

Cross-Party Group on IBD

September 20 2023 @ 6pm

Minute

Present

MSPs

Pauline Mc Neill MSP Convenor

Clare Adamson MSP Vice Convenor

Invited guests

Pamela Smith (staff)

Graham Rough, Director of Saturday School Ltd (GR)

Dr Shahida Din, Consultant Gastroenterologist at the Western General Hospital (SD)

Dr Kevin Gallagher, Specialist Trainee in Urological Surgery and Clinical lecturer at University College London and University of Edinburgh (KG)

Non-MSP Group Members

Elaine Steven (ES)

Burcu Borysik: Head of Policy and Campaigns (virtual) (BB)

Amy Deptford: Policy Manager (virtual)

Caroline Brocklehurst

Amy Bednarz

Dr Santosh Salunke

Professor Richard Russell (RR)

Nurse Consultant Seth Squires

All virtual

Liz Bardell

Graham Naismith

Kirsty Gibson

Maia Quail

Fiona McClusky (FM)

Dagmar Kastner

Lorna Kristin May

Aurdey Wild Smith

Harvey Humphrey

Apologies

Liam McArthur MSP

Colin Smyth MSP

Dr Ian Arnott

Dr Iain Chalmers

Dr Jen Veryan

Mairead Keegan

CNS Pauline Bell

Sandra McCrae

Edmund Murray

Agenda item 1

PMcN welcomed everyone to the meeting

Agenda item 2

The Minute from the meeting June 14th 2023 was approved.

Agenda item 3

Matters Arising:

NHS Scotland has now launched A Medicines Homecare Review-Call for Evidence.

[NHS Scotland -Medicines Homecare Review - Call for Evidence - Questions \(PDF\).pdf](#)

- Individuals or organisations can respond via an online survey.
- Crohn's & Colitis UK will be submitting a response and will be issuing a survey in Scotland to understand the experience of people who receive Homecare Services and if there are any geographical differences in service provision. The findings will inform their submission.

- Contact Policy@crohnsandcolitis.org.uk if anyone affected wants more detail about how to make a submission.
- **The Scottish Parliament Festival of Politics ‘Language of Poo’** session was well received.

The panel was chaired by Pauline McNeill MSP, with Crohn’s & Colitis UK’s Head of Policy and Campaigns, Burcu Borysik, the Scottish Government’s National Clinical Director, Professor Jason Leitch, and the eminent academic **Dr Josephine Adekola** from the University of Glasgow discussing with the audience why the language we use when talking about bowel symptoms is important when it comes to diagnosing and treating conditions like Crohn’s and Colitis.

The session can be seen at : [The language of poo. Can words disengage communities? | Scottish Parliament TV](#)

Agenda item 4

Election of Office Bearers:

Convenor: Pauline McNeill, Proposer: Liz Bardell/ Seconder Elaine Steven
Vice Convenor: Clare Adamson, Proposer: Elaine Steven/Seconder Pamela Smith
Secretary: Crohn`s & Colitis UK, Agreed for the time being to leave the secretary stated as the CCUK organisation.

PMcN explained that there will be no nomination of a Treasurer as Crohn’s and Colitis UK re providing administrative support and will not collect a subscription.

AGENDA Item 5.

CPG Annual Return & Work plan.

PMcN thanked everyone who has indicated that they wish to remain formally as members of the CPG and invited anyone who wishes their name to be added to the Annual Return as a member to let ES know by Monday 25th September.

PMcN added that a Work Plan for the next year’s meetings is currently being drafted.

AGENDA Item 6.

IBD Adolescent Services Update: Professor Richard Russell (RR).

Professor Richard Russell is one of 6 Consultant Paediatric Gastroenterologists working in the new Royal Hospital for Children and Young People in Edinburgh and is the clinical lead of Paediatric Gastroenterology Hepatology and Nutrition services in the east of Scotland.

RR reflected on where we are with wider IBD services with more patients than workforce to match them. Since the last update, work has been done to across the UK to characterise pre pandemic the state of mental health in young adults, using data from all 4 UK countries.

Patients with IBD have a higher risk of common mental health risks compares to peers but once they leave paediatric services, the provision for mental health need is reduced.

RR reflected that there needs to be a service for young adults for their unique needs so that they are not “drowned out” by the wider numbers in patient care. Moving forward there is a need for a group of health care professionals, to create a plan of what the service will look like (beyond an idea) – there is support for this across the stakeholders.

