AWARE-IBD: Common Ambition Learning Report

AWARE IBD

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Foreword

AWARE-IBD: Putting People with Inflammatory Bowel Disease (IBD) in Control of their Care

As someone living with inflammatory bowel disease (IBD), I am grateful for the opportunity to participate in the AWARE-IBD project, which is funded by The Health Foundation. This project has given me and others with IBD a platform to share our experiences and shape efforts to improve IBD services in the areas most important to us – access, personalised care and communication.

Too often, healthcare decisions are made without involving patients. Through AWARE-IBD, we have demonstrated the value and power of patient leadership in co-designing changes that reflect what really matters to us in IBD care. My fellow patients and I shared deeply personal, but critically important insights on the challenges we face in managing this chronic disease – struggles to access specialists during flare-ups, care that fails to meet our individual needs, and poor communication that leaves us feeling alone. Our voices guided the direction of quality improvement initiatives tested through this project.

I want to extend heartfelt thanks to the charity Crohn's & Colitis UK for providing strategic guidance and enabling AWARE-IBD to have national impact. I also appreciate the true partnership between patients like me and the healthcare professionals, researchers and coaches who worked side-by-side with us as equal partners in this endeavour.

This project showed us that it is possible for healthcare systems to genuinely collaborate with IBD patients to enhance access, personalisation, and communication. I hope the learning and recommendations from AWARE-IBD will inspire and support other IBD centres to work more closely with their patients to drive positive changes focused on what matters most to us. Our goal is for patient-centred care to become the norm for the IBD community. By working together, we can improve experiences and outcomes for everyone touched by this disease.

Vicky Buckley, Sheffield

Patient Oversight Committee (POC) Member

Introduction and background

Crohn's and Colitis are Inflammatory Bowel Diseases (IBD). One in every 123 people have a diagnosis of IBD. They are lifelong conditions, which means people living with IBD will require long-term care. Services can work with patients to understand what "good care" means for them and involve them in service change.

Our goal: To empower people with Crohn's Disease and ulcerative colitis and improve their care based on what mattered most to them.

Living with IBD can be debilitating and significantly impact a person's quality of life and wellbeing (1,2). Symptoms can range from diarrhoea, abdominal pain, rectal bleeding, weight loss, fatigue and joint symptoms. Established models of IBD care are dominated by specialist hospital units that provide long-term therapies, including medications, surgery, outpatient monitoring and counselling.

There has been increasing international attention to quality of care in IBD (3), with a drive to move away from traditional, hospital-based rescue approaches towards more tailored, personalised care (4,5). IBD UK's 2021 National Report identified four key areas for change: improvements in diagnosis and information provision; personalised care and support for self-management; faster access to specialist advice and treatment; and effective multidisciplinary team working (6).

Living well with a long-term illness like IBD requires more than medical management and should draw on patient empowerment and experience to drive quality improvement (7-9). This type of care can only be achieved in partnership with service users (10), participating on equal terms with key stakeholders to develop and implement service changes and evaluate outcomes (11,12).

We brought together people living with Crohn's and Colitis, healthcare professionals and decision makers to co-design and drive changes to the IBD service in Sheffield. Together, we aimed to improve outcomes and experiences of care for professionals, for decision makers and most importantly, people living with IBD in Sheffield. In this report we will summarise the key themes arising from this programme, as well as our learnings, challenges, impact and recommendations for future work.

For people living with IBD, to improve access to and quality of care, especially for those who are poorly served.

For professionals, to equip them to co-produce improvements to health care with service users.

For decision makers, to provide an understanding of how service users can contribute to care improvement.

Key Themes
Patient Leadership

Our aim was to create an even playing field where all participants could contribute equally. We wanted to ensure that the perspectives of those with lived experience, health care professionals, and administrative staff were heard and valued irrespective of their background.

> *"I felt that I was treated equally by the researchers, clinicians and other members although our skill sets were very different."*
>
> Patient Oversight Committee (POC) Member

The Patient Coach

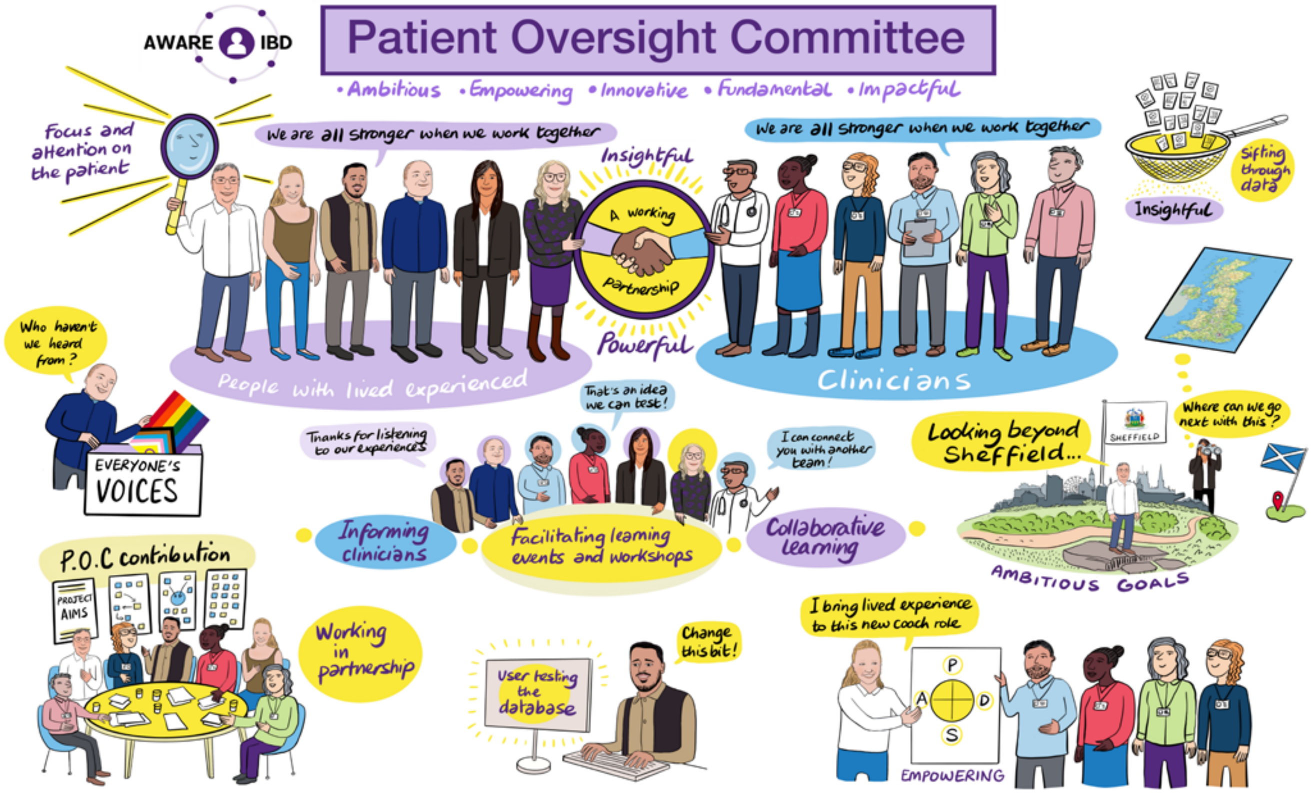
A person living with Crohn's Disease was trained to lead service changes to the Sheffield IBD Service. This is the first time that a patient was appointed to undertake quality improvement training in our established Microsystem Coaching Academy. Sam, our patient coach, led the IBD team and service users in a "microsystem" to co-design and implement change. Using the Microsystems Coaching Academy's approach to quality improvement, Sam worked with the team to identify themes, test changes and make those changes part of everyday practice.

