Cross-Party Group on Inflammatory Bowel Disease (IBD)

11 December 2024, 6-8pm

Minutes

Present

MSPs

Pauline McNeill MSP Convenor (PMcN)
Colin Smyth MSP (CS)
Dame Jackie Baillie MSP (JB)

Invited guests

Marianne Radcliffe (MR)

Thomas Preece (TP)

Dr Shahida Din (SD)

Mareta Greig (MG)

Dr Jane Burnett (JB)

Katherine Keay (KK)

Elizabeth Hamilton

Non-MSP Group Members

Phoebe Sheppard (PS)

CNS Seth Squires

Prof Richard Russell (RR)

Dr Amy Bednarz

Angus Holden (AH)

Cher-Antonia Khedim

Edmund Murray

Dr Harvey Humphrey

Kirsty Gibson

Lis Bardell (LB)

Siobhon Ross

CNS Vikki Garrick

Observers

Lorna Kirstin May

Daisy parsons

Lucy Macnair

June Brodie

Caroline Brocklehurst (CB)

Dr Eleanor Watson

Dr Jacqueline Patterson

Dr Robert Boulton-Jones

Dr Santosh Salunke

CNS Fiona McCluskey

Heather Rankine

Apologies

Clare Adamson MSP

Liam McArthur MSP

Brian Whittle MSP

Michelle Thomson MSP

Sharon Dowey MSP

Foysol Choudhury MBE MSP

Humza Yousaf MSP

Edward Mountain MSP

Dr Ian Arnott

CNS Pauline Bell

CNS Allan Boal

Angus McLean

Nancy Greig

Rob Gowans

Moira Macdonald

Angela Kidd

Dr Jen Veryan

Dr Zahra Bayaty

Audrey Wild Smith

Agenda item 1

Welcome and Apologies

PMcN welcomed everyone to the meeting

Agenda item 2

Minutes of meeting 18th September 2024 - PMcN

The Minutes from the meeting 18th September 2024 were approved.

Agenda item 3

Matters Arising - PMcN

Following on from the previous meeting of the CPG, we have written to Health Board CEOs across Scotland about the use of Faecal Calprotectin tests and how they are using the IBD UK Local Reports to improve IBD services. We will keep the group posted on any responses we receive.

Agenda item 4

IBD UK report: Overview: Marianne Radcliffe, CEO of Crohn’s & Colitis UK, and Chair of IBD UK

PMcN introduced Marianne Radcliffe (MR), who is the CEO of Crohn’s & Colitis UK and Chair of IBD UK.

MR: As CEO of Crohn’s & Colitis UK and Chair of IBD UK, I’m proud to be part of both organisations, which have worked tirelessly to bring this report to life.

This report would not have been possible without the collaborative efforts of our partners, and it’s great to see so many representatives of these organisations in the room today.

Together, we’ve combined clinical expertise, research insights, and the patient voice to create a report that is both comprehensive and actionable.

But let me be clear: our work doesn’t stop here. These partnerships remind us of the power of collaboration. By uniting charities, clinicians, policymakers, and other stakeholders, we can address the systemic issues in IBD care and create meaningful change for patients across the UK and Scotland.

17,003 adults, 651 children, and two thirds of UK services submitted responses to patient and service surveys. We are not aware of any IBD surveys of this magnitude – this benchmarking offers world-beating size and depth of detail.

Individual reports with service results are already available publicly. A detailed report is available to each service, and the national report was launch last week, and we are here today to launch the Scottish specific report, with detailed findings and tailored policy recommendations to drive change in IBD care across Scotland.

To benchmark the current state of care against the IBD standards, a UK-wide IBD Patient Survey and Service Self-Assessment were carried out in 2023, completed by 1,500 adults with IBD and 18 adult IBD services, respectively, in Scotland. This data was taken into account within the IBD UK UK-wide report and the Scottish responses have been used to form a new nation-specific IBD UK Report launched today, *Crohn’s and Colitis Care in Scotland: A Vision for Change.*

While we acknowledge the progress made in raising awareness of Crohn’s and Colitis in recent years, the stark reality is that care for people living with IBD in the UK has not improved since 2019. **No IBD service currently meets the IBD Standards for care or staffing.**

This is a sobering statement, and it should make us pause.

