Cross-Party Group on Inflammatory Bowel Disease (IBD)

26 February 2025, 6-8pm

Minutes

Present

MSPs

Pauline McNeill MSP, Convenor (PMcN)

Liam McArthur MSP

Colin Smyth MSP

Invited guests

Burcu Borysik (BB)

Thomas Preece (TP)

Christopher Hornby (CH)

Katherine Keay

Elizabeth Hamilton (EH)

Dr Shahida Din (SD)

Non-MSP Group Members

Phoebe Sheppard, Secretariat (PS)

Dr Ian Arnott (IA)

Dr Johnathan MacDonald

CNS Seth Squires

Dr Amy Bednarz

Angus Holden

Edmund Murray

Dr Harvey Humphrey

Siobhan Ross

CNS Vikki Garrick

Observers

Lorna Kirstin May

Heather Market Rankine

Lucy Macnair

Dr Santosh Salunke (SS)

Dr Jacqueline Paterson

Audrey Wild Smith

Apologies

Dame Jackie Baillie MSP

Angus McLean

Kirsty Gibson

Lis Bardell

June Brodie

Caroline Brocklehurst

Dr Jen Veryan

Pauline Bell

Cher-Antonia Khedim

Professor Richard Russell

Agenda item 1

Welcome and Apologies

PMcN welcomed everyone to the meeting

Agenda item 2

Minutes of meeting 11th December 2024 - PMcN

The Minutes from the meeting 11th December 2024 were approved.

Agenda item 3

Matters Arising – PMcN

The long-awaited Homecare Medicines Review is due to be published by the Scottish Government imminently. The British Society for Rheumatology first raised concerns about homecare medicines delivery services in 2022 after reports of patients experiencing delays in receiving medicines. We will be reaching out to the CPG on Arthritis and Musculoskeletal Conditions to see if we can work together on parliamentary engagement around this.

Agenda item 4

One of our stories – Christopher's diagnosis experience

CH explained to the group that he began experiencing symptoms at 19 years old, when he had unexplained weight loss, constipation followed by loose bowel movements, and extreme fatigue. **CH** shared that he felt overwhelmingly tired as if his legs could collapse beneath him, and he remembers thinking it wasn't normal to feel this weak.

CH visited his GP after a few weeks, who attributed it to a stomach bug despite his symptoms persisting. One morning, on his way to work, he had to stop the car three times to be sick, and when he finally arrived at work, he felt the urgent need to use the toilet. When he turned to flush, he was met with a bright red toilet bowl and panic set in. He contacted his GP who saw him a few hours later, but suspected a burst stomach ulcer this time, prescribing lansoprazole and telling him to see how things progressed over the next few weeks.

CH emphasised that during that time his health deteriorated rapidly. His weight plummeted, and he experienced daily blood loss, vomiting, extreme fatigue, and weakness. His parents insisted he return to the doctor, who agreed to refer him for an MRI scan. After waiting weeks for news, he received a letter from the head of radiology, stating that an MRI would be a "waste of resources" because his symptoms were likely due to his lifestyle, specifically drinking at the weekend with friends.

CH shared that he returned to his GP frustrated, who fought back and forth with the radiology department over the following months, pushing for a scan. Because he rarely saw the same doctor twice, it was very difficult as each one had to piece together his story from scratch.

Finally, he met with a doctor who had experience with IBD and made an urgent referral to gastroenterology. Three weeks later, having lost three stone and barely functioning due to malnutrition, bowel issues, vomiting, and pain, he underwent his first colonoscopy, but the procedure failed due to stool compaction.

CH went on to explain that the second attempt three weeks later was successful, and he was diagnosed with terminal ileal Crohn's disease. He initially felt relief – at least it wasn't cancer, but he was then told it wasn't curable, and he could only be given medication to stop it from getting worse.