> *"Being able to get patients' thoughts and views on this is so important, because we are the ones using the service, we know what we want and need. Crohn's and colitis affects everyone differently and that's why personalised care is more important than ever, there's no 'one size fits all' solution with us".*
>
> AWARE-IBD Patient Coach

Patient leadership was embedded throughout the project:

1. Patient Oversight Committee (POC):

Two local and three national patients guided and governed the AWARE-IBD project to ensure that the project was ultimately being driven to deliver benefits for people with IBD. Chaired by Crohn's & Colitis UK, the POC ensured that the patient voice remained central to the project. Examples of their impact throughout the project include user-testing of the project database, the design and content of the IBD toolkit and its dissemination to target audiences. They also facilitated engagement with underserved groups including LGBTQIA+ groups and aided in workshop delivery. The POC was also instrumental in shaping the focus of the project during its extension period by prioritising the adoption and spread of the project's key learnings.



University of Sheffield

The Health Foundation

CROHN'S & COLITIS UK

NHS Sheffield Teaching Hospitals

VoiceAbility

"AWARE-IBD = Putting People with inflammatory bowel disease (IBD) in control of their care" or 'this project' is part of the Health Foundation's Common Ambition programme. The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK.

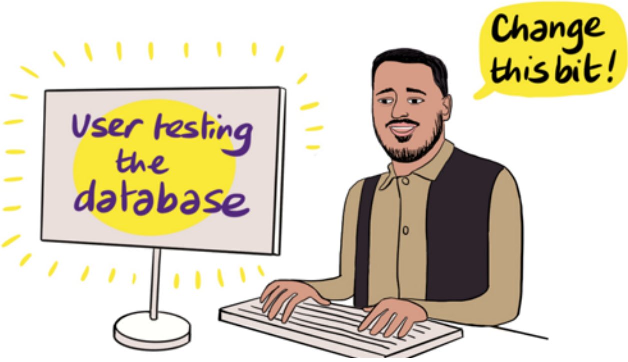
2. Co-design:

We aimed to co-design materials and service changes throughout the programme. Examples are given in the account below, but include:

- **The web application to collect a novel patient reported experience measure (PREM).**
- **The PREM itself.**
- **A personalised care plan.**
- **A toolkit to help people articulate what matters to them in a clinical encounter.**
- **An IBD educational programme.**

3. Microsystem involvement:

In addition to the patient coach, two people living with IBD (RR and SB, lived experience representatives) participated in our weekly meetings on equal standing with the clinical team, to help the group develop and implement co-designed changes. Their lived experience brought a new and different perspective to the forefront of the service and represented a shift in power dynamic between clinicians and patients by putting service users in control of their care.



4. IBD Education programme:

A pilot education programme consisting of eight sessions was implemented. The content and delivery were co-designed and delivered with and by people living with IBD. More detail on this is given within the communication section of this report.

5. Service improvement surveys and workshops:

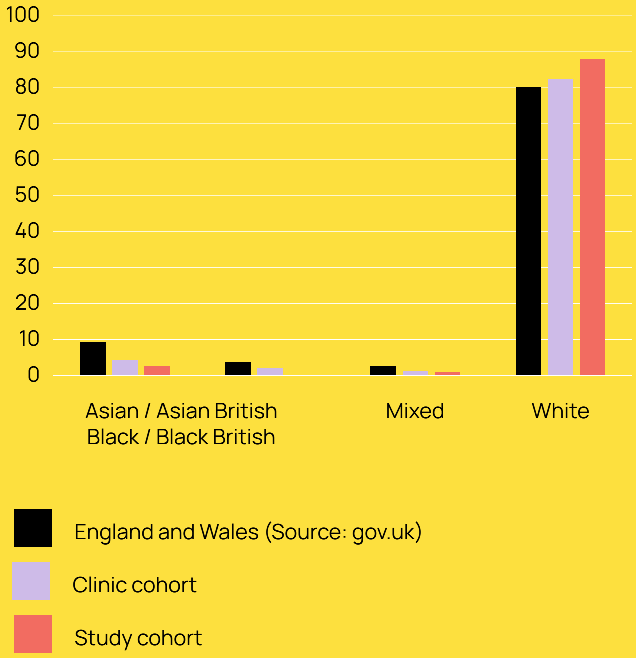
We asked people with IBD to take part in online surveys and workshops to provide ad hoc feedback on co-designed service improvements. This meant that lots of people with IBD could share their skills, experiences and insight to shape the changes.

The Central Question: What Matters to You?

We invited everyone who received IBD care from the Sheffield IBD service to answer the question "What Matters To You?". People living with IBD told us that Access, Communication and Patient-Centred Care matter most to them.

613 people living with IBD in Sheffield completed a "What Matters To You?" survey to tell us about their values and priorities. The three most important domains were: - Access (47.5%); Communication (19.6%) and Patient-Centred care (15.7%).

The graph below shows the ethnic distribution of these participants compared to clinic cohort and national distributions. Our study cohort had an overrepresentation of white patients and an underrepresentation of patients with Asian, black or mixed ethnicity. Subsequently, we tried to address this by targeting underserved communities.



We also asked this question to people from underserved communities:

We reached out to local communities from underserved groups based on deprivation, ethnicity, sexuality and deafness - who might not engage so fully with services - to understand their experiences, values and priorities for service development. We spoke to local community leaders and groups representing communities in Sheffield and South Yorkshire about what mattered most to them and the barriers they faced in accessing healthcare. They described difficulties with service accessibility, language, literacy and patient advocacy, communication (including mental health and stigma), continuity with primary care, staff attitudes and awareness of cultural considerations. These messages highlighted the challenges people face to accessing high quality health care, and have provided targets for quality improvement initiatives both in IBD and wider health services.

Patient-reported experience measure (PREM):

Experience of care is an important measure of a service, but there was no measure to specifically do this for people with IBD. We therefore co-designed a novel measure with an expert group of people living with IBD who led its development and validation (13, 14). People with IBD took part in workshops hosted by epiGenesys, a software development company, to co-design the web application that we used to collect PREM data. We wanted to make sure that it was user friendly for participants taking part in the study.

