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

Wednesday 21 February 2018, 6-8pm

Committee Room 5, the Scottish Parliament

1. Welcome and apologies

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

Apologies were received from:

Dr Daniel Gaya

Prof Richard Russell

Prof David Wilson

Alison Culpan (ABPI)

Dr Graham Naismith

Dr Jonathan McDonald

Dr Philip Gaskell

Vikki Garrick

Seth Squires

Allan Boal

2. Minutes of 6th December meeting, actions and work plan

Pauline asked for points of accuracy in the minutes of the meeting held on 9 December 2017. No points were noted, and the work plan was discussed later in the agenda.

The Group approved the minutes.

3. Election of Office Bearers

Pauline thanked everyone for attending throughout the year.

The group were content for the following people to remain in position for a further year:

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

Elaine thanked both Pauline and Clare for being part of the group and giving their support to this work.

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

Action: NG to circulate annual return form to members.

4. Two personal experiences of managing IBD

Matthew Hilferty shared his story with the group. Matthew was diagnosed at 14 after being ill for 1 year. Treatment kept his symptoms at bay until he was 19, Matthew then had surgery which appeared to be successful until his ileostomy was reversed.

Having the same IBD nurse from the age of 14 was great as it meant that it was not necessary to repeat the same story at every appointment and she knew him as a person. Also the IBD nurse was always available when accessing consultants is more difficult. Matthew feels consultants are useful in a crisis, but nurses are best for helping people to self manage. Matthew's stoma nurse also offers support and tips to help him to self manage. Matthew's family and friends have all been a great support. His mum took carers' leave, encouraging him, along with his friends and brother to continue going out socially. Matthew's girlfriend has been very supportive and has given Matthew confidence.

Matthew uses three ways to self manage; exercise, diet and daily routine. Exercise and diet have helped with fatigue and dehydration. Since he started going to the gym Matthew feels he has more energy. Developing an understanding of what foods to eat and what to avoid with a stoma helps his self management enormously. He found that food like potatoes and oats slowed output and gave him energy

With the help of his stoma nurse, Matthew has developed an individual daily routine which works for him. This has been successful, resulting in Matthew not needing to attend the stoma clinic more than once a year.

The support and encouragement of family, friends and nurses has helped Matthew maintain his mental health.

Pauline thanked Matthew for sharing his story.

Pauline then invited Edmund Murray to speak. Edmund lives with ulcerative colitis and has developed strategies for self management after a spiral of fatigue, frustration and isolation. With an unsupportive employer who timed his breaks, Edmund found things difficult at times.

Edmund's self management strategies include exercise, particularly jogging helps. It was hard at first to talk about the issues he was having but with encouragement from his gastroenterologist, Edmund is now happy to talk about his condition.

Three years on from surgery Edmund is now leading a normal life, managing fatigue as part of his day to day routine.

Social media was useful at first, especially when he was too ill to go out much, however, Edmund is not using it so much now.

Edmund has not used mental health services specifically but after hearing others' experiences he believes it would be a good idea to fight for this service to be available for people with IBD..

Pauline thanked both Edmund and Matthew for telling their personal stories, explaining that it is so useful for others to hear.

Liam McArthur queried that since mental health services are so stretched whether there would be a way interventions could be made in a sensitive manner without referral to formal mental health services.

Edmund suggested that such interventions could be included in routine conversation by an IBD Nurses or consultants, asking if a referral to a mental health service would help an individual.

Janice Taylor mentioned that while she was in hospital, a young Canadian doctor asked if she had received psychological support and was surprised to hear she had not as this is the first thing offered in Canada after diagnosis. Janice stated it is essential to talk to someone when first diagnosed. Janice went privately for counselling and found it invaluable.

Paul Johnston reinforced that it is important to tell people at the outset that mental wellbeing is key to managing their condition and that people with IBD are at greater risk of anxiety and depression.

Isabel Kolte mentioned that there is a pro-forma used after Coronary Heart Disease diagnosis which has an extra question to allow mental wellbeing to be highlighted with a check box to ensure action has been taken. Something similar for use at gastroenterology clinics may be useful.

The current version of the IBD Standards state that IBD services should have defined access to a psychologist / counsellor with an interest in IBD, however, only 9 services in the UK have a counsellor specifically for IBD services.

It was mentioned that including mental health awareness in training for IBD nurses would be useful, to encourage them to look for early warning signs of poor mental health.

5. Psychological Impact of IBD

Mary Cawley, Principal Clinical Psychologist at Glasgow Liaison Psychiatry Service presented on the psychological impact of IBD and the pilot project run in NHS Greater Glasgow and Clyde (NHSGGC). The presentation will be circulated.

The project looked at the Biological, Psychological and Social effects of IBD patients.

