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

Wednesday 23 May 2018, 6-8pm

Room TG20, Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP welcomed everyone to the fifth meeting of the Cross Party Group on IBD, a warm welcome to those attending and to MSP Liam McArthur.

Apologies were received from: Clare Adamson MSP, Claire Davidson, Christopher Doyle, Dr Daniel Gaya, Kirsty Gibson, Kate Gray, Rachel Hayward, Dr Johnathan MacDonald, Sally McNaught, Jana Moravcova, Elaine Steven, Janice Taylor, Prof Angus Watson, Prof Ian Welsh OBE.

2. Minutes of 21 February meeting, actions and work plan

Pauline asked for points of accuracy in the minutes of the meeting held on 21 February 2018. No points were noted.

Group approved minutes.

Pauline, Nancy and Elaine will be meeting in the near future to discuss and tie together the actions from this and all previous meetings. Seeking a possible meeting with the Cabinet Secretary will also be discussed and pursued.

3. Three experiences of living with IBD and support from IBD Nurse Specialists

Amy Bednarz shared her experiences with the group. Amy was first diagnosed with ulcerative colitis 25 years ago when she had a good GP who was experienced in dealing with Gastro issues. During Amy's first hospital admission she felt that there was no emotional support offered. The 1990s were a bit of a blur for Amy who wanted to hide away and take the tablets she was prescribed.

When Amy moved to Glasgow she joined a new GP practice and and was referred to a new consultant. She described the symptoms and was told to continue taking her tablets. After numerous flares, it was discovered that her tablets were not working. Amy still felt she did not receive any emotional support. However, she used to be very good at shutting out bad things so doesn't remember the details of how serious the situation was. She now feels she is more capable of saying what she wants but it's much harder to do this when she is very ill.

Amy's first meeting with an IBD Specialist Nurse was four years ago. After an initial face to face discussion, contact was made via phone and email which worked for Amy and the recommendations for self management were good.

After more regular flares Amy contacted the IBD nurse then the GP. The GP didn't know Amy and took bloods but questioned whether it was a flare as bloods were not conclusive.

Amy felt frustrated as she knows when she is having a flare but bloods don't always show how bad the inflammation is. The GP prescribed steroid tablets. At the next appointment, two weeks later, during which time the steroids had not had any effect, the GP had been in touch with the IBD Nurse and Amy was admitted to hospital.

Amy's first night in hospital was spent in a cubicle with no access to a shower or private toilet, in close proximity to other patients coughing etc. The food was not suitable. She was just given the normal hospital menu with no dietary considerations.

Once on the ward the first suggestion was that Amy see a dietician. As a 'low residue diet' was not available in Glasgow hospitals, Amy was given a 'normal diet', which she was unhappy with. This made Amy feel anxious to the point where she felt unsafe. Amy contacted her IBD Nurse at Gartnavel who confirmed that there was an IBD Nurse in the QEUH.

After she was discharged, Amy saw the IBD Nurse at Gartnavel, when she was on the day ward there for treatment with infusions (Vedolizumab). The nurse apologised that things could have gone more smoothly and said that if steroids didn't work in the first few days then they are unlikely to work at all.

Amy's would recommend that:

- GPs need to know how to prescribe steroids properly for IBD and that they begin by asking "How does what you are feeling differ from your normal?"
- Lines of communication are kept open between person, GP and IBD Nurse
- Listen and act in a timely manner. Don't just send the person away with tablets and treat flare-ups promptly to limit damage to the bowel and hospital admissions
- Low residue diets should be available in all Health Board areas.

Pauline thanked Amy for sharing her story.

Pauline welcomed Colin Smyth MSP who joined the meeting at this point and took the opportunity to welcome Helen Terry, Director of Policy, Public Affairs and Research and Isabel Mason, Service Development, IBD Nurses, from Crohn's and Colitis UK.

Pauline then invited Gillian Cowell to speak. Gillian is 42 years old and was diagnosed with Crohn's Disease at the age of 26. Gillian is currently a patient at the RAH in Paisley.

Gillian has had wide ranging experience and can't remember all of it, there has been lots of flares, resulting in fistulas and subsequently sepsis, culminating in requiring a Seton procedure. This eventually resulted in the left side of Gillian's colon being removed. Gillian had a daily wound packing service for two and a half years (including during a trip to the London Marathon!)