The PREM became a key outcome measure for the research evaluation and allowed us to formally measure how the service was addressing what was important to patients. This also allowed identification of areas for service improvement and measurement of the impact of service changes on patient experiences and outcomes. Initial statistical validation shows it to be a valid and reliable survey instrument, highlighting the importance of giving patients autonomy in choosing and refining items during survey development.

All patients in the service were invited to complete the PREM (Cohort 1). We reached out to those who did not respond and used more direct approaches for those from ethnic minorities, and the two most deprived deciles of the population to recruit for Cohort 2.

We demonstrated the feasibility of collecting prospective PREM data and other patient-reported outcomes on a quarterly basis using our co-designed web application. This data was used in a research evaluation to measure the impact of the service changes on clinical outcomes.

The experience of people attending the service improved significantly during the two years of the programme - but the measured increase was small.

Patient experience improved significantly overall (increase 0.18 points (0.95 CI 0.12 to 0.23; p<0.001)), across each domain and in both recruitment cohorts.

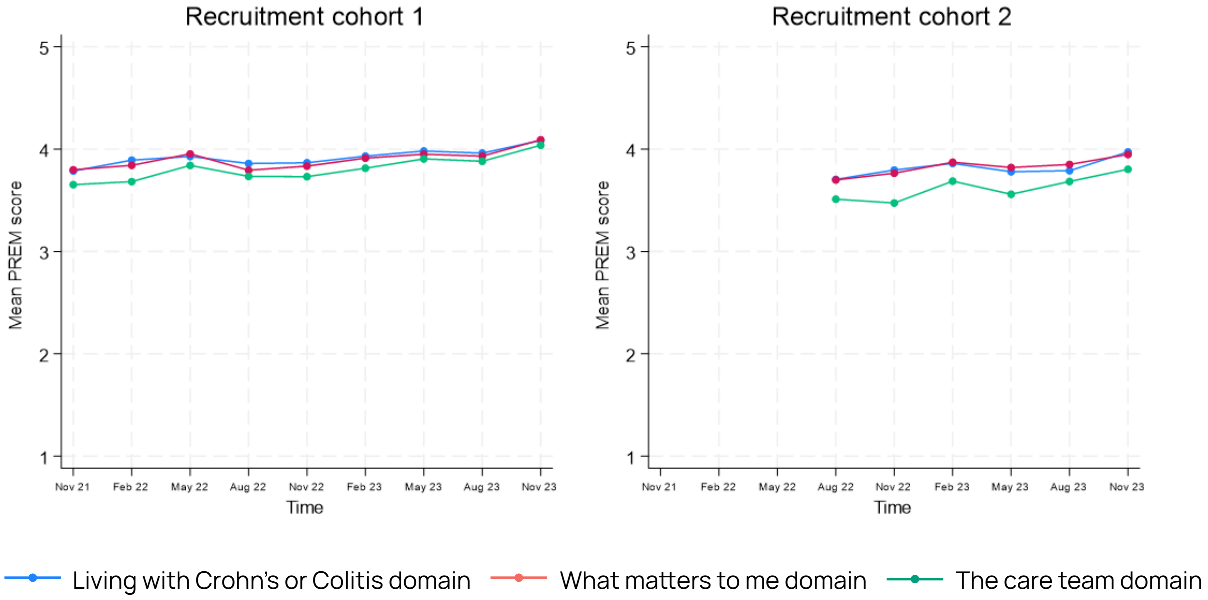


Figure 2: Graphs to show change in mean overall PREM score, and across each domain in both recruitment cohorts throughout duration of study.

Difficulty in showing improvement in PREM due to high baseline.

Distribution of patient experience (n=279)

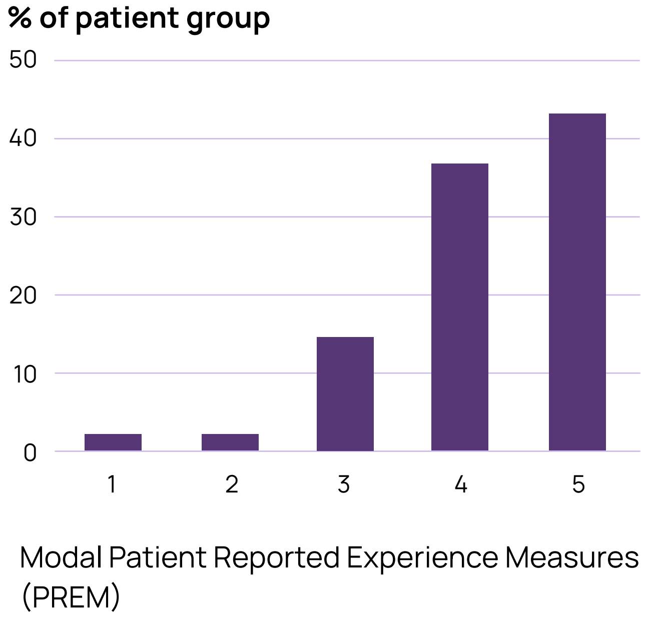


Figure 3: Graph to show distribution of patient experience (PREM scores) within study cohort (n=279).

Figure 3 shows that the distribution of patient experience in our cohort is heavily skewed to higher scores – i.e most people had a better experience. Therefore, given this high baseline, it's harder to show a difference as highlighted by the small improvement in PREM. This may also be a biased sample of people who already had a good experience.

Communication

We aimed to improve communication of information between healthcare professionals and patients. We also helped patients describe “What matters to me?”

1. Co-designed IBD toolkit

The IBD Toolkit helps people with IBD communicate confidently with those involved in their care. It supports people to think about, and build, the skills they need to self-advocate as experts in their own health and wellbeing. To find out more about the IBD Toolkit, you can watch this short video by **clicking here**.

It has been viewed online 685 times, by 370 unique users between 05.06.2023 and 08.02.2024.

Visit **voiceability.org/aware-ibd** to get your copy of our IBD toolkit.

> *“Being part of this project has made me use my appointments more effectively … I am more proactive”*
>
> Local IBD Service User

2. Language and literacy

Members of some communities highlighted the importance of considering language and literacy levels in clinical encounters and the use of interpreters when needed. This applies to communities from ethnic minority groups, as well as service users who are deaf.

The IBD toolkit is available in multiple languages, can be read aloud or viewed in simplified ‘Easy Read’ format (**voiceability.org/aware-ibd**).

A written statement in Arabic, Punjabi, Urdu, Polish, Romanian, Portuguese and Welsh was also included to explain where to find the translated toolkit online, along with a QR code for ease of access.

Community engagement also highlighted the importance of cultural competency and cultivating an awareness of cultural beliefs when communicating with people living with IBD.

3. The Sheffield Personalised Care Plan

A personalised care plan was co-designed with service users following an online survey (n=130) and two online workshops, to support a more personalised approach in clinical encounters (view the template here). Content included IBD history, service contact details, current issues, 'what matters to you' and future plans. This was co-designed with service users The care plan was piloted in clinics and used in 67 consultations. The care plan was well received by both patients and clinicians.

