Cross-Party Group on Inflammatory Bowel Disease (IBD)

17 September 2025, 6-8pm

Minutes

Present

MSPs

Pauline McNeill MSP Convenor (PMcN)
Carol Mochan MSP

Invited guests

Nicola Treanor-Robertson (NTR)
Dr Shannon Connolly (SC)
Dr Anna Clancy
Elizabeth-Ann Hamilton (Staff)
Emer O'Rourke

Non-MSP Group Members

Phoebe Sheppard (PS)
Thomas Preece (TP)
Vikki Garrick (VG)
Dr Amy Bednarz (AB)
Angus Holden (AH)
Edmund Murray (EM)
Dr Harvey Humphrey
Kirsty Gibson
Lis Bardell (LB)
Katherine Keay

Observers

Heather Margaret Rankine
Lucy Macnair
June Brodie
Caroline Brocklehurst
Sophie Semple
Dr Chris Hewitt (CH)
Angus Crawford
Angela Kidd (AK)
Dr Shahida Din (SD)
Iona Kellett
Dr Eleanor Watson

Apologies

Dame Jackie Baillie MSP
Liam McArthur MSP
Allan Boal
Professor Richard Russell
Seth Squires
Rob Gowans
Allan Faulds
Lorna Kirstin May
Daisy Parsons
Dr Jane Burnett
Mairead Keegan
Pauline Bell
Robert Boulton-Jones
Conor Cronin
Dr Johnathan MacDonald
Siobhan Ross
Dr Ian Arnott
Gillian Richardson

Agenda item 1

Welcome and Apologies

PMcN welcomed everyone to the meeting

Agenda item 2

Minutes of meeting 11th June 2025

The Minutes from the meeting 11th June 2025 were approved.

Agenda item 3

Matters Arising

There were no matters arising.

Agenda item 4

Election of Office Bearers

Convenor: Pauline McNeill MSP APPROVED

Vice Convenor: Clare Adamson MSP APPROVED

Secretary: Phoebe Sheppard, Crohn's & Colitis UK APPROVED

PMcN explained that there will be no nomination of a Treasurer as Crohn's and Colitis UK are providing administrative support and will not collect a subscription.

Agenda item 5

CPG Annual Return & Work Plan

PMcN thanked everyone who has indicated that they wish to remain formally as members of the CPG.

PMcN invited anyone who wishes their name to be added to the Annual Return as a member to let Phoebe know by Monday 22nd September.

PMcN mentioned that a Work Plan for the next year's meetings will be drafted over the next few months and will be shared at the next meeting in December for input.
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Agenda item 6

Psychological Care in IBD, Dr Shannon Connolly, Clinical Psychologist, Paediatric Psychology & Liaison Service (PPALS), Royal Hospital for Children and Young People, Edinburgh

SC shared that what she wants to cover today is why we need specialist psychological care for people with IBD, why can't we just go to generalised adult services/CAMHs services, how effective is it, the reality of this work on the ground, and a summary and any questions.

Why Specialist Psychological Care Is Needed

SC explained that all illnesses are biopsychosocial, meaning they have biological, psychological, and social components.

SC emphasised that IBD has a particularly strong brain-gut connection, where mental health affects disease progression and vice versa. **SC** stated that this makes accessible psychological care essential.

Child & Young Person (CYP) Services
SC highlighted a 2024 study (Cooney et al.) showing CYP with IBD (aged 5–25) are significantly more likely to experience PTSD, eating disorders, depression, sleep issues, self-harm, and other mental health conditions.

SC shared that NHS Lothian received 51 IBD referrals between 2018–2022, representing 28% of all GI referrals.

SC noted common referral reasons include anxiety, pain management, low mood, procedural anxiety, eating difficulties, and parental support.

Adult Services
SC explained that adult IBD services in Scotland lack regular psychological support within MDTs.

SC cited evidence showing:

- IBD carries a significant psychosocial burden
- Increased prevalence of anxiety and depression in adults
- Depression/anxiety increases risk of surgery and relapse

SC stressed the importance of specialist psychologists in adult services.

