Cross-Party Group on Inflammatory Bowel Disease (IBD)

11 June 2025, 6-8pm

Minutes

Present

MSPs

Pauline McNeill MSP, Convenor (PMcN)

Liam McArthur MSP

Colin Smyth MSP (CS)

Invited guests

CNS Angus Crawford (AC)

Kate Spence

Thomas Preece

Non-MSP Group Members

Phoebe Sheppard, Secretariat (PS)

Edmund Murray

Siobhan Ross

Dr Santosh Salunke (SS)

Professor Richard Russell (RR)

Dr Harvey Humphrey

Rob Gowans

Observers

Caroline Brocklehurst (CB)

CNS Gillian Richardson (GR)

Lorna Kirstin May

Heather Market Rankine

Lucy Macnair

Pauline Bell

Apologies

Dame Jackie Baillie MSP

Brian Whittle MSP

Angus Holden

Cher-Antonia Khedim

Dr Jen Veryan

Dr Jane Burnett

Lis Bardell

Dr Amy Bednarz

Agenda item 1

Welcome and Apologies

PMcN welcomed everyone to the meeting

Agenda item 2

Minutes of meeting 25th February 2025 - PMcN

The Minutes from the meeting 25th February 2025 were approved.

Agenda item 3

Matters Arising – PMcN

Following the last CPG meeting in February, Colin Smyth MSP tabled a motion on implementing the National Primary Care Diagnostic Pathway for Lower Gastrointestinal Symptoms. It received support from 8 MSPs. **PMc**N shared that she's sure we could do better than that and asked **PS** to remind her so she can go up the corridors and try and get a few more signatures.

Following Dr Shahida Din's concerns, I also tabled a written question on what assessment the government has made of introducing non-cancer specific local delivery plan (LDP) standards and incentives to improve access to colonoscopies for people with benign bowel conditions such as Crohn's and colitis. The government has issued a response. They did not share any intentions to introduce non-specific LDP standards or incentives but stated that Health boards across NHS Scotland have local strategies in place to ensure patients with a clinical urgency, as well as those that have waited the longest, are investigated within an appropriate time by the most appropriate person. Referrals are clinically triaged at local board level and directed to the most appropriate waiting list.

The Scottish Government expects Health Boards to ensure an investigation is undertaken, and the verified report is received by or made available to the requester, within a 6-week waiting times standard for key diagnostic tests and procedures. Health Boards must take all reasonable steps to ensure they comply with this standard.

PMcN shared that she is happy to do some follow-up questions if the group is not happy with the response. **PMcN** added that any questions should be tabled soon ahead of recess.

Agenda item 4

The importance of access to IBD Nurse Specialists for quality care and self-management

Angus Crawford, IBD Nurse Specialist, NHS Lothian

Phoebe Sheppard, Policy Lead (Scotland & NI), Crohn's & Colitis UK

Overview

PS opened the presentation explaining that the talk will cover what steps are necessary to ensure people can access care and support for long term conditions more easily, with a specific focus on the importance of IBD nurses for self-management, quality care, and timely treatment. **PS** explained that IBD Nurse Specialist Angus Crawford will be leading this presentation, but shared a quick overview of key points:

- The availability of IBD Nurse Specialists across Scotland is vital for people living with IBD. Crohn's and colitis are complex and unpredictable conditions that require specialist support to manage as not all treatments work for everyone.
- Patients with access to an IBD Nurse Specialist are often able to be better managed within the community and often have a better awareness and understanding of tools to self-manage.
- IBD nurse specialists crucially help to prevent emergency admissions and surgery, with many patients describing them as their lifeline
- Despite this crucial role of IBD nurses, services across the UK are not meeting staffing requirements as set out by the IBD Standards.
- 1 in 3 services in Scotland are not meeting these requirements and this needs to change if we want to see an improvement in care for people living with IBD.
- Crohn's & Colitis UK believe a specialist nursing plan would be a crucial step in addressing this issue, enabling the number of IBD nurses to be increased and improving access to high quality care.

PS handed over to **AC** to speak about these key areas in more detail.