They found that during periods of active disease, 66% of patients live with anxiety and 35% report living with depression. Untreated anxiety and depression worsens disease outcomes, i.e.:

- Increases severity of IBD symptoms
- More frequent flares
- Higher rate of hospitalisation
- 28% more likely to require surgery
- Lower rates of adherence to treatment
- Limits self management

The current model of care does not address both physical and psychological needs of people with IBD. Only 21 of 173 services in the UK IBD Audit reported having access to clinical psychology via a defined referral pathway.

The Pilot project within NHSGGC delivered NHS Education for Scotland (NES) 'Developing Practice' workshops to Clinical Nurse Specialists; the course combined six workshops with practical tasks to complete with patients in clinic and reflective practice sessions.

The findings were excellent:

- Training was well received by practitioners
- Increased capacity of IBD nurses to provide psychosocial support at nurse led clinics
- Encouraged and enabled increased joint working
- Reduced inappropriate referrals to Clinical Psychology during the pilot period
- Clinical Psychologists were able to provide psychological assessment and intervention for patients
- Highlighted the current unmet need of dedicated psychological support for patients
- Demand outweighs current capacity and increased financial resource is required to meet the psychological needs of patients with IBD

Mary highlighted the case of one man who felt that Crohn's Disease had "ripped my life away". After 6 months of help within the pilot project he had developed a circle of trust with clinicians and felt supported and involved in his care and confident to self manage his condition, enabling him to return to hobbies he had stopped such as hillwalking.

Mary also talked about learning from Australia, The Adelaide Model of Integrated Care for IBD. This model is:

- Underpinned by a Biopsychosocial Approach
- Collaborative – Gastroenterologists, IBD nurses and clinical psychologists forming an Multi-Disciplinary Team (MDT) with other specialists involved as needed
- Patient- centred

- Responsive – IBD nurse specialists able to provide timely advice, active nurse management of clinics and blood test monitoring protocols

The results were:

- Significant reduction in admissions to hospital from 48% to 30%
- Overall medication use reduced including steroids and opiate medication
- Treatment adherence improved in 62% of patients
- Knowledge about IBD and satisfaction with care improved
- Anxiety symptoms improved in 52% of patients and depression symptoms improved in 43% of patients

Having clinical psychology as part of an MDT and training nurses provides support to clinical care, improving psychological wellbeing, disease coping strategies and management of symptoms along with supporting adherence to treatment, readiness for surgery and self management.

Mary referenced the recommendation from the National Blueprint to “Co-design and develop access to dedicated psychological support for patients with IBD” and re-iterated that by addressing psychological care, services will save money in the long run.

Pauline thanked Mary for her contribution and recommended that this be a priority for the workplan of this group. Pauline invited questions.

Discussion continued around psychologist involvement in Multi-Disciplinary Teams and the cost savings associated with reduction of surgery and pharmacology costs. The Kings Fund have lots of evidence of the economic savings. The training of nurses and developing practice would be a very useful thing to roll out across the country.

Edmund added that the best bit of self management advice he has received was “Be good to yourself” from a Chaplain at Gartnavel Hospital, Chaplaincy Services and their supportive effect should not be underestimated.

Pauline continued that a greater level of buy-in from people on the ground is needed, warning people that there may be psychological effects as a result of their diagnosis would be a good start.

A discussion took place around how other services get psychological support, should the recommendation come from consultants, pilot projects may help to encourage this.

Nancy explained that an invitation to attend the Cross Party Group and talk about how the Mental Health Strategy applies to people with IBD and other long term conditions was sent to the Mental Health Strategy Team at Scottish Government, however, no-one was available to attend. The Mental Health Access Team within Healthcare Improvement Scotland were also invited but they felt there were not close enough links to their work.

After an audit of the IBD service in NHS Lothian psychological help was asked for. Nurses were trained but a further link to psychological services was not available due to funding issues.

Mary suggested that the money for psychological support should come from Acute Services across the country. Pauline suggested that if research highlights possible savings, this be used as evidence to push for added resource. This evidence would need to go to Health Boards.

Recruitment of psychologists was discussed. Mary explained that the only problem around recruitment is lack of funding meaning that services are very patchy across the country. There is a lot of work to do to raise the profile of IBD as it is a forgotten condition.

Pauline suggested that the group could write letters to Health Boards highlighting that the condition is on the rise and it should be addressed. This agenda needs to be pushed, and it might be a good addition to the workplan for this group.

The idea of Crohn's and Colitis UK funding a pilot project was mentioned. Elaine Steven noted that. Dr Georgina Rowse, a psychologist has been seconded to the charity and this may fit with her work.

Actions:

NG and ES to talk to Pauline about the best way of raising further awareness of the high incidence of anxiety and depression among people with IBD and the benefits of the approach outlined in Mary's presentation to Health Boards and to include this in the work plan.

Explore links with Georgina Rowse's work

6. **Crohn's and Colitis UK's self management project**

Presentation will be circulated.

