

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

Wednesday 29th September 2021

Virtual

## 1. Welcome and Apologies: Pauline McNeill MSP

Pauline McNeill MSP formally welcomed everyone to the 1<sup>st</sup> virtual meeting of the CPG since the General Election Session 6

Apologies were received from:

Angus McLean

Nancy Greig

Elaine Steven

Liam McArthur MSP

Clare Adamson MSP

## 2. Purpose of the Group: Approval of registration document

Pauline explained that this document was required in order that the CPG is fully compliant with the rules and guidance issued by The Committee for Standards, Procedure and Public Appointments. The CPG is being re-registered with the same purpose as previously.

## 3. Election of Office Bearers

Convenor Pauline McNeill: Proposer: Colin Smyth: Approved

Vice Convenor: Clare Adamson Proposer: Colin Smyth: Approved

Secretary: Elaine Steven Crohn`s & Colitis UK Proposer: Colin Smyth, Approved

Treasurer: Pauline noted that there is no requirement to appoint a Treasurer as no one is asked for a subscription.

## 4. The IBD UK Report: Crohn`s & Colitis Care in the UK: The Hidden Cost and Vision for Change: Sarah Sleet CEO Crohn`s & Colitis UK, Chair IBD UK

Pauline welcomed Sarah Sleet to the meeting and introduced her:

Sarah Sleet was appointed as CEO of Crohn's & Colitis UK in March 2019.

Sarah is an experienced and successful Chief Executive and has worked with a broad range of health and patient groups and European patient organisations, as well as government advisory and research bodies. She has also built expertise in education, social and economic policy, scientific research, income generation and campaigning.

Sarah Sleet asked if members were familiar with the IBD UK report published in April 2021 and explained that she would give an overview of UK figures within the report and some comparison with the Scottish figures.

The Benchmarking exercise, that the data from the report was informed by, is the culmination of a unique collaboration between Healthcare Professionals (HCPs) and patients offering a 360 degree view of IBD services across the UK both, measured against the IBD Standards, from the perspective of HCPs and patients.

It was explained to members that IBD UK is an alliance of 17 professional and patient organisations, involved in the care of people with IBD, reflecting the complexity of the conditions and the Multi-disciplinary working required in the care of people with IBD

Sarah gave an overview of IBD and informed the group that we now have a better understanding of the prevalence of the conditions from recent studies; the NHS Lothian study, which was previously presented to the CPG, suggesting 1:125 people in Scotland living with IBD, while a UK wide study, as yet unpublished, is citing a total figure of 530,000 people. With numbers significantly increased from previous estimates IBD services are under considerable strain.

72% of services across the UK took part in the service self-assessment with over 10,000 patients completing the Patient Survey  
In Scotland 14 services and 800 patients were involved.

Sarah presented the 4 key areas for change needed:

- Improvement in Diagnosis and information provision
- Personalised Care and support for self-management
- Faster Access to specialist advice and treatment
- Effective multidisciplinary team (MDT) working

In some areas Scotland was better than the UK as a whole and on others worse but overall there were no significant differences.

The report demonstrates clear variation in the patient experience and in service structure and capacity across Scotland.

Health Boards CEO`s should now review their IBD services and consider how they work with and support their IBD Teams to prioritise local quality improvement initiatives.

This unique report offers an unparalleled opportunity to use the findings to prioritise IBD and continue working collectively to ensure that IBD gets the recognition and resources it deserves.

Sarah summarised her presentation by calling for Inflammatory Bowel Disease to be taken more seriously and by asking governments across the UK to make IBD an NHS priority and communicate a clear strategy of how they intend to improve care over the next 5 years.

Pauline thanked Sarah and noted that there was clearly a need to understand why there was so much variation in care across Scotland and that was something the CPG was very concerned about.

Colin Smyth noted that he regularly received correspondence from constituents about IBD services and asked, given that any Health Board specific data in the report is small, were there any patterns to be seen across Scotland specific to the local HB data?

Sarah responded by saying that there had been no regional analysis of the data and that anecdotally there are beacon services and others that may be struggling. Members were pointed member to the top line local report data publicly available [Local Service Reports Map | IBD UK](#)

Pauline welcomed Liam McArthur MSP who had joined the meeting.

## **5. Vision for IBD In Scotland: Dr Ian Arnott, IBD Clinical Lead Modernising Patient Pathways Programme (MPPP), Consultant Gastroenterologist, Western General Infirmary, Edinburgh.**

Pauline introduced Dr Ian Arnott adding that the CPG was always delighted to welcome him to meetings:

Dr Arnott trained in medicine at St Andrews and Manchester University. He completed his postgraduate training in Gastroenterology in Edinburgh and UCLA, Los Angeles, USA. He is an accredited Specialist in Gastroenterology. He has been a consultant at the Western General Hospital, Edinburgh since 2003 and is an honorary senior lecturer at the University of Edinburgh. He deals with a broad range of gastrointestinal disorders including inflammatory bowel disease, and other diarrhoeal conditions, gastrointestinal bleeding and upper GI cancer. His interests

are teaching and research, particularly in the cause and treatment of gastrointestinal inflammation.