RR mentioned a 15 month incidence study of paediatric cases UK wide. Results are being collated now; every year diagnosing more under 16s.

PMcN: noted that this is an important subject and that we need recognition of dedicated services particularly with the higher incidence. She reflected that if drug regime not resolved by the time patients get to 18 it can cause problems, and committed to continuing to campaign on this.

AGENDA Item 7.

Saturday School and The Catherine McEwan Foundation Scholarship: Graeme Rough (GR)

Graeme Rough is the Director of Saturday School Ltd and spoke to the group about the Saturday School and The Catherine McEwan Foundation Scholarship.

GR explained how Saturday School Ltd have been providing paid for services, tuition and revision for home educated young people and adults for 13 years. Seven years ago it became an SQA approved centre and supports young people and adults looking to begin or enhance qualifications who have difficulty accessing colleges. The main delivery site is Glasgow Academy and a second delivery site will be launching at Sighthill Campus at Napier university.

GR explained that the Scholarships programme:

1. Works with the Royal Society of Chemistry to support mostly young black afro Caribbean women to consider a career in STEM. This is now in its 3rd year.
2. Includes the Saturday school scholarship programme which offers educational enhancement or recovery to young people in Scotland living in poverty. The objective is to close the poverty gap.
3. Includes the Catherine McEwan Scholarship, now in its 5th year and supports young people at school or college whose learning has been impacted as a result of IBD. Provides fully funded enhanced educational support in SQA National Qualifications. The aim is to get them reconnected with school, and helping them achieve qualifications to move on to further education. Scholarship programme is funded through Catherine McEwan fundraising activity.

CA thanked **GR** for the presentation and for highlighting the work of Saturday schools.

FM noted that she recognised one of the young people in the presentation – Alexandra – who told her about the service.

AGENDA Item 8.

IBD National Steering Group Endoscopy Workstream update: Dr Shahida Din/
Dr Kevin Gallagher

PMcN introduced Dr Shahida Din who is a Consultant Gastroenterologist at the Western General Hospital in Edinburgh and a Research Clinician leading a scientific programme, identifying factors predictive of inflammatory bowel disease (IBD) associated colorectal cancer. In 2021, Shahida was appointed as the National IBD Surveillance lead for Scotland and is Senior author on the BSG interim framework for addressing the COVID-19-related backlog in IBD colorectal cancer surveillance. Shahida is a member of the BSG IBD Committee and Gastroenterology specialty advisor to the Royal College of Physician's Edinburgh. Shahida is passionate about patient advocacy, sharing good clinical practices and mentoring the next generation of gastroenterologists. AND

Dr Kevin Gallagher who is a Specialist Trainee in Urological Surgery, East of Scotland and Clinical lecturer at University College London and University of Edinburgh

Kevin is also a Clinical fellow for Data Driven Innovation at the Centre for Sustainable Delivery, part of Public Health Scotland; as an academic specialist surgical trainee and researcher, Kevin is currently working to develop improved national data systems related to endoscopy surveillance waiting lists and prostate cancer outcomes.

SD explained:

- Team are looking at bowel cancer risk in IBD endoscopy capacity and how to manage the risk
- IBD affects 1 in 125 people, possibly will reach to 1% of population by 2028
- IBD sufferers have increased risk of bowel cancer
- Recommend surveillance, regular colonoscopy to detect. No other test or markers exist so endoscopy capacity is crucial
- Issue with demand on endoscopy, not enough just now, seen during Covid 19. Demand is increasing exponentially.
- IBD Population based on Lothian data approx. 33,000 with IBD, likely to be an underestimate, and only considers those within primary care, within which 1000 patients in Lothian waiting on investigations – so the risk of bowel cancer in those is unknown. Data exists for those in the general population, those in the Bowel Cancer Screening Programme, and those with symptoms

who are escalated, however those with IBD have higher risk but there is no national waiting times for colonoscopy. For IBD Patients no national diagnostic waiting times for appointment for procedure they need; compared to route to colonoscopy.

- Many thousands of patients on endoscopy surveillance waiting lists, which continues to grow during which time the cancer risk is unknown.

SD discussed the identified stakeholder group across the country to look at surveillance improvement and the creation of a framework for addressing backlog in IBD colorectal cancer surveillance. Done with patient feedback.