CH explained that at his follow-up GP appointment, the doctor seemed confused as to why he was there. The GP looked up the medications he had been prescribed, looked up Crohn's disease, printed out the Wikipedia page and sent him home.

CH emphasised that in total it took eight months from his initial GP visit to get a diagnosis, and he believes much of the pain, suffering, and lost time could have been avoided if GPs were more knowledgeable about IBD and if the radiologist hadn't been so dismissive.

CH highlighted that delayed care after diagnosis can be just as harmful ad delayed diagnosis itself.

CH added that after 13 years of living with this disease, he has learned to manage it well. He has been on various treatments, and apart from occasional flare-ups and a diagnosis of another autoimmune disease – Ankylosing Spondylitis – he's generally lived well.

However, in January he experienced a severe flare-up. He repeatedly contacted his IBD helpline, which as he later found out was unstaffed for five months. During that time, he was only given entry-level steroids which weren't working, and he was unable to speak to a specialist directly.

After five months, he was finally put on infliximab infusions, but by then the damage was already done and he saw no improvement, even after months of treatment. He was eventually referred for an MRI scan, but it took seven months from his initial request to have the scan done and during that time he was offered no additional tests and was being treated blindly. The MRI revealed multiple obstructions along a meter-long section of the small intestine, extending into the large intestine. Some parts of the intestine had narrowed to just 1mm in diameter due to scarring from untreated inflammation and ineffective steroids.

CH explained that in December 2023 he underwent major bowel surgery. An 8-inch incision was made from his belly button to his hip and the damaged section of the intestine was removed, along with his appendix, and his intestines were reattached. He spent several nights in intensive care and still feels the effects of the surgery to this day.

CH shared that the hospital acknowledged that the delay in investigating and treating his condition was unacceptable and promised to improve, but as he is speaking today his team is already three weeks late in calling to follow up on a possible new flare up.

CH concluded by sharing that he is not sharing his story to shame or attack any hospital or doctor. CH shared his hopes that his story can be used to improve diagnostic times and post-diagnosis care for others with IBD. No one should have to fight this hard to receive proper medical attention.

Discussion

PMcN thanked CH, adding that it really is important for the Cross-Party Group to always be reminded of some of the issues he has talked about which is common with a lot of people who have spoken to the group, this endless period trying to get a diagnosis in the first place and it being dismissed as something else. It is a very important issue so thank you for sharing your experience.

CS echoed **PMcN**, thanking Chris for sharing his story. **CS** asked if we know whether there is a perception in the NHS that it doesn't really change your overall outcomes in the end, is that the reason why there doesn't seem to be an urgency when it comes to diagnosis? **CS** shared that there seems to be an idea that a late diagnosis doesn't really matter because outcomes don't change once you've got a diagnosis, and he wonders if it's because of complacency.

CH shared that he feels like some people do have this perception like when he was trying to get hold of his IBD team for 5 months in 2023 during a flare-up and it resulted in him needing surgery, he put a level 2 complaint in stating that he thinks it could've been nipped in the bud if he was given the right treatment at the right time. They responded saying that this probably would've happened even if he had received treatment. **CH** doesn't know how they can say that given they don't know that for sure. **CH** shared that he feels like it depends on who you deal with but does think some believe surgery is inevitable.

CH added that his care has gotten worse. For 13 years every time he would phone the IBD advice line they would be there and get back to him within 48 hours and issue the necessary tests to see if he is in a flare up, as well as provide timely treatment. In 2023, that failed and right now it's failing again. **CH** shared that he has been waiting 3 weeks for a returned phone call from the advice line. **CH** added that he is sitting right now with pain under his left rib and there is nothing he can do about it, so for him this year is echoing 2023 when he needed major surgery and he's not receiving the support to do anything about it.

