

Cross-Party Group on Inflammatory Bowel Disease

13th December 2023, 6pm

Minute

Present

MSPs

Pauline McNeill MSP
Clare Adamson MSP
Liam McArthur MSP

Invited guests

Ruth Wakeman (Director of Services, Advocacy and Evidence, Crohn's & Colitis UK)
Amy Deptford (Policy Manager, Crohn's & Colitis UK)
Pamela Smith (Staff)
Alexandra West (Staff)

Non-MSP Group Members

Dr Santosh Salunke
Amy Bednarez
Edmund Murray
Dr Harvey Humphrey
Seth Squires

Observers

Dr Husnain Jafferbhoy
Erin Bailey
Caroline Brocklehurst
Gillian Richardson
Fiona McCluskey
Dr Eleanor Watson

Apologies

Angela Kidd
Dr Dagmar Kastner-Cole
Treaasa Ody

Dr Ian Arnott
Claire Rush
Lorna May
Michael Smith
Rob Gowans

Agenda item 1

Welcome and Apologies

Agenda item 2

Minutes of meeting 20th September 2023

Agenda item 3

Matters Arising

Noted that Crohn's and Colitis Awareness Week ran from 1st to 7th of December, with a First Minister's Question on inflammatory bowel disease.

Noted the ongoing Scottish COVID-19 Inquiry, "Let's Be Heard".

Agenda item 4

CPG 2024 workplan

Focus of work for 2024 to include raising awareness of the state of IBD care following the launch of IBD UK's benchmarking report, raising awareness of the impact of delayed diagnosis of IBD and the need for a lower gastrointestinal primary care pathway.

Agenda item 5

Presentation: NHS Scotland Medicines Homecare Review: Seth Squires (IBD Clinical Nurse Specialist) and Amy Deptford (Policy Manager, Crohn's & Colitis UK)

- Presentation on homecare medicines services and the risk to patient health and wellbeing when these services do not work as intended.
- The Chief Pharmaceutical Officer, Professor Alison Strath has commissioned an independent review into this. The hope is that the final report from this review will be provided to the Chief Pharmaceutical Officer by the end of March 2024.
- Discussion on patient experiences of services, the impact on IBD services, the different experience of services in rural vs. urban areas, and the reasons behind service issues.
- Discussion of the recommendations that emerged following the House of Lords Public Select Committee inquiry into homecare medicines.

Agenda item 6

Presentation: Crohn's & Colitis UK update: Amy Deptford (Policy Manager) and Ruth Wakeman (Director of Services, Advocacy and Evidence)

- Crohn's and Colitis Awareness Week, with a focus on tackling stigma. The week included an awareness pack for healthcare professionals, a radio advert, bus adverts, drop-ins at the Senedd and Westminster, and over 500 people contacting their Parliamentarians.
- Over 30,000 completions of the symptoms checker.
- Question from Clare Adamson MSP in First Minister's Questions, "What action is the Scottish Government taking to highlight Crohn's and Colitis Awareness Week?"
 - Response from First Minister details the Early Diagnosis campaign, and the efforts to reach marginalised and under-served communities.
 - Clare Adamson MSP highlights the impact of delayed diagnosis, and the need to improve recognition of symptoms. What action will the Government take to raise awareness of symptoms and tackle stigma?
 - Response from First Minister thanks Crohn's & Colitis UK for their work.
- IBD UK survey had 15,000 patients respond. Findings to be reported when available.
- Ongoing piece of work identifying most significant impact of IBD on patients.