

# Cross-Party Group on Inflammatory Bowel Disease (IBD)

18 September 2024, 6-8pm

## Minutes

## Present

### MSPs

Pauline McNeill MSP Convenor (PMcN)

Michael Marra MSP

## Invited guests

Kate Spence (Staff)

## Non-MSP Group Members

Amy Bednarz

Angus Holden

Burcu Borysik

Edmund Murray (EM)

Fern Howard (FH)

Harvey Humphrey

Patricia Kelly (University of Strathclyde)

Seth Squires (SS)

Siobhan Ross

Thomas Preece (TP)

## Observers

Caroline Brocklehurst (CB)

Cher-Antonia Khadim

Daisy Parsons

Fiona McCluskey

Jacqueline Paterson (JP)

June Brodie

Lucy Macnair

## Apologies

Dr Daniel Gaya

Dr Ian Arnott

Dr Santosh Salunke

Julie Gorman

Liam McArthur MSP  
Marianne Radcliffe  
Phoebe Sheppard (PS)  
Prof. Richard Russell  
Rob Gowan

## Agenda item 1

### **Welcome and Apologies**

**PMcN** welcomed everyone to the meeting

## Agenda item 2

### **Minutes of meeting 13<sup>th</sup> December 2023**

The Minutes from the meeting 13<sup>th</sup> December 2023 were approved.

## Agenda item 3

### **Matters Arising**

The IBD UK National Report is due to be published later this year. This will be followed by the IBD UK Scottish Report, which will provide tailored recommendations for Scotland.

## 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 23rd September.

**PMcN** mentioned that a Work Plan for the next year's meetings is currently being drafted and invited suggestions to Phoebe by Monday 23rd September.

## Agenda item 6

### **Update on local IBD UK reports: Thomas Preece, Policy Manager, Crohn's & Colitis UK**

**TP** shared that there have been a lot of changes to the team at Crohn's & Colitis UK since our last meeting in December last year.

**TP** introduced the new team:

- **Thomas Preece**, Policy Manager
- **Phoebe Sheppard**, Policy Lead, Scotland and Northern Ireland & Secretariat for the CPG
- **Burcu Borysik**, Head of Policy & Campaigns, has returned from maternity leave
- **Fern Howard**, Interim Director of Services, Advocacy and Evidence

**TP** explained that he will be going through the Glasgow local IBD UK report as it felt the most relevant to this meeting.

**TP** provided background, explaining that the IBD Standards say what high-quality care should look like at every point of the patient journey. The IBD UK Benchmarking supports hospitals to assess how they're doing against the 2019 IBD Standards and identify where they can improve.

**TP** shared that we now have a lot of local IBD reports to assess how different hospitals are doing against those standards. The reports were based on the IBD Standards from 2019, which are going to be updated next year, and the reports were based on a slightly old population estimate of people living with IBD. Some of the numbers will be updated next year and that may impact what we expect to see from these numbers going forward.

**TP** provided an overview of the results for Glasgow Royal Infirmary:

- Glasgow Royal Infirmary covers a population of 500,000. Unfortunately, no data was provided on how many adult IBD patients the service supports or how many of which were diagnosed in the past 12 months. We do have this information for other local reports, it just depends on how much information each service has provided us.
- The IBD standards define the ideal make-up of the IBD team in terms of full-time roles. Ideal numbers based on the reported population size have been mapped against the numbers of staff the service has in the IBD team in reality. In Glasgow there are 6 Consultant Gastroenterologists and Consultant Colorectal Surgeons. For this size of population, we would expect there to be at least 4.
- Sadly, the same can't be said for a lot of the other roles. There are 4 IBD Nurse Specialists when there should actually be 5. There are no Psychologists, Stoma Nurses, when there should actually be at least 1 Psychologist and 3 Stoma Nurses.