Patients highlighted how the personalised written care plan adds value to an IBD consultation:

> *"It highlighted things that might have been regarded as not important, like minor symptoms that the patients would have initially said it's fine, I feel fine it's a minor thing I've got a bit of discharge, for example. But then when we probe and I say what matters to you they say well actually it matters to me that I don't have to change clothes at work."*
>
> **Healthcare Professional**

> *"it made me ask the difficult questions which I sometimes shy away from so it frames the difficult conversations."*
>
> **Local IBD Service User**

Use of the personalised care plan in a pilot of 67 people attending clinic showed improved experience relating to questions about their knowledge of the care team and this was most evident in the three most deprived population deciles.

However clinicians were concerned about time in clinic to undertake the personalised care plan and explore the issues raised.

> *"I think it's the right step forward, in previous years you turned up to see a doctor, you sat there, you saw them, you come out with a box of tablets, you end up looking at them thinking oh it's three times a day whatever, whereas your mind's just gone blank because he's just told you something from results and you just can't remember it. But for me, if it [the personalised care plan] had come out years ago it would probably have been an absolute dream."*
>
> **Local IBD Service User.**

4. Consulting skills

We ran three workshops for members of the clinical team to help develop a common approach to consultation across disciplines.

5. An IBD Education Programme

An IBD Education Programme was co-designed by a small working group of clinicians and IBD service users - led by one of the service users - to address 'Communication'. An online survey (n=104 respondents) was used to collect patient feedback on priority topics for the education sessions and determine the format for delivery.

Eight face-to-face education sessions were delivered at local venues by members of the IBD team and a patient representative. Topics included: What is IBD and how does it affect me physically?; Care and treatment options in IBD; Worry and anxiety in IBD; Fatigue and pacing in IBD; Diet and nutrition in IBD; Self-management in IBD; Employment; and Benefits and Finances.

These sessions were aimed at service users and their family/carers to access information about their condition and care in a supportive environment. Sessions were well received and attendees appreciated the opportunity to share their experiences with other people living with IBD, as well as feeling more informed on their condition and treatment options.

> *"We can ask some of these questions now that we've become more informed as a result of those sessions. Which we have, they were very informative."*
>
> **Local IBD Service User**

> *"it made me ask the difficult questions which I sometimes shy away from so it frames the difficult conversations."*
>
> **Local IBD Service User**

Access

We trialled changes to the IBD service to improve access to the service.

We looked at whether being in remission affected service user experience as measured by the PREM. We found that PREMs completed during a spell of active disease were associated with worse experience.

We also looked at whether being overdue for clinic appointments affected service user experience as measured by the PREM (Table 1). We found that PREMs completed during a spell of active disease (n=175 patients, PREMs=536) being overdue for a clinic appointment was associated with a significantly lower PREM score (i.e. a worse experience), a mean difference of -0.10 (p=0.004, 95% CI:-0.16 to -0.03). However, for PREMs competed in remission (n=137 patients, PREMs 429) being overdue for an appointment was not associated with a significantly different PREM score (mean difference is -0.02 (p=0.528, 95% CI: -0.10 to 0.05)) (Figure 4).

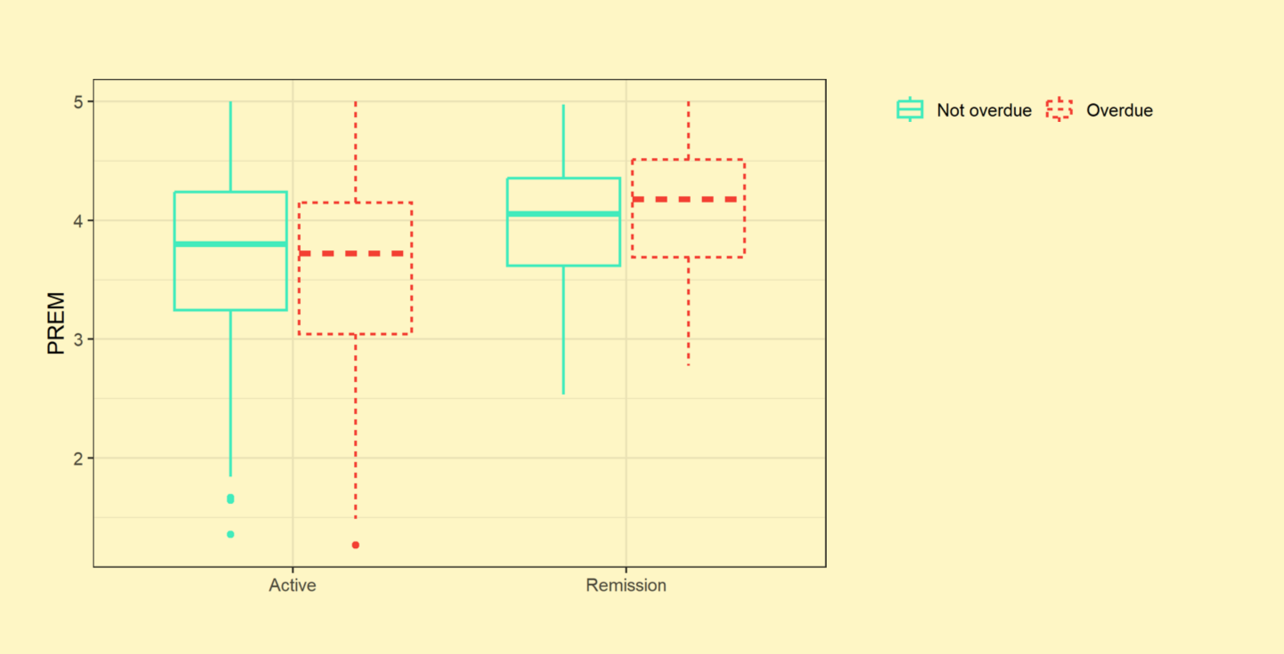


Figure 4: Box plots of Patient Reported Experience Measure (PREM) scores by disease status (active / remission) and appointment status (overdue/ not overdue). Boxes represent the median, upper and lower quartile. Whiskers and dots represent minimum and maximum values, with dots used for values more than 1.5x the interquartile range below the lower quartile.

Table 1: Patient Reported Experience Measure (PREM) scores by group. Matched PREM where score has been matched to a clinic attendance.

	All (n=1894)	Matched PREM (n=1251)	Clinic appointment overdue (n=466)	Clinic appointment not overdue (n=785)
n	1766	1251	466	785
Mean (SD)	3.84 (0.68)	3.79 (0.69)	3.78 (0.74)	3.80 (0.66)
Median (IQR)	3.93 (3.44, 4.33)	3.91 (3.38, 4.29)	3.78 (0.74)	3.80 (0.66)
Min, Max	1.24, 5	1.24, 5	1.27, 5	1.24, 5

1. Nurse led clinic

A clinic led by IBD Nurse Specialists was trialled for patients attending the Clinical Investigations Unit for biologic treatment as part of their IBD care. Patients who were due a three-monthly clinical review were seen by an IBD nurse in conjunction with their treatment appointment.

