

AWARE-IBD NEWSLETTER



WELCOME

This is issue 6 of the AWARE-IBD Newsletter.

RECRUITMENT

We have recruited **279 patients to the study!**



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Happy birthday to AWARE-IBD!

We started this project funded by The Health Foundation 2 years ago today! We have achieved SO much, with over 250 patients involved and lots of service changes underway including personalised written care plans and new consultant clinics!



MEET STEFAN

Hi everyone,

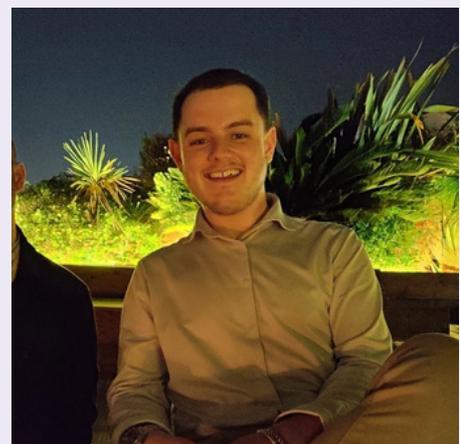
I am the Clinical Trials Assistant for AWARE-IBD in gastroenterology and for pulmonary hypertension in respiratory medicine. I have been involved in research since I studied for a bachelor's degree in psychology and a master's degree in clinical neurology, at The University of Sheffield. Currently, I am involved in all aspects of the research process. This includes aiding with site initiation, recruitment, data acquisition and analysis, study close and dissemination.

For AWARE-IBD my main responsibilities have been in recruitment, leading the 'What Matters to You?' response analysis, and trialling personalised written care plans. An additional focus for me is to now speak to as many people as possible on our inpatient wards about their experience of IBD and the care that they receive.

It has been only from your willingness and extensive input of information that we have now been able to have the discussions needed to make meaningful changes to our IBD service. It is also through this process that I have had the absolute pleasure of speaking to such a great number of you that live with Crohn's and colitis.

Thank you for the tireless interest, insight, and investment that you bring to our work.

Stefan Roman



UPDATES

RECENT SERVICE CHANGES

We're now 2 years into the AWARE-IBD project and we have tested three changes to the IBD service. The aim of these changes is to improve access to the service and provide more patient-centred care.

You said you wanted better access to the IBD service, improved communication and more patient-centered care. We did this by...

1. A face-to-face clinic led by IBD Nurse Specialists on the Clinical Investigations Unit for people who receive infusions as part of their IBD care.
2. A new clinic led by IBD consultants targeting patients who are newly diagnosed, have changed biologic treatments or require urgent clinical review for flare symptoms following a call to the helpline.
3. Introducing personalised written care plans to clinic appointments. The care plan has been designed by people with IBD, and you can view a copy by clicking [here](#). If you have an upcoming appointment with the IBD service and would like to try the care plan, please let your clinician know.



After trialling these changes, we're now looking at data to see if these changes improved your experience of the IBD service and your outcomes.



Your voice matters! It's really important that we keep collecting data every 3 months so that we can show whether or not the changes we're making improve the IBD service. We want to make sure that the service changes reflect what matters to you, so we really appreciate your continued participation in the AWARE-IBD project.

Given the positive feedback we received for the consultant-led clinic, we are trialling the clinic again this month – but this time for 4 weeks!



We are also trialling the care plan on a larger number of patients with upcoming appointments with the IBD team. If you have an upcoming appointment and would like to use the care plan, please get in touch by e-mailing: aware-ibd@sheffield.ac.uk



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!

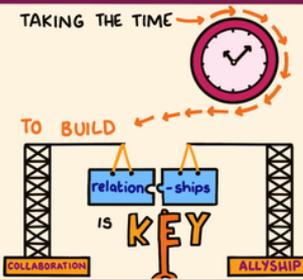
HEALTH FOUNDATION COMMON AMBITION EVENT

Back in October 2022, the Common Ambition grant holders came together with the Health Foundation to share all the work we've been doing for the past 2 years!