- This data is extremely helpful to us as a policy team to see where there are gaps and where we need to do our influencing work, but also hopefully will be useful for hospitals to see their own gaps and what number they should be expecting. The reason I mentioned earlier about the population change is going forward when the numbers are updated, we will potentially need more consultant gastroenterologists if there is a slightly higher prevalence than we think in that area.
- When asked how they would rate the quality of their Crohn's or Colitis care over the last 12 months, 45% of patients rated it as 'excellent' or 'very good'. 21% of patients rated their care as 'good' and 34% rated it as 'fair' or 'poor'.
- The reports then go into the patient journey, starting at the pre-diagnosis stage. This service achieved 3 key IBD standards in relation to diagnosis:
  - All patients with IBD are seen within 4 weeks from their first referral. Glasgow is doing better than most as this was only achieved by 48% of services across the UK.
  - All newly diagnosed patients are offered written information on their condition.
  - New diagnoses and the care plan that has been agreed are communicated to GPs within 1 week.
- However, 36% of patients attended A&E before their diagnosis. This is slightly higher than the UK average of 35%.
- Concerning flare management, 90% of patients contacting the IBD advice line get a response within 2 working days. This is higher than the UK average, which was 77%. However, a process does not yet exist at this service for communication of a management plan for the optimization of IBD care within 5 working days of a flare.
- Regarding surgery and inpatient care, very little data was available for this service. Insufficient data was provided for the percentage of patients given clear information before their operations. There was no available data on whether the surgical outcomes are regularly audited for elective IBD surgery, if all inpatients with IBD are seen by a gastroenterologist within 24 hours of emergency admission, and whether all elective IBD surgery takes place within 18 weeks.
- In relation to ongoing care and monitoring, Glasgow exceeded the UK average in all areas apart from in the provision of a written personalised care plan, which it does not yet provide to all IBD patients.
  - 91% of patients have contact with an IBD nurse specialist, performing higher than the UK average (88%)
  - 54% of patients have regular reviews even when their condition is stable, in comparison to a UK average of 44%
  - Just under half (48%) of patients believe their care is well-coordinated between their GP and gastroenterologist
  - 28% of patients discuss wider life and priorities as part of planning their care
- Glasgow did not achieve some aspects of the IBD standards relating to the IBD service including:
  - All patients have access to outpatient colonoscopy or flexible sigmoidoscopy within 4 weeks (only achieved by 31% of services)
  - IBD patients are directly involved in service development (only achieved by 24% of services)

- Furthermore, only 5% of patients have been given the opportunity to feedback on their care in the past 12 months, in comparison to a UK average of 18%.
- Glasgow has achieved:
  - Having a senior leadership team in place
  - Providing copies of clinical letters to IBD patients routinely
- We would encourage people to go and look at their local IBD UK report online. If you would like to find your local report, you can by:
  - Visiting the IBD UK [homepage](#)
  - Clicking on [reports](#)
  - Clicking on [Local Service Reports Map](#)
  - Typing in the name of your hospital
  - Clicking on view service webpage
  - And downloading the IBD Benchmarking 2023/24 results overview report
- We haven't got it for every service across the UK, but we do have the majority.
- What's next? The IBD UK National Report will be published later in 2024. This will be followed by the IBD UK Scottish Report, which will provide tailored recommendations for Scotland in particular. Both reports will hopefully be discussed in more detail at the next meeting in December.

**EM** commented that Dr Ian Arnott isn't here but there is an NHS Scotland project he's involved in looking at the headcount and benchmarking services and care plans so there is work going on behind the scenes to look at those which is ongoing. Dr Ian Arnott is unfortunately not here to give more details about it

## Agenda item 7

### **Update on the primary care diagnosis pathway for screening and testing of lower gastrointestinal (GI) symptoms in Scotland: Fern Howard, Interim Director of Services, Advocacy and Evidence, Crohn's & Colitis UK**

**FH** Thanked the group for inviting her to speak. **FH** introduced herself as the Interim Director of Services, Advocacy and Evidence, which covers our work to influence change, research, supporting people with information and guidance.

**FH** explained that she is here today to talk about the work we have been doing across health services to create this primary care diagnostic pathway.

**FH** spoke about the issue – long waiting times and no agreed pathway for lower gastrointestinal (GI) symptoms in primary care.

- When it comes to diagnosis, we know that people are waiting far too long to get a diagnosis of Crohn's and Colitis. Around 1 in 10 visits to the GP are concerning a lower gastrointestinal symptom.
- There are challenges in people delaying seeking help from their GP, but we know that it is very difficult to diagnose gut symptoms because common symptoms can be caused by many different conditions.