SC added that most IBD diagnoses occur between ages 15–30, a vulnerable life stage.

SC noted the lack of transition pathways from paediatric to adult psychological services, leading to disengagement risks.

Service Model
SC described the service as offering formulation-based care, helping individuals understand their difficulties and plan tailored interventions.

- assistant psychologists provide guided self-help strategies.
- non-directive therapies (e.g. art/play therapy) are available for younger children.
- monthly psychosocial MDT meetings take place to discuss cases collaboratively.

SC shared that each service uses the funding they have for GI differently. NHS Grampian don't see some GI conditions, so have a greater emphasis on IBD. As a result, every young person who has a new diagnosis can meet their psychologist if they would like to, which really helps to normalise the role of psychologists.

Effectiveness of Therapies

SC stated that more evidence exists for adults than CYP due to research focus.
- newer CBT approaches (acceptance and commitment therapy, compassion focused therapy) are particularly effective.
- improvements in quality of life and reductions in anxiety/depression have been reported following therapy (outside active flare).

SC acknowledged that more research is needed but current findings are promising.

Reality on the Ground
SC reported increasing waiting times, with most patients now likely to wait for a year. **SC** shared that this not only impacts patients but takes an emotional toll on clinicians.

SC shared that within NHS Lothian, they have seen 40% increase in paediatric GI referrals from 2018–2022, affecting wait times for IBD patients.

SC reiterated the lack of adult psychology services during transition.

SC mentioned a bottom-up approach via the Paediatric Gastro Psychology SIG to develop guidelines, starting with service evaluations across the UK.

Case Example
SC described a case involving an 11–13-year-old with a complex IBD course and fear of NG tube placement.

SC responded to an urgent MDT referral and supported the patient on the ward during the procedure.

SC used CBT to address fear of sickness and eating difficulties and continued work on coping with symptoms and social challenges.

SC reported a successful outcome, attributing it to MDT integration and flexible, formulation-driven care.

SC emphasised that this type of work relies on being embedded in the MDT and available across settings, something that is not easily captured in protocols.

Reflections & summary

SC noted that Inflammatory Bowel Disease (IBD) has a bidirectional relationship with mental health: IBD impacts mental health, and mental health in turn affects the course of IBD.

SC emphasised that there is a significant and growing demand for IBD psychology services within paediatric care. However, there are currently no adult IBD psychology services available in Scotland, creating a gap in transitional support for young people moving into adult services.

SC highlighted that other chronic and complex conditions such as Cystic Fibrosis (CF), diabetes, and oncology receive substantially more funding and service provision. While historical factors may explain this disparity, **SC** emphasised that IBD is similarly complex and warrants equivalent psychological input.

SC also raised the economic case for embedding psychologists in IBD services, citing the impact on employment and healthcare utilisation.

SC expressed hope that progress will be made in addressing these service gaps.

Questions & discussion

Economic Impact of IBD and Mental Health

- **EM** asked whether the economic impact of IBD flares and associated mental health issues has ever been quantified, particularly in terms of lifetime costs and potential savings.
- **SC** responded that no such data is currently known but agreed it would be valuable to evidence the cost-effectiveness of integrating psychology into IBD services. She highlighted the clear link between flares and mental health, which affects work, relationships, and caregiving.
- **SD** noted that Crohn's & Colitis UK has shown that the health economic impact for people experiencing flares is three times higher than for those without. However, existing research only focuses on financial implications without capturing wider quality of life impacts. Further work is underway and expected later this year.
- **CH** referenced a 2018 retrospective study of 35 IBD patients, which found that depression increased annual healthcare costs by approximately $18,000 USD per patient, a figure likely higher today. This could have significant implications when scaled to the Scottish IBD population.

Patient Experience and Treatment Access

- **AB**, a long-term patient, shared personal experiences of anxiety linked to treatment cycles and fatigue. She noted that CBT was challenging due to tiredness and lack of IBD-specific support. She advocated for earlier access to biologics and better treatment options, acknowledging that not all approaches work for everyone but emphasising the importance of trying.

