project since we started in February 2020. I am proud to work with the project partners, including the Sheffield IBD Team, Crohn's & Colitis UK and our Patient Oversight Committee.



Involving people with Crohn's and Colitis is at the heart of the AWARE-IBD Project and enables us to make meaningful changes to the IBD service. I want to thank everyone for being involved so far – whether you're a research participant, part of our microsystem team or have provided feedback on the service change ideas. With your help, we've made great progress and we're now testing some of the service changes – which is so exciting! In November 2022 we trialled a new face-to-face clinic led by the IBD Nurse Specialists for patients receiving biologics infusions at the Royal Hallamshire Hospital. We also trialled a new IBD 'consultant of the day' clinic for patients who are newly diagnosed, have changed biologic treatments or require urgent clinical review due to a flare. We've designed a template for a personalised written care plan based on your feedback and will be testing this very soon! Finally, we're finalising our upskilling toolkit developed by people with IBD and VoiceAbility, which we'll be looking to share with you early next year. I am really excited to see what the final year of the project brings!

And last but not least, Happy Holidays to everyone!





UPDATES

PERSONALISED CARE PLAN



As part of the AWARE-IBD Project, we are introducing written personalised care plans to improve the IBD service.

Since our last newsletter, we've done a survey and two workshops to decide on the content of the care plan and what would be most beneficial to you. We've now developed a template for the care plan, which you can view here:

https://docs.google.com/presentation/d/1wXKL-R0LeWb5Mp3ZN_gOhMF6dIdONZAt/edit?usp=sharing&ouid=109178071820313023972&rtpof=true&sd=true

The next step is to test our care plan with a number of people with IBD to see how acceptable it is and whether or not it improves their experience of care. If you take part in the AWARE-IBD research study and have an upcoming clinic appointment in December 2022, we may be in touch individually to organise this with you.

Sheffield Inflammatory Bowel Disease Centre
Personalised Care Plan

Sheffield Teaching Hospitals
IBD Foundation Trust

We will use this to talk about how you are feeling and what matters to you. Knowing what matters most to you will help us to work together to live your best life.

Your name: _____ Hospital number: _____ Date: ____/____/____

My Preferred Pronouns are: _____ (optional)

Diagnosis

My diagnosis is: _____

Year I was diagnosed: _____

What is affected? Use this space to draw a diagram.

Background and Support

My IBD History
What treatment or operations I have had in the past, results from procedures, allergies or bad reactions:

What should I do if I have a flare up?

What should I do out of hours?

Contact

Who's on my IBD Care Team and how do I contact them?
My Consultant is: _____
My consultant's secretary is: (Name and contact details) _____
IBD Nurse Helpline (0114) 271 2209
Monday to Friday 9am - 11am, messages picked up daily

Other useful contacts:
Infusion Appointments: (0114) 2712133
Outpatient Appointments: (0114) 220660
Endoscopy Appointments (0114) 2713173
Capsule Endoscopy Service: (0114) 2713743
Investigations Unit: (0114) 2713156

Sources of IBD Information and Support:
Sheffield IBD Centre: <https://www.sheffieldibd.co.uk>
Crohn's and Colitis UK: <https://www.crohnsandcolitis.org.uk>
On the Crohn's and Colitis UK website you can find information on symptoms, diet, sex and relationships, drug treatments, surgery, employment and education, benefits and finances.
Sheffield IBD Improving Access to Psychological Therapies: <https://www.sheffieldibd.co.uk>

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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.

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.

Current treatment, next steps and review date Please note any current treatment, follow up appointments, referrals, planned investigations or surgeries. This may also include future options or alternatives to your current treatment.

Managing my diet, lifestyle and other health-related conditions Please use this space to 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?

Safeguarding statement: This care plan is part of your hospital record and is visible to your IBD Team and ?? if there is a safeguarding concern or breach, please contact _____



NEW CLINICS

To improve access to the IBD service, we introduced new face-to-face clinics at the Royal Hallamshire Hospital. The first clinic was led by IBD Nurse Specialists on the Clinical Investigations Unit for people who receive infusions as part of their IBD care. Those with an overdue 3-monthly review were invited to a clinic appointment in November 2022 on the same day as their infusion appointment.

The second clinic was led by IBD Consultants and was targeted at patients who are newly diagnosed, have changed biologic treatments or require urgent clinical review for flare symptoms following a call to the helpline. These new clinics were trialled over a period of 2-4 weeks in November 2022. We have collected patient and staff feedback on how the clinics went and will use this information to evaluate and reflect whether or not they improved the IBD service.