Simply put, too many patients face significant delays and barriers in all aspects of their care.

To provide an overall assessment of IBD care, patients were asked how they would rate the quality of their care over the past 12 months. Over a third of adults rated their care as ‘fair’ or ‘poor’—a higher proportion than in the last survey in 2019.

Agenda item 5

MR introduced Dr Shahida Din (SD), Chair of the BSG IBD Committee.

The IBD Standards

SD: The IBD Standards were introduced in 2019 and are a framework to define what should be in place to deliver high-quality healthcare for people with IBD. They specify what high-quality care should look like at every point of the patient journey and how IBD services need to be organised. They intend to encourage IBD services to recognise what they are doing well and identify where they need to improve. The latest version was launched in 2019, with 50 specific recommendations along the patient care pathway.

Quality of Care

SD: Although various quality improvement initiatives have been introduced in Scotland, including 'The Endoscopy and Urology Diagnostic Recovery and Renewal Plan' and the 'National Blueprint', when asked how they would rate the quality of their care over the past 12 months, **approximately 1 in 3 people (33%) who responded to the IBD Patient Survey selected fair or poor.** This reflects results from across the benchmarking exercise, which indicate that people with IBD in Scotland are not receiving high-quality care they require. This compromises the physical health, emotional wellbeing, quality of life and financial security of people with IBD, whilst also contributing to greater financial pressures on NHS Scotland.

Diagnosis findings

SD: Diagnosis is too frequently made at a time of crisis, a crisis which could have been easily prevented with earlier diagnosis. Early diagnosis is critical for managing IBD effectively and preventing complications, but patients are waiting months to be seen by a specialist or to undergo crucial diagnostic tests.

In Scotland:

- Almost 4 in 5 (77%) reported waiting longer than four weeks after experiencing symptoms to see a healthcare professional, and almost 3 in 10 (29%) waited over a year.
- Delays to diagnosis also occur in primary care. Over 3 in 5 (65%) people reported waiting more than four weeks between their first primary care consultation to being referred to hospital, and 1 in 6 (16%) waited over a year. Reasons for these delays include appointment waiting times, delays to completing investigative tests, a lack of access to key diagnostic tools (like faecal calprotectin tests) in primary care and the changing nature of IBD symptoms.
- Only around 2 in 5 (44%) agreed that their GP is knowledgeable about the conditions, suggesting that guidance, education and awareness in primary care are key issues that must be addressed to support primary care professionals to identify and prioritise people with IBD.
- Even after referral, many continue to experience significant delays, with around 1 in 5 (22%) people waiting over 6 months between being referred and receiving a diagnosis.

These delays throughout the diagnosis process risk disease progression and emergency presentations, which worsen outcomes for people with IBD and are costly for NHS Scotland.

Diagnosis recommendations

SD: Recommendations for action include:

- The 'National Primary Care Diagnostic Pathway for lower GI Symptoms' should be implemented across all Health Boards in Scotland, to support primary care professionals to make appropriate, timely referrals for tests.

I was fortunate to co-chair this pathway and enlisting practitioners to give us an idea of what an ideal pathway should look like. We are hoping that this will be implemented across the nations and can share that in Scotland we are a bit ahead of the curve than everywhere else.

- High-profile public health campaigns to raise awareness of the seriousness of IBD and its symptoms, such as the Crohn's & Colitis UK initiative 'Cut the Crap' and the Scottish IBD 'awareness campaign', should be a priority for the Scottish Government to invest in, with support from dedicated experts and a focus on tackling inequalities in diagnosis.

Treatment findings

SD: Treatments for people with IBD aim to induce and maintain disease remission, prevent complications and restore a normal quality of life. Flares (a period of relapse) occur in the majority of people with IBD and, if left untreated, can lead to life-threatening complications, emergency surgery and a deterioration of mental health.