Paediatric vs Adult Services

- **SD** highlighted the stark contrast between paediatric and adult IBD services.
- **PMcN** asked whether paediatric patients seen by **SC** were typically surgical cases.
- **SC** clarified that while some young people are referred for surgery, most cases involve procedural anxiety, low mood, and adjustment issues, especially around exams and embarrassment.

Education and School Support

- **LB** raised concerns about school-aged children with IBD and the need for improved understanding and support within schools.
- **PMcN** confirmed a previous commitment from the Education Minister to write to schools but acknowledged that follow-up has been lacking. Suggested adding this to the workplan to ensure accountability and impact assessment.
- **LB** reflected on the importance of integrated working and learning from failures, suggesting schools should be proactive in identifying and supporting children with IBD.
- **PMcN** confirmed agreement to include in the workplan a proposal to ask those responsible for the education system to remind schools that children with IBD may be present in classrooms, emphasising the importance of awareness and support within educational settings.

Agenda item 7

The Catherine McEwan Foundation Mental Health Service for people living with IBD, Vikki Garrick, Director of Patient Services and Advanced Clinical Practitioner IBD, The Catherine McEwan Foundation & Nicola, Lived Experience Representative

Introduction

VG opened by explaining the background of the Catherine McEwan Foundation.

- Catherine McEwan was the mother of Derek, the Foundation's CEO. She passed away at age 37 due to complications from IBD. Derek was 16 at the time.
- Derek founded the charity in her memory and to support others affected by IBD.

VG shared her experience as a former NHS nurse consultant.

- Highlighted the dominance of the biomedical model in IBD care.
- Emphasised the Foundation's focus on non-clinical aspects of life: work, holidays, social events, and education.

Services Provided

VG outlined the Foundation's key services:

- Adult Mental Health Service
- Young Person's Mental Health Service (currently in pilot phase with 4 patients)
- Benefits Advice Service
- Wellness Programme
- Scholarship Programme – supports young people struggling to remain in education due to IBD
- Coaching Programme

Person-Centred Approach
VG stressed the Foundation's commitment to person-centred care.
- Services are designed around individual stories and lived experiences.
- Mental health support has significantly improved clients' self-esteem and motivation.

Mental health service statistics
VG reported:
- The service launched in September 2021.
- 161 individuals supported to date.
- Rolling caseload of approx. 30 clients per month.
- Average of 5 new referrals per month (approx. 1.5 per week).
- Gender ratio: approximately 2:1 female to male.

VG described the service model:
- Easy access via online enquiry form.
- Initial face-to-face review followed by telephone/video support.
- Many clients require only 1–2 sessions to feel supported and regain confidence.

VG highlighted the importance of lived experience in service delivery.
- Therapist Avril has a son with IBD and offers empathetic support.
- Clients value speaking to someone who understands their condition without needing to explain extensively.

VG confirmed that all discharged clients are evaluated.
- Feedback consistently shows increased resilience and self-belief among service users.

Nicola's story
Introduction
- **NTR** introduced herself as a 37-year-old living with Ulcerative Colitis, who has worked as a civil servant for 18 years.
- Diagnosed with Ulcerative Colitis at age 18 after years of misdiagnosis, with symptoms dating back to age 9.
- In sixth-year her school attendance dropped to 50% due to illness and lack of diagnosis.

Impact of IBD
NTR described the significant physical and mental toll of IBD:
- Extensive self-research post-diagnosis.
- Multiple medications with severe side effects.
- Chronic fatigue, joint pain, inflammation, and urgency.
- Urgency led to severe embarrassment and anxiety, affecting travel and social life.

- Life activities became ‘military operations’ highly planned around toilet access.
- Public transport and long-distance outings became mentally challenging.
- Missed key family events and made difficult career decisions.
- Workplace adjustments required disclosure of sensitive personal health information.
- Stopped team sports and avoided gyms and social visits due to fear and embarrassment.