Complexity and unpredictability of the conditions

AC explained that Crohn's Disease and Ulcerative Colitis and Microscopic Colitis are complex diseases to manage that require specialist support. The availability of IBD Nurse Specialists across Scotland is vital for people living with IBD to be able to access responsive health services and improved clinical outcomes, and many patients describe them as their 'lifeline'. This is especially true as GPs are not specialists and cannot provide the same level of information and support, so the timely information and advice provided by IBD nurses can prevent costly interventions like hospitalisation and A&E admission. 'Flare ups' of IBD are difficult to predict and manage. Not everyone will respond to initial treatments, which, is why having access to a specialist nurse is so important.

AC provided an example, sharing that their IBD advice line in Edinburgh receives approximately 100 phone calls a week of which approximately half are patients having a flare of their IBD. The nurses can prescribe remotely, and organise further tests and if necessary, escalate to a consultant. This service relieves pressure on an overstretched primary care service. Research by Rebecca Grant et al during the pandemic showed that access to a rapid access clinic and the IBD advice line reduced overall hospital admissions and reduced the prescription of corticosteroids and improved patient outcomes. The reduction in hospital admissions also brings cost benefits to the service.

AC explained that Crohn's & Colitis UK partnered with the Scottish Government Modern Outpatient Programme and a working group of patients and healthcare professionals to co-produce a patient flare card, which was rolled out in Autumn 2019. It helps people to recognise signs of a flare, gives simple steps to follow during a suspected flare, includes information on dose escalation for 5 ASAs, and prompts patients to ask their GP to test for faecal biomarkers. It also advises patients about medications that should not be stopped or altered without discussion with the IBD team. This is a really useful tool to support patients to self-manage, although not everyone will respond/see improvement after taking these initial steps and therefore patients often need further guidance from an IBD Nurse Specialist, which is why access is so important.

Flare card

AC talked the group through the flare card, explaining that it is an important self-management tool that patients can carry with them and refer to whenever they have a flare up of IBD. Research has shown that self-management of chronic illness empowers the patient, reduces stress and improves mental health. Having a flare card helps patients to get out and to worry less about the IBD. Approximately 40% of IBD patients were found to struggle with anxiety or depression and self-management is an important part of improving mental resilience.

Work by Gareth Jones et al has also highlighted the increasing prevalence of IBD within the community with IBD set to effect 1 in 28 of the population in NHS Lothian by 2028. Without self-management tools that have been designed by specialist such as IBD nurses services will struggle to cope with the increasing demands without self-management tools and patient initiated follow up.

How IBD nurses can help

AC emphasised that everyone living with IBD should have access to a suitable trained IBD nurse specialist, to ensure responsive health services and improved clinical outcomes through rapid response to flares with prompt treatment and escalation of treatment.

IBD nurses can:

- Reduces corticosteroid use
- Improves outcomes
- Reduce A+E visits
- Reduce emergency surgery
- Reduce hospital admissions
- Reduce visits to GP practices
- Reduce costs

AC added that a study by Middleton et al in the early 2000's showed that access to a specialist nurse improved rates of remission in IBD.

AC reiterated that specialist IBD nurses play a fundamental role in delivering high quality patient care and experience, lead patient centred service redesign, improve the quality of care and represent excellent value for money. They are the most frequent first contact for specialist advice for people living with Crohn's or Colitis.

AC emphasised that patients who have access to an IBD Nurse Specialist are more likely to be able to manage their condition, stay well for longer and avoid unnecessary A&E visits.

Typical IBD Nurse Specialist Duties

AC shared some of the typical duties undertaken by IBD Nurse Specialists:

- **Running a follow up service and IBD advice line**- running a follow up nurse led service allows close monitoring of patients IBD whilst also releases more clinic time for consultants to focus on the more complex patients.

- **Providing in-patient - support** - Our patients are often younger and being in hospital can be a challenging environment where complex advanced treatments or surgery is often needed the IBD nurse is essential in communicated these complex treatments in a way that is easily understood.

- **Administration and monitoring of anti-TNF therapy**- assessing response and monitoring for side effects are an essential for the safe use of these medicines.

- **Providing nutritional advice** - managing diet and monitoring for nutritional deficiency improves symptoms of fatigue and general wellbeing.

- **Education and support -** empowers the patient, reduces health anxiety and stress and has demonstrable improvement in patient outcomes.

- **Developing and defining IBD services** - quality improvement is key to our role; we have been involved in an IBD nurse led mental health support. New diagnosis pathway/clinic.

