

# **Minutes of the Seventh Meeting and AGM of the Cross Party Group on Inflammatory Bowel Disease (IBD)**

**Wednesday 13 March 2019, 6-8pm**

**Committee Room 4, Scottish Parliament**

## **1. Welcome and apologies**

Pauline McNeill MSP welcomed everyone to the seventh meeting and AGM of the Cross Party Group on IBD, a warm welcome to those attending for the first time and to MSPs Clare Adamson and Liam McArthur.

Apologies were received from:

Miles Briggs MSP  
Dr Ian Arnott  
Kirsty Gibson  
Paul Johnson  
Dr Daniel Gaya  
Prof. Ian Welsh OBE  
Christopher Doyle  
Cher-antonia Khedim  
Rachel Hayward  
Angus McLean  
Gail Grant  
Jana Moravcova  
Louise Horne  
Janice Taylor  
Matthew Hilferty  
Sally McNaught  
Prof Richard Russell

## **2. Minutes of 6<sup>th</sup> December meeting, actions and work plan**

Pauline explained that the minutes for the meeting held on 19<sup>th</sup> September 2018 were tabled for information as they were circulated and approved by email.

Pauline mentioned that the exhibition held in Parliament in February went very well with lots of interest from MSPs including a visit from the Cabinet Secretary for Health and Sport, Jeanne Freeman. This will be followed up with a letter to the Cabinet Secretary who had personally asked for the Group to write to her.

## **3. Election of Office Bearers**

Pauline thanked everyone for attending throughout the year.

The group were content for the following people to remain as office bearers:

- **Convener** - Pauline McNeill MSP
- **Deputy Conveners** – Clare Adamson MSP and Dr Ian Arnott

Pauline proposed that in order to continue to provide a good balance of patients, carers and clinical staff on the Cross Party Group, pharmaceutical companies can no longer be members of the group. Crohn's & Colitis UK corporate supporters will be kept informed of the group's work and will be welcome to send representatives as observers to meetings. Employees of pharmaceutical companies with a personal interest in the work of the group will also be able to join as individual members.

**This proposal was carried by majority.**

The Cross Party Group annual return will be circulated by email to ensure everyone is happy with the details.

**Action: Nancy**

#### **4. IBD and Me – Why self-management is important**

Roisin Robertson talked to the group about what self-management of Crohn's Disease means to her, how and why she got involved in the process to co-design the self-management tools and following on from that how she became involved in IBD research.

Self-management to Roisin meant power and having the confidence to ask questions when required.

Roisin took part in the Self-Management co-design workshop following a particularly bad couple of months where she felt out of control. She felt that she might find out something which would help her self-management of her condition. Roisin came away from the workshop feeling hopeful and powerful. She believed the flare card which resulted from the workshop will be very useful for new patients but will also be an excellent resource for existing patients. Roisin felt strongly that change can only happen if patients take part in workshops and trials.

Roisin took everyone through a typical day for her which usually begins with a bath a dressing her fistula wounds, taking painkillers, her Crohn's Disease medication and antibiotics for a persistent Urinary Tract Infection. Roisin must think carefully about what she eats and drinks depending on how well she is.

*She said: "I think about the future - will this illness affect me having children? Will I pass this disease on to any future kids? It's constant - because for me - the most important part of my disease is feeling able and feeling confident to self-manage, self-medicate and to 100% be a part of the decision-making process for how my disease is managed."*

Pauline thanked Roisin for sharing her story and pointed out that a mock-up of the flare cards produced after the workshop was on the table for information only at this stage.

A discussion took place around patient experience and the use of the word 'sufferer'. It was felt that suffering was not knowing what is happening to your body and feeling that you have no choice. Self-management and self-education avoid suffering and allows a person to come to terms with symptoms. Suffering happens when there is no management plan in place. It was also pointed out that it is very difficult for families to feel powerless watching their loved one 'suffer' with symptoms.

It was noted how inspirational the young people who have attended the Cross Party Group have been in how remarkably they have coped with the disease.

It was suggested that sufferer is not a good word, but disability is something which is generally understood. It was noted that as IBD is still a taboo subject for a lot of people. People don't feel comfortable talking about their disease, this leads to a lack of support and understanding from friends and has led to bullying for some people.

The comparison was made with people with a cancer diagnosis, this is much easier for people to talk about and therefore, much more support is made available. The impact on quality of life for many children and adults is also similar to cancer. Dr Dagmar Kastner pointed out that that 80% of children with cancer are cured, whereas, IBD is not curable and is lifelong.

#### **5. Royal College of General Practitioners IBD Spotlight Project and Flare Management Resources**

Dr Philip Gaskell, General Practitioner and IBD Spotlight Champion for Scotland talked to the group about his new role with the Royal College of General Practitioners (RCGP) IBD Spotlight Project and his involvement in the process of co-designing self-management tools in Scotland.