The results from the surveys suggest that treatment is sub optimal and that primary care teams are also under pressure and feel like they cannot provide the support that patients need.

One of the services that has transformed everything we do is the IBD nurse advice line. Often patients find it easier to speak to nurses about what they are going through than speaking to their doctor.

Waiting times for surgery are a huge concern for us – patients often have to wait months on a waiting list and risk ending up unwell and malnourished.

- Almost 3 in 5 (57%) people reported experiencing a flare in the last 12 months, with more than 1 in 10 (13%) reporting more than 5 flares in the last year
- 1 in 5 (20%) IBD services and 3 in 5 (58%) people with IBD reported that patients do not have access to a review by the IBD team within 5 working days and are not started on a treatment plan within 48 hours of review during a flare

Treatment recommendations

SD: Recommendations for action include

- Increased support and resources must be allocated to essential IBD advice line services, to ensure responses during a flare can be received by the end of the next working day. Reviews during a flare should be conducted within five working days and treatment initiation or escalation within 48 hours of this review.
- Waiting times for surgery must be reduced to less than 18 weeks, to improve outcomes for people with IBD and reduce avoidable presentations at Accident & Emergency (A&E) departments.

Personalised care findings

SD: Personalised care is a coordinated approach that addresses the complex interaction between physical symptoms, mental health, nutritional needs, and social factors, and should be a guiding principle when providing care to people living with IBD.

Up to half of people with IBD experience extraintestinal manifestations and yet only 1 in 3 (36%) people reported being asked about conditions beyond their gut, suggesting a narrow clinical focus that risks missing people's broader needs.

Living with IBD can also severely impact a person's mental health. Across the board we have issues with access to psychology services. Only half (53%) of Scottish IBD services agreed that people with IBD are routinely asked about their mental health and no service reported having a policy in place for investigating and treating people with IBD who are also struggling with their mental health. As a result, only 1 in 5 (20%) people agreed they were asked about their mental health and given treatment options to manage it. We also need to promote the fact that mental health issues are a natural response to having the condition, to normalise seeking help.

Finally, the findings illustrated that people living with IBD are not able to access vital specialist advice and support on diet and nutrition. Over 3 in 5 (65%) people did not agree that they have access to such advice and support, placing them at increased risk of malnutrition.

This represents a missed opportunity to provide personalised care.

Personalised care recommendations

SD: Recommendations for action include

- Mental health and nutritional support should be integrated throughout the IBD services and adequately resourced. Alongside this support, referral and signposting to mental health services and the promotion of self-management apps should be prioritised.
- IBD services should be supported to utilise technology, such as secure messaging platforms, to enhance collaboration with primary care colleagues, and ensure consistent and coordinated care for people with IBD.

Workforce findings

SD: Adequate staffing of the IBD multidisciplinary team is essential to deliver high-quality care. **However, no IBD services in Scotland met the IBD Standards for whole time equivalent staffing across the team**

- No IBD service met the IBD standards for psychologists
- Only around 1 in 10 (13%) services met staffing requirements for dieticians

Workforce recommendations

SD: Recommendations for action include

- All IBD services should be supported so that multidisciplinary teams meet the IBD Standards for staffing, ensuring that staff are available and have the capacity to deliver high-quality care.
- The number of IBD nurse specialists should be increased and opportunities for their development should be ensured, such as Master's level qualifications.

Agenda item 6

One of our stories – Mareta’s IBD journey

MG explained that her story started 24 years ago when she was 13 and started to experience symptoms, believing it was a stomach bug. She was late to school every day because of symptoms and her parents believed she was being bullied. This continued until she was 21, when she was eventually diagnosed with UC. MG shared that at the time she believed she would simply get medication and then be completely fine.

From 21-30 her condition was managed with different interventions such as steroids and immunosuppressants.

MG expressed gratitude that she had an IBD nurse specialist who knew everything about her. In 2017 her condition worsened, and things took a dramatic turn. She had to visit A&E and ended up in hospital for 2 months. Even whilst in hospital, her IBD nurse was her first port of call, and she contacted her when she noticed that within 5 minutes her pyjamas were saturated in sweat. Instead of ringing the alarm bell, she emailed her IBD nurse who responded within 17 minutes. Her bowel was perforating at that point, and she didn’t know. She had to go in for emergency surgery and her family were advised that she probably wouldn’t survive. Luckily the operation went well, and she was fitted with a stoma.