- **Liaising with MDT** - communication between medical staff, dieticians, radiologists and pharmacists. The IBD nurse is at the heart of the service and acts as the patient advocate.

- **Performing endoscopy** – some nurses also perform endoscopy.

- **Coordinating colorectal cancer surveillance for patients** – making sure patients get their scopes at the right time.

Self-management

AC stated that people living with Crohn's and Colitis should have access to the tools, resources and specialist support they need to feel empowered to manage their condition and take more control of their care.

AC shared that self-management can enable people with Crohn's or Colitis to live fuller, freer lives by empowering them to take more control of their condition. This has been shown to reduce stress and health anxiety, which then improves patient outcomes. It has also been shown to improve engagement with healthcare professional's as they navigate having a chronic health care condition.

AC explained that prevalence of IBD is also increasing, and self-management is therefore essential in order to maintain current levels of support.

AC shared that at Western General Hospital they have a patient initiated follow up service for patients in long-term remission which means instead of regular appointments they get in touch with them when they need to. This then allows them to focus on patients with more poorly controlled IBD.

AC explained that when people with IBD have difficulties self-managing their condition, this can lead to complications, and poorer mental and physical health outcomes. The evidence shows that good self-management means fewer symptoms and hospitalisations and less need for treatment escalation. Self-management in IBD enables people to have more control over their lives, by giving them the knowledge and skills to develop life goals, make healthy choices and manage their condition.

AC added that where people living with IBD report having contact with an IBD Nurse Specialist, they are also more likely to have the information and skills to manage their condition. However, a recent audit found that more than 1 in 3 IBD services in Scotland are below safe staffing levels for IBD nurses according to the recently published IBD standards.

The current situation

AC shared that people in Scotland are facing difficulties reaching IBD nurses through advice lines and are experiencing delays in getting advice and treatment during flares.

AC explained that this is because workforce numbers have not kept up with increasing demand. The IBD Standards set out the number of IBD nurses required in IBD services. 2.5 WTE IBD Nurse Specialists are required for a catchment population of 250,000 people (the average for a district general hospital), yet only around a third of IBD services in Scotland meet these recommended staffing levels, leaving gaps in care.

What’s more, these ratios were set in 2017 and the number of people estimated to be living with the condition has nearly doubled since then and is expected to continue to rise, so in reality the discrepancy in the number of IBD nurse specialists there are, and the number needed is even wider.

Roughly 1 in 4 people with IBD in Scotland reported that they did not receive a response within 48 hours of contacting a medical practitioner for advice when experiencing a flare.

Additionally, almost 3 in 5 (58%) people living with IBD reported that they did not have access to a review by the IBD team within five working days of contacting them during a flare, increasing the likelihood of complications and emergency admissions.

Expanding the workforce of IBD nurses

AC shared that expanding the workforce of IBD nurses could:

- **Reduce Emergency Admissions:** Patients with direct access to an IBD nurse are able to get specialist advice they need and will therefore be less likely to require A&E visits or unplanned hospital stays.

- **Reduce costs for NHS Scotland**: fewer A&E visits or unplanned hospital stays will reduce costs for services and increase the number of beds available in emergency services.

- **Improve Primary Care Management:** Equipping GPs and other primary care providers with the support of specialist nurses could reduce unnecessary referrals to secondary care.

- **Enhance Patient Wellbeing and Self-Management:** Timely intervention and structured support through well-resourced IBD helplines will empower patients to manage their condition proactively, reducing reliance on other NHS resources.

A national specialist nursing plan

AC shared that this summer Crohn’s & Colitis UK will be responding to the government's consultation on the Long-Term Conditions Strategy, emphasising the need for a national specialist nursing plan including IBD nurses and supported self-management.

AC added that recruiting and retaining appropriately trained IBD Nurse Specialists is crucial in providing and maintaining high quality care. As explained, expanding the workforce of IBD nurses could reduce emergency admissions, improve primary care management, and enhance patient wellbeing and self-management. Therefore, the number of IBD nurses must be increased in line with service standards so patients can be supported to stay well in the community, with referrals to secondary care initiated when appropriate.

AC concluded by explaining that a national specialist nursing plan would not only support people living with Crohn’s and Colitis but would also mean that people with other conditions such as Parkinsons are able to access essential specialist nurses, improving quality of care and access to care for people with a number of long-term conditions, and reducing pressure on emergency services.

