

# Minutes of the 11<sup>th</sup> Cross Party Group on Inflammatory Bowel Disease (IBD)

Wednesday 16<sup>th</sup> September 2020

VIRTUAL

## 1. Welcome & Apologies

Pauline McNeill MSP welcomed everyone to the 1<sup>st</sup> virtual meeting of the CPG

Apologies were received from:

Dr Jonathan McDonald

Dr Susan Bunn

Seth Squires

Allan Boal

Angus McLean

Dr Iain Chalmers

David Pratt.

## 2. Minutes from 19<sup>th</sup> February 2020

The minutes of the previous meeting were approved as an accurate record.

It was noted that any outstanding actions will be reviewed by Pauline McNeill & Elaine Steven considering the time and changed environment since the last meeting

## 3. Updating the CPG since Covid-19:

**Scottish Parliament:** Pauline McNeill MSP

Pauline acknowledged that, given the Covid situation, the CPG had been unable to meet until now but that it was important going forward to continue the work of the CPG and was pleased that this meeting was taking place. She further noted that although it would be difficult to maintain a focus on IBD in Parliament at the current time it would, nevertheless, be important to understand the impact of Covid on people with Crohn`s and Colitis and feed this in wherever possible and appropriate.

**Crohn`s & Colitis UK:** Ruth Wakeman Director of Services, Policy & Evidence

Ruth introduced herself and explained some of the impacts the Covid crisis has had on the charity since February.

Income had been drastically affected, a number of staff had been furloughed and it had been necessary to reduce the size of the charity which had led to an internal re-structure. At the same time there had been a huge increase in demand for the charity`s services, particularly caused by confusion around shielding and risk to patients.

As an example, visits to the website surged by 65%, emails to the Helpline by 125% and to the Live Chat by 100%.

Focus and priority was given to maintaining the core, critical services so that our community's needs for information could be met. There had been an enormous amount of work gone into constantly updating information and FAQ's etc as well as working collaboratively with The British Society of Gastroenterology (BSG) and the IBD Registry to develop patient friendly risk assessment tools.

As a result of the re-structure the Charity will continue to focus its work in all 4 UK countries while the development of a new Policy Team will build on previous work but with a broadened remit that will include education, employment, benefits, access to toilets, access to medicines and other issues that impact on people with IBD as well as a continuing focus on health.

Plans for 2021 will maintain a focus on the Charity's critical Information & Support Services, Policy and Communications and refresh and re-start our research programme after the recent suspension, enabling us to continue to support and influence with the patient at the centre of everything we do.

The work with IBD UK which produced the 2019 IBD Standards, a Patient Survey and IBD Service Benchmarking and self-assessment will see a National Report published in February 2020.

Ruth went on to highlight concerns around the eligibility criteria for this Winter's Flu Vaccine and informed members that Crohn's & Colitis UK in partnership with the BSG and BSPGHAN (British Society of Paediatric Gastroenterology, Hepatology & Nutrition) had written a letter to The Joint Committee on Vaccination & Immunisation (JCVI) highlighting these concerns and asking, that in order to alleviate the confusion caused by the guidance around the eligibility for immunosuppressed, patients, that everyone with IBD should receive a free vaccination this year. It is the intention to highlight these concerns to the appropriate authorities in the Devolved Nations.

Ruth explained that it is currently understood that the eligibility criteria for any forthcoming Covid-19 vaccination would follow the same guidance.

Richard Russell informed the group that there are 2 types of flu vaccine, one that can be used for people with IBD on immunosuppressive therapies and another not and that as a live vaccine the Oxford Covid-19 vaccine currently being developed would not be suitable for those people taking immunosuppressants. This was noted as an important point.

Pauline suggested that the CPG could write to Ministers raising this issue:

**ACTION:** ES to liaise with Pauline

**IBD Services (adult):** Dr Ian Arnott Western, General Hospital Edinburgh

Dr Arnott explained that at the start of the crisis many NHS services shut down across a significant number of centres; Helplines closed, routine appointments stopped, staff were re-deployed and Home Care services would not accept any new patients putting pressure on pharmacy services.

Patients were not able to access the information and services and investigations they needed, compounded by them, understandably, not wanting to attend or visit a hospital if at all possible.

This led to a great deal of anxiety not just for patients but for healthcare staff as well. Dr Arnott stressed that the impact of this 1<sup>st</sup> phase of the pandemic is difficult to overestimate.