2. Rapid access clinic

A consultant rapid access clinic was established for three particular groups of patients, which the microsystem had identified an important need for:

(a) Newly diagnosed.

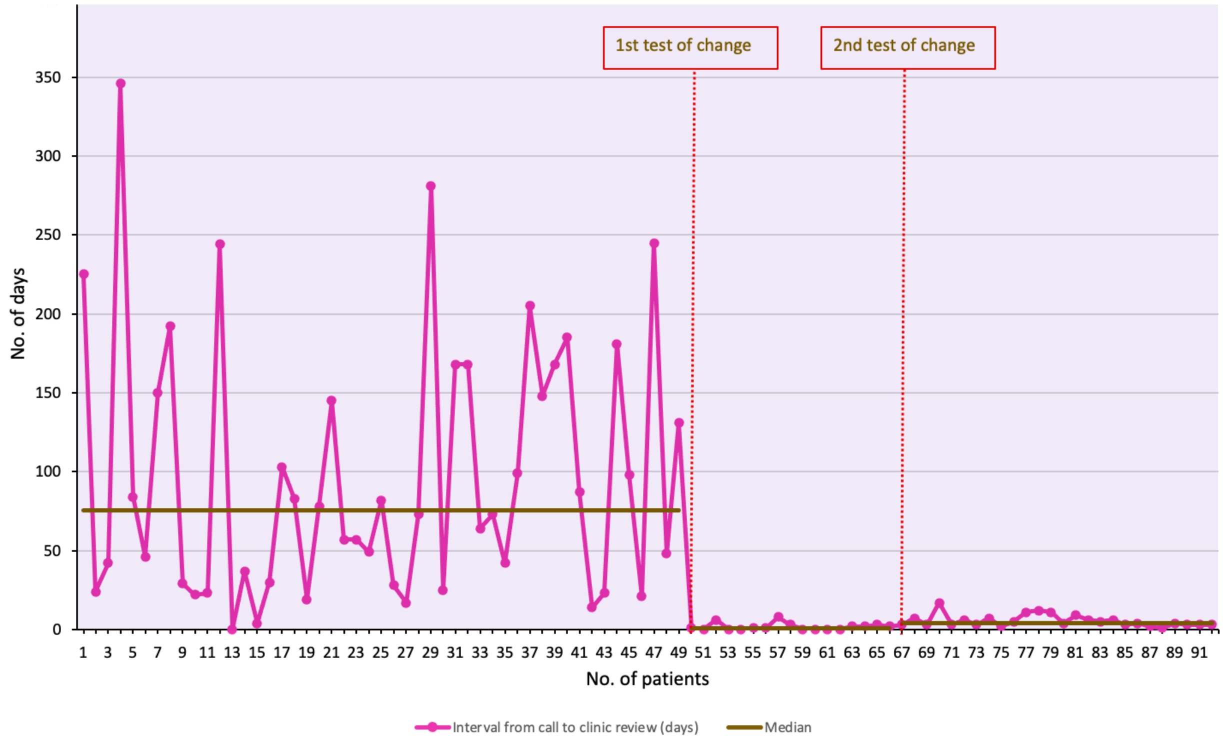
(b) Starting or changing a biologic treatment.

(c) Urgent clinical review needed for flare symptoms following a call to the helpline.

Patients seen in consultant priority clinics were seen more rapidly and with a reduced variation in interval to be seen. For example, for those with suspected flare there was a reduced time to be seen (median baseline 76 days; 1st test of change median 1 day; 2nd test of change median 2 days) and a markedly reduced variation (Figure 5). However, important caveats include available clinic capacity and the need for nurses staffing the helpline to prioritise some calls and initiate treatment for others directly from the helpline. Time to initiate treatment was not reduced, possibly due to this prioritisation and multiple steps to treatment that were not addressed simply by arranging a clinic appointment e.g. infusion room availability, patient pre-treatment screening and patient availability.

Access

Figure 5. Chart to show change in interval (days) from helpline call to clinic review for those seen in special clinics during AWARE-IBD programme.



In semi-structured interviews, benefits and limitations reported by staff and service users were:

- Rapid access to detailed discussion with specialists.
- Reduced pressure when dealing with calls to the helpline because an urgent appointment was available.
- Nurses staffing the helpline still felt a need to manage the available capacity by making a judgement about specialist appointment allocation rather than being managed on the telephone.

> *"Knowing that I can talk to someone on the same day, I think that made me less stressed that you know if things go wrong or if you have a flare up in the future, I think you know you have that reassurance that if it needs to happen, it will happen faster."*
>
> **Local IBD Service User**

> *"It was the only way that it could happen at that level of speed."*
>
> **Local IBD Service User**

> *"It's about managing patients in a timely manner and preventing complications and preventing possible admissions... It's timely interventions to reduce patient morbidity"*
>
> **Healthcare Professional**

What's Needed For Personalised Care?

Throughout the project we have placed focus on:

- **Patient Leadership**
- **What Matters to you?**
- **Communication**
- **Access**

This has helped us to develop the personalised care that service users also highlighted as their priority. We have addressed personalisation in a number of ways.

1. Personalised Care Plan

A personalised care plan template was co-designed by service users and piloted in patient consultations to enable more patient-centred appointments. By starting consultations from the patient perspective on what matters most to them, the care plan facilitated difficult but important conversations and revealed issues impacting patients' lives, leading to more tailored and meaningful interactions.

2. IBD Toolkit

The IBD Toolkit empowers patients to advocate for their health by facilitating communication with care providers. By encouraging self-reflection on needed skills and providing tailored support, it promotes patient-centred IBD management.

3. Education Sessions

The education sessions were co-designed by clinicians and patients based on survey feedback to cover topics addressing the needs and priorities of the local IBD community. Attendees valued not only receiving medical information from professionals but also having the opportunity to share personal experiences and have their individual perspectives and questions incorporated into the sessions.

Challenges

Our ethos was to build and support collaborative partnership working with IBD patients. However, we faced a number of challenges during the initial set-up phase and the delivery phase of the project.

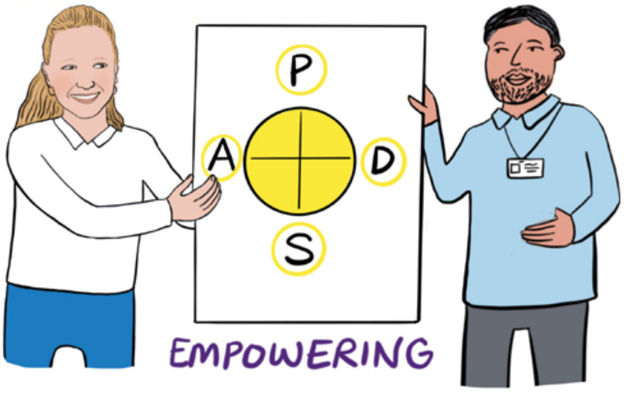
Introducing the 'patient coach' role

We experienced challenges in establishing the patient coach role in an NHS Trust with no precedent to which the AWARE-IBD team and supporting Departments such as Human Resources (HR) could refer. The main challenge was to create a novel job description and person specification that met NHS Agenda for Change (AfC) requirements. The post needed approval by several faculties before the post could be advertised and recruited to.