SD added that she is very sorry to hear **CH's** story, but sadly it is not a rare thing that happens to our patients, and we are seeing massive delays in diagnoses and treatment. **SD** referred back to what **CS** had said, adding that he is absolutely correct, people do not appreciate how active inflammation even for short periods of time can lead you to have long lasting complications that need surgery. If you went to a specialist centre, they would be able to show you data to illustrate that when you treat people affectively it does mean that they have less time in hospital, they don't have to be admitted, there's a lower chance of having surgery, but getting that information out to the masses is actually very difficult. **SD** shared that she has done some work looking at trials to see what happens when people with IBD are given effective therapy versus no therapy and it is really acute that absolutely people without treatment for the disease will come to more harm. **SD** went on to explain that they will be admitted, lose parts of the bowel during operations and will face an immense impact on their lives more generally, not being able to go to work or socialise due to toileting.

SD reiterated that so much more needs to be done to raise awareness of the impact and IBD sadly is one of those non-cancer conditions, so it is not high priority. Access to endoscopy is therefore severely restricted, access to clinics can be restricted, when we do have specialist nurses they often get pulled away if there is a shortfall elsewhere. **SD** added that it's that lack of recognition of the need for people to get timely treatment. **SD** finalised by saying she is very sad to hear CH's story, but this is the reality of what a lot of our patients live with.

CH agreed and **PMcN** thanked **SD**.

PMcN thanked **CH** again for sharing his experience and wished him all the best.

Agenda item 5

Factors contributing to delayed diagnosis & the impact on patient outcomes, Dr Ian Arnott, Consultant Gastroenterologist, Western General Hospital, NHS Lothian

IA opened the presentation by saying that just as **CH** as so elegantly said, delays in diagnosis are a real problem and we have seen them for a long period of time. As **SD** just mentioned, when **IA** first started in gastroenterology there was a perception that if you didn't make the diagnosis, it didn't really matter because people would get to a diagnosis in the end. **IA** added that this is just not true.

People who experience the longest delays in diagnosis are four times as likely to have serious bowel complications and twice as likely to have surgery. This is now being replicated in a number of different studies from around the world. **IA** commented that you would hope IBD services over the last 10 or 20 years have improved, but one area we have not seen much improvement is in the diagnostic phase. **IA** thinks it is very important and quite appropriate that we are talking about this now.

IA explained that a lot of evidence comes from the recent IBD UK report, and if people haven't read it already it is worth at least looking at the first few pages. It's a very significant piece of work that took place across the UK. In Scotland over 1500 people completed the patient survey and the majority of IBD services completed the service survey. The patient and service survey are meant to ask broadly similar questions that we can tie together. The service questionnaire asks services about what they do and don't offer, whereas the patient survey asks about people's experiences of IBD right throughout the phases that are outlined in the UK IBD standards such as diagnosis, outpatient and inpatient care and surgery.

IA added that there is a recommended journey to diagnosis and treatment outlined by the IBD Standards, but as **CH** has already explained this often doesn't work properly. People will develop symptoms of IBD, go and see their GP, the GP should recognise that, and the patient should be referred to see a specialist and a diagnosis should be made. A lot of people delay going to see their GP and then when they see the GP there is a delay in referrals. There are delays in every part of the process. Although delays from GPs have already been mentioned, delays in secondary care are just as important and are unfortunately just as bad, if not even worse.

Engaging with healthcare

IA shared that most people will wait between 1-6 months after the onset of symptoms before making an appointment with a healthcare professional. **IA** commented that it's staggering that almost a third of adult patients with symptoms waited over a year to see a healthcare professional.

IA added that we need to ask ourselves why people are delaying visiting their GP. 10% of people believe their symptoms will not be taken seriously and that is a cold hard fact to us in healthcare - we have a duty to always take people's concerns seriously.

There is also a misconception that you must have continuous symptoms to have Crohn's or Colitis and many people, especially initially, think that it's a stomach bug or a bit of IBS and will hang on and wait before seeing their GP. A lot of people are also embarrassed and some of the campaigns that Crohn's & Colitis UK have done about raising awareness and trying to destigmatise GI symptoms are very important.

