

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

Wednesday 13th September 2017, 6-8pm

Room TG 20-21, the Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP gave a warm welcome to those attending the second meeting of the Cross Party Group on IBD and to MSPs Clare Adamson, Colin Smyth and Paul Wheelhouse. Pauline noted a particular thanks to Colin Smyth for representing the group at the Standards Committee in April.

Apologies were received from:

Dr Ian Arnott
Angus McLean
Claire Davidson
Gail Grant
Dr Daniel Gaya
Prof Richard Russell
Seth Squires
Allan Boal
Pam Rogers
Dr Jonathan Macdonald
Dr Graeme Naismith
Prof David Wilson
Ian Welsh
Deborah O'Neil
Kate Gray

2. Minutes of 22nd February meeting and workplan

Pauline explained that due the previously arranged meeting in May being postponed at short notice, the minutes of the February meeting had been circulated and approved by email.

She also explained that the postponement of the second meeting until September had been unavoidable due to security measures, leading to timescales for the work programme being a little behind schedule.

There was further discussion on the workplan in the section on discussion and actions towards the end of the meeting.

3. What patients want from an IBD service- Kirsty Gibson

Pauline introduced Kirsty to the group. Kirsty was diagnosed with ulcerative colitis 20 years ago when she was 7 years old. During that time she has had good and bad experiences of services. At the time of diagnosis her parents took the lead in looking after her and advocating for her. Kirsty was suffering from blood and mucus in her stools and diarrhoea. Her parents were initially told that she may have a burst blood vessel. She couldn't fault the paediatric team. It took about three months from the first investigations to diagnosis.

From age 7 until 9 or 10 Kirsty was on steroids. She managed to get into remission at age 11. Due to funding cuts in NHS Ayrshire and Arran Kirsty was transferred to adult services around this time. Her consultant treated her as an adult from the age of 12. Kirsty didn't always understand what he was telling her which was not helpful. He told her just to "deal with it".

Because of the difficulties in communication with the consultant, the IBD nurse had to advocate for Kirsty. Kirsty often went to the GP when she had problems and the GP told her to go to the consultant. When she was flaring up the GP wrote a letter to the hospital to admit her.

When Kirsty was actually admitted to hospital the triage took six hours. In Ayrshire and Arran people do not go straight to a gastro ward or a medical ward so Kirsty had to spend two days in an admitting ward.

Recently Kirsty's consultant has changed to someone who recognises that she is a person and a mental health nurse. If Kirsty has a problem she phones the IBD nurse who liaises with the ward. The staff on the ward know her. Now she is an adult her mum can't be there on the ward when she is admitted but she thinks the team are caring and can offer her the support she needs at those times.

When Kirsty has infusions she goes to the medical ward. There used to be a dedicated infusions nurse but the funding has now gone for this so Kirsty says that patients have been "left hanging".

Kirsty has 6-monthly review appointments, but sometimes these are cancelled so she has to wait for a year to see someone. At other times Kirsty is well so feels that she doesn't always need the appointment.

A big area of need that Kirsty highlighted was access to psychological support. She recognises that as a child she suffered from low mood and used to self-isolate. During a low period when Kirsty experienced a bereavement she eventually spoke to her GP. At the time she was having suicidal thoughts, but she was discharged from mental health services because she was managing and was not depressed enough.

Because Kirsty can function with her depression she is not seen as needing any help. She believes there is not enough understanding about the knock-on effects of

living with IBD or another condition on someone's mental health. Things have developed a lot in the last 20 years, but this is still a huge gap in IBD services.

Becoming a nurse was how Kirsty was able to show her gratitude for the care the paediatric nurses gave her. The University of the West of Scotland made adaptations to her placement hours and when she asked for help she was also allowed extensions for some of her essays. Her GP did a lot in terms of writing to the university to explain how her conditions affected her daily life. Her current employers have also been great at adapting her working day to suit her needs and ensure that her patients get the best service from her.

Paul Wheelhouse MSP entered the meeting at this point.

4. Service redesign and innovation in NHS Highland -Professor Angus Watson

Professor Watson explained that his surgical specialty is IBD. He is based at Raigmore Hospital in Inverness and also covers Wick. He is passionate about IBD as he has relatives and friends with IBD and now friends whose children have been diagnosed with IBD.

Professor Watson explained that a few years ago he was sent to an international forum on safety and quality in healthcare in Paris by NHS Highland. At the end of the meeting delegates went to the top of the Arc de Triomphe where they were encouraged to make a pledge. His was to transform the quality of care for IBD patients in Scotland.

A copy of Professor Watson's slides will be made available to CPG members. Some of the key points he covered were:

- Working with Crohn's and Colitis UK on the national service improvement project to take forward the IBD Standards was very professionally satisfying for him.
- The patients with IBD in the Highlands and Islands are very geographically dispersed with around 600 IBD patients in the region. Raigmore is a tertiary care centre.
- The service improvement pilot in NHS Highland started in 2014 with process mapping the pathway of care and creating an aspirational pathway.
- Together the multi-stakeholder steering group co-produced a gap analysis which led to a series of workstreams.
- Quality Improvement measures were used to get a formal sense of the process.