These processes led to significant delays that put pressure on the team to shortlist, interview and recruit the patient coach in time for the MCA training cohort. Identifying the right people in HR and having earlier conversations would have helped avoid or reduce some of the delays.

Acceptance of service change

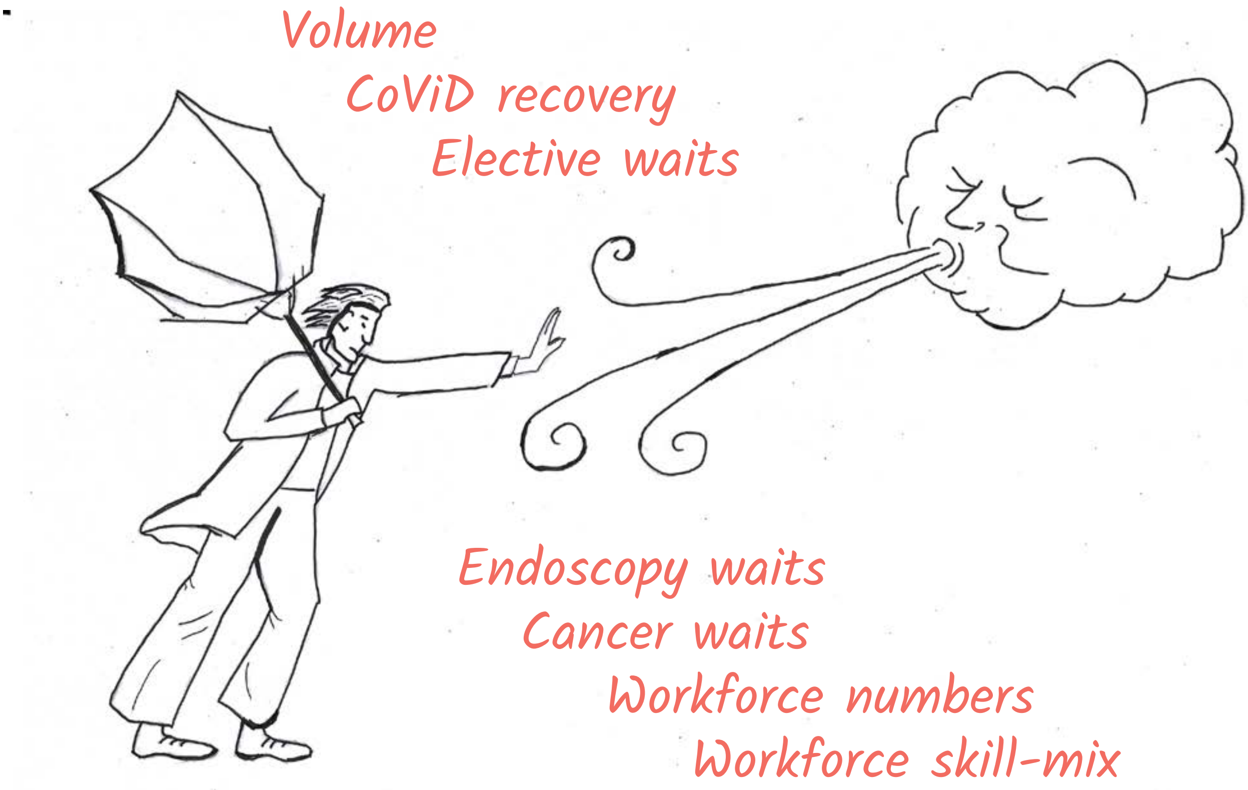
Service changes may not always feel like an improvement to everyone. Some staff value what it offers to care management, whereas others may perceive it as unnecessary extra steps and work in an overloaded system. Service change that doesn't make 'the job' easier, when staff are already facing unprecedented pressures on their time and workloads, is difficult. There may also be differing priorities between different groups. Post COVID-19 recovery in the NHS has required specific focus. This may be for example, on procedures and not on long term conditions. Even within IBD care there may be a requirement to deliver volume rather than qualitative improvements with benefits that are more difficult to measure or may be seen in the longer term. Processes for implementing service changes should fit with existing capacity in order to sustain longer-term engagement in a clinical setting.



Undertaking quality improvement

In a stretched and stressed system - and despite the best of intentions at all levels of organisations - capacity for quality improvement can be hard to find. This includes time for discussion, planning and data collection in defined meetings and in between those meetings. Data collection to demonstrate impact was challenging for clinical, managerial and clerical teams with other competing priorities.

Current NHS IT systems are designed to do things to patients, they are not designed to do with. Different formats on the electronic patient medical record system are not sufficiently streamlined to speed up the transfer of knowledge between patients and healthcare professionals, and there are delays and cost issues with printing and posting. The process for implementing service changes such as the personalised written care plan are therefore dependent on the effort of key individuals rather than operating reliably within a system that is fit for purpose.