MG explained that despite the success of the surgery, it took a massive toll on all aspects of her life. She had to learn how to walk again, lost all her hair and had to wear a wig, which is not what you expect to experience at just 30 years old.

MG emphasised that since then, the service provided has gotten worse and the same access to IBD nurses isn’t afforded to everyone. Other patients aren’t so lucky and have to repeatedly present at A&E because they can’t contact an IBD nurse for advice and support.

MG spoke about the issue of personalised care, explaining that she has only seen a dietician once in the 7 years she has had a stoma. She has had to work out herself what she can and can’t eat.

MG explained that in 2019 she tried to have a stoma reversal but that failed, and she ended up with sepsis. She again tried to have it reversed last year but that also failed, and she now has a permanent stoma. She struggled last year as a result, and it took a toll on her and her family.

MG reiterated that it’s important that people are aware of the wider picture. She shared that her surgical team are fantastic, but they don’t time to answer emails and respond quickly, such as when she needed an iron infusion.

MG shared that she was only offered psychological support once when she spent a long time in the hospital in 2019. Other than that, her employer has had to offer counselling, which should not be the case.

MG shared with the room that she is now very happy and lucky to have travelled the world, but this is for all those who haven’t been as lucky, and for all those in the room who have a voice to make change.

TP thanks both speakers MG and SD and asks the meeting if there are any questions before moving onto the 2025 Workplan.

PMcN commented that it is heartbreaking to hear MG's story, but her contribution tonight is so valuable to people in the room and others living with the condition. **PMcN** also commented that MGs story highlights how far we still must go in improving care for those living with IBD.

LS asked whether there's any process we could take to make specific recommendations for example how we can progress adopting a multi-agency approach. LS explained that her son was diagnosed with UC in his 20s and is now 38. He got respite and access to several other support services not specific to IBD through his trade union. He said that if he could keep one thing it would be counselling and has spoken about the difficulty of coming to terms with having the conditions and its impact on his aspirations, children and partner. **LS** commented that these are practical elements of IBD that could be supported through funding / agency contributions to IBD care.

MG responded highlighting the importance of holistic care, explaining that she has had to navigate nutrition herself due to not having access to a dietician. **MG** also stated she needed a physiotherapist post-surgery. Moreover, her employer had to send her for counselling, and she had to pay for her own wig when her hair fell out following treatment. **MG** also emphasised that there are other factors to consider such as egg freezing. After requesting this she was refused.

MG also emphasised that once you are discharged it feels like you are left on your own, and the stigma surrounding the condition and having a stoma bag is not spoken about.

PMcN asked whether we can get a picture across Scotland of access to IBD nurses.

TP explained that inside this report and the local service reports we can see the entire makeup of the IBD team, however not every service in Scotland completed the survey. Some do well and others not so well, psychologists are an area that is particularly lacking.

PMcN emphasised that it is important that MSPs keep writing to their health boards specifically on behalf of the group to monitor this, as they are more likely to receive a response.

CS commented on the fact that the report illustrates a postcode lottery of care and expressed interest in scrutinising that more closely, especially looking at discrepancies between urban and rural areas. **CS** emphasised the importance of tabling a number of questions surrounding the report and explained success he has had doing so for other CPGs.

TP commented that we will continue to encourage the tabling of parliamentary questions and are not just influencing policy makers but are talking to clinicians. Crohn's & Colitis UK have sent the report to all MSPs and shared embargoed versions with the Chief Medical and Chief Nursing Officers.

SS commented that Mareta's story very much reflects the data of the report presented by Shahida. **SS** asked **SD** if there are units that are doing better than other units and if this is the case, can we learn valuable lessons from these units that can be implemented in units not providing the same standard of care. **SS** also asked if this is a resource issue and if the necessary resources were made available, would change be made in the standard of care?

