

Cross-Party Group on IBD

Wednesday 22nd June 6pm

Minute

Present

MSPs

Pauline McNeill MSP

Invited guests

Burcu Borysik: Crohn`s & Colitis UK
Amy Deptford : Crohn`s & Colitis UK
Chloe Hutchinson: Crohn`s & Colitis UK
Robert Crawford: Galapagos Biotech
Kyle Crawford: Patient Speaker
Rose Johnston: Patient

Non-MSP Group Members

Pamela Smith: Caseworker, P. McNeill MSP

Elaine Steven

Denyse Aitken

Dr Ian Arnott

Dr Iain Chalmers

Seth Squires

Apologies

Colin Smyth MSP

Liam McArthur MSP

Brian Whittle MSP

Sue Webber MSP

Claire Adamson MSP

Dr Dan Gaya

Prof Richard Russell

Dr Dagmar Kastner

Dr Su Bunn

Cher-Antonia Khedim

Nancy Greig

Edmund Murray

Sandra McCrae

Amy Bednarz

Kirsty Gibson

Carrie Thomson

Agenda item 1: Welcome and Apologies

Pauline McNeill MSP welcomed everyone to the meeting and asked for approval to record the meeting for the purpose of minute taking

Agenda item 2: Notes from Meeting 1st December 2021

It was noted that as the meeting was not quorate and that Parliament was still in session this, therefore, did not constitute a formal meeting of the CPG

Approval of the minute of the last meeting on December 1st 2021 would be deferred until the next meeting.

Agenda item 3: Matters Arising

Pauline informed the group that responses have been received to the letters sent from the CPG to the Cabinet Secretary for Health & Sport and CEO`s of Health Boards.

These are being reviewed and further responses from the CPG are being considered

Pauline informed the group that she had tabled A Written Question to the Scottish Government and a response received: [S6W-09041 | Scottish Parliament Website](#)

Pauline informed the group that she, and Elaine Steven, had met with Prof Russell to agree actions arising from his presentation at the CPG Meeting on December 1st 2021 and the accompanying discussions regarding the need for Adolescent Clinics at the last meeting. There will be further information on this at the September 2022 meeting which will re-focus on paediatrics and young people.

Agenda item 4: A Personal Experience: Kyle Crawford

Pauline introduced Kyle explaining that he is 26 years old and works as a customer advisor in the banking sector. Kyle was diagnosed with Ulcerative Colitis in 2017 and with associated arthritis a few years later as his condition deteriorated. Kyle currently lives in

Fife but has moved council areas a few times since his diagnosis and his talk will tell us about how he was `Lost to the system post diagnosis`

Kyle thanked Pauline for her introduction and went on to explain to the group that in 2017 he experienced some rectal bleeding but put off getting checked by a GP for months; at that time he had no fore knowledge of IBD and was concerned that his symptoms indicated cancer. After a colonoscopy he was diagnosed with Ulcerative Colitis and given the NHS Lothian nurse helpline and some information sheets.

After being OK for a couple of years he experienced a flare but put off calling the nurse helpline as he was not sure if his decline was related to his IBD and where he should go for help; he did go to his GP and subsequently spent time in hospital.

Kyle described his struggles accessing Personal Independence Payment (PIP) being initially given 0 points in every category; after having to go through the appeal process and face a tribunal his application was eventually successful. This `fight` added a great deal of stress at an already difficult time and Kyle hopes that the new Adult Disability Payment (ADP) will improve the process greatly.

In 2021 Kyle needed a second hospital stay and was prescribed Infliximab, a biologic therapy given by IV infusion in hospital, which necessitated an increased need for monitoring and support. A reaction to his first dose caused intense nerve pain, which has never gone away, but an MRI scan did not show any problems.

Having moved it was at times difficult to travel to Edinburgh for a morning infusion appointment and subsequently Kyle transferred his care to Kirkcaldy

He has experienced difficulties in accessing both follow up and GP appointments for appropriate tests, resulting in delays to his hospital treatment and long waits for medication; all of this has caused both his physical and mental health to deteriorate.

Kyle has not always been able to work because of his condition, has found himself to be extremely unwell, exhausted and unable to leave the house and not knowing who to contact.

Kyle finished his talk by telling the group of his fears for the future with regard to his ability to work, and stressing the need to be seen by healthcare professionals face to face rather than by phone appointments given his complex health needs.

Pauline thanked Kyle for offering the group his experience. She then left the meeting at this point to attend to Chamber business and passed the chairing of the meeting to Elaine Steven.

Burcu: Thanked Kyle for raising good points about the management of his condition and difficulties about accessing PIP. She asked Kyle if there was one thing he could change about his experience what would it be.

Kyle responded by saying that streamlining the move between HB`s, which must be a broader issue, having access to more regular clinic slots and the need to talk to someone for support and reassurance should be part of the system

Seth commented that transfers of care is an ongoing issue and reflected on recent clinical group discussions.

Seth also commented that IBD Nursing Service are able to give the kind of service and support that Kyle needs.

Ian Arnott thanked Kyle for his talk adding that it was chastening to hear from patients and interesting to note the disconnect between what the IBD Service thinks they offer and what patients feel confident to access.

Dr Arnott added that despite routine appointments being challenging patients should know to contact their IBD service at any time for advice and support.

Dr Arnott and Elaine noted that these insights will be useful to feed into the work of the Supported Self-management Project that is currently underway.

Pauline left the meeting to attend to business in the chamber and handed the chair to Elaine Steven.