Mental health struggles

NTR shared her experience of long-term mental health challenges:

- Suffered in silence for years, not wanting to burden loved ones.
- Mental health deteriorated even during IBD remission.
- Felt defeated and was close to taking sick leave from work.
- Reached breaking point and was referred to the Catherine McEwan Foundation by her IBD nurse.

Support from the Catherine McEwan Foundation

NTR contacted the Foundation on 19 January and was seen four weeks later by nurse therapist Avril.

- Described the support as **life-changing**:
    - Felt heard and understood without judgment.
    - Diagnosed with high-functioning anxiety and received tools to manage it.
    - Gained confidence and ability to enjoy life without constant fear.
    - Recently returned from a holiday to LA where she was able to fully participate in activities for the first time.
    - Support positively impacted her, her partner, and her family.

Reflections

NTR expressed deep gratitude and passion for the Foundation’s work.

- Emphasised the importance of making this incredible service more accessible to others with IBD.
- Shared that she now looks to the future with positivity and excitement.
- Highlighted the importance of being able to enjoy everyday life again.

Closing Remarks

NTR concluded by thanking attendees and reinforcing the value of the Catherine McEwan Foundation’s support.

PMcN responded:

- Thanked Nicola for her powerful and inspiring testimony.
- Highlighted the importance of hearing patient stories and the value of the Foundation’s open-door policy.
- Encouraged wider awareness of the service for those who may benefit.

Agenda item 8

The Importance of Nutritional Support for IBD, Angela Kidd, Gastroenterology Specialist Dietician, Western General Hospital, Edinburgh

Overview of Dietitians’ Role in IBD

The role of dieticians

AK explained that dietitians are qualified and regulated experts in maintaining nutritional status across all stages of IBD: active disease, remission, and pre/post-surgery.

They provide advice on:

- Diet and supplements
- Enteral and parenteral nutrition when absorption is compromised
- Managing IBD-related symptoms through diet to improve quality of life

AK noted growing evidence supporting diet as a tool for preventing and treating IBD and explained that dietitians are recognised as integral members of the Multidisciplinary Team (MDT) by key organisations.

Malnutrition and Sarcopenia

AK highlighted that treating malnutrition is a significant part of the dietitian's role.

- Up to 85% of people with IBD may be malnourished.
- Malnutrition can occur even in overweight individuals due to muscle and micronutrient depletion.

AK explained that consequences of malnutrition include:

- Physical and functional decline
- Poorer clinical outcomes (e.g. infections, wound healing, post-op complications)
- Increased healthcare use
- Reduced quality of life
- Higher morbidity and mortality

The 2023 IBD UK patient survey showed <10% of patients were assessed for malnutrition on hospital admission across Scotland and the UK.

Nutritional Screening

AK advocated for robust and regular nutritional screening for all IBD patients.

- Screening should occur at diagnosis and regularly thereafter.
- The MUST tool is widely used but relies heavily on weight.
- Common IBD-related eating patterns that increase risk include:
    - Skipping meals
    - Continuous eating
    - Eating at inappropriate times
    - Extreme restriction
    - Poor variety and knowledge of intake
    - Fussy or disordered eating

AK emphasised the need for tools beyond weight-based assessments (BDA, 2022).

Nutritional Assessment

AK stated that all IBD patients in remission should receive dietetic counselling (ESPEN 2019 – 100% agreement).

On referral, dietitians conduct comprehensive assessments including:

- Weight history and anthropometric data
- Clinical picture
- Eating habits and beliefs
- Micronutrient levels (e.g. folic acid, B12, iron, zinc)
- Estimated nutritional requirements
- Development of realistic dietary plans with follow-up

Pre-operative Optimisation

AK stressed the importance of nutritional optimisation before surgery.

- Many Crohn's patients require surgery; dietitians should be involved early.
- 30–40% of patients were not nutritionally assessed pre-op in two reports.

Dietetic Resources

AK referenced IBD Standards recommending 1 WTE dietitian per 250,000 population.