SS asked an additional question to the meeting generally in particular to **PMcN** and **CS**, what can the representatives of this group, Parliament and policymakers do to bring about change at a grassroot level. **SS** adds that he would be happy in his role as a CMO Speciality Advisor to link the group with the CMO Office.

SD commented that we need to look at how we can do better and how we can share learnings. Services in cities tend to be better, but how do we share best practice.

SD added that perhaps a succession of webinars and meetings could be a productive way to share learnings.

MR shared that this is something that IBD UK are talking about, and they are currently in the process of planning a series of webinars.

MR added that city vs rural is certainly a huge variant. IBD UK are keen to not just support those services that are doing well to do better but also supporting those who are struggling. Simply sending the report and saying that they are doing badly isn’t helpful, we need to look at how we can provide further support.

PMcN commented that the work **PS** has been doing over the last few weeks has been important. Parliament has not given much acknowledgement of the conditions.

PMcN added that we need to get more backbench MSPs to ask questions from the report and certainly one about access to IBD nurses and speeding up diagnosis through access to calprotectin testing in primary care.

CB shared that she will be speaking at the IBD UK Webinar Report Launch on 12 December and there are four key areas within the report access, personalised care, experience and communication. She added that there is no point in one of the services thinking they provide all the aspects but not communicating that with patients.

CB commented that the wider UK report illustrated that almost all IBD services felt that they were supporting patients to be active in decisions in their care, but in reality, only around half of patients agreed with that. Communication with patients needs to be improved, including around what services are available and how they can contribute to decisions surrounding their care.

RR added that he has been in the IBD space for two decades, but it feels like we have gone back to where we are before. **RR** highlighted that the number of IBD patients has changed significantly over the last 20 years and the workforce gap has not changed to meet these new numbers. **RR** added that there must be political pressure put on individual health boards and Scotland generally for any significant improvements to occur. **RR** shared that he is an optimistic person in nature but for those of you who haven’t been in this space for a long time, we need to take a step back and have a meaningful think about what we have learned from before, how things have changed and how we can make a meaningful change going forward.

SS commented that this is a key group and should be key in influencing change at the parliamentary policy making level. **SS** added that in his communication with the CMO he has mentioned the group and suggested that the Government work in collaboration with the CPG and listen to the group's recommendations.

SS also stated that there are KPIs and targets for cancer, but similar targets are not in place anywhere in the UK for IBD. Patients on the endoscopy waiting list do not necessarily get the same waiting time as those on suspected cancer list. We should give consideration for bringing in targets for patients with IBD waiting on endoscopy lists across the country.

KK commented that when she was diagnosed, all she received was a paragraph of information on the condition. **KK** shared that she used to be a dietician, and she went back to look at her notes to see what was suggested for patients, but when she was practicing IBD was not something that was a big thing within the dietician space. **KK** added that it would be interesting to see what priorities the dietetic association and universities place on teaching IBD.

AH shared that he was diagnosed in 1988 with UC and would be happy to share his story another time. He commented that as his symptoms increased, his mental health declined and that shouldn't be underestimated. **AH** added that he would be interested in engaging with any additional support networks of patients with the conditions who can come together and support each other.

JB commented that we need to get backbenchers more involved in the group. **JB** asked if the Cabinet Secretary was invited and shared that he should be invited to the next meeting again. It's often if you ask for a meeting and they refuse, so worth trying again. **JB** also stated that we should raise the issues presented by the report at FMQs.

JB also asked if there is someone in the press who would run a campaign on this using real stories.

MG responded sharing that STV news interviewed her and she's happy to share her story again for any future media opportunities.

Agenda item 7

Workplan for 2025 – overview: Crohn's & Colitis UK

PMcN introduced Phoebe Sheppard (PS), Policy Lead at Crohn's & Colitis UK, to give an update on the workplan.

PS: Hello everyone and thank you for all your valuable contributions today.