Referral and diagnosis

IA commented that what **SD** said earlier is very important. Many other conditions, particularly cancer, have very clear waiting time guidance about when and how quickly you should see someone and have a scope, but that just isn't present for IBD. If people wait a very long time, they are more likely to be admitted to hospital and outcomes will be worse. In Scotland, 1 in 6 (16%) adults reported waiting more than a year to be referred to a hospital after speaking with a healthcare professional. The UK average was roughly 1 in 7 (14%), so this is higher than the rest of the UK but both figures are unacceptable.

Availability of faecal calprotectin tests

IA shared that the availability of faecal calprotectin tests is another factor that plays into delays in diagnosis for IBD. Calprotectin is a stool test that detects inflammation, and it is elevated in the vast majority of people with IBD. It can be difficult to exactly tell the nature of gut symptoms when they present themselves and faecal calprotectin is a fantastic thing that can differentiate between inflammatory and non-inflammatory causes of gut symptoms. Faecal calprotectin tests are only available in primary care in 70% of Health Boards across Scotland. The guidance and availability of these things has probably become worse, particularly in some Health Boards over the years and there is now quite strict guidance in many about the frequency of retesting. Retesting calprotectin can however be very useful in that diagnostic phase.

IA reiterated that there are delays in every part of the process. **IA** shared that bowel conditions are very difficult to diagnose. Sometimes taking a history, it can be very difficult to differentiate between Inflammatory Bowel Disease (IBD) and irritable bowel syndrome (IBS), particularly in a young population.

IA added that until very recently there was no real pathway to support that diagnosis and there has been confusion about which referral pathway from primary to secondary care people should go down. There is a lot of different practice that goes on in different parts of the country and a streamlined approach for healthcare professionals would be very helpful. When accessing healthcare, people often see lots of different professionals with different skillsets, so if there is a clear resource all professionals can access that will certainly be helpful.

Endoscopy delays

IA commented that endoscopic delays are a bug bear. The pandemic really brought endoscopy delays to a head and not many services have recovered. Approximately a year ago there was a financial crisis in many health boards and Lothian were right in the middle of that. The response from health boards was to stop any form of outsourcing and so colonoscopy waits went up again. Endoscopy waiting times have therefore been compounded by a sequence of things over the years and do remain a real issue.

Almost a quarter of people waited over 6 months between being referred to receiving a diagnosis and data from Public Health Scotland published this week revealed that the highest proportion of patients were waiting a year or more for a colonoscopy in December last year since January 2023. In January 2023, waiting lists were still recovering from the pandemic but as we hit spring 2023 things were stable, however, in recent times waiting times over a year have got significantly worse. **IA** commented that we need to make sure we do endoscopy on the right population because if we do it on the wrong population it leads to longer waiting lists.

Recommendations

The ‘National Primary Care Diagnostic Pathway for lower GI Symptoms’ should be implemented across all Health Boards in Scotland and all primary care practices should have access to screening tests (e.g. Faecal Calprotectin) to make appropriate and timely referrals.

Services should look at their diagnostic waiting lists and stratify those waiting lists, so you ensure you scope the people with the greatest need. This should include considerations for disease progression or regression, functional status (e.g. activities of daily living), quality of life, patient satisfaction, adverse events (such as emergency surgery) and mortality rates.

For many patients, the current waiting times mean further deterioration of their condition(s), with far-reaching implications. This applies to all conditions but is especially tough for people experiencing physical pain, such as those living with Crohn's and Colitis. Patients should be provided with clear information delivered in a way that suits them (visual, online or in print) on how to manage symptoms, particularly information on pain relief and psychological support to deal with pain. This should be matched with adequate capacity in primary care to carry out routine monitoring and interim interventions and treatments as required; as well as adequate specialist advice capacity and clear pathways to specialist advise if symptoms escalate.

