

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

Wednesday 2nd October 2019, 6-8pm

Committee Room 4, Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP welcomed everyone to the ninth meeting of the Cross Party Group on IBD. She also welcomed Colin Smyth MSP to the meeting and offered the group's thanks to Nancy Greig, who has moved to a new role in The Alliance, for her hard work in support of the CPG.

Apologies were received from:

Joe Fitzpatrick Deputy Minister for Public Health

Kirsty Gibson

Dr Daniel Gaya

Prof Richard Russell

Prof Angus Watson

Janice Taylor

Gail Grant

Angus McLean

Seth Squires

Allan Boal

Dr Jonathan MacDonald

Prof Ian Welsh OBE

Christopher Doyle

Cher-antonia Khedim

Vikki Garrick

Roisin Robertson

Dr Philip Gaskill

Michelle Convery

Peter Convery

Prof Angus Watson

2. Minutes of 22nd May & actions

The minutes of the previous meeting (Wednesday 22nd May) were approved as an accurate record.

It was noted that:

- A follow up with The Parliament's Diversity and Inclusion Manager about accessible toilet signage was required
- The CPG will consider a possible discussion around awareness of Crohn's and Colitis in schools in it's 2020 workplan or work jointly with another CPG

3. IBD UK & the new IBD Standards. Dr Ian Arnott, Consultant Gastroenterologist, Chair of the BSG IBD Committee, IBD Clinical Lead for the Scottish Government.

Dr Ian Arnott gave a presentation on the newly published IBD Standards and their development by IBD UK. <https://ibduk.org/>

Dr Arnott highlighted the immense amount of work undertaken by the many people representing the 17 professional organisations that make up IBD UK and their involvement in developing The Standards and thanked Crohn`s & Colitis UK for their support of the process in terms of time, resource and finances.

The Standards follow the patient journey and include sections on The IBD Service, Pre-diagnosis, Newly Diagnosed, Flare Management, Surgery, In patient Care and Ongoing Care & Monitoring.

A Benchmarking Tool is available for IBD Services to assess themselves against the Standards and allow them to make plans to address challenges and disparities in their own service.

A Patient Survey, which is live until November 22nd 2019, will allow patients to assess their own experience of care against the Standards thus offering their own IBD Service a patient perspective of the service received.

Dr Arnott informed the meeting that these new Standards are in alignment with the newly published BSG Guidelines on IBD

<https://www.bsg.org.uk/resource/bsg-consensus-guidelines-ibd-in-adults.html>

and that the BSG are urging all IBD Services to maintain a focus on Quality Improvement and register to complete the Benchmarking Tool as a means of doing this. The Benchmarking exercise will be repeated every 2 years.

Action: Add presentation on publically available Benchmarking results and report to Workplan for 2020

Dr Arnott also informed the meeting that recent research in NHS Lothian has highlighted the increasing prevalence of IBD in Scotland

<https://gut.bmj.com/content/68/11/1953> Other studies are also starting to show similar figures and Crohn`s & Colitis UK in partnership with Coeliac UK have commissioned a piece of work to understand prevalence across the UK of these conditions for delivery late 2020.

Action: Consider presentation on Prevalence of IBD and the impact on service provision in the Workplan 2020.

Discussion ensued with issues raised by members including the lack of knowledge of IBD, particularly in relation to children and young people, among GP`s and the need for good Transition processes to be in place between paediatric and adult services.

ES mentioned The Spotlight Project partnership work that Crohn`s & Colitis UK are involved in with The Royal College of GP`s that has developed the IBD Toolkit <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/inflammatory-bowel-disease-toolkit.aspx> and the work of the project`s Regional Champions who deliver educational sessions to their own networks and colleagues in Primary Care.

Dr Kastner further informed the meeting that she teaches 4th year Medical students at Dundee University about how to recognise gastroenterological conditions in children.

It was noted that although The Deputy Minister for Public Health was unable to attend this meeting, there was a meeting scheduled between him, Pauline McNeill MSP and Elaine Steven on November 7th at which these issues could be raised.

4. My experience of IBD services in the current system and why I want to be involved. Katie Wightman: Patient

Katie spoke about her experience of navigating health systems and IBD services which was not always a positive one for her.

Katie was diagnosed with ulcerative colitis 4 years ago after a year of visits to her GP, a 12 month wait for an endoscopy which had been flagged as urgent and eventually an emergency admission to hospital. Her parents had paid privately for a consultation.