Discussion

SS asked what the population is that **AC's** local team covers.

AC responded, sharing that in 2019 Gareth Jones did some research and there were around 8,500 patients at that time. **AC** added that they diagnose around 358 patients a year, so they should now have around 10,000 patients in their population with IBD.

RR asked if there was any way to centralise nursing resources because there are often geographical gaps as AC pointed out and it's often difficult for those areas to increase the number of IBD nurses in the short term; do you think there's a possibility of centralised resources where you could have an equivalent to NHS 111 for IBD nursing that can help areas where IBD nurse numbers are lower than the national average

AC responded, saying that's something to think about in the future. At the moment, they are just managing with what they have, and they have quite a large nursing team in comparison to other parts of the country, and there are times when they still struggle. AC added that they would need a lot more nurses in their team to develop such a service and manage the increase in workload.

RR responded that it was more of a philosophical question, but he wonders if Crohn's & Colitis UK or other charitable bodies can host a nurse to help areas with a low number of nurses as a practical step to push things in the right direction while workforce numbers are waiting to increase.

PS responded sharing that Crohn's & Colitis UK do have a nursing programme, but it is currently paused for recruitment. They continue to train nurses already on the programme, although there aren't any Scottish nurses enrolled currently. If it were to resume, we would hope to attract some Scottish nurses.

Agenda item 5

IBD Standards Update with a focus on patient experience

Caroline Brocklehurst, Lived Experience Representative, IBD Standards Working Group

CB began by introducing herself, explaining that she was diagnosed with Crohn's Disease in 2009 at the age of 33, and was a mum of a 5-year-old at the time. Following a lengthy delay to diagnosis, 10 years later in 2019, **CB** was diagnosed with Extra Intestinal Manifestations of IBD including Ankylosing Spondylitis (also known as Axial Spondylarthritis), which is an incurable inflammatory spinal disease, and Uveitis, which is an inflammatory eye condition.

CB shared that she is a volunteer Peer Support Host for Crohn's & Colitis UK, hosting IBD meet-ups across the UK and is also a peer supporter in a variety of other contexts.

CB explained that she also has a number of patient representation roles in a variety of health policy and guidelines areas, health research and peer support strategies.

CB shared that she was asked to join IBD UK's IBD Standards Working Group in Autumn last year as a lived experience representative.

IBD report theme areas

CB explained that the IBD Standards were originally designed and published in 2009 and since 2019, the Standards have been used to benchmark IBD services around the UK, both through a Service Survey completed by IBD services and a separate Patient Survey.

CB added that In December, she was asked to present a patient perspective on the 2024 IBD Report.

CB shared that 4 key priority theme areas were highlighted by the report and these priorities resonate in both her own journey with IBD, as well as the testimony from her peer support work.

Access

Access to services and support is crucial. Whilst this of course matters in journey to diagnosis, it is also crucial throughout all stages of IBD patient journeys, with consistency.

Communication

Effective communication in IBD care is not a "nice to have", it's a crucial safety feature in patient care. Poor communication is a leading cause in many patients' harmful experiences. Almost all IBD services agreed people with IBD were supported to be actively involved in management decisions of their care. However, only 55% of patients agreed that they were. Effective access and communication is crucial between specialties as well as between primary care, secondary care and community services.

Personalised Care

Effective Personalised Care means focussing on "what matters to me". The report denotes that self-reported access to a personalised care plan in adult IBD was only 7%.

No two patient journeys with IBD are ever exactly the same. Personalised care optimises IBD care to make a difference with proactive warm hand support which is focussed on individual overall needs. The report identified that only 31% of adults are being asked questions about conditions beyond their gut, despite up to half of patients experiencing extra intestinal manifestations of their disease and only 20% of people with IBD said that they were asked about their mental health in reviews.

Patient Experience

Finally, the report highlights divergence between service reported delivery and patient reported experience. Measuring my outcomes, is not just measuring inflammatory markers against a population average. Like every patient, my diseases don't exist in a vacuum. We know What gets measured gets done. So, gathering, analysing and acting on patient reported health and life outcomes, *and* patient reported experiences of care, are a crucial piece in improving outcomes. Meaningfully incorporating expertise by experience into authentic co-design is also part of the solution.