- Only 13% of Scottish IBD services met this standard (IBD UK, 2023).
- Only two Health Boards have dedicated IBD dietetic funding (0.3 and 0.1 WTE).
- Just 7% of services reported having sufficient dietetic staffing.
- 65% of Scottish IBD patients reported lack of access to specialist dietetic advice.

Consequences:

- Diet not considered for many patients
- Prioritisation of only the sickest/malnourished patients
- Missed opportunities for personalised care
- Reinforced need for full resourcing of IBD teams, including dietitians

Evidence for Dietary Interventions

AK noted increasing interest in dietary interventions to induce or maintain remission.

- Exclusive Enteral Nutrition (EEN) is gaining traction, especially in adults.
- EEN is a restrictive liquid diet (6–8 weeks, 5–10 supplements/day) used to rest the gut and promote healing.
- Benefits include reduced need for steroids, biologics, surgery, and hospital admissions.
- Drop-out rate for EEN in adults is 40–45% without dietitian support.
- Current audit underway across 3 Scottish Health Boards to develop a national pathway.
- EEN can be used up to 4 weeks pre-surgery to reduce complications.
- Referrals increased significantly during 2018–2021 (COVID period) at WGH, highlighting need for resourcing.

Opportunities for Dietitians in IBD

AK highlighted key areas where dietitians can support IBD patients:

- Nearly 40% of IBD patients also have IBS, compared to 5–15% in the general population.
- The low FODMAP diet is effective for persistent GI symptoms, with up to 80% success when supported by a dietitian.
- Around 20% of IBD patients may develop eating disorders over time.
- Patients are often exposed to misinformation online, leading to restrictive diets and long-term nutritional depletion.

Vision for Future Dietetic Services

AK outlined priorities for a future-focused dietetic service:

- Use of specific IBD screening tools to identify at-risk patients.
- A patient-centred, accessible, evidence-based service with long-term support.
- Nutritional care throughout the IBD journey, including pre/post-surgery.
- Support for self-management and diet therapies to prevent/manage flares.
- Collaborative MDT working and training for other health professionals.
- Emphasis on focused nutritional research in IBD.
- With these elements in place, the goal is improved quality of life for patients and cost savings for the healthcare system.

Discussion

Reflections on Dietetic Services

PMcN thanked **AK** for the presentation and shared personal reflections:

- Noted that diet and nutrition have not been widely discussed by the group before.
- Shared experience of niece with UC who is seriously underweight, with malnutrition not addressed.
- Expressed dissatisfaction with current dietetic services, describing them as too general.
- Highlighted the importance of assessing nutrient intake and the influence of fad diets, particularly the current focus on protein.

AK explained:

- Dietitians often cover all of GI, making it difficult to isolate IBD-specific care.
- Acute dietetic teams are stretched across multiple areas.
- Ringfenced funding for IBD nutrition would be beneficial.

AK added:

- Agreed protein is important, but emphasised the need to assess a range of nutrients including iron, calcium, and vitamin D.
- Stressed that nutritional concerns are not limited to low weight but affect a broad spectrum of patients.

Observations on Mental Health and Diet

EM shared:

- In virtual social events, diet is a frequent topic.
- Fear of food triggers leads to restrictive diets and increased risk of malnutrition.
- Noted cases of anorexia and the need for integrated support from dietitians and psychology teams.

AK added:

- Common to see patients cutting out foods and following increasingly restrictive diets.
- Emphasised the importance of regaining confidence to enjoy food again, especially after interventions like FODMAP or EEN.

Personal Experience with Liquid Diets

AH shared:

- Lifelong UC sufferer; underwent a liquid diet in 2017 during a severe flare.
- Managed 6 out of 10 weeks before experiencing psychological distress.
- Felt his body was warning him to resume solid food intake.
- Stressed the need for close monitoring of patients on liquid diets.

AK agreed:

- Liquid diets are difficult to follow and even harder to transition off.
- Strong support and monitoring are essential.

PMcN concluded:

- Reflected on how psychological responses to diet can be powerful, even if not medically harmful.
- Thanked **AH** for sharing his experience.
- **PMcN** suggested:
    - Including dietetic support in the group's work programme.
    - Writing to ministers to address the lack of consistency, noting only two Health Boards have dedicated IBD dietetic funding.