Public health campaigns are also vital in raising awareness of the conditions and to ensuring that more people come forward to healthcare professionals when they experience symptoms.

New NHS Scotland IBD diagnosis pathway

IA added that he will close by publicising some of the work that has been done by Seth Squires, who is in the audience today, on a new pathway for IBD diagnosis. **IA** commented that this pathway and the lower GI pathway will be used by different people in different situations. The pathway refers to both primary and secondary care and is going through the Centre for Sustainable Delivery (CfSD) processes. **IA** shared that it will be released very soon and asked the group to take this opportunity to inwardly digest and use it where appropriate.

Discussion

PMcN thanked **IA** and commented that his presentation was very informative.

Agenda item 6

Lower GI pathway update and discussion, Burcu Borysik, Head of Policy & Campaigns Crohn's & Colitis UK

PMcN introduced **BB**, Head of Policy & Campaigns for Crohn's & Colitis UK.

BB shared that the lower GI pathway was created because Crohn's & Colitis UK and other charities supporting people with lower GI conditions have had longstanding concerns about the impact of delayed diagnosis in the people they represent. The pathway has been endorsed by a number of organisations including the BSG and RCGP.

Our reach so far

BB explained that as part of IBD UK national reporting, Crohn's & Colitis UK have included the pathway as a best practice clinical case study and have been sharing this in a limited capacity so far at various conferences.

BB shared that at the moment the people most interested are patients who are looking for resources to take to their GP to enable conversations and understand what tests they should be pushing for. Whilst it is enabling a conversation for patients, it is an education tool for GPs and other primary care professionals.

The Leona M. and Harry B. Helmsley Charitable Trust

BB shared that this year Crohn’s & Colitis UK have received some funding from the Helmsley Charitable Trust, which is a US based fund. Their aim is creating stronger, healthier futures for individuals and communities. They have been investing in the charity and various other initiatives across the country to improve diagnosis and care for people living with Crohn’s and Colitis.

Progress in 2025

BB explained that Crohn’s & Colitis UK have are able to use this funding to promote the pathway and have set up a steering project group internally and externally.

BB added that the charity also begun market research on the most effective and efficient ways to engage and educate GPs, which will inform our work throughout the project.

BB shared that they are currently testing some engagement on digital screens for patients in GP surgeries.

BB added that yesterday a successful roundtable in Manchester was held on the implementation of the pathway, particularly focusing on England. Shahida has been kindly supporting this work, and Crohn’s & Colitis UK intend to host a similar roundtable in Scotland in the coming months.

Implementation in Scotland update

BB shared that thanks to **SD,** Crohn’s & Colitis UK have been engaging with the Centre for Sustainable Delivery (CfSD) and know that the pathway is currently going through their process. They are of course very busy with their schedule, and it might take a few more months for us to get the full approval, but the initial engagement so far suggests no barriers. It is more of an administrative issue.

Once the pathway is approved health boards will be sent letters explaining that the pathway is recommended and encouraging implementation.

Discussion

BB asked to pause here and asked for the group’s expertise to have a discussion around how we might be able to best implement the pathway in Scotland and take it forward.

BB welcomed any contributions on the following discussion points:

- How do we measure the impact of the pathway? What elements do we need to be monitoring?
- How do we make sure new referrals coming through the pathway are being seen, given significant backlogs?
- What is the role of health boards in this?

- How can we support GPs to get educated on the pathway?

SD shared that she went to the roundtable meeting in England yesterday and feels it may be helpful to share some of the thoughts that were coming from that discussion.

At the roundtable when speaking about key barriers, it was more about raising awareness of the pathway and how we can do that. One idea was to refer to the pathway as a toolkit that primary care professions can do Continuous Professional Development (CPD) on because then it does engage them and explain the purpose.

One of the GPs involved with developing the pathway ran a session on it in one of the main GP education days that attracts GPs across the UK. That is one way to raise awareness of the pathway.