Dr Arnott is a previous Chair of the British Society of Gastroenterology IBD Section Committee and IBD Clinical Lead for the Scottish Government.

Dr Arnott gave a presentation highlighting work of the Modernising Patient Pathways Programme (MPPP) to improve services in Scotland which includes aspects of care across different conditions; specific to Gastroenterology IBS, Coeliac Disease and IBD.

Dr Arnott noted that pre-existing service issues had been compounded by pandemic and that if current increasing trends in prevalence continue that IBD clinic capacity will need to increase by 56% by 2028 leading to a significant unmet need for people living with IBD

The MPPP IBD Workstream is intended to deliver equity across Scotland to good quality care in the Right Place, at the Right Time by the Right Person

Dr Arnott praised the National Blueprint for IBD in Scotland as an important support to IBD services

Challenges to improving services include a mismatch between supply and demand and IBD not being seen as a priority with NHS managers

Dr Arnott went on to suggest that Supported Self-management could contribute significantly to quality of life and highlighted the MPPP work in this area that included the co-production of the Flare Card and Personalised Care Plan

To ensure a `Once for Scotland` approach a National IBD Steering Group has been set up which includes HCP`s from across Scotland and patients.

Priority areas of work going forward have been identified as:

- To digitise the Care Plan
- To map all IBD services in Scotland against the IBD Standards
- To support site specific Quality Improvement Plans
- To work collaboratively with Crohn`s & Colitis UK on the Alliance funded Supported Self-management Project

Dr Arnott finished his presentation by setting out a number of challenges that included the need to prioritise surgery for IBD appropriately and the strain on services increased by the pandemic and agreed with Sarah Sleet that it was vital that IBD is seen as a national priority.

Pauline thanked Dr Arnott for his very thorough presentation and invited comments and questions.

## 6. Discussion

Edmund Murray asked how far from meeting the IBD Standards did the National Report data suggest?

Dr Arnott answered that this would depend on which metrics were being asked about i.e access to psychological support and dietetics would be worse than access to IBD Nurses in some areas

Sarah Sleet answered that most services are struggling to meet all the standards

Dr Naismith informed the group that Clyde are critically short of consultants equating to 1 consultant for 78% of Scotland and supported the Service Mapping exercise  
Dr McDonald thanked both Sarah Sleet and Dr Arnott for highlighting the issues in IBD services in Scotland and posted on the Chat Function the recently published BSG Workforce Report which revealed that the West and North of Scotland were notably understaffed in terms of consultants.

There was agreement that there is a need to build sustainability and leadership to re-establish services and that the CPG and patients should lobby for better services.

Elizabeth Bardell suggested that lobbying for a service pilot based on optimal staffing levels would be beneficial

Amy Bednarz suggested that patient engagement in lobbying activity was vital

It was noted during the discussion that patients needed a more holistic approach to care to ensure that issues and concerns regarding pain, fatigue and emotional wellbeing were acknowledged and addressed.

Pauline thanked everyone for their contributions and summarised the key points from the meeting:

- The disparity in service provision highlighted in the National Report
- The increasing prevalence figures
- The Work force issues raised
- The need to ensure that surgery for IBD is appropriately prioritised
- The need to show what a difference to both patients and the NHS that self-management approaches to care can make
- The need to engage with Health Boards directly
- The need to keep raising awareness in Parliament of the conditions

**Actions:**

The CPG to write to The Cabinet Secretary for Health & Sport and The Cabinet Secretary for Mental Health & Wellbeing

The CPG to engage directly with Health Boards and write to Health Board CEO`s

To consider a Members Debate in 2022

To raise awareness with newly elected MSP`s

## 7. Dates of future meetings

Dec 1<sup>st</sup> 2021 @ 6pm

- 16<sup>th</sup> March 2022
- 15<sup>th</sup> June 2022
- 21<sup>st</sup> September 2022
- 7<sup>th</sup> December 2022

## 8. AOB

There was no other business

## In Attendance:

Pauline McNeill MSP

Colin Smyth MSP

Liam McArthur

Pamela Smith

Sarah Sleet

Ruth Wakeman

Jackie Glatter

Dr Ian Arnott

Denyse Aitken

Fiona Bernardis

Prof Richard Russell

Dr Daniel Gaya

Cher-Antonia Khedim

Dr Su Bunn

Dr Iain Chalmers

Dr Dagmar Kastner

Dr Graham Naismith

Alan (Alliance)

Seth Squires

Edmund Murray

Amy Bednarz

Lis Bardell