- It's really challenging for a GP or another healthcare professional in primary care to make sure those who come to them are referred for the right test at the right time.
- There is no nationally agreed pathway to help primary care professional make decisions on which tests should be done, and in which order, for those presenting with lower gastrointestinal symptoms. This means there can often be delays to diagnosis and confusion about what the right pathway to diagnosis should look like. This can cause a lot of worry for people who are experiencing those symptoms.
- We did a Freedom of Information request which found that only around 70% of health boards in Scotland offer a faecal calprotectin test to those who present with symptoms in primary care. Also, there are huge gaps in consistency and how a pathway is implemented. There really is no agreement around what the right pathway should look like.
- The solution to this was for us to work with other organisations to look at what pathway would support clinicians to make sure that anyone presenting with lower GI symptoms would be able to then signpost or refer people for the right tests. So really making that pathway to diagnosis a lot smoother not only for adults, but also for children because Crohn's and Colitis can affect anyone of any age.

FH spoke about the pathway:

- [This pathway](#) was developed by leading UK charities in partnership with healthcare professional organisations and patients.
- It has been endorsed by: The BSG, BSPGHAN (British Society of Pediatric Gastroenterology, Hepatology and Nutrition), RCGP and the Royal Pharmaceutical Society.
- Throughout this process it hasn't just been about working with organisations to pull this together, but also engaging with clinicians and patients.
- This is a snippet of the [adult diagnostic pathway](#) created for healthcare professionals. It sits on a dedicated microsite, which anyone can look at.
- [Downloadable and printable resources](#) have been created to support healthcare professionals to shorten time to diagnosis, reduce variation and improve experiences of care. Pathways have been created for both adults and paediatrics and a patient information version is also available.
- This is an [example](#) of information that has been created for patients to help people experiencing symptoms to advocate for the right test at the right time.
- We know that this is a very stressful time for people experiencing symptoms and it can be a long journey. We know that it is taking people months, or even years just to get a referral for further tests. So really this information has been put together to help explain to people what is happening at each stage of that experience.
- The guide explains lower gastrointestinal symptoms, possible conditions, possible tests their GP can offer, what test results mean, and other actions GPs may take. It equips patients with the right tools to communicate issues with their GP and push for further investigations, contributing to earlier diagnosis.

**FH** went on to explain progress so far and next steps:

- We are working very closely with clinicians across the four nations. Dr Shahida Din, who is a consultant at NHS Lothian has also been working with us on this.
- In Scotland, the Centre for Sustainable Delivery (CfSD) will be responsible for implementing the pathway. We met with Claire Rush and Robert Boulton-Jones from the CfSD in May to look at how we could go about implementing the pathway, what that would look like, and how we can make sure this is embedded as part of everyday practice in primary care.
- It's just the start of the journey. Bringing this here today, I wanted to really talk through what success could look like and what next steps look like for progressing this.
- As I mentioned at the beginning, there is patchy access to faecal calprotectin tests in Scotland and this is a vital test to diagnosis, so it is absolutely vital that it's addressed. In order for the pathway to be implemented and to make the diagnosis process faster it's essential that tests are available throughout primary care.
- The next step is around education, so making sure that healthcare professionals and GPs are aware of the pathway and that they feel able to use it to make those referrals. We know that the waiting lists for endoscopies are also very long, so making sure people are referred for the right tests and those appropriate referrals are going through as quickly as possible.
- This is a whole system approach and to reach GPs we need to really think about who the leaders are and the way that we work across primary care to show that this is going to benefit and reduce pressures on really stretched services. We need to raise awareness and look at system change as well as looking at how we work on the ground with primary care professionals on how we move this forward.
- As a key action for today, we have a template letter available that people can write to their health board to find out what is happening in their local area and to push for the implementation of the pathway.

## **Discussion**

**PMcN** mentioned that in a previous meeting we had a presentation from one of the doctors from Teesside and she mentioned about the results of tests not being widely available.

**FH** responded, explaining that from the FOI we can see that information, including where they are and aren't available and that gives us an overview, but we need to bring together health leaders to really think about what that means in practice. We will be looking at how we can bring together clinicians and health leaders from Scotland to identify where those challenges are, what best practice is, and where it's happening. But we really do know that the availability of faecal calprotectin is patchy at the moment, so that's something for further investigation. If there are areas where things are going well, we really do need to know about them and share best practice.