SD explained that the main barriers discussed were about how this pathway has not come from a governmental process but from a need expressed by patients, partly because QFIT was rolled out and there's a lack of access to calprotectin, as well as that GI symptoms can present in a number of ways and there's several different conditions it could be. It's about how we help patients to actually access the care that they need.

There's two parts of the pathway; one is for healthcare professionals to read and use. From a patient perspective, there is information, including for parents and carers of paediatric patients. It demonstrates how to talk about symptoms, which can often be embarrassing and quite isolating.

One of the biggest barriers is that GPs are bombarded with a number of different specialties, and they have to remember so much. **SD** said we need to look at how can we encourage GPs to actually use the pathway as this will be more efficient for them.

SD added that we have to remember that patients don't just go and see GPs, they will meet a number of healthcare professionals. **SD** said we need to consider how we get that level of knowledge shared around that group of different health professionals. The pathway really is really bringing it back to the basics, and **IA** talked about having history sometimes doesn't help. **SD** shared that she thinks it does help, but you need to learn how to take a good history and a lot of people don't have time to do that all the time. SD reiterated that we need to break down barriers to this.

SS thanked the three presenters, sharing that they were all very helpful. **SS** explained that there are a few barriers from a GP perspective. Firstly, there are a lot of pathways that are being thrown at GPs and sometimes it's very hard for them to keep up, and especially in the GI world quite a few pathways have been in development. On top of that, the education around basic skills such as history taking and the time for history taking is a barrier, and that on basic investigations before arranging more advanced investigations.

SS shared that one of the things he found very helpful with the new lower GI pathway is in a world where lots of things are test based, the pathway brings us back to the basics in terms of what was the presentation, what symptoms does the patient have, and how do you work systematically through the pathway. The lower GI pathway is very good in addressing that. When it was out for consultation, **SS** was having conversations with lots of GP colleagues locally and what they found helpful was that systematic approach the pathway follows. **SS** argued that it would be good to sell that strength of the pathway to secondary and primary care colleagues. **SS** added that there are various platforms. Locally they use Create Sessions for our primary care colleagues, where they have monthly or two-monthly education afternoons where primary care colleagues from the entire region meet. Often when they have gone to those groups from secondary care, the buy in from primary care has been very good. **SS** added that sometimes they learn the challenges primary care colleagues face and that it might be a good platform.

SS explained that CfSD is again a great platform because they have GI endoscopy representation and primary care representation. They also engage with managers and each hospital should have a CfSD champion within the management team, so it is a good platform to take the pathway. **SS** shared that he knows that in the CfSD they have reviewed and discussed the lower GI pathway and certainly in the GI community there has been a good buy in and Shahida, Ian, and Seth would agree. **SS** added that from a GP perspective GP education and buy in is very important especially at a time when lots of pathways are being thrown at them.

SS shared that his wife is a GP and a few months ago she kept talking about different pathways being thrown at them, talking about a new iron deficiency anaemia pathway, and he didn’t have the courage to tell her he was the one leading that piece of work nationally.

SS concluded by arguing that if we sell the strength of the pathway, it should be easy to get buy in.

PMcN thanked everyone for their contributions.

Agenda item 7

Actions and next steps, Pauline McNeill

PMcN commented that all items have been excellent as usual. **PMcN** shared that MSPs should always use the opportunity to table questions on this matter so civil servants see we are asking them. PMcN added that it does flag up the importance of IBD to the health strategy, so please feel free to send questions to her or to Colin.

SS commented that what Ian presented is fantastic and this is something this group has spoken about for a while, and he has been doing some work in the background locally and would like the opportunity to present some data around times for a specialist review and what they are doing locally.

PMcN shared she does not know much about what support is out there for young people in relation to the benefits system. She shared that she had experience with her niece recently, but as Chris mentioned it’s very hard to hold down a job that is quite physical especially hospitality. She applied for ADP and was successfully getting a lower rate once she had verified with her doctor, but it might be worth adding an item about what Crohn’s & Colitis UK are already doing to point in the right direction those that may need support.

