Minutes of the Sixth Meeting of the Cross Party Group on Inflammatory Bowel Disease (IBD)

Wednesday 19th September 2018, 6-8pm

Committee Room 6, Scottish Parliament

1. Welcome and Apologies

Clare Adamson MSP introduced herself as the Deputy Convener, chairing the meeting this evening and gave a warm welcome to those present. She explained that there had been a lot of people unable to travel to the meeting due to the amber weather warning.

Apologies were received from:

Pauline McNeill MSP (Convener), Jackie Baillie MSP, Kirsty Gibson, Paul Johnson, Edmund Murray, Janice Taylor, Dr Daniel Gaya, Professor Richard Russel, Vikki Garrick, Seth Squires, Allan Boal, Dr Jonathan MacDonald, Dr Graham Naismith, Professor David Wilson, Professor Ian Welsh OBE, Christopher Doyle, Dr Dagmar Kastner, Dr Amy Bednarz, Dr Philip Gaskell, Elaine Steven, Susan Brooks, Dr Chris Evans, Louise Horne, Emma Howie, Matthew Hilferty, Rachel Hayward, Gillian Cowell.

2. Minutes of 23rd May and actions

Clare asked for points of accuracy in the minutes of the meeting held on 23rd May. No points were noted.

The minutes were moved by Dr Ian Arnott and seconded by Colin Smyth MSP.

3. How video clinics and 'on-demand' review can make the IBD service more patient focused, Dr John Thomson, Consultant Gastroenterologist and Clinical Lead Electronic Patient Record, NHS Grampian.

Scottish Government Consultant Digital Health Lead: The Modern Outpatient

Dr John Thomson explained that half his role is spent as a gastroenterologist and the other half as a digital lead locally with NHS Grampian and with the Scottish Government. Most of his clinical time is spent with the Inflammatory Bowel Disease service at Aberdeen Royal Infirmary.

Quite a few years ago Dr Thomson noticed that many patients were travelling a very long distance for a 6 or 7-minute appointment with him. He looks after patients from Shetland and Orkney and they spend a 'ridiculous' amount of time travelling to Aberdeen for short consultations. He was also spending so much time seeing people who were relatively well that there was less time to see people who were far more unwell. He investigated the idea of an urgent return clinic so people could easily access the service when they need it.

Dr Thomson gave the meeting a live demonstration of the Attend Anywhere video clinics he uses in Grampian. Previously the old NHS video conference software didn't work so well. There were often sound issues and there was no virtual 'waiting room' for patients.

Attend Anywhere is an Australian tech-enabled healthcare product which is now branded as "NHS Near Me" in Scotland. People can connect to the virtual clinic from anywhere and

it can be fitted around their daily life. Dr Thomson has had a consultation with someone in Dubai, someone in a cupboard in their office and with women who were breastfeeding during the consultation.

Dr Thomson showed members the virtual waiting room on the screen which showed that Professor Angus Watson who was at home in Inverness had been waiting for 11 minutes. He explained that there are a few nuances to learn when getting used to using Attend Anywhere, such as where to look so the webcam shows the doctor looking at the patient and not the screen. New undergraduates are taught this as part of their consultation skills. The only thing doctors can't do as part of a video consultation is physically examine the patient, but this can be done locally by a GP or nurse.

Although there are patients who travel huge distances for appointments, the average travel distance in NHS Grampian for outpatient appointments is 40 miles and this is made up largely of many shorter journeys. It is mainly the working age population who would otherwise need to take time off work for appointments who are self selecting to use Attend Anywhere. People can avoid taking a whole day of unpaid leave to travel to and from a 6-minute appointment.

Dr Thomson explained the open review process where people come back into clinic when they need an appointment by phoning the IBD helpline or the gastro reception. He noted that the majority of people with chronic disease know their disease well and when they need to see someone. Using this system the IBD waiting list in NHS Grampian has halved.

