

Cross-Party Group on IBD

March 22nd 2023 @ 6pm Hybrid

Minute

Present

MSPs

Clare Adamson MSP Vice Convenor

Liam McArthur MSP

Sue Webber MSP (online)

Invited guests

Pamela Smith (staff)

Burcu Borysik: Crohn's & Colitis UK (BB)

Amy Deptford: Crohn's & Colitis UK

Sarah Sleet: Crohn's & Colitis UK

Non-MSP Group Members

Elaine Steven: Crohn's & Colitis UK (ES)

Dr Ian Arnott

Dr Dan Gaya

Dr Santosh Salunke

Prof Richard Russell

Dr Jacqueline Paterson

Dr Jen Veryan

Dr Zahra Bayaty

CNS Selina Lamont

CNS Pauline Bell

CNS Seth Squire

CNS Allan Boal

CNS Gillian Richardson

CNS Fiona McCluskey

Pharmacist Michael Smith

Claire Rush National Improvement Adviser CfSD

Gerald Bailey (NHS Healthcare Improvement Scotland)

Cher-Antonia Khedim (Lecturer)

Elisabeth Bardell

Kirsty Gibson

Kyle Crawford

Matthew James

Caroline Brocklehurst

Dr Amy Bednarz
Dr Harvey Humphrey
Audrey Wild Smith

Apologies

Pauline McNeill MSP
Kathleen Carolan, Director of Nursing & Acute Services NHS Shetland
Dr John Thomson
Dr Rob Bolton Jones
Dr Dagmar Kastner
Deborah Russell
Mairead Keegan

Agenda item 1

Clare Adamson (Chair) welcomed everyone to the meeting.

Agenda item 2

The minute from CPG Meeting December 7th 2022 was approved

Agenda item 3

Matters Arising:

The CPG Workplan for 2023 has now been distributed to members.

The Crohn's & Colitis UK Early Diagnosis campaign launch event on December 14th in parliament was well received and attended by Maree Todd, Minister for Public Health, Women's Health and Sport.

Thank you notes to the 38 MSPs who had signed the MOTION in support of the campaign resulted in meetings between Crohn's & Colitis UK and 3 MSP's to discuss the campaign and what support is available for their constituents.

Representatives from Crohn's & Colitis UK had a productive meeting with Humza Yousaf, Cabinet Secretary for Health, to discuss Scottish Government support for the campaign.

Representatives from Crohn's & Colitis UK and the Scottish IBD Nurses met with the Chief Nursing Officer Prof Alex McMahon.

Modernising Patient Pathways Programme (MPPP) National IBD Steering Group Staff Mapping exercise: Dr Arnott updated the group saying that the Staff mapping exercise is now complete and a report being drafted. Consideration is being given as to the dissemination of the final report.

Another Service specific QI workshop as a follow on to last year's is being planned.

A digital version of the Care Plan is currently being piloted.

The CPG were invited to submit a proposal for a panel session, which has broad public appeal, at the Scottish Parliament Festival of Politics 9-11 August 2023. After discussion with Pauline a submission was made and has been accepted. The session entitled: **The Language of Poo. Can words disengage communities?** will explore how our choice of language could create barriers for people to understand their health and access health services and consequently exacerbate health inequities. Members will be updated as the session is further planned and developed.

Agenda item 4

Update Crohn's & Colitis UK Early Diagnosis campaign: Presentation Burcu Borysik, Head of Policy and Campaigns Crohn's & Colitis UK.

BB gave a presentation updating the group on the progress of the Crohn's and Colitis UK Early Diagnosis campaign whose key aims are:

- To raise awareness of the symptoms of lower gastrointestinal so that people can get checked and take control of their health.
- To develop a national pathway for primary care to build confidence among the public and the healthcare profession so that people can be diagnosed and treated without delay.
- For clinicians to be able to prioritise endoscopies based on patient need and clinical risk

Lis Bardell informed the group that, after raising a question in Westminster related to IBD, Hannah Bardell MP and her constituent and campaigner Steven Sharp had been invited to meet with the Prime Minister, date to be confirmed. Lis also informed the group that another MP had approached Hannah afterwards suggesting the possibility of initiating an All Party Parliamentary Group (APPG) on IBD in Westminster.

Liam McArthur MSP commented on the great campaign suggesting that a debate would receive good cross party support and saying that the CPG should consider which particular issue to highlight.