- The project had huge support from Crohn's and Colitis UK.
- There was already a good relationship at Raigmore between the medics and the surgeons and the team were early adopters of biologics.
- Gaps identified included:
 - The IBD service was under-resourced and over-worked
 - No telephone helpline
 - Erratic Multidisciplinary Team (MDT) Meetings
 - Transition services were patchy
 - No self management strategy
 - Fecal calprotectin testing outsourced
 - Outpatient services were overwhelmed
 - They had no idea of how many patients the service had.
- New innovations tested included:
 - A re-launched telephone helpline
 - ROCS-IBD (a new patient -facing app and patient management system)
 - Telephone / video clinics
 - Wednesday morning MDT meetings (staff bonded as a team and this was pivotal to changing culture). Professor Watson believes that all complex cases should be discussed by the MDT and that no one member of staff should sign off on a treatment that costs £20,000.
 - Switching from biologic to biosimilar drugs- the IBD team managed to get senior Board management to invest the savings from the switch directly back into the service instead of the Board's bottom line.
- Now the service runs over 200 video clinics per month and these are critical.
- They are trialling capsule endoscopies (where a pill containing a tiny camera is swallowed by the patient) delivered in the community in the Western Isles. This allows people to have an endoscopy without travelling to the mainland.
- NHS Highland has joined in and sponsored the IBD SBRI Challenge (an innovation challenge where £400,000 has been made available to empower companies to innovate around new technology solutions for IBD).
- The NHS Highland IBD service is now award-winning and the service improvement pilot led to transformational change.

Professor Watson talked about the benefits of sharing best practice and breaking down 'silos' of good care. Pauline McNeill commented that she had not been aware that Scotland was leading the way with some of these new innovations. Professor Watson explained that Scotland is also leading the way in the field of research with major studies such as the PREDiCCT - The Prognostic Effect of Environmental Factors in Crohn's and Colitis led by Dr Charlie Lees.

There was a question from Edmund Murray about the capsule endoscopy. Professor Watson explained that it is painless, requires no sedation and can be done anywhere. Images from the pill are Bluetoothed to a device where they can be downloaded. It is currently being used by hospitals in London and Sheffield but the trial in the Western Isles is the first time it is being used with GPs.

Helen Terry asked if GPs have been enthusiastic and Professor Watson said that those they are working with have been. The pills could also be used by pharmacists or local health hubs.

Professor Watson commented that his service have still not go things completely right. 40-50% of people with a long term condition will experience mental ill health and two striking findings of the survey that was carried out by the IBD service improvement project were that over 36% of patients didn't know their IBD nurse and that there was a real lack of psychological services for IBD.

There followed some discussion about a lack of clinical psychologists in training and training others to do low level psychological interventions for IBD patients.

Elaine Steven asked how the Cross Party Group could get Health Boards to notice the Blueprint for IBD in Scotland and elevate examples of good practice.

Professor Watson said that there is no more money in Health Board budgets so they have to work smart. For example, his team made the argument for reinvesting the saving from the biologics switch directly into the IBD service. This required the Health Board Chief Executive to 'un-silo' the financial structure, diverting money from pharmacy to medical services. They used to spend money on locums to fill gaps, but have now invested in virtual clinics which are much cheaper.

Helen Terry commented that switching to biosimilars has been a great opportunity for many services. She spoke about a consultant in England who is developing 'benefit calculators' which have been quite persuasive.

Professor Watson said that there is a culture in England of payment by results in healthcare and in Scotland we need to be smarter about making the argument for cheaper options.

Paul Wheelhouse MSP said that he was interested in the mental health aspect. He queried whether the costs of dealing with mental health issues were greater than that of an IBD nurse.

Again, Professor Watson suggested working differently. In the Glasgow pilot of the Service Improvement Project, training staff to provide rapid interventions had been tested and shown to be effective. Kirsty Gibson said that it is important to

find nurses with a passion for mental health and build on this. For example, training nurses to deliver interventions around smoking cessation has worked well. Kirsty said she believed this approach could also work for IBD.

Paul Johnston explained he had depression for a long time and that if patients were informed about the impact of chronic conditions on their mental health they might be able to better manage their mental wellbeing. Having a nurse who was trained in mental health would make a huge difference. Another huge issue for him had been lack of peer support.

Vikki Garrick said that paediatric IBD teams have access to a health psychologist, but there are not enough of them.

Helen Terry talked about the trial of Mindfulness-Based Cognitive Therapy in Highland which made a big difference to those who took part.

Kirsty said that non-psychological staff don't want to talk to people about how they are feeling because of the stigma of mental health and being afraid to "open a can of worms". She has been involved in giving social work staff training about when to signpost to other services and when to escalate to mental health services.

5. David Pratt, Update on the Modern Outpatient programme IBD workstream

The Convenor welcomed David who is National Improvement Advisor with the Modern Outpatient Programme. A copy of David's presentation will be made available to CPG members.