Dr Arnott went on to explain that the situation had, however, acted as a stimulus for services to change, evolve and improve the way they were delivered. As an example Dr Arnott explained that in his own service at The Western General Hospital, Edinburgh the IBD Team had changed the way they delivered their Out Patient Clinics and, although they had never closed the clinic, they now offer a range of options as to how they see people; patients can now be `seen` in a Telephone clinic, the service now uses NHS Near Me video consultations for large numbers of patients while maintaining a small number of face to face appointments for those people who need to be seen in this way.

The team instituted a Flare Clinic with slots available every day for patients experiencing a significant exacerbation of their condition; these patients are seen by both nursing and medical staff in one visit with the benefit being that decisions can be made rapidly. The impact of the stopping of Endoscopy has meant that patients with new symptoms can now be seen quickly with all their investigations and assessments being done in a short space of time allowing speedy diagnosis and initiation of treatment; all proving what can be achieved when hospital services are aligned appropriately.

The research data and understanding of the risk to IBD patients from Covid-19 has reinforced the value of a steroid free remission for patients leading to a change in approach to drug treatments and a stepping up of the treatment pathway more quickly.

Similarly to most IBD services across the country calls to the IBD Helpline at The Western General increased by 100% and fortunately their IBD nurses had not been re-deployed. Most of these calls from patients were around the uncertainty of the risks from contracting Covid-19 while the partnership approach between the BSG and Crohn`s & Colitis UK had been vital in being able to give people high quality information and advice online. The Risk Tool developed by the IBD Registry, The BSG and Crohn`s & Colitis UK had been invaluable to enabling people to define their own personal risk. This had been used by 32,000 people to date.

The crisis had engendered a very positive collegiate feel amongst the IBD Community across the country with the interactions between the BSG, Crohn`s & Colitis UK producing the online risk grid or Decision Tree for patients, and the BSG producing updated clinical management guidance for HCP`s.

Dr Arnott finished by saying that the focus is now moving again, that we understand that Covid is not going away which will lead to significant Winter challenges and that a continuing partnership approach between patients, Crohn`s & Colitis UK and The BSG will be integral to getting us all through.

Pauline thanked Dr Arnott for his interesting talk and insights and agreed that as well as all the downsides, there were also a number of upsides emerging from the crisis.

Dr Arnott felt that overall the team at The Western General were now more robust in terms of working under stress than before the crisis.

Edmund Murray informed the group that despite his willingness to be seen remotely using technology such as NHS Near Me, the staff at the hospital where he receives his care were reluctant to use the technology.

Pauline added that her niece has had a similar experience and has seen a registrar but not her consultant for 6 months and that there were differences in approach across the country.

Dr Arnott added that NHS Scotland was ahead of NHS England with regard to the use of technology with NHS Near Me being readily available and that, although hospitals had been affected in different ways, the crisis should be used as an opportunity to improve services and that, although things are starting to get back on track we can't go back to the ways things were before the crisis.

**IBD Services (paediatric): Dr Dagmar Kastner, Tayside Children`s Hospital Dundee**

Dr Kastner Dr Kastner started by ensuring that everyone understood that children under 12 years of age had a significantly reduced risk of infection from Covid-19 and that there had been no deaths in healthy children without any underlying long-term conditions

Dr Kastner went on to explain that it was difficult to talk about services across Scotland as there have been no formal meetings between sites but that she understood that services will have experienced things in the same way with the suspension of all non-essential in and outpatient services and endoscopy and with paediatric staff being re-deployed to adult services.

Telephone Clinics and the use of NHS Near Me Video consultations were initiated early on and generally work well and will be a major part of the service in the future and while video consultations save on considerable travel time allowing for more patient consultations it should also be noted that some children can't be managed by Near Me due to the need for weight, height and clinical monitoring.

During the crisis teamwork had been exceptional with staff showing flexibility and adaptability and rural GP`s had been very helpful regarding the taking of blood and other necessary tests.

There was now a gradual move back to normal services but access to theatres remains difficult and the impact on endoscopy remains huge

Mirroring Dr Arnott`s comments Dr Kastner summed up by adding that there are still significant Winter challenges to overcome.

Pauline thanked Dr Kastner for her interesting talk and candour.

**Modernising Patient Pathways Programme (MPP): Denyse Aitken National Improvement Adviser Scottish Government**

Denyse explained to members that she had taken over the IBD work from David Pratt just prior to the Covid-19.

All of the MPP Test of Change Boards across different specialties had similar experiences to what had already been described with staff redeployed and recruitment stopped.