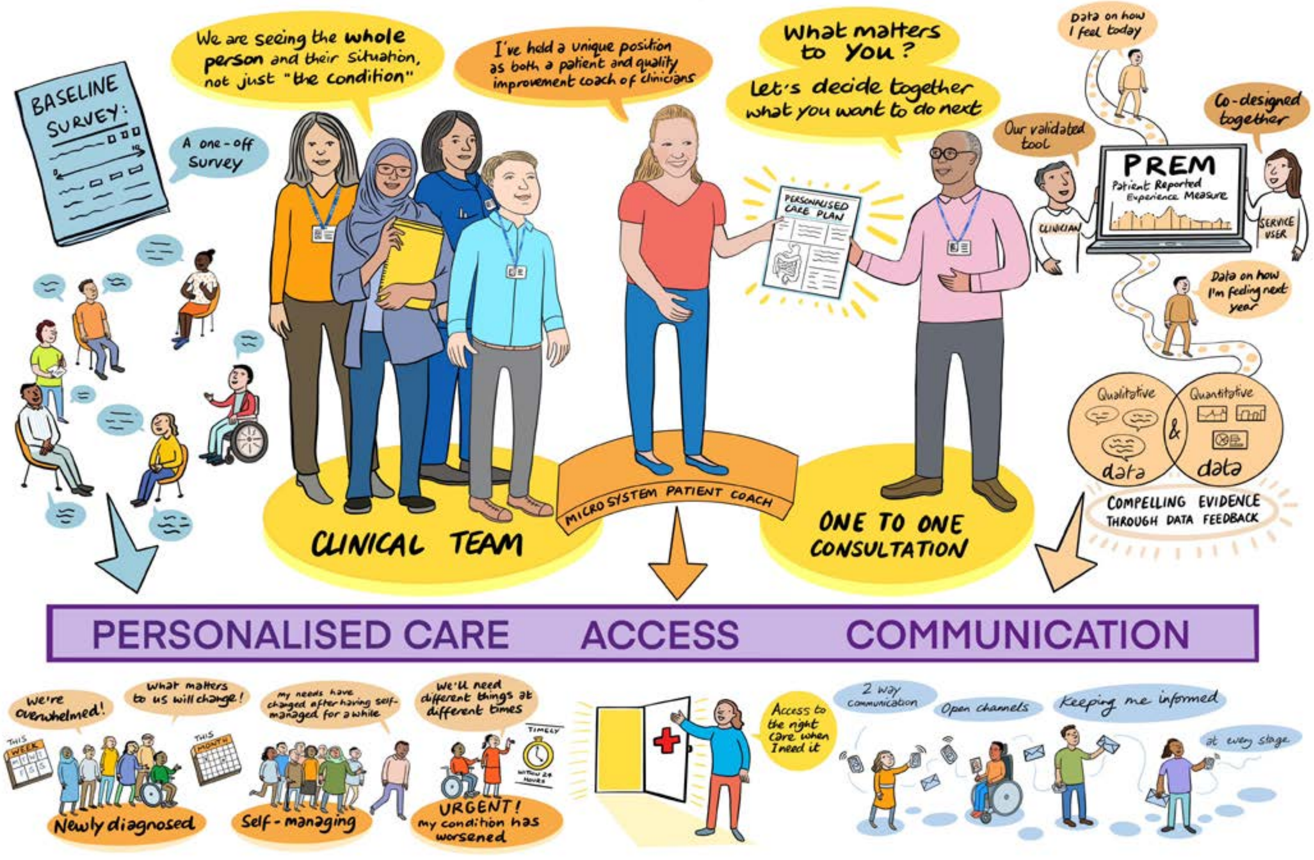
What Have We Learnt?

Our key learnings from this project include the importance of positioning patients as improvement leaders, working in partnership with local community groups and ensuring service changes reflect the priorities of service users.

1) What Matters To You?

A key learning of this project was the importance of focusing on what was important to service users. Our "What Matters To You?" survey was completed by people living with IBD to tell us about their values and priorities. We also spoke to local community leaders and groups in Sheffield about what mattered most to them and the barriers people face to accessing healthcare. The main themes concerned personalisation, access and communication. We prioritised these aspects of patient experience when making service changes.

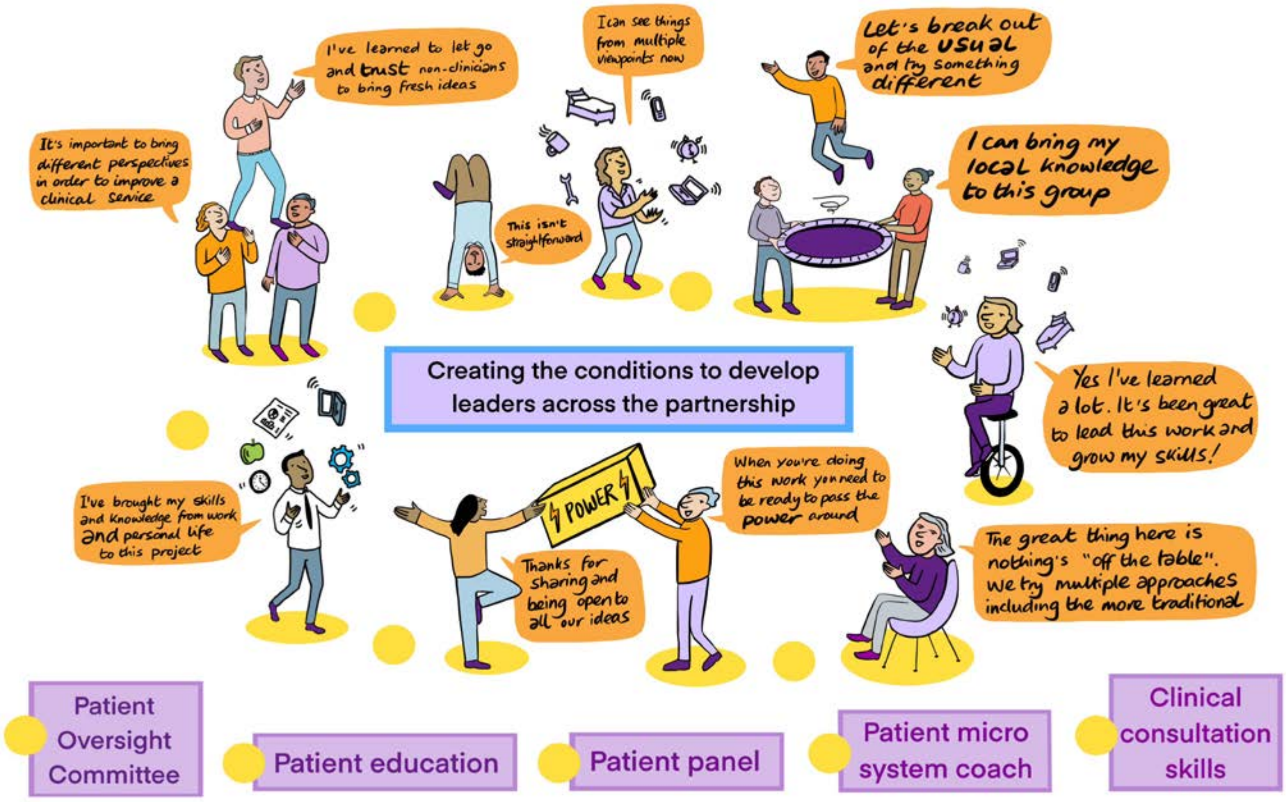
Experience is an important reflection of service delivery. A new, co-designed, specific IBD PREM allows its measurement and comparison of experience over time and across centres.



What Have We Learnt?

2) Patient leadership (Improvement Leaders);

Patients were at the centre of the project from start to end by leading from different places/positions. Our patient oversight committee was made up of both local and national patients, and they played a crucial role in steering the focus of the project to ensure benefit to patients. Our education sessions were designed and led with patient input, including determining the focus/format of the sessions. A patient panel was set up during the project to give patients a forum in which they can voice their views and support improvements to the delivery of the IBD service through collaborative working with the IBD clinical team. Our patient coach led the IBD team and service users in a "microsystem" to co-design and implement change. Sharing power and working in partnership with patients, led to more creative working and changes that best benefited patients. Furthermore, utilising different backgrounds and points of view allowed for fresh perspectives and innovative ideas. This was particularly pertinent for underserved local community groups, from which learnings fed directly into the quality improvement programme to allow prioritisation of changes to the IBD service and to identify opportunities for further collaboration.



What Have We Learnt?

