

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

Wednesday 22nd February 2016, 6-8pm

Room TG 20-21, the Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP gave a warm welcome to those attending the first group of its kind and to MSPs Liam McArthur and Colin Smyth. She thanked Crohn's and Colitis UK for their support in setting up the group and for support with her fundraiser for Crohn's and Colitis held in Glasgow on 17th February. The evening was a great success raising awareness and money.

Apologies were received from:

Dr Richard Russell

Professor David Wilson

Clare Davidson

Vikki Garrick

Professor Angus Watson.

An attendance list is attached as an appendix.

2. IBD In Scotland- The Journey So Far

Helen Terry, Director of Policy, Public Affairs and Research welcomed everyone to the meeting on behalf of Crohn's and Colitis UK. Helen used her presentation to set the scene and history of Crohn's and Colitis UK's work around service improvement in Scotland from the first IBD audit of services in 2006 and the launch of the IBD standards in 2009 to the publication of 'Scotland Leading the Way; A National Blueprint for Inflammatory Bowel Disease' in in 2016 and was well received.

Helen explained there is still a lot to do in terms of implementing the recommendations from the Blueprint, but it has been influential in other parts of the UK. One of the main objectives of this new Cross Party Group will be to support the implementation of the Blueprint and to look at what further work needs to be done. A copy of Helen's presentation will be made available on the Crohn's and Colitis UK website

3. Purpose of the Group

Pauline explained that a registration document needs to be submitted to formally register the Cross Party Group. Attendees had an opportunity to look through a draft registration document.

There was a question from Gail Grant about whether she could represent a company rather than attend as an individual. Gail is Government Affairs Adviser for Abbvie and wishes to represent Abbvie at meetings. Pauline stated this would be possible.

There were no further comments at this stage on the draft document or the purpose of the group.

4. Office Bearers

A nomination was made for Pauline McNeill MSP to be Convenor of the group by Liam McArthur MSP. This was formally agreed.

Elaine Steven nominated Clare Adamson as Deputy Convenor and this was also agreed.

A question was raised about whether an external member of the group could hold the Vice Convenor position. Pam Rogers nominated Dr Ian Arnott for this position. Pauline agreed she would check whether this would be possible.

Elaine Steven nominated Nancy Greig as Secretary to the group and this was formally agreed.

It was noted that there would be no nomination of a Treasurer as Crohn's and Colitis UK are providing administrative support and will not collect a subscription.

5. What is IBD?

Pauline welcomed Dr Ian Arnott, Consultant Gastroenterologist at the Western General in Edinburgh to talk about Crohn's and Disease and Ulcerative Colitis (UC).

Ian explained the difference between the two conditions and talked about the high prevalence of IBD in Scotland including the five-fold increase in childhood Crohn's in the last 30 years. He also talked about research into causes of IBD and the pyramid of care where patients have traditionally been treated with milder treatments before moving onto stronger drugs.

Ian noted that there is variable service provision around Scotland. There has been some improvement in recent years but we need to keep the momentum going and this is not easy. Ian is leading work on IBD with the Delivering Outpatient Integration Together (DOIT) gastroenterology collaboration and hopes that the Cross Party Group will be able offer support to this vital piece of work.

A copy of Ian's presentation will be made available on the Crohn's and Colitis UK website.

Ian took questions following his talk and other members joined the discussion:

Q. Liam McArthur MSP asked if there was a problem with conditions becoming resistant to certain treatments.

A. Ian explained that the paradigm of treatment has changed and some of the newer drugs do work better as doctors are using biochemical markers to control the disease. However, there is still a group of people for whom the treatment options do not work.

There is no diagnosis coding in outpatient services. For example, we have no idea how many people with IBD seek out of hours care. A lot of the data collected in the NHS is suboptimal.

Q. Colin Smyth MSP asked why there are regional differences in Scotland between north and south in terms of numbers of people affected. He also asked whether there has been a real increase in people with IBD or if we are betting better at diagnosing people?

A. Ian said there had been a real increase in numbers and we don't know why there is a north /south divide. Vitamin D has been suggested as one factor that could affect people's susceptibility to IBD.

Pam Rogers explained that there is now better communication between paediatric and adult services. Lee Curtis said that there is now more recognition among health professionals of IBD being a condition that affects people in their teens and early adulthood.