IBD Standards Review

CB shared that the aforementioned patient priorities have been in the forefront of her mind in her role as a lived experience representative within the IBD Standards Review Working Group.

CB explained that the working group is formed of IBD UK Board Members, including a full range of healthcare professionals who care for people with IBD, tasked with updating the IBD Standards, alongside lived experience representatives.

CB shared that the review of the IBD Standards has had some guiding principles:

- They are aspirational Standards for all stages of the IBD patient journey and they are about IBD service delivery rather than clinical guidelines
- Continuing consistent benchmarking is important, so Standards have only been modified where necessary.
- A key aim is the future proofing of the reviewed standards and there will be supporting guidance issued in addition to the revised Standards.
- Whilst the Standards are primarily for IBD services, the Standards review has taken a partnership approach with lived experience representatives and patient-centred care is at the heart of the revised standards.

Consultation

CB explained that the Working Group’s reviewed Standards are now live in consultation until the 6th July and there are 65 Standards across 7 separate areas.

CB encouraged sharing this consultation with relevant stakeholders throughout the consultation process and to contact Jess Turner, Head of Health Services at Crohn’s & Colitis UK, with any queries.

Agenda item 6

Specialist review times, initiatives, and challenges at NHS Forth Valley

Dr Santosh Salunke, Consultant Gastroenterologist & IBD Lead, Clinical Director-Scheduled Care Medicine, FVRH, NHS Forth Valley

Gillian Richardson, IBD Nurse Specialist, NHS Forth Valley

SS explained that he will be focusing on one particular aspect of the patient experience during this presentation. **SS** added that there are several things they have heard about the disease burden and the impact the disease can have on their patient cohort: on their physical health, mental health, sexual health, social health, economic productivity, school and work absenteeism etc.

SS explained that there was one thing that has hit him time and again over the last few years of attending these meetings, and it was the same thing expressed by **CB** in her presentation, access to specialist services at the time of diagnosis.

Crohns and Colitis Care in Scotland: A Vision for Change

SS explained that the IBD Standards recommend early access to diagnosis and specialist review, and the IBD UK survey published earlier in the year illustrates there is a significant delay to getting specialist access for patients across the UK, but particularly in Scotland we have noted that a third of patients waited up to a year to be referred in, and in some cases a further 6 months to have a diagnosis. SS explained that whilst some patients are waiting a few weeks, more widely patients are waiting anything from 6 months to a year and a half prior to their diagnosis. **SS** emphasised that that is quite concerning, and his question was how he is performing in Forth Valley and whether he keeping his patients waiting too long.

Access QI New OP Referrals

SS shared that they get just under 2,500 referrals into gastroenterology every year and this data is as of 8 June 2025.

Of the 2,500 referrals, about 10% are for IBD. In the past year they have seen 242 referrals, of which they accepted 241 into the service. Of the 241 patients, they have so far seen 238. 3 patients have not been seen yet, but this is very recent data so perhaps they were referred in the last week or two, and they should be seen very soon.

New referrals

They have created a flexible system to try and accommodate as many appointments as possible, both routine and urgent. That has been reflected in their waiting times over the past year. Waiting times have gradually got better, particularly over the last 6 months or so.

Routine referrals

Looking at the routine patients, there is literally no one who has waited more than 18 weeks.

In the past 6 months, they have been able to see 100% of new patients for an outpatient appointment in less than 12 weeks. In fact, they managed to see most of them in less than 6 weeks.

About 6 months ago there were patients waiting over 12 weeks for an outpatient appointment, but in the last 6 months the number waiting this long has gone down to almost zero.

They have also been successful in reducing their DNA rate for IBD patients to 0.

Urgent referrals

For urgent referrals, they have managed to create appointments and see them in a timely way. Almost 100% of patients get seen within 6 weeks. Again, for urgent referrals, their DNA rate has been zero.

As of this afternoon, **SS** was looking at the urgent referrals and how many are waiting. There were 2 patients on the waiting list that are yet to be seen across the entire gastroenterology waiting list. One has been dated for Monday and the other one doesn’t need to come to them and is waiting for and outpatient investigation – they think they can manage that patient in a slightly different way.