3) Partnership Working is essential; Reaching out

A key highlight has been working together as a partnership across Crohn's & Colitis UK, Sheffield Teaching Hospitals NHS Trust, The University of Sheffield, epiGenesys, VoiceAbility and people living with and affected by Crohn's and Colitis. Without the strength of this partnership, AWARE-IBD would not have been possible. Furthermore, engaging with people from a range of communities and backgrounds is imperative for ensuring that service improvements in IBD are accessible, relevant and representative of patient needs and values. By reaching out and working with local community groups we found several barriers experienced by underserved groups in healthcare access and utilisation. These included service accessibility, language, literacy, advocacy, being dismissed, lack of continuity, mental health, social support and safe spaces. Where possible, these barriers acted as a lever to co-producing service changes that are responsive to the health and social care needs of these groups. Our approach to meaningful engagement with underserved communities provides a pilot process for future research and quality improvement programmes. Centres planning patient and public involvement (PPI) activity in underserved communities should give consideration to: seeking initial advice from communities and their leaders; venue choice; language, literacy and use of interpreters; adopting a flexible approach and using existing events if available; evolving based on experience; respect for community values and building lasting relationships by providing feedback on the impact of their engagement.

Impact

Our ethos has been to build and support collaborative partnership working with patients, families and carers for their benefit.

Over the last three years, we are proud to have delivered a patient-led IBD quality improvement programme and a patient-led research evaluation.

We put the patient voice at the centre of the programme and embedded a culture of what matters to patients in an IBD service.

During the three-year funding period, we have:

1. Shown that participation in an extensive quality improvement programme was associated with significantly improved patient experience over a 2 year follow-up.
2. Established a Patient Oversight Committee who have provided direction and governance to the AWARE-IBD partnership.
3. Achieved patient leadership and involvement in the redesign of an IBD service.
4. Built meaningful, genuine and collaborative relationships with underserved local community groups and lesser heard voices in the IBD service.
5. Trialled four novel co-designed service changes that prioritised what matters to people with IBD.
6. Co-designed, published and validated a patient-reported experience measure (PREM) which we used to collect prospective, longitudinal patient-reported data, via a co-designed patient app, to evaluate the impact of service changes on patient outcomes and experience.
7. Co-designed a novel toolkit to support people with IBD to better communicate with professionals in the service [voiceability.org/aware-ibd], which is available in EasyRead and multiple translations.
8. Co-designed, trialled and undertaken initial evaluation of a novel personalised care plan which would allow centres to implement this in practice in line with the IBD Standards (IBD UK, 2019). This improved experience relating to the relationship to the care team with greatest impact in those from the most deprived deciles.

Impact

9. Established a Patient Panel for the IBD service who will support the service in the planning and implementation of this work in the future.

10. Embedded a culture of quality improvement in an IBD service, prioritising what matters to people living with the condition. This has included creating a one hour slot each week for the IBD Team in Sheffield to meet and discuss quality improvement initiatives and programmes of work.

We have demonstrated the feasibility of this approach and shown the benefit of combining ways of engagement to gather rich information, valued by those using the service. A patient who helped to co-design the IBD Toolkit said that:

> ***"Just being part of this project has made me use my appointments more effectively as I am more proactive. I am now a better patient. Before, if I was feeling rubbish, I'd be a bit feeble, but now I am taking more control"***
>
> **Local IBD Service User**

Our Recommendations

Patient-led and structured quality improvement processes, supported by prospective data collection, should be incorporated into IBD service delivery.

IBD services are a complex adaptive system with a dynamic interplay of capacity, demand, staffing, expertise, need for continuity, local and national priorities leading to marked variation in access. This variation can be reduced and qualitative improvements delivered but require detailed 'buy-in' from managerial staff, clerical and clinical teams to address conflicting priorities.

Our top 5 recommendations for inclusion in future protocols guiding quality improvement programmes for IBD care are:

1. Service changes in IBD must be led by patient priorities and co-designed by people with lived experience. Patient leadership should be welcomed in quality improvement forums and patient panels.

2. Services should aim to understand what matters to people with IBD and ensure personalised care, good communication and access to the service.
3. Patient experience can be measured and embedded in IBD services.

4. Listening to underserved patient groups should be undertaken in a meaningful way that acknowledges their needs, preferences and values and addresses barriers to engagement
5. Form a partnership with relevant stakeholders with a shared goal to improve IBD services. This should include primary and secondary care services, community organisations, academic groups and third sector organisations.

Next Steps

A key priority for Sheffield Teaching Hospitals will be to build on our pilot experience and lead discussions on how to embed quality improvement processes as sustainable and scalable parts of the service. This includes the service changes that were trialled as part of the AWARE-IBD Project, and any new change ideas that target priorities for underserved patient communities.

The project team has identified three key audiences to focus on the spread of key messages. These are managers/policy makers, clinicians and service users.

The project team plans to use targeted messaging tailored to each of these audiences in order to ensure effective spread of the programme. Crohn's & Colitis UK as lead for the project will use and integrate the learning from AWARE-IBD into their quality improvement plans and partnerships. On top of this, Crohn's & Colitis UK chair and provide the secretariat to IBD UK, a partnership of 17 patient and professional organisations. IBD UK aims to provide support and best practice sharing to enable quality improvement across the UK and a key driver for this will be the IBD UK benchmarking surveys in 2023. Findings from the surveys will be used to support quality improvement efforts across IBD centres nationally, with the AWARE-IBD Project providing an example of how this could be done.

References

1. Irvine EJ. Patients' fears and unmet needs in inflammatory bowel disease. Aliment Pharmacol Ther [Internet]. 2004 Oct;20:54–9. Available from: https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2036.2004.02053.x

2. Knowles SR, Graff LA, Wilding H, Hewitt C, Keefer L, Mikocka-Walus A. Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses—Part I. Inflamm Bowel Dis [Internet]. 2018 Mar 19;24(4):742–51. Available from: https://academic.oup.com/ibdjournal/article/24/4/742/4944346

3. Mikocka▒Walus A, Massuger W, Knowles SR, Moore GT, Buckton S, Connell W, et al. Quality of care in inflammatory bowel disease: actual health service experiences fall short of the standards. Intern Med J [Internet]. 2020 Oct 27;50(10):1216–25. Available from: https://onlinelibrary.wiley.com/doi/10.1111/imj.14683

4. Dulai PS, Singh S, Ohno-Machado L, Sandborn WJ. Population Health Management for Inflammatory Bowel Disease. Gastroenterology [Internet]. 2018 Jan;154(1):37–45. Available from: https://linkinghub.elsevier.com/retrieve/pii/S0016508517363370

5. Fiorino G, Lytras T, Younge L, Fidalgo C, Coenen S, Chaparro M, et al. Quality of Care Standards in Inflammatory Bowel Diseases: a European Crohn's and Colitis Organisation [ECCO] Position Paper. J Crohn's {\&} colitis [Internet]. 2020;14(8):1037–48. Available from: http://ovidsp.ovid.com/ovidweb.

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