Prof Angus Watson joined the meeting by video and said that in NHS Highland, the average travel distance saved per patient using Attend Anywhere was 120 miles. In total, thousands of miles of travel have been saved and this has enormous benefits in terms of the carbon footprint and patient convenience. He noted that video clinics are an acceptable way of doing business when there is good connectivity. Clinicians and patients can go over blood results and x-rays the same way as they can in clinic.

Dr Ian Arnott asked about the process for sharing the screen so that patients can see copies of test results that are on the doctor's desktop. Dr Thomson explained that this is possible even when people are using their smartphone.

Next in the 'waiting room' was Rebekah Middleton, Senior Project Manager at the Outpatient Transformation team in NHS Grampian. Clare Adamson asked Rebekah if Attend Anywhere is being rolled out more widely than the IBD service. Rebekah explained that it is, but her role is to do a test of change with the IBD service. Dr Thomson's clinic is almost full of patients using NHS Near Me and this is part of the culture of change, However there are still people who prefer to come and sit in a room with their consultant.

Lis Bardell asked if people can still develop a relationship with their consultant if they don't meet in person. Dr Thomson explained that they have offered NHS Near Me to people coming back as a return patient, but it is up to the patient which they prefer. He is now so used to it, that the video clinic is just part of a normal clinic.

Gail Grant asked if use of this technology has reduced DNAs (Did Not Attends). Dr Thomson said that rates are much the same as there are still people who are less accepting of their condition or have other reasons for not attending. Staff try to phone people if there has been a technology failure at either end, but people can still forget they have an appointment.

There was some discussion over the potential to roll out NHS Near Me around Scotland. It requires both parties to use the Chrome browser, but NHS Lothian has barred the use of Chrome. It is not clear if this is because of a security concern or because Lothian do not want to use a third internet browser. The National Project Manager for NHS Near Me, Dawn Robb joined the meeting via the video link and said that she is 'chipping away' at the browser issue nationally.

NHS Grampian is by far the biggest user of NHS Near Me and has needed project management to integrate it into the service. There is now a second screen and webcam in every consulting room.

Miles Briggs MSP asked if people get email reminders for their appointments and Dr Thomson said they do. They receive a text with a link for their appointment either the day before or on the morning of the appointment.

Lis Bardell asked about the safety issues of the open review process for people taking long term medication. Dr Thomson explained this is built into the algorithm and that people are invited to an appointment at least every 2 to 3 years, sooner if required for monitoring. People can also choose when they want an appointment and there does not need to be a medical reason. You do not need to justify it if you just want to have a chat with your consultant.

Group members thanked Dr Thomson for a very engaging presentation and Prof Angus Watson, Rebekah Middleton and Dawn Robb for joining the meeting by video

4. **Why I want to be involved in redesigning IBD services**
   A patient from NHS Borders

Nancy Greig explained that the patient from NHS Borders who had been due to speak was very disappointed that she was unable to attend and speak in person because of the weather but had given Nancy permission to read from notes she had prepared.

Patient X had been a victim of parental neglect and was admitted to a children's ward aged 13 where she had and emergency colostomy due to a recto-vaginal fistula. X developed a huge fear of hospitals growing up.

She has experienced many hospitals, but the care she has received as an adult at Borders General hospital surpasses all these. She explained:

"Borders General Hospital is the first hospital where I haven't felt like giving my last name as Houdini and smuggling myself out of the waiting room in a barrel. The staff there don't only treat you as a friend, they treat you like part of their team."

Patient X recently joined a process-mapping exercise with the staff from the Borders IBD service despite her fears. She felt compelled to join in because the staff were fully committed to the process. X believes that a radical redesign of the service is needed.

She gave an example of one of many harrowing experiences she has had related to travelling to the Western General Hospital in Edinburgh for treatment:

"Ever spent £12 you couldn't afford, to travel for 2 hours on a jam-packed bus to Edinburgh with a leaking ostomy on a work-day with no paid leave, to be told in a five minute appointment with a stranger who can't pronounce your name that you're probably

going to have to get that pesky rectum taken out if you don't want to get cancer, then left to deal with that knowledge, in tears, on the two hour trek back home?