Gillian finds obstructions are her main issue, which occur on average four times a year. At the moment Gillian has a right-sided hernia around her stoma which she is waiting for surgery to correct. This will be the third site for her stoma. Gillian has tried lots of drugs to alleviate symptoms.

Access to a stoma nurse, although they don't have as much input into Crohn's as the IBD nurses, makes Gillian feel human. Having the correct stoma equipment makes life much better.

Gillian has found psychological and art therapies accessed through her GP and the Centre for Integrated Care have helped her cope, although she feels that many psychologists don't understand IBD.

Support from the IBD Nurses makes life bearable and gives Gillian security as they are able to take the time to explain things to her and this helps with the psychological effects of having a severe form of Crohn's and its resulting surgeries. Prior to the IBD nurse service life was full of fear, not knowing where to go for help. GPs didn't have specialist knowledge and NHS24 is difficult as you have to explain symptoms over and over on the same call.

Gillian remembers very clearly the first day the IBD nurse phoned to introduce themselves, it was a relief to know there would be quick access to individualised information and support.

It has proved to be a great service, because the nurses constantly upgrade their knowledge and are happy to review care and make referrals to new and innovative services, taking the case to Multi Disciplinary Team meetings (MDTs). This has helped to reduce Gillian's fear and isolation and to advocate on her behalf in both inpatient and outpatient appointments. They make sure the correct people get to see scans and get answers about care when required.

Gillian feels that sometimes treatments and surgery can be de-humanising and that complementary care is vital to 'bring the human back into the body'. Gillian suggests:

- Support and training should be available for IBD nurses to help with psychological effects of IBD
- eHealth tools and patient education systems would be helpful
- Specialist dietary advice for all IBD patients
- Training for psychologists to work with IBD patients
- Legislation needed to increase IBD Nurse numbers.

Pauline thanked Gillian for sharing her story and invited Joseph to speak.

Joseph Logan is 14 years old and he was diagnosed at 11 years of age. His mum was worried about him as he looked pale and thought it might have been due to lots of exercise as Joseph played a lot of tennis at the time. Eventually Joseph found it difficult to walk short distances. Joseph was admitted to Royal Hospital for Sick Children (RHSC), diagnosed with Crohn's Disease. Joseph's parents explained what this was and that treatment would help.

Joseph started a Modulin diet which he felt was OK at first but “got a bit boring”, friends were very supportive. Joseph has now had two lots of Modulin and is now on Methotrexate.

Joseph feels that the support from the IBD Nurses, Vikki, Lee and Lisa has been amazing, always there for you with information, support and encouragement to take control. They made sure Joseph knew exactly what he had to do with medications and took a real interest in him. Now Joseph doesn’t worry about having Crohn’s, the support of the IBD nurses helps.

Joseph still plays tennis to a high standard, winning tournaments such as the Lanarkshire Open Singles around the country. This helps him keep fit and healthy. He has fantastic support from family, friends and his medical team which helps him carry on with his tennis.

Pauline thanked Joseph for his contribution and took the opportunity to welcome her own niece, Angela, who knows all about support from IBD nurses from her own personal experience.

4. **Why IBD Nurse Specialists are a “lifeline” – The UK-wide picture**

Isobel Mason has been seconded to Crohn’s and Colitis UK to lead and shape their IBD Nursing Campaign ‘More IBD Nurses – Better Care’. Launched in May 2016, the campaign recognises the invaluable impact IBD nurses have on patient experience and outcome. The aim is that, across the UK 95% of charity supporters, have access to IBD specialist nursing services.

An article was published in the Health Service Journal about all the benefits and value to the NHS of IBD nurses, amongst these were:

- Reduced admissions
- Reduced attendance at GPs, Outpatient Clinics and A&E
- Improved clinical outcomes
- Central to managing high cost drugs – 15% of NHS prescription budget
- Valued by patients – medical, emotional and psychological support.

The campaign collected data from 5000 members which showed that in 2016 - 68% of members had access to IBD nurses, 32% did not. Between the national audits in 2012 and 2016 into IBD nursing, roles and activity, the IBD nurses did increase. There are significantly more in England than the other UK nations.