Liam also suggested that a Westminster APPG for IBD could be supported by the Scottish Parliament CPG and that the two should liaise with one another. He further suggested that an APPG would be better set up towards the beginning of the next parliamentary session.

Agenda item 5

Proposal for CPG: Scrutiny of access to Endoscopy as a key diagnostic test for people with suspected Inflammatory Bowel Disease in Scotland:

BB presented the proposal, which had been sent to members, asking the CPG to consider an evidence gathering project to highlight the issue of increased waiting times for endoscopy for people with suspected Crohn's and Colitis. Discussion ensued.

In general, feedback on this proposal highlighted that this is a topic of interest for MSPs, clinicians and patients. Clinician experts advised on the complexity of endoscopy data collection, highlighting that Health Board collection and coding processes and referral routes to endoscopy may differ.

The group advised that an FOI/PQ based approach may therefore not uncover the data we require and recommended either a retrospective or prospective research exercise through the Information Services Division (ISD) Scotland. This suggestion was also supported by Clare Adamson MSP who has had similar experience of successfully working with ISD to improve data collection through the CPG on Accident Prevention and Safety Awareness.

Key Points Raised:

Dr Salunke suggested that approaching services directly could gain better information and data in a similar way to the Staff Mapping exercise.

BB Responded by saying that engaging with Health Boards would be helpful to understand the gaps in currently recorded and available data.

Sue Webber MSP commented that much endoscopy capacity is 'out sourced' to external (private) providers and asked if we intended including private providers as part of the proposal.

BB responded by saying that this would be considered as part of the next stage of further scoping the next steps for the proposal.

Dr Harvey Humphrey (patient) encouraged interim data gathering and asked what are the experience of rural, island vs urban, data gathering and can we support with qualitative work?

Sandra Macrae (patient) asked: Will the data gathering provide us with a realistic picture of the time lag that exists between the point of endoscopy being performed and 'diagnosis' and/or endoscopy report given to patients in a follow-up clinical consultation?

Dr Salunke commented that we don't have a good handle on data and a systematic gathering of data would be extremely valuable. However he questioned if the FOIs

were the best mode of collection suggesting that most Health Boards will not have the information needed. He added that patients are referred based upon symptoms and not with a diagnostic label. He added that we want to understand what data is available suggesting that this could be explored in different ways; finding out what is publicly available now and then deciding whether we would need to explore whether to bring IBD teams in. He would be happy to be involved in the project.

Caroline Brocklehurst (patient) was interested in understanding how people are referred and what clinical markers suggest a suspicion of IBD.

Caroline also asked if patient voice and experience will be included in the project.

ES assured her that patient voice would be integral.

Kyle Crawford (patient) asked if we know if there is any historical data that could be of use? Using people who have been diagnosed and looking at their endoscopy results to get a historical data and tracking trends?

Professor Richard Russell commented that the issue is not just about the time in accessing endoscopy but also about appropriate triaging beforehand, access to FC testing as well as time from diagnosis to treatment.

Dr Eleanor Watson told the group that NHS Lothian have some data on waiting times for suspected IBD but this may not be complete. This was from the IBD Team making a specific endoscopy request option for this; some people are diagnosed via the suspected cancer pathway so the data is likely to be muddy. Eleanor added that it is likely each health board will have a different process which could include:

- GP referral (someone that doesn't have cancer)
- Secondary care request
- Surgical pathway.
- Some will have 2 referrals - one from the GP and another through medical gastro's.

CNS Seth Squires reiterated the differing referral routes suggesting that the CPG could benefit from surgical representation.

Clare Adamson MSP, commented that the collection of data was a shared interest for a number of CPG's and suggested engaging directly with ISD via the CPG. Could ISD give a presentation to the group to explore what might be possible?

Dr Arnott suggested that we could look at retrospective data using ISD adding that coding is only used for people admitted with IBD.

Dr Salunke mentioned that there may be a need to consider whether we want retrospective or prospective data collection.

In response to being asked to consider the key stakeholders to be invited to attend the CPG suggestions were:

Health Board Endoscopy Leads

Surgical Leads
ISD

ACTION:

BB finished the discussion by saying that we would consider all the comments and suggestions and come back to the group with a revised proposal.

Agenda item 6

AOB: There was no other business.

Dates CPG Meetings 2023:

June 14th
September 20th
December 13th