Q. Liam picked up on Ian's slide and asked about risk factors for developing IBD and asked for more detail on smoking.

A. Ian explained that smoking can make Crohn's Disease worse, but conversely can be protective against flare ups of UC.

Q. Angus McLean asked if funding was the reason not everyone could see an IBD nurse. He noted that there are currently fewer IBD nurses at the Western Infirmary than there should be to meet the IBD standards.

A. Seth Squires talked about a big piece of work underway looking at the number of IBD nurse specialists for the population of Scotland and another piece of work that Vikki Garrick is leading on looking at the role of IBD nurses and how this feeds into service planning and provision.

Ian explained that provision of IBD specialist nurses is variable throughout the UK. Liam agreed that making the case for specialist nurses is difficult but there is

surely more of a case in high prevalence areas. Helen Terry noted that the work in the Highland pilot showed that an additional nurse improved care in a cost-effective way.

Seth commented that there is a limited evidence base for nurses in the Blueprint. Elaine explained that getting the appropriate health economic data to prove the business case for nurses or other activities had been a huge challenge.

There was further discussion about how the Blueprint will be monitored. It was agreed that it was part of the role of the CPG to monitor implementation. It was also noted that it was a challenge to implement the recommendations of the DOIT programme in every Health Board.

The group discussed this issue of targets and how these do not place emphasis on keeping people well in the community. This is a challenge, but an opportunity not to be reactive and to look at ways of prioritising good outpatient care. Colin Smyth suggested that the group feed into Harry Burns's work on targets.

Pauline talked about the work of David Conway around vitamin D which showed that Scotland was one of two places in the world with the highest number of grey days with no sunshine. Liam replied that this was a recurring discussion in relation to prevalence of MS in Orkney.

Liam McArthur left the meeting at this point.

6. Impact of IBD

Paul Johnson who lives with ulcerative colitis talked about the impact of the condition on his life. He was diagnosed at 36 when he stopped smoking. At the time, he was living in the Western Isles and had some challenges accessing treatment. Paul is a serving Police Officer and was trying to stay in work throughout his illness.

For around eight years he had recurring flare ups and steroid treatment and had to return to Inverness on many occasions for colonoscopies. When he was ill he would go to the toilet around 25 times per day and this had an enormous impact of his lifestyle, family and mental health. He was not able to continue with his hobbies which included kayaking and hillwalking.

After a period of being relatively well taking immunosuppressant drugs Paul underwent emergency surgery to remove his large intestine in 2015. In some ways, he felt relatively well afterwards although it was a big adjustment for him. Paul has decided to keep his stoma on a permanent basis. He continued to suffer from persistent mouth ulcers which affected his enjoyment of food and his speech so he took the decision to start smoking again and this has improved his quality of life.

Paul was involved with the steering group for the pilot project in the Highlands and felt this produced some good ideas such as video clinics for remote areas and a second IBD nurse at Raigmore Hospital. There is now a rapid access clinic and although Paul has not been unwell recently he knows that he can call the helpline and get a call back in 24 hours if he has a problem.

Paul would like to see more awareness raising around the psychological and emotional impact of IBD. Paul suffered from depression and tried to ignore it because he didn't want to be labelled. He believes that it would not be costly to talk to IBD patients about their mental health and flag up the higher risk of anxiety and depression. He would like to see a clear pathway for referrals for people struggling with their mental health. Paul's talk also covered lack of continuity between specialities in the wider Multi-Disciplinary Team e.g. between gastroenterology and oral health.

Finally, Paul mentioned the issue of lack of toilets on the gastro ward in Raigmore. As an inpatient he had to go up and down seven flights of stairs to use the public toilet as there were insufficient toilets on the ward.

7. Themes/ workplans for future meetings

Edmund Murray talked about some of his own experiences of living with IBD and asked that the group consider the impact of IBD on mental health. It was suggested that the group could seek a speaker on mental health issues and referral pathways for people with IBD.

Kirsty Gibson explained she is a mental health nurse as well as living with IBD and she finds that referral to mental health services is often a postcode lottery for people with IBD; some people get direct access to support and for others there is a huge gap.

Elaine noted that psychological support and self management clearly dovetail in terms of future topics. There was some discussion of shared decision making and how this can support self management.

The group also discussed opening dialogue with Health Board Chief Executives. There was consensus that this would be a key role for the CPG. The Blueprint has been sent to all Health Board Chief Executives and was designed to help them to meet their targets and map their IBD services. It was agreed that it would be a good idea to invite NHS Dumfries and Galloway Chief Executive, Jeff Ace who chairs the Health Board Chief Executives group.