If you want to have your say in what changes we make to the service, join us on Monday lunchtimes 12:15–13:15 for our weekly microsystem meeting. You can join us face-to-face at The Medical School or you can join online via MS Teams!

SITE VISIT

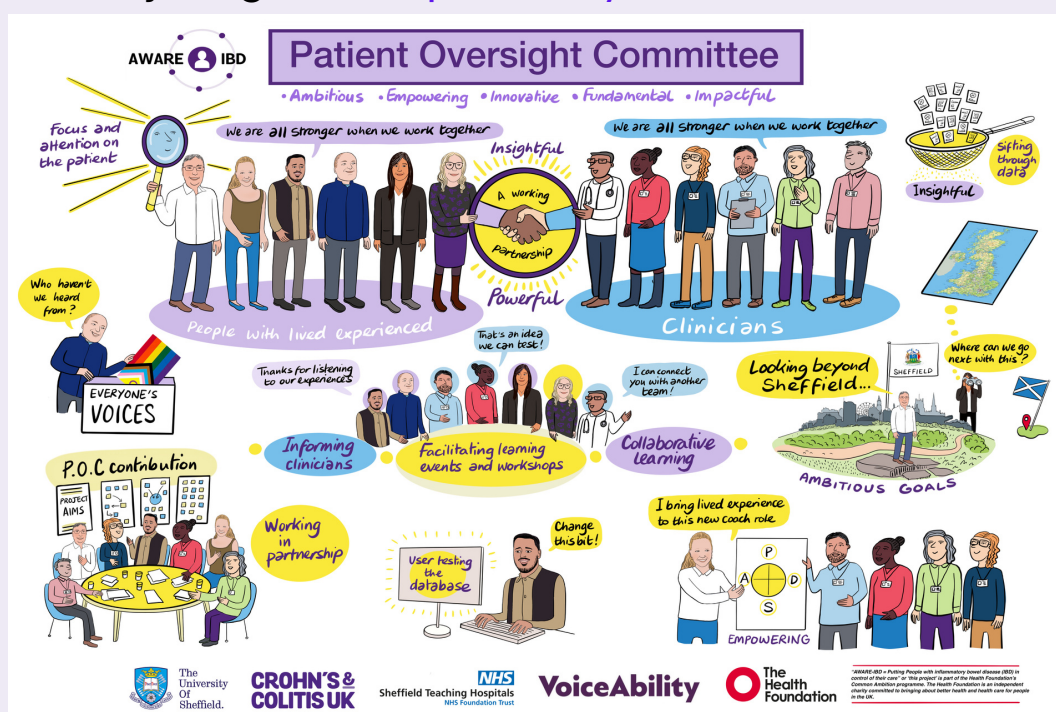
The Health Foundation (funders of the AWARE-IBD Project) visited us in October to find out what we've been up to and our plans for the final year of the project. It was an inspiring day with lots of examples of how patient leadership can shape service improvement!



PATIENT OVERSIGHT COMMITTEE

The AWARE-IBD Patient Oversight Committee includes people with Crohn's and Colitis from Sheffield, Rotherham, London, Cambridge & Wales. They provide invaluable support to the project and ensure IBD patients are at the centre of service change. If you want to find out more about the POC, and their important role in the AWARE-IBD

Project go to: <https://bit.ly/AWARE-IBD-POC>



MEDIA APPEARANCES

Just in case you missed it, check out very own Professor Alan Lobo and patient microsystems coach Sam McCormick talking about the AWARE-IBD Project on Look North! You can watch their interview on YouTube here:

<https://www.youtube.com/watch?v=YzW8KUz2iPI&feature=youtu.be>



CHRISTMAS THEMED ACTIVITY

Christmas Word Search

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

CHRISTMAS	STOCKING
HOLLY	JOY
ORNAMENT	MERRY
MISTLETOE	CARD
GREEN	PRESENT
RED	BOW
SILVER	SNOWFLAKE
BELLS	TREE
JINGLE	GINGERBREAD
HOOHO	WREATH
STAR	SNOWMAN
SANTA	CANDLE
HOLIDAY	



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

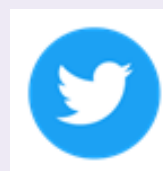
AWARE-IBD [Launch Webinar on YouTube](#)

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!