X expressed her gratitude to the IBD team in Borders, saying that they are an incredible team of fully engaged people with a sense of purpose. However, she noted that the department is understaffed and each team member does a huge amount of work over and above their job description.

In X's opinion the interface with the Western General for Borders patients who require outpatient care or surgery there needs to change. She explained:

"There are huge issues with lack of communication and a lack of information about the practicalities of attending hospital in Edinburgh. Spending money you can't afford AND losing a day's wage to get to a place you don't want to go is bad enough - the fact that you've done all that only to be told by a stranger that they don't have your scans, notes or results, are unfamiliar with your case, but think you look well enough, is not a trust-inspiring exercise. It dissuades you from ever going back to the hospital again."

X said that for a number of reasons, including negative experiences and practical issues like having to book hotels, she has not attended appointments at the Western for years. However X would happily attend a local GP Hub to see an IBD nurse if a community service like this was available. This would free up clinicians to treat more complex patients in clinic. She also believes that self management tools can help people with IBD to be responsible custodians for their own condition.

Since moving to the Borders, X's phobia has been replaced by a sense of trust thanks to the kindness and competence of the IBD team. Being part of the process mapping exercise has shown her how much better things could be.

X explained that the staff at Borders General Hospital have changed her life. Their determination to help her is what gave X the strength to tell a room of strangers she'd been so badly neglected as a child. X's IBD nurse was the first person apart from her husband she ever told about it. Because she noticed something was wrong with X and made the time to ask, despite her busy schedule**.**

X believes that service redesign could help to make her IBD nurse's workload more manageable, allowing more time for this important, holistic, emotional support.

Clare Adamson MSP asked Nancy to go back and thank X for her open and witty testimony and said that the group hoped to see her at a future meeting.

5. NHS Borders Community Gastroenterology Service
Dr Jonathan Fletcher, Consultant Gastroenterologist, NHS Borders

Dr Jonathan Fletcher noted patient X's kind words and eye-opening comments. He went on to speak about the service redesign work in the NHS Borders IBD Service.

A copy of Dr Fletcher's slides will be made available for the group. Key points covered in his presentation were:

- The service is under pressure with similar waiting times to other areas. Waiting times for appointments are just under 12 weeks and endoscopy is also under pressure. The new FIT bowel screening test generates a lot of positive tests and the service is feeling the impact of an ageing population.

- GI nurses make a huge difference to patient care, but the two specialist nurses in the Borders are general gastro nurses so they are not only dealing with IBD patients.

- Dr Fletcher said that staff are grateful to Crohn's and Colitis UK and the Modern Outpatient Programme for supporting them to lift their heads from the coalface to look at what is working well and what could be improved in their service.

- Among the areas highlighted by the mapping exercise were the process around diagnosis and the interface with the Western General Hospital.

- The team are keen to trial new national self management tools that are being developed by Crohn's and Colitis UK and the Modern Outpatient Programme.

- Dr Fletcher outlined plans for a radical redesign, i.e. a community-based gastro nursing service. This would be a move away from a traditional policy of routine clinic appointments. Other strands have been added into the proposal include community dietetics. The service would employ one whole time equivalent GI nurse specialist, 1 whole time equivalent administrator and a dietitian. The service would be based in GP Hubs in the community. In the Borders, travel can be a huge issue.

- Dr Fletcher explained that the proposed service would be very much part of the Primary Care team. This proposal fits in with the NHS Borders Clinical Strategy. Buy-in from GPs is very important so they do not think they are being asked to take on more work.

- Activities that are likely to take place in the community-based service would be; clinic reviews, drop-in clinics, telephone clinics, virtual clinics (video), blood test monitoring, dietetic clinics, developing self management tools. Activities would have some overlap with those carried out in the Borders General Hospital IBD service but would allow clinicians to work at the top of their 'tariff'.

- It is very important to have patient support to develop this new service. Staff need to have time to provide emotional support, which was highlighted as key during the mapping exercise.