I am currently working on drafting our workplan for 2025, which I will be circulating with members for approval in the coming weeks. We plan for the 2025 workplan to use the IBD UK report as a basis to address specific areas of concern relevant to IBD care in each quarterly meeting

This important insight from patients offers a powerful opportunity for us to work together to push up standards of IBD care in Scotland. It is timely too as the Scottish government plans to consult on a strategy for long term conditions next year – working in partnership with clinicians, policymakers and other charities and CPGs, we can make a big impact on the way people with long term conditions, such as IBD, experience their healthcare.

During the last meeting, Pauline mentioned the importance of having concrete actions. Building on this, At the end of each meeting time will be allocated to discuss next steps, including specific actions for MSP members. The secretariat will send agreed actions, such as written and oral questions, as discussed, to MSPs following the meeting.

Basing our workplan around the report, we will be talking about one aspect in each meeting. Our rough plan is the following:

- Meeting 1: Diagnosis, 26 Feb (Online)
- Meeting 2: Treatment, 11 June (Hybrid)
- Meeting 3 (AGM): Personalised Care, 17 Sept (Hybrid)
- Meeting 4: Workforce, 10 Dec (Hybrid)

We will ensure that we work with other relevant CPGs, clinicians and patients for each CPG meeting, so we have the right people in the room.

PS explained the next steps:

- **PS** will circulate the workplan with CPG members next week for approval and invite any feedback.
- Members will have until 15 January to share any comments/feedback to be implemented.

Agenda item 8

AOB

LB shared that her daughter got a meeting with Rishi Sunak and Steven Sharpe in the past and Steven would be keen to continue his involvement. **LB** requested Steven be invited to future meetings.

PS responded that she could add him to the distribution list.

PMcN shared that **EM** will be pleased to know that she has looked at the new shopping centre plans and they are looking to incorporate more toilets**. PMcN** added that many MSPs believe this should be a planning requirement when building large department stores and shopping centres for those who need accessible toilets.

SS commented that the group previously had a discussion about reaching out to services across Scotland to find out the state of patients on their waiting list with suspected IBD. SS asked whether we asked for that information specifically for endoscopy access.

SD answered that services are unable to give this information as this is not recorded well within services. Therefore, we are unable to have a definite number of patients with suspected IBD as they are waiting to be investigated/assessed.

SS commented that if an IBD specific recommendation of waiting times is created, hopefully the time to diagnosis from primary care referral and initiation of treatment will shorten.

SD commented that we have developed an IBD specific referral process we want to deploy across Scotland and if implemented, we will be able to tell you how many people have been referred and how many people are waiting. It is currently going through CfSD sign off.

CB shared that Glasgow are currently conducting a public lived experience survey on public toilet access across the city for both residents and commuters coming into Glasgow. **CB** commented that this a great opportunity for the IBD community to contribute to this consultation and that it would be beneficial for CPG members and Crohn's & Colitis UK to offer insight into the strategic design for future plans for public toilet access to assist in meeting the needs of IBD patients across Scotland. CB adds that if implemented well, there could be potential for Glasgow to be used as a blueprint for other cities across Scotland.

JB shared that she works at RefHelp, an interface organisation that host referral pathways. **JB** added that getting GPs involved is a key part of initiating improvements particularly IBD diagnosis and she would be keen to help with this. **JB** highlighted the high number of correspondence GPs receive from those with a number of conditions. **JB** stated that they are looking to develop specific information pages on the RefHelp website, and all NHS Lothian GPs use that. **JB** added that they are looking to develop an IBD specific referral pathway which will raise awareness amongst GPs and allow secondary care to have the information they need to triage patients and decrease the lengthy waiting times. **JB** also commented that NHS Lothian is looking to go beyond the national plan in having an IBD specific referral pathway in the Sky Gateway system so the majority of primary care referrals will go into secondary care allowing better data and raising awareness amongst GPs.

JB asked whether Crohn's & Colitis UK would be willing to meet to discuss how we can work together.

PS responded thanking **JB** for attending, especially as we have little engagement with GPs as a group. **PS** shared that she would be happy to organise a meeting with **JB** to discuss how we can work together.

PMcN concluded the meeting and thanked everyone for attending.