Nancy provided an update on the UK wide project to inform and develop Crohn's and Colitis UK's policy position on self management. This work fits with the charity's Operational Plan and 5 year strategy.

The first stage is gathering the views of people living with IBD and research. This work has been co-produced with people with lived experience and clinicians.

Two surveys were sent out, the first to people with lived experience which resulted in 166 responses, the second was aimed at health professionals. The initial findings suggest that health professionals don't always know enough about self management of IBD to feel confident to recommend it.

Phone lines/ nurse helplines were given as an example of services being put in place to support people's self management. Time and resource are still seen as the biggest barriers to BD services developing self management support.

The majority of people with lived experience who responded had not spoken to clinicians about self management. However, most people employed self management strategies.

Some of the barriers to self management were seen as not being listened to by clinicians and reliance on biomedical markers like blood results rather than having person-centred conversations with the person.

The recommendations so far from people with IBD have included good quality information at the right time, information packs for newly diagnosed people, and access to counselling and peer support.

It was important to hold focus groups and engage with stakeholders in all four Home Nations as although self management is central to Scottish Policy it is not as prominent in the other countries.

A workshop was carried out in November 2017 to highlight the survey results to the Modern Outpatient team and IBD clinicians. This work is very closely aligned with the Modern Outpatient programme's Guided Self Management workstream and is key to implementing "Scotland Leading the Way: A National Blueprint for Inflammatory Bowel Disease in Scotland."

A position statement will be released in the near future, however, there will be further opportunities to feed into this work. Please get in touch with Nancy if you are interested in doing so.

7. The Modern Outpatient IBD Guided Self Management workstream

Dr Ian Arnott, Consultant Gastroenterologist at the Western General Hospital in Edinburgh updated the group on the work being done on the Scottish Government's Modern Outpatient Programme and the IBD Guided Self Management workstream.

Dr Arnott explained that IBD clinics are vastly oversubscribed resulting in very quick consultations and important issues not being addressed at appointments.

The aim of the Modern Outpatient as a whole is to get people seen at the right time by the right person for maximum benefit from appointments. Tools developed for this are making sure the clinician has good information around asking the correct questions and suggesting appropriate treatment.

The Action Plan for the Guided Self Management workstream has been developed in line with the Blueprint document. The self management work aims to make care more effective for people, getting appropriate care when required. For this to be achieved, local services are needed which are more accessible in a timely manner. Each person should have an individual care plan and psychological services could fit into this.

8. Work Plan for 2018

The next meeting of the Cross Party Group is due to take place on 23rd May 2018, this will focus on the role of IBD Nurse Specialists. The RCN Scottish IBD Nurse Network have been invited to attend and contribute. Nancy reminded the group that the meeting scheduled for 5th September has been moved to 19th September.

Pauline has put a motion down about IBD and asked for a debate on the work of the Cross Party Group, the group will be kept up to date on progress of this.

It was felt that a meeting to explore all the points raised at the meetings so far would be worthwhile. This could also be a chance to draft a letter to Health Boards and the Chief Executives Group.

An approach will be made to the Cabinet Secretary from Pauline inviting the Minister to a future meeting.

In place of a December meeting it was felt that to coincide with Crohn's and Colitis Awareness Week the Group could plan for a number of awareness raising activities including publication, a stand in Parliament and social media activities. The idea of a stand in Parliament during this week was addressed and the group thought that would be very useful.

Actions:

NG, ES and Pauline to meet to pick up actions from this and previous meetings and draft a letter to Health Boards/ plan to engage with the Cabinet Secretary.

NG to circulate text of motion to the Group.

NG to progress plans for awareness-raising activities.

9. AOCB

Pauline mentioned that this would be the last meeting before the deadline for the Regulated Lobbying Act coming into force. The CPG does not fall under the Act but if a conversation is struck up with an MSP outwith the meetings this might fall within it.

Action: Nancy to circulate information on the Lobbying Act to the Group

10. Date of next meeting

Wednesday 23rd May 2018, 6-8pm, Room TG20.

Pauline thanked everyone for attending and closed the meeting.

Attendance List

Members

Pauline McNeill MSP

Clare Adamson MSP

Miles Briggs MSP (first part of meeting including votes)

Liam McArthur MSP (first part of meeting including votes)

Edmund Murray

Janice Taylor

Paul Johnston

Angus MacLean

Edmund Murray

Gail Grant

Sally McNaught

Christopher Doyle

Cher-antonia Khedim

Dr Ian Arnott

Jana Moravcova

In attendance:

Nancy Greig - Crohn's and Colitis UK

Susan Brooks – Health and Social Care Alliance Scotland (minutes)

Elaine Steven- Crohn's and Colitis UK

Monika Brzozowska-Neroth - Crohn's and Colitis UK

Rhona Millar- Health and Social Care Alliance Scotland

Mary Cawley - speaker

Matthew Hilferty- speaker

David Pratt- Scottish Government

Isabelle Kolte

Rachel Hayward