**PMcN** commented that the CPG needs to do more action wise, rather than just meetings. **PMcN** proposed that she and Clare Adamson write to every health board on behalf of the

group and ask them what their plans are. PMcN stated that we can all learn something from these discussions, but unless we take an action the group can't really fulfil its true purpose.

**FH** agreed that as an action, writing to the Health Boards would be very helpful. She explained that although Crohn's & Colitis UK have had some positive conversations with NHS Scotland, we need to make sure this is a multi-pronged approach. FH highlighted that alongside PQs that can be put forward, we have a lot of local data so looking at some of those results in more detail would allow us to draw out conclusions about what action is needed across Scotland. **FH** stated that the IBD UK Benchmarking sets the scene and state of play, but the pathway is a solution to that. FH explained that the end of the year going into next we will have a clear path for making change and some of those solutions.

**PMcN** asked whether it is possible for Crohn's & Colitis UK to put something together for her and Clare Adamson to sign on behalf of the group.

**TP** responded, explaining that Crohn's & Colitis UK can get a letter drafted and sent over to **PMcN** in the next few weeks. TP mentioned that workplan is still in its draft stage and so to share any ideas with **PS** so they can be added in. We will then have some actionable tasks taking place next year.

**PMcN** shared that unless we start doing actionable tasks, we aren't maximising potential. PMcN added that Health Boards are really terrible at responding. PMcN asked whether we can we agree that she and Clare Adamson will write to all Health Boards and then they can share the responses with us.

**TP** agreed.

**CB** thanked **FH** for her hopeful and encouraging presentation, adding that we can all agree that the pathway to earlier diagnosis from primary care is much needed. CB stated that she was just curious as to the lack of noting extraintestinal manifestations in the red flag symptoms. CB noted fatigue and mouth ulcers but given that up to 50% of IBD patients actually experience either extraintestinal manifestations or correlating conditions, CB is curious as to why that isn't part of escalating that pathway and flagging those correlating conditions/symptoms.

**FH** commented that it's an excellent question. FH added that extraintestinal manifestations do come into it, but the presentation was just an overview. FH shared that we know from people that extraintestinal manifestations are usually a reason for them to visit the GP. FH stated that the pathway does talk about those other elements as well, which is also why there's an adult and child pathway. FH added that we know that diarrhoea in children, for example, whilst it can be a key symptom for Crohn's and Colitis can also be a sign of many other conditions. FH explained that it's why the pathway was built with clinician and patient input to make sure all of those symptoms were taken into account.

**JP** introduced herself, explaining she is a Consultant Gastroenterologist at Teesside where previously it was only the paediatric population that had access to faecal calprotectin. JP added that they did have it in secondary care, but they had to outsource to different laboratories to get it analysed. JP updated the group that over summer they moved the laboratory in-house to analyse the tests. JP added that it's still available in secondary care, but if GPs get in touch with them, they send kits out to patients. JP stated that they're catching up.

**FH** commented that this is why a forum like this is so important, to show how things are changing and drive collaboration on moving improvements forward. FH added that it's about bringing all stakeholders together and looking at what we can learn from others. FH explained that the pathway is an example of something we were told would be fantastic but would be



impossible to get all the organisations involved and develop a pathway that was truly multi-condition, and we now have that. FH concluded that now it's about how we work together to drive that forward.

**PMcN** asked whether we know anything about the rate of diagnosis in Scotland and Crohn's and Colitis. PMcN recalled from previous discussions that GPs will see very few people in their surgeries over their career with IBD. PMcN added that we know that incidence in Scotland is higher in Scotland but asked whether there any detail around rate of diagnosis per year.

**FH** responded that she's not sure if there's anything Scotland specific, and they would need to look into that. FH added that we do know in the UK there are around 25,000 people diagnosed every year. FH stated that the challenge we have is that's the number of people getting a diagnosis, but from the IBD Benchmarking we know that there's that step before and the IBD diagnosis is taking so long that there are these hidden waiters who wouldn't appear in those statistics, but we know are experiencing symptoms and challenges in getting a referral for much needed tests. FH concluded that there are a lot of statistics that we'd really benefit from but will be very difficult to gather.

**SS** asked FH why there is no RCN endorsement for the pathway. SS stated that he has asked this before but not had a straightforward answer.