PS shared that we can definitely look at that for future meetings. Crohn’s & Colitis UK have a quick guide to disability benefits on their website, which includes information on ADP. Whilst they do not have a specific resource dedicated to ADP, they do have one on PIP which can help constituents apply for ADP too. This is because the point-scoring system is the same.

IA said that a call from this meeting should be for all of us to publicise the national lower GI pathway and IBD pathway. We all have different contacts and spheres of influence and if we all do it on multiple different levels, then it’s much more likely to be successful.

PMcN said it might be worth doing a motion on the lower GI pathway, suggested **CS** do it in his name. **PMcN** agreed to be first supporter and do anything we can to bring awareness to it in Parliament.

CS shared that he is happy to table a motion and circulate it to other members, so they are aware of it and to seek support from other MSPs.

SD asked if a parliamentary question can be tabled on what framework they have for patients to access endoscopy when they suspect it’s not cancer because that is a real big thing clinicians struggle with. **SD** added that unless someone has a QFIT that is positive for example, people can’t get on red flag pathway. **SD** doesn’t know if there are any other pathways in Scotland not for cancer, but we need to look at how we can get there because that is one of our biggest difficulties is getting access to endoscopy.

SD also commented that the QFIT system of ref-flag referrals can overwhelm cancer services, as there will be lots of positive QFITs from people who do not have cancer. **SD** wants to know what other pathway can we have, or if there something already in place we are not aware of.

PMcN shared that she is happy to pick that up, and requested **SD** share more information following the meeting to help with he wording.

SS agreed with **SD** and had made some similar comments in the last meeting. One of the reasons that patients experience delayed diagnosis and access to endoscopy is because we don’t appear to have an IBD specific endoscopy KPI. We have urgent referral targets and routine referral targets and cancer referral targets that health boards are expected to meet, but no suspected IBD target and that may be the reason why there is no huge amount of investment or interest by the purse holders and health boards to prioritise them.

SS shared that clinicians have to manually push some of these things forward. He is a Clinical Director for endoscopy in his health board and tries to make sure patients aren’t suffering from undue delay, but it takes a lot of manual work because of the number of different pathways they can be referred into. If there is a suspected IBD target, then health boards would be expected to meet those targets.

PMcN asked about the faecal calprotectin test and whether it is expected to be used first and then go to endoscopy to confirm a diagnosis.

IA explained that they have tried to allow people to use both QFIT and calprotectin because they are aware that people in some health boards will have access to one and some have access to the other. IA added that they have put advice to both as a pragmatic way to approach this. QFIT is a very sensitive marker of blood in the stool and is first line for cancer diagnostic pathways.

PMcN asked whether GPs should be using either of those tests before endoscopy then.

IA explained that in a practical sense GPs will have access to one or the other. In Lothian the advice is that if a patient is young and presents with gut symptoms, they should do a faecal calprotectin test first but the advice is different in every health board.

PMcN asked but whether in an ideal world if you have gut symptoms, the first job of a GP would be to do either of those tests.

IA said yes, there is good evidence that a calprotectin test is able to distinguish between inflammatory and non-inflammatory conditions very reliably with a sensitivity of 99%. If you're asking the specific question of could this be IBS or IBD, then calprotectin is a very good test to do that. The evidence for QFIT in IBD is probably less rigorous but many people with IBD will have a positive QFIT as well and end up on the cancer pathway.

IA finalised by stating that they have written this pathway to acknowledge that access to these tests varies across the country so primary care professionals should do one, not nothing.

PMcN thanked everyone for their attendance and great contributions. **PMcN** will follow up with **PS, EH** and **CS** around next steps.

PMcN closed the meeting and reminded the group that the next meeting will be on Wednesday 11th June at 6pm.