

Minutes of the 12th Cross Party Group on Inflammatory Bowel Disease (IBD)

Wednesday 2nd December 2020

VIRTUAL

1. Welcome & Apologies

Apologies December were received from:

Liam McArthur MSP

Miles Briggs MSP

Iain Gray MSP

Dr Daniel Gaya

Prof David Wilson

Angus McLean

2. Minutes from 16th September 2020

With a minor amendment, raised by Amy Bednarz, noted the minutes of the previous meeting were approved as an accurate record

3. Matters Arising

Pauline McNeill informed the group that she had not, as yet, received a response from the recent letter to Minister for Health raising the issue about people with IBD receiving a flu vaccine and being prioritised for Covid vaccination when this becomes available. Pauline will prompt this response.

4. Raising Awareness of IBD in Scotland

On behalf of Pauline McNeill, Elaine Steven gave a short presentation on the achievements of the CPG since its 1st meeting in 2017, noting that the meetings had raised many important issues and discussed many different topics including IBD Service re-design, paediatric services and the needs of young people and the use of health technology such as NHS Near Me video consultations.

Patients speaking to CPG about their personal experiences of IBD had offered the group greater insight and understanding of what it is like to live with these conditions.

A Stand in the Garden Lobby had raised awareness with MSPs with the debate in March 2019 expanding on the issues faced by people living with IBD further.

The need to keep raising awareness: Crohn's & Colitis in Numbers: NHS Lothian data: Dr Gareth Rhys-Jones from NHS Lothian gave a presentation on his research which demonstrated the robust process that he and his team had undertaken in order to understand the prevalence of IBD, how many people are living with the condition, in the NHS Lothian area, using coding from secondary care, pathology, drugs, treatments and the paediatric registry. The research found:

- 1:125 people in Lothian have IBD (this would extrapolate to 515,000 in the UK)
- Incidence and mortality are static

- Prevalence will rise 4.3% per year
- The majority of the IBD population by 2028 will be under 50 years of age.

SAIL Data: Wayne Lewis Policy Lead for Wales Crohn`s & Colitis UK

Wayne explained that with the development of the multi-stakeholder group IBD Wales, it`s subsequent engagement with the Welsh Government and a meeting with all Health Boards it was apparent that current data was inaccurate and that, therefore, further research was needed in order for service planning to use accurate figures.

The Charity commissioned The Swansea Anonymised Information Linkage data bank, an internationally acclaimed organisation, to conduct the research using GP Read Codes.

The resulting research showed:

- 1:117 people in Wales are living with IBD
- This was twice the previous estimate that was being used for service planning

Both speakers were thanked and praised for their presentations and discussion ensued highlighting the power of good quality data and its importance in service planning and to support the re-design of services for the future.

5. Crohn`s & Colitis UK Awareness Week 2020 : Sarah Sleet, Chief Executive Crohn`s & Colitis UK gave an overview of this years` Awareness Week highlighting the need to raise awareness of what it is like to live with these conditions to the wider community.

Events every day of Awareness Week will be asking people to talk to people they might not have spoken to before and get the message out. Ask people to use the IN MY Shoes APP, an experiential 24 hours that give an insight into what it is like to live day by day with Crohn`s or Colitis. We are also asking people to write to Councils and Local Authorities asking them to display The Not Every Disability is Visible (NEDIV) sign on accessible toilet doors.

In support of the week, Pauline McNeill MSP had asked MSP`s to use the APP and made a video for Purple Friday for promotion on Social Media

6. Update from Scottish Parliament Standards, Procedures & Public Appointments Committee re Cross Party Groups 2021:

Elaine Steven informed the group that with the forthcoming elections on May 6th 2021 and the dissolution of Parliament prior to the election, all CPG`s would be cease to exist and would be required to re-register after May 6th. Any dates for meetings in 2021 previously circulated would, therefore, not necessarily apply.

7. Any other business

There was no other business

Pauline thanked everyone for their attendance and closed the meeting.

Attendance December 2nd:

Pauline McNeill MSP

Clare Adamson MSP

Elaine Steven

Wayne Lewis

Dr Graham Naismith

Dr Ian Arnott

Prof Richard Russell

Dr Jonathan McDonald

Dr Gareth Rhys-Jones

Ruth Wakeman

Sarah Sleet

Kirsty Gibson

Edmund Murray

Amy Bednarz

Nancy Greig