Agenda item 9

BSG and Lower GI Pathway Pilot Update, Dr Shahida Din, Chair of the BSG IBD Committee & Consultant Gastroenterologist, Western General Hospital, Edinburgh

Primary care diagnostic pathway for lower gastrointestinal symptoms in adults: pilot study

Diagnostic Delays and Lower GI Pathway
SD highlighted ongoing concerns around delays in diagnosis for patients with lower GI symptoms, noting the long-term impact on care and outcomes.

- The Lower GI Pathway is now finalised and available on the *WhatsUpWithMyGut* webpage.
- Crohn's & Colitis UK secured over $500,000 from the Helmsley Charitable Trust to support implementation.
- Roundtables were held across the four nations to explore community-level adoption, enabling primary care teams to refer patients to secondary care with appropriate testing and timely triage.

Pilot Sites for Implementation
SD announced that NHS Lothian and Portadown (NI) were selected as pilot sites for the pathway implementation.

- Funding has been awarded for a 12-month implementation plan.
- Emphasis on collaboration with primary care teams to co-design responsive services for patients.

OPTIMISE-IBD Project

SD introduced the **OPTIMISE-IBD** initiative: *Outcomes and Performance Targets to Improve Management and Integration of Services for Equity in UK IBD Care*.

- The project aims to:
    - Measure diagnostic and treatment timelines
    - Track steroid exposure over 12 months
    - Monitor safety checks prior to treatment initiation

- **BSG** has awarded funding for a pilot study across 10–12 UK sites to test audit data collection and drive service improvements.
- Proposed site distribution: 2 in Scotland, 1 in NI, 1 in Wales, remainder in England.
- **SD** invited Scottish sites to express interest when the call is released.

Contact Information
- For queries or expressions of interest: IBD@bsg.org.uk
- Project leads:
    - Dr Christian Sellinger
    - Dr Shahida Din (BSG IBD Section Chair)
    - Mrs Nikki Husband (BSG Head of Projects)
    - Dr Bettina Kluettgens (BSG Project Support)

IBD-Endoscopy Access
SD acknowledged collaboration with **PS** in requesting information from the Scottish Government regarding endoscopy access.

- Parliamentary questions and motions have helped raise the issue on the political agenda.

- SD is working with NHS England on the *Getting It Right First Time (GIRFT)* initiative, focusing on:
    - Non-cancer urgent endoscopy access
    - Early exposure to IBD endoscopy training

- Collaboration with the BSG Endoscopy Committee has led to the development of a competency framework aimed at improving patient outcomes.

Closing Remarks

- **PMcN** thanked **SD** for the presentation and ongoing work, noting its critical role in advancing care for IBD patients.
- **PMcN** suggested continuing work on motions such as **Faecal Calprotectin (FCP)** to highlight the importance of early diagnosis.
- Reaffirmed the earlier agreement to **engage schools** to support young people with IBD.

Agenda item 10

Actions and next steps, Pauline McNeill MSP

Workplan and Group Membership
PS reminded members to send any suggestions for the upcoming workplan via email over the next few months.

Members who wish to remain part of the group should confirm by Monday 22nd September via email.

PS asked if there was any other business to raise.

Future Meetings and Political Engagement

PMcN emphasised the importance of targeting NHS priorities to make progress.

- Proposed that December will be the final meeting of the group in this Parliament due to the upcoming elections.
- Encouraged strong attendance and a well-structured agenda for the December meeting.
- Highlighted the value of in-person participation, noting today's good balance of online and physical attendees.
- Confirmed that work on the group's workplan will continue in the meantime.
- Urged members to submit parliamentary questions to raise the profile of IBD.
- Stressed the importance of educating future Ministers on IBD as a major health issue.
- Expressed gratitude to all speakers for their contributions and reaffirmed the importance of continued political pressure.

Closing Remarks

- **PMcN** thanked attendees and expressed hope to see everyone at the December meeting.