**FH** responded, stating that she believes it's in progress, but can Fern go away and find out where we are with it.

**SS** added that the reason he is bringing it up again is because all those individual organisations that Crohn's & Colitis UK have worked with on this have nursing embedded in their services and you really need to include that group particularly when you're producing pathways and have your endorsements on that. SS stated that he is wondering what nursing groups are being consulted and talked to about this.

**FH** apologised that she can't give more of an update, but stated she is aware of groups they are talking to, and nurses are a key part of that. FH added that they have examples of advanced practitioner nurses within primary care and the role they can play there and as an organisation they are going to events and speaking with nurses about their role with this and their interface with patients going through diagnosis which are very useful conversations to guide that.

## Agenda item 8

**Statement on behalf of Jen Mills (JM) on living with Crohn's Disease and her diagnosis story: Read by Phoebe Sheppard, Policy Lead for Scotland & Northern Ireland, Crohn's & Colitis UK**

**TP** played a recording of Jen's story, read by PS.

Jen was diagnosed with Crohn's Disease in 2020, but her journey to diagnosis goes back much further than this.

In March 2012, after losing her dad to lung cancer and experiencing the breakdown of a long-term relationship, Jen accepted a job in England and the impact of the immense stress she had faced for a long time began to hit her physically.

She was eventually diagnosed with Uveitis, a condition that causes painful inflammation inside the eye. Uveitis can often be caused by other conditions such as IBD. Jen had multiple tests to investigate what was causing it, but at the same time returned home to Edinburgh and was told results would be passed on, but enquiries with NHS England were met with “well you’ve left now, it’s not our problem”.

Towards the end of 2019, Jen started to get painful abdominal cramps every time she ate and got painful sores in the groin but was told it was simply down to her lifestyle when she reported it to her GP.

Jen experienced a major flare up in January 2020. She had an excruciating headache and struggled to stay awake or eat, as well as abdominal cramps so painful she couldn’t sit down. She was vomiting uncontrollably through the night – but put it down to food poisoning.

In March 2020, after being told that her work was closing their doors for the foreseeable due to the COVID-19 pandemic, she was nauseous and began uncontrollably vomiting at work. Everyone at work thought it was just the stress of it all, and she went home feeling ashamed. Jen felt extremely alone, knowing something was likely medically wrong at the worst possible time in the history of the NHS.

Jen had a sudden onset of the same symptoms 6 weeks later, but the GP didn’t listen, saying she was probably hormonal, and suggesting trying the contraceptive pill. She was then sent to A&E after begging to see a GP face to face as her cramps became particularly bad, she was unable to stay still and was vomiting again. She felt heard and cared for the first time at A&E at the Royal Infirmary Edinburgh, who provided pain relief, anti-sickness medication, and performed an examination, x-rays, an ultrasound and CT. She was referred to the gastroenterology team a few days later.

In November 2020, following periods of total normality, Jen had received no further appointments from the gastroenterology team, but experienced a flare up of symptoms again. After spending close to 6 hours vomiting constantly, she called NHS 24 who were concerned enough to book her into A&E. She was visited by a pair of Gastroenterologists who told her “We can’t be sure, but at the moment our bets are it’s either Crohn’s Disease, or cancer”.

The following day she was moved to the gastroenterology ward and told she would be getting a colonoscopy, which by the end of they were sure it was Crohn’s subject to the return of biopsies. They found a roughly 15cm stricture in her terminal ileum, which was caused by years of unnoticed, untreated inflammation.

Whilst she was relieved it was not cancer, she began to panic as she did not know what Crohn’s was and had no one to talk to. Her consultant struck a deal with her – she was allowed to look at one website, no googling. Crohn’s & Colitis UK only.

She began steroids immediately and was sent home to wait for an appointment with the IBD team at Western General. She didn’t realise then that getting her diagnosis wouldn’t just be the end of it.

Whilst Jen appreciated her fantastic IBD team who treats her as a person not a patient, engages her in her care plan, and emphasise and act fact when they need to, she shared the difficulties of trialling new medication including at home injections. She received instructions from a YouTube video and although she thought the first biologic would be her ticket to health, it brought on several symptoms that made her feel even worse such as joint pain, fatigue and urgency.