Crohn’s and Colitis UK have commissioned some academic work, led by Professor Alison Leary looking at mathematically modelling the number of IBD nurses required. A large survey of 164 nurses was done to discover how many nurses are needed. This survey found that IBD nurses tend to be younger and earlier on in their career. With complex case management they are stretched, on average doing 4½ hours unpaid overtime per week. The results suggested that a new standard of 2½ nurses per 250,000 patients is required. This new standard is evidence based. Nowhere in the UK has reached the new standard but Scotland has not even reached the old standard.

There are difficulties filling vacancies for IBD nurses. Crohn's and Colitis UK are running a campaign/pilot to encourage nurses to train in IBD as a speciality. There is also an area on the Crohn's and Colitis UK website specifically designed to help services build a business case for more nurses. There is an interactive map on the website to find IBD nurses with contact details for nurses.

Any IBD nurses not on the map can enter their details at https://www.surveymonkey.com/r/DV7TV2M.

Isobel is available to IBD nurses for support in planning how to show the value of their service and building a case for more nurses.

In Wales, services are looking at running a new pilot to develop specialist nurse services encouraging proactive treatment and self management for patients.

Pauline thanked Isobel for her contribution and introduced Dr Graham Naismith.

5. **IBD Nursing: the Gastroenterologist's perspective**

Dr Graham Naismith is a consultant Gastroenterologist in Paisley Royal Alexandra Hospital (RAH) where he acts as lead for IBD for NHS Greater Glasgow and Clyde (Clyde Sector). When Dr Naismith was a 1st Year doctor in 2000, the Specialist Nurse Role was just being developed in response to patients saying that they felt 'abandoned' and lacked information after being seen at clinics.

In looking at the consultant's role Dr Naismith explained why a team is needed:

- Consultant gastroenterologists often are specialists in lots of areas, including
    - Procedures such as tube insertion, capsule endoscopy
    - Bleeding, weight loss and nutrition
    - Covering General Medical cases including overdoses, strokes, heart attacks

- They also have other calls on their time, including
    - Cancer MDT meetings
    - IBD Nurse meeting
    - Ward Round – 15-20 patients
    - Endoscopy lists

During on-call weeks there is no time to catch up with IBD nurses and IBD work. On other weeks, as the lead for IBD, he can still only spend 5-6 hours on IBD.

MDT meetings are ad hoc due to pressures of appointments. Gastro referrals are up 108% over the last few years.

Gong forward we need to consider the following:

- For the best possible results teams need to be innovative to help patients. At the RAH, innovations have included a self management programme, rapid access and an endoscopy algorithm.

- GPs need support to have the same confidence in making treatment decisions that IBD nurses have.
- More co-ordination is needed with teams across the hospital including Home Care teams

IBD Nurses can:

- Front load patient information – this needs a team approach
- Reduce the need for consultants to see patients as frequently
- Provide training for junior doctors.

Graham gave examples of great feedback patients have given about the IBD Nurse service on Care Opinion and how feedback can inform service change.

Pauline thanked Graham for his contribution and introduced Allan Boal and Vikki Garrick to the Group.

6. IBD Nursing in Scotland and the work of the RCN Scottish IBD Nurses Network

Allan Boal has been IBD Clinical Nurse Specialist at Royal Alexandra and Vale of Leven Hospitals for 6 years and Vikki Garrick has been an IBD nurse specialist since 2006 when she set up and managed the specialist nursing service in the Royal Hospital for Sick Children in Glasgow. Allan and Vikki co-chair the RCN Scottish IBD Nurse Network.

Allan and Vikki thanked the Group for the opportunity to present the nurse perspective. Key points are:

- IBD Nurse Specialists have lots of different roles, the roles have developed to the point so that nurses now have extended roles and additional responsibilities
- It is difficult to fill a vacancy if the role is so varied.

In 2015 Vikki scoped IBD nurses around Scotland for a report to Scottish Government. Of the 14 Health Boards, 3 did not have an IBD Nurse Specialist – Western Isles, Orkney and Shetland. People still say to IBD nurses: “What do you actually do?”

A UK IBD Audit identified where IBD Nurse Specialists are and what they did, i.e.

- Patient education
- Phone advice lines
- Follow up clinics
- Biologics take up a lot of nurse time
- First prescribers
- Vigilance and rescue work
- Expedite treatments, liaising between clinicians and patients
- Intervene at timely intervals, dealing with incidents saving the NHS money and patient trauma and upset.