It was agreed that Elaine Mead from NHS Highland could be invited to present on service redesign that has taken place in Highland and that would fit well with the invite to Jeff.

It was suggested that a speaker could be invited to talk about Delivering Outpatient Integration Together (DOIT) (Chair of the DOIT Stakeholder Group?). Ian

said he hoped the CPG would also be able to provide support to drive the implementation of the DOIT gastro workstream in Health Boards.

There was further discussion about staffing levels of both gastroenterologists and IBD nurses, business cases for IBD nurses and job planning for other specialities. It was noted that it is difficult to reach decisions without full attendance at multidisciplinary team (MDT) meetings.

There was a query over membership of the group and representation from other health professionals. There is currently no GP member although there was a GP on the Scottish Service Development Steering Group. Edmund Murray and Janice Taylor agreed to approach a GP who had previously spoken to the Clyde Group of Crohn's and Colitis UK.

Lee Curtis explained that many of her patients will go to their GP for support as the Glasgow Hospital for Children covers a wide geographical area. It was suggested that service redesign must involve GPs providing care for people with IBD in the community.

Lis Bardell joined the meeting at this point.

Pauline summarised some of the ideas for speakers and topics:

- Numbers of IBD nurses, their roles and the business case for nurses
- A discussion with the Health Minister- offer her one of the future dates
- Mental health and self management
- Higher incidence of IBD in Scotland
- Children and young people with IBD
- Service redesign/ outpatient services
- Data and technology.

It was agreed that Pauline and Nancy, with support from other staff, would draft a work plan that the group could amend.

At this point there was further discussion of Fecal Calprotectin (FC) testing (a simple stool test for inflammation) in the community. The DOIT programme is working to introduce FC into all primary care settings.

Pauline also raised the issue of support for children and teenagers with IBD in schools. Other members talked about the nature of IBD as an invisible condition and lack of support and understanding for adults in the workplace and other settings. There was discussion over the stigma attached to IBD and possible solutions to raise awareness of issues such as access to toilets.

Lee Curtis said that from the nursing point of view staff are seeing many young people excluded from school because they have to use a nasogastric tube. Many of these pupils do not get sufficient home support. If there is no one available to give them two hours per week they simply do not get it.

Janice Taylor spoke about her experience as a learning support teacher and aunt of two young people with Crohn's Disease. Her nephew who is in 6th year has missed a lot of school because of his Crohn's and methotrexate treatment and is disillusioned. Janice would like to see a team of people to talk to schools about the needs of young people with IBD in addition to the packs that Crohn's and Colitis UK produce.

Pauline said she felt it would be remiss not to include some of these issues in the work plan. There was discussion as to whether the aims and objectives of the group set out in the draft registration document needed further amendment. The first line of the group purpose was:

“To raise awareness of the issues faced by people living with IBD among parliamentarians.”

It was agreed the this could be reworded or a new line added to widen the group's remit and specifically mention children and young people.

8. Dates of future meetings

The following dates were tabled:

24th May 2017, 6-8pm, Committee Room 5

6th September 6-8pm, Committee Room 5

12th December 6-8pm, Committee Room 5

There was no other business and the meeting concluded at 7.50pm.

Action	Who?
Explore how the CPG could feed into the Review of NHS Targets led by Sir Harry Burns	NG /ES
Review any gaps in CPG membership (include other specialities e.g. GPs, pharmacists)	All
Approach GP contacts	ES/NG EM/JT
Insert additional wording as required to the registration document to widen the purpose of the group in order to reflect members' discussions.	PM/NG/ES
Draft work plan and topics for future meetings	PM/NG/ES All to amend
Circulate dates of future meetings to all members by email	NG

Attendance List

Members

Pauline McNeill MSP- Convenor

Dr Ian Arnott- Depute Convenor

Kirsty Gibson

Paul Johnston

Angus MacLean

Edmund Murray

Janice Taylor

Dr Daniel Gaya

Dr Graham Naismith

Dr Jonathan MacDonald

Lee Curtis (attending for Vikki Garrick)

Seth Squires

Pam Rogers

Gail Grant- Abbvie

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

Colin Smyth MSP

Liam McArthur MSP (attended part of the meeting)

In attendance

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

Elaine Steven- Crohn's and Colitis UK

Helen Terry- Crohn's and Colitis UK

Andy McGuinness- Crohn's and Colitis UK

Peter McDade- Pauline McNeill's office

Lis Bardell- Clare Adamson's office