- The service redesign project team includes consultants, lead GI nurse, dietitian, patients, primary care involvement, staff from the Western General in Edinburgh and Crohn's and Colitis UK. They are also trying to secure project support from the Health Board. Among other sources, a funding bid will be made to the Endoscopy action plan.

- Key benefits of a community gastro service would be:
  -When needed vs. routine follow up
  -Local patient review
  -Patients as partners (empowered and involved with decision making)
  -Release more consultant time for complex cases
  -Better collaboration with primary care

Clare thanked Dr Fletcher for his presentation and Miles Briggs MSP left the meeting at this point.

6. Discussion, 2019 work plan and future actions

The meeting was opened up for questions and discussion. Clare proposed that because of the lower than usual turnout as a result of weather conditions that discussions about the 2019 work plan could be postponed so as not to disadvantage people who could not attend.

Clare asked how IBD nursing posts are funded and whether there is a national strategy. Dr Ian Arnott explained that there is he variation in IBD nurse roles with many working as gastro nurses or covering a number of different specialities. IBD Nurse posts are funded at Board level, but the IBD Blueprint is central to this agenda.

David Pratt. National Improvement Adviser from the Scottish Government explained that the Modern Outpatient Programme is working closely with Crohn's and Colitis UK to implement the IBD Blueprint and that the NHS Borders pilot is guided by the recommendations from the Blueprint.

Dr Arnott thanked all the presenters and noted that he was very excited about the work in the Borders. He talked about the benefits of co-designing new service developments with patients and explained that as an individual clinician you cannot do this kind of work alone. He also noted the huge input of the Scottish Government. He said that chronic disease management has taken a low position in the pecking order both politically and a Board management level.

Dr Arnott, who is the national IBD lead for the Modern Outpatient, said technology such as Attend Anywhere frees up time for patients and clinicians. He outlined the aims of the programme, i.e. the patient sees the right person at the right place at the right time. This often means it would be better for someone to see a health professional in the community rather than in hospital.

Gail Grant asked if the work in NHS Borders was driven or managed by the Integrated Joint Board. Dr Fletcher explained that it was wholly within the remit of NHS Borders and Dr Arnott said it would be important to engage IJBs with this process.

Nancy told the group that the Cross Party Group and Crohn's and Colitis UK has been offered an MSP sponsored exhibition in the Garden Lobby of the Parliament during the week beginning 25th February 2019. Lis Bardell suggested that it might also be possible to have a members' debate that week.

7. Date of next meeting

Provisional dates for next year's meetings are yet to be agreed and will be circulated shortly.

A draft work plan for 2019 will also be circulated for discussion by email.

8. Any other business

Angus McLeod drew members' attention to a Patient Education Evening being held in Edinburgh on 11th October by Dr Charlie Lees. Nancy agreed to circulate the Eventbrite booking link. A link to a recording of the evening is available on You Tube at: **https://youtu.be/Gi1TngvZm_U**

Actions:

Nancy to agree a draft work plan for 2019 with Pauline McNeill MSP and circulate to members for comments and discussion.

Minutes of this meeting to be approved by email in view of the time between September and the AGM at the start of 2019.

Nancy and Pauline to pick up the issue of how IBD nursing posts are funded in any further communication with the Chief Nursing Officer, following on from the group's correspondence with her.

Nancy to keep members updated about any Ministerial correspondence and communication with the NHS Chief Executives Group.

Attendance List

Members:
Clare Adamson MSP (Deputy Convener)
Colin Smyth MSP
Miles Briggs MSP
Dr Ian Arnott
Angus McLean
Lis Bardell
Dr Jonathan Fletcher
Gail Grant – Abbvie
Sally McNaught- CICRA
Prof Angus Watson (via video link)

In attendance:
Nancy Greig- Crohn's and Colitis UK
Paul Cassidy- office of Pauline McNeill MSP
David Pratt- Scottish Government
Dr John Thomson
Rebekah Middleton- NHS Grampian (via video link)
Dawn Robb- NHS NSS Information Technology (via video link)
Fiona Hamill- Janssen Cilag Ltd