Key points were:

- The Modern Outpatient is a new Scottish Government programme with the job of improving outpatient services. David is focusing on the work with people with IBD.
- The programme aims to make the best use of the skills and experience of staff.
- Many people with IBD share similar experiences of services, i.e. not being able to get rapid access to services during flare-ups.
- The programme is trying to minimise return appointments.
- Using technology to deliver these services.
- A minimal dataset for IBD has now been agreed nationally.

- This is about more than standardising practice, the programme is also involved in training junior doctors.
- They want to develop a locally responsive service with local action plans.
- They are in phase 1 of a work stream on ‘Guided Self Management’. This is being supported by colleagues at Crohn’s and Colitis UK and the ALLIANCE. The working group is looking at current research and scoping the views of clinicians and people with IBD. Phase 2 will involve small pilots and tests of change.
- The SBRI challenge (mentioned above) is an open innovation challenge to stimulate ideas from industry. Five companies with ideas for new technology to improve IBD services are now through to the next stage. It is too early to tell what the results will be. Some ideas will fail and there will be some unexpected results.

Edmund Murray asked what happens to the companies that are unsuccessful in the SBRI challenge. David Pratt explained that not winning does not mean all channels are cut off to these companies. Winning solutions may take the form of a combination of the “best bits” of a number of entries.

There followed some discussion about GPs being one of the first ports of call for people with IBD when they have a flare-up. Elaine Steven spoke about the Royal College of GPs Spotlight Programme which is educating GPs about IBD and the toolkit on the RCGP website.

Action: David to be invited to the RCGP Spotlight meeting in Edinburgh on 5th December.

Elaine Steven asked about the SBRI challenge and technology. She said the Crohn’s and Colitis UK experienced some difficulties trying to implement existing technology solutions in Scotland such as My IBD Portal, an interactive, patient management system on the PatientView platform. She asked how to get the push from Scottish Government to make this happen. There had been various meetings with strategic leads but seemed to be a great disconnect between the policy rhetoric and what actually happened in Health Boards’ IT departments.

David commented that the NHS does have IT systems which are frankly “dinosaurs” and getting things through the firewall is nearly impossible.

Professor Watson shared his concerns about the SBRI challenge as it will lead to companies producing products that they cannot then procure into the health service.

Paul Wheelhouse MSP said he was working through procurement issues with Aileen Campbell and others. It would be useful to have practical examples of where things are not working. Colin Smyth MSP said the Health and Sport Committee Inquiry into Technology in the NHS is still open for views.

Although Crohn's and Colitis UK have already submitted a response to this Inquiry, it was agreed that the CPG would pull together a submission focusing on digital services, use of 'Attend Anywhere' videoconferencing etc.

Kirsty Gibson said that the table in a consultation room can be a physical barrier to good interactions. You can be yourself in the home environment using virtual technology. Vikki Garrick noted that telephone clinics really work in breaking down the doctor/patient patriarchal dynamic. She talked about the newly reorganised Scottish IBD Nurse Network which currently has two distinct workstreams looking at MDT working and telephone clinics.

6. Discussion and Actions

Although Crohn's and Colitis UK have already submitted a response to the Technology Inquiry, it was agreed that the CPG would pull together a submission focusing on digital services, use of 'Attend Anywhere' videoconferencing etc. This could be given as oral evidence.

Action: NG and ES to explore best way to provide further evidence to the Health and Sport Committee.

There was further discussion about psychological support which will be the topic of meeting 4 along with self management. It was agreed to invite representatives from a Health Board and from the Scottish Government's Mental Health Strategy team.

Actions:

-Pauline McNeill and NG to invite Elaine Mead, Chief Executive of NHS Highland and Jeff Ace, Chair of the NHS Chief Executives Group who were both unable to attend this time.

-Chris Doyle and NG to investigate who would be the most appropriate person from the Scottish Government Mental Health Strategy team to invite.

-Professor Watson to arrange a demo of the Attend Anywhere video conferencing facility for a future meeting.

-All members to think about the possibility of holding an event in Parliament next year/ asking parliamentary questions from the group etc.

-NG to liaise with Janice Taylor who offered to provide some support with content for the CPG newsletter.

- ES and NG to use the upcoming RCGP Spotlight meeting in Edinburgh as an opportunity to encourage one or more GPs to join the CPG.

7. Date of Next Meeting

Wednesday 6th December, 6-8pm in the Scottish Parliament, Committee Room 5.

Attendance List

Members

Pauline McNeill MSP- Convenor

Clare Adamson MSP- Depute Convenor

Colin Smyth MSP

Prof Angus Watson

Claire Davidson

Kirsty Gibson

Paul Johnston

Edmund Murray

Janice Taylor

Christopher Doyle- Health and Social Care Alliance Scotland (the ALLIANCE)

Vikki Garrick

In attendance

Paul Wheelhouse MSP (part of meeting)

Nancy Greig- Crohn's and Colitis UK (minutes)

Elaine Steven- Crohn's and Colitis UK

Helen Terry- Crohn's and Colitis UK

David Pratt- Scottish Government

Jana Moracova

Pamela Smith- Pauline McNeil's office

Lis Bardell- Clare Adamson's office