After 20 years practice in Edinburgh and 12 years in Stirling Dr Gaskell has retired but does locum work in the West of Scotland.

Dr Gaskell made a few observations:

- The number of IBD patients are now much larger than he could remember seeing earlier in his career.
- Progression into the role of a GP was seen to be 'risky' by junior doctors
- Continuity of care is becoming increasingly difficult as lots of GPs are working less than full time.
- GPs are experts in people not disease, this sometimes leads to delayed diagnosis.

Dr Gaskell explained the RCGP Spotlight Champion Project

- GPs need to know how to navigate their local services and who will respond quickly
- For GPs in Out of Hours more information is needed to gauge whether hospital admission is necessary, if patients feel empowered to deal with a flare, why should they be taken into hospital automatically?

- Good notes being shared with Out of Hours teams would help them to advise appropriately.

Dr Gaskell has also attended the co-design workshop in Perth last year to develop self-management tools. He notes that this proved very informative and it was very interesting to hear the patients' perspective.

Dr Gaskell said that Scotland is leading the way with tools to help GPs and Practice Nurses, although producing guidelines for best practice are useful for specialist services, they are not so useful for general practice. He felt it might be a good idea to promote good practice through RCGP faculties as GPs need to document 50 hours Continuing Personal Development per year. This is quite onerous to most GPs, but it would be useful if the training they access through the faculties of RCGP included best practice around IBD.

Dr Gaskell suggested GPs should have a Flare Pathway attached to the back of all follow up letters to GPs after clinic appointments as this would serve to educate GPs as well as giving a good reference point for future appointments.

Further discussion around how to reach GPs concluded that It would be a good idea to offer training or educational opportunities to practice nurses who can then feed back to the whole practice including Practice Manager and GPs. It was also suggested that patients could help to educate GPs by sending information to the Practice Manager to be circulated to the GPs as sometimes there is one GP who has specialist knowledge on specific conditions.

Another suggestion was to have a responsible GP with additional knowledge of IBD in each GP cluster who could take on patients with IBD and be the IBD Champion for the cluster.

Short education sessions with local GP clusters could be a good starting point, these could provide a process of sharing experiences and expertise which could include promoting new treatments within practices. This would make Shared Decision Making easier to achieve, one of the main points in Realistic Medicine.

Concerns were expressed about continuity of care if the responsible GP moved practice, as having a trusted Specialist Nurse is the most important relationship for most patients.

Suggestion was made that communication needs to be standardised across all areas, patients should be routinely copied into letters to GPs, this would be very useful as patients can then react to the letter and use the letter to start a conversation with their GP. This was acknowledged as something to strive towards.

## **6. Update on the development of national self-management tools**

Slides will be circulated.

Nancy Greig, Health Service Project Manager with Crohn's & Colitis UK provided an update on the process to co-design self-management tools in Scotland and other self-management resources being developed by Crohn's & Colitis UK.

One of the recommendations of the National Blueprint for Inflammatory Bowel Disease in Scotland was the 'Development of Scotland-wide supported self-management tools' and therefore our joint work with the Modern Outpatient Programme which has led to this point is very much in line with the objectives of the document. A workshop was held in Perth in November last year as part of the Modern Outpatient IBD Development Day with the following objectives:

- To present the findings from the scoping work undertaken by Crohn's & Colitis UK
- To stimulate thinking about areas of improvement to outpatient clinics for people with IBD around supporting self-management.
- To provoke and encourage ideas from colleagues that can be taken into phase 2 of this work.

The next steps were to bring together a small group of people with IBD, clinicians and other stakeholders to start to develop these tools and resources. It was decided to kick start this work with a co-design workshop. That meant around 25 people including people like Roisin, living with the condition, doctors, IBD nurses, dietitians and other stakeholders all working together on an equal basis to decide what might work best for them to help people self-manage their IBD.

In 2017 the charity carried out some scoping work to define what was meant by self-management. This helped to provide the basis for Crohn's & Colitis UK's position statement on self-management.

This comprised of:

- Two surveys- one aimed at IBD professionals, the other at people with IBD.
- A commissioned evidence searches for peer-reviewed secondary literature on self-management for adults with IBD.
- Focus groups which looked at the themes highlighted in patient survey in more detail.

The position statement seeks to define the component parts or pieces of the jigsaw that need to be in place for a person with IBD to successfully self-manage.

The workshop involved focused working in two distinct groups to co-create two complementary resources: 1. A flare-card and 2. A personalised care plan

- Flare card- The idea was based on a similar card created and evaluated in NHS Greater Glasgow and Clyde. It includes details of key symptoms during a flare-up, what to do next and where to get help quickly. It lists drug side effects to watch out for and supports the interface with Primary Care, signposting people to tests that can help them to 'get on top of' a flare-up

before it gets out of control. It also features advice on safe medication tweaks for people on certain types anti-inflammatory medication.