Agenda item 5: Study on the Incidence and Prevalence of Inflammatory Bowel Disease: Burcu Borysik Head of Policy & Campaigns Crohn`s & Colitis UK

Elaine introduced Burcu explaining that she was appointed as Head of Policy and Campaigns of Crohn`s & Colitis UK in March 2022 and joined from Royal Society from Public Health where she led policy and communications for the charity. Burcu brings a decade of experience in designing policy to tackle health inequalities and leading service design and innovation for people who face severe and multiple social exclusion.

Burcu informed the group about the report from the jointly funded project by Crohn`s & Colitis UK and Coeliac UK that summarises the incidence of IBD across the UK between 2020-22 and the prevalence in the year 2020.

Researchers from the University of Nottingham carried out the research with the health care records of 38.3 million people registered to GP`s across the UK contributing anonymised information to the Clinical Practice Research Datalink (CPRD)

Burcu explained that the study found that there are over 500,000 people or 1:123 people living with IBD in the UK. Scotland had the highest incidence of IBD in the UK with over 50,000 or 1:103 people living with IBD.

The significant increase in numbers from previous estimates raises concerns about the ability of the capacity of the NHS to care for thousands of patients in Scotland.

Burcu presented the group with some further detail but as the research has still to be published as an academic article in peer review journals, all the detail is not yet able to be shared more broadly.

Seth Squires thanked Burcu and commented that understanding the research methodology would be useful and enquired where and when the study would be published?

Burcu responded that these questions could only be answered by the University of Nottingham and that the charity would keep Seth and members updated as to any publication details.

Burcu offered to facilitate a conversation between Seth and the researchers if that would be helpful.

Dr Chalmers reiterated that understanding the details in the data will be helpful and that paediatric data is showing increasing incidence particularly in the adolescent population. This data will have relevance to discussions the CPG is having about robust service provision and smooth transition from paediatric to adult care.

Elaine informed the group that a Policy Briefing about the study report had been sent to all MSP`s raising concerns about the ability of NHS Scotland to effectively manage the care of over 50,000 people living with IBD in Scotland and asking MSP`s to put pressure on Health Board CEO`s to ensure that IBD Services are fully resourced.

For more information: [New research shows over 1 in 123 people in UK living with Crohn's or Colitis \(crohnsandcolitis.org.uk\)](https://crohnsandcolitis.org.uk)

Elaine thanked Burcu for her presentation and handed the chair back to Pauline as she had returned to the meeting.

Agenda Item 6. The implications of the study findings for IBD Service provision in Scotland: Dr Ian Arnott. IBD Clinical Lead Modernising Patient Pathways Programme (MPPP), Consultant Gastroenterologist, Western General Infirmary, Edinburgh.

Pauline introduced Dr Ian Arnott and explained that Dr Arnott had trained in medicine at St Andrews and Manchester University, completing his postgraduate training in Gastroenterology in Edinburgh and UCLA, Los Angeles, USA. He is an accredited Specialist in Gastroenterology and 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 started his presentation by saying that having heard from a patient, and in the knowledge that the number of people living with IBD is increasing, that his presentation, about the current service provision in Scotland might suggest a `perfect storm` for IBD but that this is something that we can come together as a community and CPG to influence Health Boards and make a difference.

Dr Arnott explained that the National IBD Steering Group of the Modernising Patient Pathways Programme (MPPP) had as one of it`s Quality Improvement targets for 2022 to map out the current IBD Service Staffing provision in Scotland. Some data was available from the IBD UK Benchmarking survey but that more granular detail was needed.

A detailed IBD Service staffing questionnaire was developed and sent out. The responses were then mapped against the IBD Standards [IBD Standards | IBD UK](#)

Dr Arnott noted from his slides that although there had been an expansion in IBD Nursing since 2007 that the current resource is still under the IBD Standards recommendation in many Health Boards.

A similar picture exists from a medical point of view and that the data doesn't tell the whole story i.e in Greater Glasgow and Clyde the North and South Sectors are relatively well provided but the Clyde Sector is deficient in medical staffing.

Psychology support is at very low levels across all Health Boards, pharmacy provision is improving as are dietetics but no services meet the recommended levels.

Dr Arnott explained that this work is at an early stage and that a Work Plan has been developed to drill down into the data so that the required granularity can be achieved to complete the picture of IBD Service provision across Scotland.

Dr Arnott further informed the group that this granularity has never been available before and that he believes a complete understanding of service provision across Scotland will be a strong tool for IBD Services to campaign for the staffing resources they need to run their services properly

Pauline thanked Ian for his presentation commenting that some of the information was quite shocking and suggesting that all MSPs` could be asked to write to their own Health Boards asking why they don't meet the IBD Standards.

Pauline commented further on the need from a patient perspective of access to psychological support and dietetic support, particularly for newly diagnosed.

Dr Arnott agreed that the data, when completed, should be used for letters to Health Boards.

Elaine suggested that the details in the responses already received from the previous letter to Health Board CEO`s should be look at with regards to any tailoring of letters with the new patient numbers and staff mapping information.

Burcu asked if Health Board CEO`s could be invited to CPG meetings?

Pauline explained that we have invited them on numerous occasions previously and would do so again now that this new information offers the CPG an opportunity to work more strategically on this issue.

Seth asked if a question about Transition arrangements between paediatric and adult services might be added to the staff mapping questionnaire? Ian agreed that this could be considered.

Pauline noted that it would be important going forward to regularly table PQ`s in order to maintain a focus on IBD with Ministers.

There was no other business.

Pauline closed the meeting by thanking everyone for their contributions
The next meeting will take place on: Wednesday 21st September at 6pm