Allan and Vikki discussed how to raise the profile of the IBD Nurse Specialist. The development of the RCN Scottish IBD Nurse Network aims to align nurses around the country. Sixty one nurses across Scotland are members including both Paediatric and Adult services. The starting point for the network was the IBD Blueprint and the first two workstreams the Network tackled were Telephone Advice Lines and MDT working.

Problems identified by the Network have included:

- Nurses around Scotland aren't resourced to be able to attend meetings in order to share good practice.
- Misunderstanding of what nurse specialists do.
- Difficulties when managers do not take into consideration that nurse specialists have patients in the community and not in hospital. Nurse Specialists are asked to work on wards so cutting down the time they have to answer phone advice lines, run clinics etc.
- Case loads are so varied that job descriptions are difficult to develop
- One Nurse Specialist per 500 patients is the new recommended adult caseload, however in paediatrics needs to be more like 2 Nurse Specialists per 500 patients due to the time it takes to work with the whole family.
- IBD Nurse Specialists are currently invisible at Health Board level because they cannot assign job codes to much of their work.

Solutions:

- Identify Nurse Specialist support to help with admin tasks/ ancillary Support
- Cross Boundary working Primary/Secondary/Tertiary care

7. Discussion and actions

Liz Bardell pointed out that she knew how important it has been to have an IBD Nurse Specialist to advocate for her son who has recently been diagnosed.

Amy Bednarz asked how much of what IBD Nurse Specialists do can be done by someone else. Allan said that admin support is invaluable and has cut down the phone calls his team need to take by 50%. However, there is no admin support built into Clinical Nurse Services when they are being designed.

Crohn's and Colitis UK are helping IBD Nurses to write business cases. Helen Terry mentioned that it is all about supporting greater access and it may be that providing admin support for IBD Nurses means they are freed up to have more clinical time which will mean patients having greater access to the service and in turn reduce the number of nurses required.

It was pointed out that while doctors are allocated time and finance to access training/ education to keep up to date with developments in treatment, Nurse Specialists do not have this built into their posts, would it not be better to have both doctors and nurse specialists educated in developments?

Pauline told the group she is still chasing the Cabinet Secretary for attendance at a future meeting.

Dr Philip Gaskill suggested that it might be a good idea to engage with Integrated Joint Boards, especially patient representatives.

Actions:

- Submit an opinion piece on IBD nursing and the challenges faced to the Health and Social Care Alliance Scotland (the ALLIANCE) for publication on their website and bulletin. NG/ IBD Nurses Network.

- Add issues facing IBD nursing to the group's letter to the Cabinet Secretary for Health and Sport and the agenda for any future meeting. NG/ ES/ Pauline.

- Summarise key points from this meeting in a letter to the Chief Nursing Officer and invite her to a future meeting NG/ ES/ Pauline.

- Contact Integrated Joint Boards to invite them to engage with the CPG NG/ ES/ Pauline.

- Crohn's and Colitis UK to continue to support the Scottish IBD Nurses Network to ensure alignment and involvement with health service development work in Scotland.

8. Date of next meeting

Wednesday 19th September 2018, 6-8pm, Committee Room 5.

Pauline thanked Pamela Smith for all the support she has given the group in the last year and wished her well from the group as she goes off on maternity leave.

Pauline thanked everyone for attending and closed the meeting.

Attendance list

Members:

Pauline McNeill MSP (Convener)

Colin Smyth MSP

Liam McArthur MSP

Dr Ian Arnott

Paul Johnston

Edmund Murray

Gail Grant

Dr Daniel Gaya

Prof Richard Russell

Vikki Garrick

Seth Squires

Allan Boal

Dr Dagmar Kastner

Cher-antionia Khedim

Amy Bednarz

Dr Philip Gaskell

Matthew Hilferty

Lis Bardell

In attendance:

Nancy Greig- Crohn's and Colitis UK

Helen Terry- Crohn's and Colitis UK

Isobel Mason – Crohn's and Colitis UK

Susan Brooks Health and Social Care Alliance (minutes)

Pamela Smith – Pauline McNeill MSP's office

David Pratt- Scottish Government

Julie Duncan

Fiona McCluskey

Brigid Aitken

Joseph Logan

Guy Logan

Gillian Cowell

Andrew Cowell