COMMON AMBITION - KEY LEARNINGS



<p>THERE IS NO RIGHT OR WRONG WAY TO WORK TOGETHER TO BRING ABOUT IMPROVEMENT AND CHANGE IN HEALTH AND CARE.</p>  <p>THE APPROACH THAT EACH PARTNERSHIP HAS TAKEN SUITS THEIR MISSION AND LOCAL AREA.</p>	<p>THE PROCESS OF BRINGING ABOUT CHANGE AND WORKING IN PARTNERSHIP IS MESSY BUT IT'S IN THE MESS THAT THE MAGIC HAPPENS.</p> <p>WORKING IN THIS WAY CAN BE EASIER OR HARDER FOR DIFFERENT PEOPLE.</p> 	<p>THERE WILL BE UNEXPECTED OUTCOMES AND BENEFITS.</p>  <p>THESE CAN BE AN IMPORTANT PART OF YOUR LEGACY TOO... SOMETIMES MORE IMPORTANT THAN THE LEGACY YOU EXPECTED.</p>	<p>TAKING THE TIME TO BUILD RELATIONSHIPS IS KEY.</p> 
<p>A LARGE AND IMPORTANT PART OF WHAT THE PARTNERSHIPS DO IS UNDERSTAND OTHER PEOPLE'S PERCEPTIONS AND CHALLENGE... ASSUMPTIONS.</p> 	<p>OUR WORK HAS UNCOVERED CHALLENGES FOR HEALTH AND CARE SERVICES ... BUT ALSO SOLUTIONS.</p> 	<p>"PEOPLE WHO ARE AFFECTED BY A SERVICE ARE BEST PLACED TO HELP DESIGN IT."</p> 	<p>THE ROLE OF A SUPPORTER/ CARER OFTEN MEANS THAT YOU, AS AN INDIVIDUAL, NEED PERMISSION TO SHARE YOUR EXPERIENCE.</p> 
<p>REPRESENTATION MATTERS.</p> 	<p>THE PERSPECTIVE OF HEALTH AND CARE PROFESSIONALS IS EXTREMELY IMPORTANT TOO.</p> 	<p>SOLUTIONS NEED TO SEE YOU AS A WHOLE PERSON.</p> 	<p>THE EVENT WAS AN IMPORTANT REMINDER TO TAKE THE TIME TO PAUSE AND REFLECT ON HOW MUCH WE HAVE ALL ACHIEVED.</p> 

The aim of the Common Ambition programme is to build sustainable change across health care through collaboration between those who use services and those who deliver them.