SS genuinely feels comfortable and proud that they have been able to serve their patients in terms of timely access to specialist service, but when you perform well in one area there are challenges that come up in other parts of the service. SS emphasised that what he is showing today is only a small part of the jigsaw. **SS** invited **GR**, their IBD nurse to comment here, but very briefly explained that whilst they are great in serving new patients, they have a huge burden of over 6,000 patients across the GI cohort of which 18% of the return waiting list sit under IBD nurses. They serve the helpline, manage biologics, and they have issues around endoscopy like many other units. They have been able to manage the urgent new referrals for endoscopy much better, but once the diagnosis is established, those patients who suffer from flares and need urgent access to endoscopy often struggle.

SS would like to see more of an automated process for them to serve existing IBD patients better with easier access to endoscopy.

SS invited **GR** to comment.

GR emphasised that it isn't anything that **AC** and **CB** haven't already touched on in their presentations, but IBD nurses really are the lynch pin who try very hard to holistically manage these very complex patients. The lack of IBD nursing staff, particularly in Forth Valley is very challenging, and trying to provide the best, timely, and effective care for patients that they can. They just do not physically have the time to do it properly and as a result patients are suffering and coming into harm unnecessarily because of circumstances out of their control which includes things like access to endoscopy services.

Urgent patients are waiting for appointments for up to 6 weeks at the moment and trying to manage someone who is young and flaring and trying not to miss the last week of 6th year at high school and their high school prom is very stressful for patients, but also very stressful for nurses too.

There are only 1.8 WTE IBD nurses at Forth Valley trying to manage over 2000 patients so things are a bit of a struggle at the moment although they do try their best.

SS added that nursing workforce has been a particularly big challenge for them in the last few years.

SS concluded by saying that there are some good pieces of work they are doing, but there remain significant challenges that need to be addressed.

SS added that despite this the service provided by the IBD nurses is fantastic and this is reflected in the IBD UK patient survey where Forth Valley patients provided positive feedback about the service that they receive from the nurses. **SS** is also frequently told about the great service they are providing, and that's despite the many challenges they are facing.

Discussion

RR asked what the barriers are to appointing new IBD nurses – is it lack of business cases being received by Forth Valley Health Board, or is it a lack of people wanting to do the job? What are the main barriers and what can we do to help?

SS shared that the main barrier is around financial resources and like many units every service is needing additional financial resources and that seems to be the biggest restraint. There are significant financial pressures at NHS Forth Valley at the moment, but they are trying to see if they can get some additional resources from somewhere else on a temporary basis, at least for a year or two, so there is someone in post to take on part of the service.

RR asked **SS** if they have any patients advocating for this specifically.

SS responded that they don’t at the moment but that is something that has been floated, and they are thinking about bringing in patient advocates.

Agenda item 7

Actions and next steps, Pauline McNeill MSP

PMcN highlighted that we are coming to the end of this parliamentary session so there is not going to be a lot of time left for this CPG to pursue anything we are not already doing.

PMcN suggested **PS** sends any questions or anything we want to write to ministers about as soon as possible so we don’t have to wait until September for a response.

PMcN suggested circulating a request to members alongside the minutes to raise any questions they would like tabled.

PMcN thanked all members for keeping this issue live in Scottish Parliament.

PMcN asked **CS** if he can circulate the aforementioned motion on the lower GI pathway to members to get some more signatures.

CS agreed.

PMcN added that we should definitely follow up on the endoscopy issue.

CS commented that **CB’s** quote ‘what you measure gets done’ is so accurate. **CS** attended a roundtable on lung disease recently and that’s the biggest issue that came up – what we are measuring and what we are not recording. The inability to even be able to say how many people have a certain condition. We don’t speak across IT systems across the health system, so we don’t know enough information. Another issue that comes up as well in the CPG on heart disease is around that mental health support issue for people as well. We focus on the physical and not the mental health impact the physical condition can have on a person. Anything on those areas would be great as it just cuts across so many conditions and we are just not addressing it at all.

SS completely agrees with **CS**, what gets measured either gets done or reflected and this is something we have spoken about in this meeting a few times. In terms of IBD care, there are IBD standards but there are no IBD KPIs and therefore they don’t get the same weightage as for example cancer. Certainly, when we go out with business cases to get things done this is a big challenge.

PMcN thanked the speakers for their presentations and the group for their continued engagement and support. **PMcN** shared that the next meeting will be the AGM on 17 September and closed the meeting.