Speaking of her disease pathway, Katie mentioned that the care at The Western General Hospital was excellent but that a lack of support from and access to the IBD Team led to her feeling that she was harassing her GP who had no specialist knowledge of IBD. She had at times felt abandoned by the IBD Service and asked for help several times but was always referred back to her GP. Katie told the meeting that she would have appreciated better access to outreach specialist care and a helpline service to support her through this very difficult time.

Katie shared her experience of 5 operations including an Ileostomy and a failed J Pouch and reiterated that the care in hospital was very good but she received little support on nutrition or her mental health and wellbeing concerns despite suffering from Post Traumatic Stress Disorder following her surgeries.

Katie also spoke of her difficulties with work, social and family life during this period and of her ongoing fear of falling through the `cracks` in the IBD Service; she has received no follow up care after her J Pouch corrective surgery 12 months ago and while appreciating that she may not always need to see a Consultant would nevertheless welcome more ongoing support from an IBD Nurse.

Having listened to Dr Arnott`s presentation on the IBD Standards, Katie was pleased and excited to hear about the national initiatives now in place to improve IBD Services.

Discussion on the need to support patients to self-manage their condition and the lack of psychological support for patients followed Katie`s talk.

In response to Katie`s experience with GP care, Dr Kastner raised her concerns about the inequitable access to Faecal Calprotectin testing in Primary

Care with not all Health Boards offering GP's access. This test is considered critical in the identification and timely referral of patients with suspected IBD.

Action:

Consider discussion about access to FC Testing in Primary Care to the Workplan for 2020

Consider discussion about the lack of Psychological support to the Workplan for 2020 and what self-management resources are available.

The meeting agreed that there is a need for Ministers to understand the seriousness of IBD and to commit to action to improve the provision of services.

Action: Raise at forthcoming meeting with Joe Fitzpatrick

5. Developing a new model of care for IBD Services in Scotland: 3 distinct pilots. David Pratt; National Improvement Adviser, Scottish Government.

David's presentation explained the principles of The Scottish Access Collaborative:

- Patients should not have to travel unless there is clear clinical benefit
- Referrals into secondary care should have senior or protocol led vetting
- Referral pathways should be clear and published for all to see
- Clearly defined access to diagnostic services
- Referral systems need to understand balance between demand and capacity, and link this to unscheduled care
- Improve metrics of the system, especially of remote access and advice pathway

These principles lead to a need to move away from traditional models of care which are acute based, consultant led and with routine return appointments to new and evolving models which will be on demand by patient initiated review, community based and patient-centred.

David explained that the Modernising Patient Pathways Programme and Crohn's & Colitis UK are currently working together with IBD Teams on 3 distinct Pilot Projects to develop *Community Based IBD Clinical Nurse Specialist (CNS) Services* in support of these objectives. In answer to a question David explained that each of these pilots have different funding sources; NHS Lothian from the Health Board, NHS Borders from Scottish Government Endoscopy Funds and NHS GG&C from The Modernising Patient Pathways Programme.

The 3 pilots are taking place in NHS Lothian, NHS Greater Glasgow & Clyde & NHS Borders. Each pilot is at a different stage of development with slightly differing proposed models and focus but with shared objectives.

The evaluation of all the pilots will follow a similar format to ensure that 'like for like' data and experience is being captured and compared.

David introduced the newly developed Flare Card to the meeting and explained that these cards, alongside Individual Care Plans will support patients to self-

manage their condition and will be integral to and linked into the development of these Community Based IBD CNS Services.

Dr Kastner asked what the decision making process is for where pilots such as these take place, adding that the North of Scotland would benefit from this type of service having a diverse and challenging geographical area. David explained that opportunity and clinician and management interest and `buy in` was an important aspect of any decisions and ES added that the bulk of the service re-design work that developed the recommendations within The National Blueprint for IBD in Scotland had taken place in NHS Highland for the reasons mentioned by Dr Kastner.

6. Topics for 2020 Workplan

Deferred

7. AOB

There was no other business and Pauline McNeill thanked everyone for their contributions and closed the meeting.

8. Date of AGM 2020 To be confirmed.

**Cross Party Group on Inflammatory Bowel Disease (IBD)
Ninth Meeting, Wednesday 2nd October 2019
Committee Room 4, the Scottish Parliament
Attendance list**

Members:

Pauline McNeill MSP- Convenor
Colin Smyth MSP
Edmund Murray
Dr Dagmar Kastner
Lis Bardell
Matthew Hilferty
Dr Ian Arnott
Paul Johnson

Attendees:

Elaine Steven: Crohn`s & Colitis UK
David Pratt: Scottish Government
Katie Wightman
Fiona Wightman