COMMON AMBITION - THE MORNING



<p>ABOUT THE HEALTH FOUNDATION</p> <p>We are an INDEPENDENT CHARITY committed to bringing about BETTER HEALTH & HEALTHCARE for people in the UK.</p>	<p>ABOUT COMMON AMBITION</p> <p>BELIEVE IN US</p> <p>BRISTOL & HOVE COMMON AMBITION</p> <p>AWARE IBD</p> <p>Evaluator: SQW</p> <p>Funder: RUBISQI</p> <p>Support Partners: National Voices</p>	<p>PURPOSE OF TODAY</p> <ol style="list-style-type: none"> 1 CONNECT 2 CELEBRATE 3 SHARE 4 REFLECT 	<p>GETTING TO KNOW EACH OTHER</p> <p>What have you liked about being part of Common Ambition?</p> <p>I've enjoyed getting to know other people in the partnership.</p> <p>It's great to see people with lived experience at the table.</p> <p>Learning people's experiences has been really enlightening.</p> <p>It's been a big learning curve.</p> <p>The best part is the people.</p>
<p>ABOUT AWARE-IBD</p> <p>Partnership between national and local organisations.</p> <p>Aim: empower people with Crohn's and Colitis to improve their care</p> <p>AWARE IBD</p>	<p>CHALLENGES WE FACED</p> <p>Recruitment of people with lesser heard voices.</p> <p>Phoning and emailing was not working</p> <p>... so we're going into hospitals to talk face to face.</p> <p>NHS pressures and systems.</p>	<p>HOW WE DID IT</p> <p>Microsystem coaching method</p> <p>What matters to you survey</p> <p>Personalised written care plans</p> <p>Now looking at national application</p>	<p>WHAT HAVE WE LEARNT?</p> <p>Patients found it hard to talk to their consultants.</p> <p>Information was hard to find</p> <p>Things need to be accessible.</p> <p>We need to understand additional barriers.</p>
<p>BRIGHTON & HOVE COMMON AMBITION</p> <p>Bring together people with lived experience of homelessness to improve healthcare.</p>	<p>OUR PROCESS</p> <ol style="list-style-type: none"> 1 ENGAGE 2 REVIEW THE SYSTEM 3 DESIGN CHANGE 4 EVALUATE 	<p>WE MAPPED THE PATHWAY FOR PEOPLE WITH EXPERIENCE OF HOMELESSNESS</p> <p>Lived experience front and centre</p> <p>Trauma informed approach</p> <p>People's existing conditions can be exacerbated.</p> <p>Recovery</p>	<p>WE CO-PRODUCED TEN GOALS:</p> <ol style="list-style-type: none"> 1 Create POSITIVE change. 2 Bring the VOICE of lived experience. 3 Encourage collaboration & allyship. 4 Expose the system CHALLENGES. 5 Develop training & share learning. 6 Advocate and CAMPAIGN for change. 7 Encourage adoption & spread to other services/cities. 8 Ensure sustainability. 9 Recognition and understanding of our work and its value. 10 Create & use Common Ambition resources for citywide engagement. <p>Bring people to the room, make the room accessible & their voice can be heard.</p> <p>We almost made the map complicated on purpose to demonstrate peoples' pathways are COMPLICATED.</p> <p>Big changes could be made if the NHS took a more trauma-informed approach.</p>

Here are some of the key things we learned from listening to the other 3 teams that presented at the event



COMMON AMBITION - THE AFTERNOON



<p>OUR AIMS</p> <ul style="list-style-type: none"> ↑ Increase HIV awareness ↓ Reduce HIV stigma ↑ Increase HIV testing ↓ Reduce late diagnosis <p>There are DISPROPORTIONATE rates of STIs and HIV in the communities we serve.</p>	<p>PROJECT DELIVERY</p> <p>Our team comes from the community.</p> <p>We're a bridge between the community and healthcare professionals.</p>	<p>NO community is "hard to reach." You are just not doing the right things to reach them.</p>	<p>WHAT WORKED WELL</p> <p>BARBERSHOPS</p> <p>RESOURCES</p>	<p>CLINICS & TESTING</p> <p>EVENT PRESENCE</p>
<p>OTHER THINGS WE TRIED</p> <p>ROADSHOWS</p> <p>CAB TABLE TALKS</p>	<p>WOMEN'S SPACE</p> <p>MULTIMEDIA</p> <p>Our video and street work increased clinic visits by 400%.</p>	<p>Sometimes it can be by ACCIDENT that you produce your GREATEST piece of work.</p>	<p>BELIEVE IN US: PROJECT TIMELINE</p> <p>April 2021 - June 2023</p> <p>Discover → Define → Develop → Deliver</p> <p>MAKE IT SMOOTH!</p> <p>HAVE FUN</p> <p>BELIEVE IN YOURSELF</p>	
<p>DESIGN JAMS</p> <p>3 THEMES:</p> <ol style="list-style-type: none"> 1 Connection 2 Communication 3 Being heard 	<p>I've enjoyed the activities and they have made me feel more able to... SPEAK OUT</p>	<p>WORKSHOPS</p> <p>We used PICTURES ...and creative activities to help people communicate.</p>	<p>Believe In Us is a genuinely SAFE SPACE Encouraging people to Let go...</p>	<p>We have unlocked something that is UNSTOPPABLE</p>

SUDOKU ACTIVITIES



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	4				9	3		8



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!