In June 2021, after breaking down on a call to her IBD consultant, Jen managed to get an appointment with a colorectal surgeon within weeks. She also managed to engage a GP and her practice who apologised for the lack of care she had received and said that they don't know much about IBD but would take her lead. Jen spoke to her GP about the toll her condition was taking on her mental health. The focus had always been on the physical, not on whether the pain she felt was only due to physical symptoms or the fact she was coming to terms with living with a lifelong condition.

In November 2021, Jen received a date for surgery with 2 weeks' notice following a cancellation. Her surgical team were superstars, it felt like something as straight forward as a haircut. In reality, 30cm of bowel spanning her small and large bowels plus my appendix and caecum were removed via keyhole surgery. Jen's recovery was quick, and she felt like a new person; she believes surgery saved her life. Jen has gone on to achieve so much: carving a new career in the pension's industry, doing a part time degree through the open university, meeting and marrying her ever-supportive husband, buying their first house and hopefully starting a family is around the corner, if her Crohn's allows her.

Jen emphasised, however, that her life remains far from normal, even in remission. She continues to have physical issues due to bile acid malabsorption post-surgery and is reliant on daily medication. She often fears eating and has to cancel plans last minute due to urgency. Jen continues to get severe joint pain, is easily dehydrated and has fatigue that is so draining at times she can't wash or feed herself. And despite having a poor immune system, because she is not on immunosuppressants for Crohn's she is not entitled to COVID-19 boosters or flu jabs. As a result, she has had COVID-19 4 times, the last of which was severe enough her husband had to call NHS 24 who sent paramedics to check on her.

Jen went on to share that she is one of the lucky ones. Not every IBD is as responsive, open and helpful as hers and even others under the same team she's spoken to have had different experiences. Others also have more severe symptoms or other conditions in combination which make managing IBD a lot harder.

Jen concluded by saying that without the NHS those living with IBD can't function. IBD isn't temporary and it doesn't fix itself. People with the condition need engagement from all healthcare professionals, research to find out why people get IBD and more treatment options. They need a support network and it to be accepted that just because you can't see their disability or understand their condition it doesn't mean they don't need help. Jen reiterated that she doesn't need to sit there and tell us all how much the NHS is on its knees, but she hopes that her recent journey with IBD has given the group some insight into the lives of over 50,000 people across Scotland today.

**PMcN** commented that it's always really helpful to hear people's stories and see themes that come through about how long it takes for diagnosis. PMcN added that it's disappointing that you're still up against a health service that takes too long to diagnose people. PMcN concluded that she's very grateful to Jen for sharing her story.

**TP** added that they will pass on our thanks to Jen for putting this together for the group.

**PMcN** added that it's so illustrative of what a debilitating condition it really is and how it impacts on your mental health and everything in your life, but how it's possible to come out the other end with the right support. PMcN continued, stating that's why Crohn's & Colitis UK are such an important organisation for people who are living with the condition.

## AOB

**PMcN** stated that we are required to do a plan and send an email around to all the members on what they would want us to focus on. PMcN added that this includes concrete things the group could do, specific asks, and questions to ministers. PMcN stated that it's important to keep doing this, as PQs are there for all time. PMcN concluded that this is an important subject for many people in Scotland, so we need to regularly send through PQs and try and get the Health Minister to come along to a meeting to make sure Crohn's and Colitis are on their radar.

**PMcN** shared that a new member of staff will be starting in December, taking over Pamela Smith's previous role. They will be attending the next meeting on 11 December.

### Actions

- Members to confirm with Phoebe if they would like to remain members **before 31 September**, if they haven't already, so they can be listed on the annual return.
- Members to send any ideas for the workplan to Phoebe [phoebe.sheppard@crohnsandcolitis.org.uk](mailto:phoebe.sheppard@crohnsandcolitis.org.uk) for consideration. A draft workplan for 2025 will then be shared with members and will be on the agenda at the next meeting for discussion and finalisation.
- Crohn's & Colitis UK to draft a letter to be sent out to Health Boards and send to Pauline McNeill and Clare Adamson.
- Pauline McNeill and Clare Adamson to sign and send out the letter to all Health Boards in Scotland on behalf of the CPG.

**Next Meeting: Wednesday 11 December, 6pm**