Dr Kevin Gallagher discussed his work within this presentation.

- Reiterated no national patient level data about endoscopy surveillance waiting lists.
- Data that does exist is bland; no detail about why they are on the list, no variables about their clinical risk of cancer which would allow the team to prioritise
- Now have patient level data coming in from all health boards, this is work in progress, but an important innovation, as it allows them to begin risk prioritisation
- Commissioned a change to the waiting list booking system, which captures more information including conditions, diagnosis, clinical risk category, to identify the groups at risk and will link with other systems.
- This will allow that in the event of another pandemic all information will be held on one platform.

PMcN asked if a referral for colonoscopy, there is no data on why they are on. **KG** confirmed this is correct broadly for the surveillance list, although differs across boards. The clinician will have access to patient details at that point, but this is not held on the system.

PMcN asked who decides who is seen first. **SD** confirmed that this is a clinical decision. **KG** reflected that moving forward this should be done on a nationally agreed way.

CA asked at the moment who decides what the risk factor is, if health boards doing this differently. **SD** acknowledge need for better system.

Dr J McDonald, Glasgow reflected that currently clinicians can add notes with regards to urgency when referral being done, however this is placed with all other info and used in a way which doesn't utilise this information.

ES reflected whether it would be possible to set up a similar process for GP referral at potential diagnosis stage. **KG** confirmed that currently a new referral doesn't have this function but agreed that it could be helpful.

AGENDA Item 9.

Crohn's & Colitis UK update: Burcu Borysik: Head of Policy & Campaigns

PMcN introduced Burcu Borysik, now well known to most CPG members, adding for anyone new to the group that Burcu joined the charity as Head of Policy and Campaigns March 2022, joining from the Royal Society from Public Health where she led policy and communications for the charity.

- Early diagnosis campaign: 100,000 completions on the symptom checker. 7 in 10 people go on to visit their GP.
- Continuing to advertise digitally and in selected areas in Scotland, e.g. student accommodation, shopping areas at Christmas time
- Joint working with Boots: displaying symptom checker in stores, training Boots pharmacists on IBD and will be integrating the symptom checker on the Boots patient hub.
- 1 November launch of the campaign film "No Excuses" in Cinemas, Channel 4, ITV and Sky streaming platforms.

- Lower GI Pathway – in conjunction with other charities working to improve the journey for those displaying lower GI symptoms in recognition that people present with symptoms rather than conditions. The pathway will be going out to consultation in October and will be shared with clinician CPG members. The pathway will be supported by a patient toolkit – both of which will be launching next year.
- IBD UK survey now closed, reports will be available from early 2024.

BB ended with thanks to **ES** for her hard work and dedication to the charity, and wishes her well in retirement.

ES thanked **BB** and the group. Acknowledged the patient voice that brings home the importance of the work.

AOB

The Independent Scottish Covid-19 Inquiry.

Crohn's & Colitis UK have been approached by the legal team involved in the Scottish Covid-19 Inquiry (SCI) to give an organisational statement about their experience, and that of their membership and community, during the COVID-19 pandemic. This is to understand as broadly as possible the impacts suffered by members of the public during the covid period.

The charity has also been asked to help the Inquiry Team in the identification of people from their membership and networks, who may be willing to give a statement to the inquiry team about their personal experiences during the COVID-19 pandemic and relating to the Inquiry themes of:

- admission to hospital during the pandemic (emergency or otherwise)
- hospital care during the pandemic as well as access to non-hospital services such as GP services
- lived experience of shielding, those who were not advised to shield but nevertheless believed they had a condition warranting inclusion on the

Highest Risk List, as well as those who “wrongly received” a letter advising them to shield.

Individuals can share their experiences by using the Let’s Be Heard online survey. [Let's Be Heard online form | Let's Be Heard | Sharing Scotland's COVID experience \(covid19inquiry.scot\)](#)

Anyone who might wish to speak in person to the Inquiry Team can get more information by contacting Policy@crohnsandcolitis.org.uk.

PMcN informed the group that that Burcu will be going on maternity leave in November and gave her the group’s best wishes.

ACTION:

PmcN to liaise with ES regarding a CPG statement to the Scottish Independent Inquiry Team.

There was no further business and **PMcN** closed the meeting by thanking everyone for their contributions.

Dates CPG Meetings 2023:

December 13th