- Care Plan- Workshop participants wanted it to support person centred conversations and a more holistic approach during consultations. Based on principles of Care and Support Planning, this tool was developed by listening to what mattered to people in their interactions with their consultant or IBD nurse. It prompts individuals and healthcare professionals to focus more on mental wellbeing and activities of daily living rather than the number of bowel movements and treatments.

Both the Flare Card and the Care Plan developed during the co-production workshop have undergone a few reviews and amendments, maintaining the structure and person centred ethos wanted by patients. The Flare Card was also redrafted with health literacy in mind, i.e. a larger font size than the original, simpler text.

The Care Plan was tidied up and re-written to ensure prompts made sense and it was easy to understand.

Flare pathways have been developed by the RCGP as part of the Spotlight Project. These have been endorsed by the RCGP and the British Society of Gastroenterology (BSG) and the Primary Care Society for Gastroenterology.

The Flare Card and Care Plan will have an NHS Scotland logo for the trials in Scotland. They will be designed with a similar look and feel to the pathways and information around drugs and dosages is in line with the pathways developed by the RCGP.

The Care Plan is owned by the patient so can be used by them during any consultation and is good way of sharing information. Although designed for use at a secondary care consultation the plan will be updated after consultations with the information that would normally go into the GP letter.

Work is currently being done on what processes need to be put in place for using a paper copy. It is accepted that it will be much easier to use it electronically, but for the purposes of the testing phase, paper-based versions will be used.

The hope is to test with a cohort of at least 100 patients in 3 or 4 IBD services, possibly Borders, Lothian, Glasgow, Lanarkshire. The testing phase will run from March to October with evaluation built in. Findings will be presented at a national event in November before they are rolled out more widely.

Crohn's & Colitis UK also plan to produce a self-management guide for healthcare professionals. This will provide a single point of reference defining good self-management in IBD care. It would also enable professionals to take a person centred approach, confidently recommending and encouraging self-management for IBD patients.

This will form part of a complementary suite of resources including the self-management tools being developed in Scotland, Crohn's & Colitis UK's new patient

pack and a Patient Empowerment Guide, designed to help people get the most out of appointments.

## **7. AOCB**

The question of whether letters from consultants should be routinely copied to patients was raised. It was also asked whether this formed part of the Modern Outpatient programme. David Pratt, National Improvement Adviser at Scottish Government said that it was not part of the plan at present. This can only be recommended to Boards but cannot be made mandatory. Pauline suggested this could be raised with the Health Minister and the group could ask to speak to the Chief Executive's group.

Prof. Angus Watson asked if the Care Plans could be included in the test areas for the new Digital Health App being developed by SBRI through the Can Do Fund. Nancy confirmed that discussions have taken place about this and the long term plan is for this to happen

Pauline reiterated the good response the exhibition she sponsored in Parliament with many MSPs taking time to discuss the work of the Cross Party Group on IBD, the issues for IBD services in Scotland and having their picture taken with the pledge card. A tailored letter will be drafted to go to local health boards from those MSPs who are happy to be involved in this.

Pauline was also delighted to say that confirmation was received earlier this week that a Members' Debate will be held on Wednesday 20th March 2019. Pauline will lead the debate and Clare Adamson MSP will also hopefully be able to speak in the debate. Pauline and Nancy will produce a briefing for MSPs. The central message is that Scotland has the highest incidence of IBD in the UK and rising rates among young people, also highlighting the wonderful work happening in Scotland around IBD.

## **8. Date of next meeting**

Wednesday 22<sup>nd</sup> May 2019, 6-8pm.

Pauline thanked everyone for attending and closed the meeting.

## Attendance List

### **Members:**

Pauline Mc Neill MSP, Convener  
Clare Adamson MSP, Deputy Convener  
Liam McArthur MSP  
Dr Jonathan MacDonald  
Edmund Murray  
Prof Angus Watson  
Seth Squires  
Allan Boal  
Dr Dagmar Kastner  
Amy Bednarz  
Dr Philip Gaskell  
Lis Bardell

### **Attendees:**

Nancy Greig, Crohn's & Colitis UK (secretariat)  
Susan Brooks, Health and Social Care Alliance Scotland (minutes)  
David Pratt, Scottish Government  
Alastair Guild  
Michelle Convery  
Peter Convery  
Roisin Robertson  
Matthew Robertson-Greig  
Neil Robertson  
Christy Robertson  
Kathy Robertson  
Sybil Greig  
Bryan Greig  
Corran Masson  
Finlay Geddes

Maddie Simpson

John Simpson

Eck (Alexander) Thomson

Simona Selim