NHS Near Me taken had taken off considerably though with feedback from Health Boards and patients about it`s use being overall positive. Moving forward again The Community IBD Clinical Nurse Specialist projects were re-starting and the work of the MPP Programme continuing.

Pauline thanked Denyse for her update and then left the meeting due to another Parliamentary commitment, handing over the chairing of the remainder of the meeting to Elaine

#### 4. A Patient Experience of Lockdown: Kirsty Gibson

Kirsty told the group that her personal experience of shielding had been `horrendous` and that she felt `shielders` to be a forgotten group of people. Kirsty commented that while the use of technology had been helpful, not everyone could use or access online information and that conflicting information given from the 4 UK nations was compounded at times by the use of Facebook and other social media platforms as often you could be sharing and communicating with people from other countries.

Kirsty had found shielding to be very lonely and at times `terrifying` and that the lack of human contact was incredibly difficult. Kirsty commented that the experience may have worsened any existing mental health conditions for many people and used her own experience of having to access her GP during this time as an example to highlight that people were human beings and needed human contact; there was no explanation of the processes and procedures now in place for appointments, the PPE was intimidating and scary and that sitting in a waiting room alone, without anyone to support her on her 1<sup>st</sup> trip out of the house was frightening. When the practice nurse realised that Kirsty was shielding and living on her own she commented that she would have given a longer appointment had she known. Kirsty felt that this highlighted her concerns about those shielding not being considered as a defined group and their particular needs at times forgotten about.

On a more positive note Kirsty had discovered Tik Tok which allowed her to interact with other people! Kirsty finished by saying that the thought of another Lockdown was terrifying particularly through the winter months and that the impact on people`s physical and mental health couldn`t be underestimated.

Elaine thanked Kirsty for being so open in sharing her experience.

Amy commented that she too had been shielding but that, unlike Kirsty, she had a daughter at home with her which made things a little bit easier. She too was not looking forward to winter and suggested, regarding the flu vaccine, that family and carers living with anyone with IBD should also be vaccinated.

#### 5. Presentation: Crohn`s & Colitis UK`s Life in Lockdown Survey: Elaine Steven Policy Lead Scotland & NI

Elaine informed the group that Crohn`s & Colitis UK had undertaken a survey between 19<sup>th</sup> June to 10<sup>th</sup> July 2020 to offer us insights into how patients felt services had been impacted by the pandemic. We asked questions about Access to Healthcare Services, Employment, Daily Life and where people accessed support and information.

Elaine highlighted findings that told us that during the height of the pandemic 82% of people turned to the charity for information.

There had been positive impacts with 55% of respondents saying they had more time for rest, and negative impacts such as 57% of people being anxious about accessing a toilet when going out.

61% had not been pressured by their employer to return to work and 42% of respondents said that the pandemic could change the way we work for the better in the future.

In Scotland 18% of respondents didn't get the correct Shielding letter with 13% not being able to access their IBD Team at all.

When asked about access to tests and procedures 47% told us that they could access these as normal leaving 56% unable to do so and 16% had had a flare.

Looking forward 54% of Scottish respondents would like a choice of virtual OR face to face appointments in the future

The full Life in Lockdown Survey details can be viewed:

<https://www.crohnsandcolitis.org.uk/healthcare-professionals/healthcare-professionals-blog/life-in-lockdown-what-patients-told-us-about-their-healthcare>

#### 6. Any other business

Edmund informed the group that he had contributed to the Kay Adams radio show about the need for access to public toilets

The group were alerted that the Flare Card which had been launched at a CPG Meeting had been shortlisted for The Alliance Self-Management Resource of the Year Award with the award ceremony taking place on 29<sup>th</sup> September.

ES thanked everyone for attending and to those who had given talks.

7. Next Meeting 2nd December 2020 VIRTUAL: A review and celebration of the CPG to date.

**In Attendance:**

Pauline McNeill MSP

Colin Smyth MSP

Liam MacArthur MSP

Elaine Steven Crohn`s & Colitis UK

Ruth Wakeman Crohn`s & Colitis UK

Jackie Glatte Crohn`s & Colitis UK

Sarah Sleet Crohn`s & Colitis UK

Denyse Aitken Scottish Government

Dr Ian Arnott

Dr Dagmar Kastner

Prof Richard Russell

Dr Dan Gaya

Kirsty Gibson

Edmund Murray

Amy Bednarz

Nancy Greig

Michelle Convery