ALL PARTY PARLIAMENTARY GROUP FOR BLADDER AND BOWEL CONTINENCE CARE

VIRTUAL MEETING

14.00-15.30 Monday 29th November 2021

MINUTES

Attendees:

Parliamentarians:

Rosie Cooper MP (Lab West Lancashire) (Chair) Baroness Greengross (CB) (Co-Chair) Baroness Finlay (CB) (Vice-Chair) Ruth Jones MP (Lab) (Officer) Tonia Antoniazzi MP (Lab)

APPG Secretariat:

Tracy Stewart Helen Newey Pat Murtagh

APPG clinicians and invitees:

Mahreen Pakzad, Consultant Urologist, University College Hospital
Dr Lesley Booth MBE – Director of Research and PPI, Bowel Research UK
Prof Nikki Cotterill, Associate Professor in Continence Care, University of West England
Sharon Eustice, Nurse Consultant Bladder & Bowel, Cornwall NHS Foundation Trust
June Rogers MBE, Continence Specialist
Wendy Colley OBE, Continence Specialist
Jacq Emkes, Patient Advocate
Charlie Podschies, NHSEI Senior Policy Manager, Maternity and Womens Health Team
Kevin Hodges, BHTA, PIPS stoma professionals and patient group
Lindsay Lorton, Advisory Clinician AHPMA

Apologies:

Dr Satinder Kumar Baroness Masham

1. Welcome:

Rosie Cooper MP welcomed all to another virtual meeting. The last meeting and AGM of the APPG took place on 22 April 2021. She hoped the next meeting in 2022 would be in person.

2. UK Pelvic Floor Report:

Rosie said the APPG was delighted to endorse the major report led by Prof Charles Knowles which was launched on 28 April 2021. The Report 'Seizing the opportunity to improve patient care: Pelvic Floor Services in 2021 and beyond'. The report published on behalf of the Pelvic Floor Society challenges under-funding and underresourcing of the UK's pelvic floor services. It proposed recommendations for six key areas for change:

- a. Awareness and education
- b. Technology-enabled care
- c. Integration of expertise
- d. Surgery procedures and premises
- e. Utilising human resource
- f. Novel approaches to freeing up work.

Rosie invited Consultant Urologist, Mahreen Pakzad (UCL) and Lesley Booth to update the meeting and asked how the APPG might assist in supporting the Pelvic Floor Report.

- Mahreen Pakzad stated that more operating time needed to be allocated and the report had been used to speak to NHS clinical directors
- Failure to secure timely care with patients operations delayed had resulted in mental health problems such that and a part-time psychiatrist was being recruited
- Cancer awareness high but pelvic floor patients are also important but they get low priority or overlooked
- The pandemic had worsened an existing problem which can involve getting a team of specialists together along with scarce theatre time
- Sharon Eustice concurred saying her colleagues hadn't had theatre lists for ages as patients with bladder and bowel problems were simply not regarded as urgent. She said quality consultation was needed to properly diagnose and
- Rosie asked for Mahreen Pakzad to send some notes to her regarding her experiences especially re mental health implications so she could write to Ministers.
- Nikki Cotterill conducted a survey via Healthwatch which revealed similar issues of impact on mental health and a further study on services
- Mahreen said it was clinical priorities that ensure that cancer always goes to the top of the list but this means others fall to the bottom. She proposed engaging with the Royal College of Surgeons and Royal College of Psychiatrists re priorities
- Rosie offered to write to Minister and Royal Colleges to ask questions about prioritisation and current impact on patient's psychological problems where bladder and bowel treatment has been delayed.

• Jacq Emkes proposed a letter to Dr Clare Gerada, now President of the RCGP (formerly Chair of the RCGP)

3. CONfidence APP:

The APP was launched by the Florence Nightingale Foundation on 21 June 2021 in World Continence Week. It is designed as a self-help tool for anyone with symptoms of bladder and bowel leakage. The APP received significant publicity and was well received by the Nursing Times, BBC local radio and other journals. Dr Nikki Cotterill and her team received an award on 26 October 2021 – the Nursing Times Continence Promotion and Care Award. Rosie Cooper MP congratulated Nikki and her team along with APPG clinicians on the success:

- Rosie asked if there was any help the APPG could give to support and promote this.
- Nikki said they were in the phase of disseminating it and there had been 1,000 downloads and positive feedback from patients and clinicians.
- Need to consider a national campaign with information on the APP on the back of toilet doors, libraries, churches, charities.
- Pat proposed contacting Dr Clare Gerada on this
- Sally proposed contacting the new Health Minister in the House of Lords and the Chief Nurse for Adult Social Care, Deborah Sturdy
- Sharon proposed using the WI speakers to spread the word and Nikki said there was a toolkit they could use
- Tracy proposed contacting Woman's Hour and wondered what input NHSEI could have
- Pat suggested going to Healthwatch with feedback

4. Overactive Bladder (OAB):

- Ruth Jones used to be a physiotherapist and worked with people who had OAB. She noted that the APPG had done a survey and whether a new one might be appropriate given patchy continence services?
- Nikki pointed out they had done a Healthwatch survey which was specifically related to the impact of the pandemic but the information could be used to support a further continence survey in future
- Baroness Finlay suggested including information on low grade infections and pushing for self testing options
- Mahreen suggested that GPs have to be the ones to initiate treatment. A
 problem of access to GPs urine testing meant delays with botox treatment for
 bladder problems
- Sharon confirmed that the journey is too long from primary to secondary care
- Nikki confirmed there was information on the CONfidence APP about selfmanagement

5. Bins for Boys:

The APPG proposes resuming the campaign for 'Boys Need Bins' and pqs in Parliament will be proposed. It is also suggested that the APPG can contact the Equalities Minister as well as the Department for Housing, Communities and Local Government

- Tracy confirmed that there had been discussion with DEFRA and water groups on the need for bins to prevent blockages. Tracy has also raised this with Fleur Anderson MP who has an interest in preventing wastewater pollution
- Pat proposed that the APPG writes to Lyndsey Hoyle, Speaker, to ask for this to be brought to the attention of Parliament's services
- Nikki confirmed that the Healthwatch survey had found what a major impact the closure of public toilets had on bladder and bowel patients.
- Tracy proposed referring back to the London Assembly to request information regarding bins in men's toilets following their pledge to install bins in all toilets throughout City Hall
- Sally confirmed she was very happy to raise the issue and facilitate a meeting with the LGA at their HQ in London. Local Authorities have responsibility for providing facilities.

6. Colley Model:

Wendy Colley produced the Colley Model which is a brilliant tool to assist both experienced and less experienced clinicians in their diagnosis and path to treatment for those with bladder problems. A clinician in Jersey has expressed interest in using the Colley Model and work is in progress to adopt the tool for use with the NHS EMIS software systems. More work will follow to promote the model in 2022 with plans for a Facebook event.

- Wendy confirmed that the hits on the website had reduced and more publicity was needed. A 3000 word article had been requested. There was a need for someone to talk about EMIS to assist Wendy understand and then see how things can move forward
- Sharon pointed out that they have got multiple software programmes and would be happy to collaborate with Wendy on this
- June pointed out that she had adapted the Colley Model for children and had passed this on to Davina Richardson at Bladder and Bowel UK.
- Tracy confirmed there would be an event in the first quarter of 2022 on Facebook.

7. Health and Social Care Select Committee

The Select Committee on Health and Social Care is to conduct an inquiry into "Workforce recruitment, training and retention in health and social care'. The terms of reference were published on 24 November 2021 and written evidence is requested by 19 January 2022. Two particular areas are relevant to the APPG and it is proposed that a short submission should be drawn up with input from APPG clinicians. Pat proposed to circulate the full terms of reference and request input.

- 'Whether the curriculums for training doctors, nurses and allied health professionals need updated to ensure the staff have the right mix of skills?'
- 'What should be in the next iteration of the NHS People Plan, and a people plan for the social care sector, to address the recruitment, training and retention of staff.'

8. Nursing Training for Continence and Stoma

The issue of nursing training for continence and stoma could well also be included in the select committee submission.

- Kevin reported that there were 500 stoma care nurse specialists and around 1,000 continence specialists with no NHS training for either specialism. So training was left to industry and some of the nursing associations summer schools. He pointed out there's an ageing problem with a succession problem looming.
- Lesley Booth commented that there was no consistency across trusts and access to stoma care had got worse during the pandemic.

9. AOB

- Charlie reported on the perinatal pelvic health services new pelvic health tools. He said there were 13 early implementation areas but the pandemic had complicated progress with a challenge finding pelvic physios.
- Perinatal assessment tool for women could also be used postnatally. Delivery time is 2024 at the latest
- Jacq pointed out that the National Bladder and Bowel project is still going forward. She is now a pelvic floor group member on the steering group.
- Tracy asked if Charlie could help signpost the CONApp and Colley Model and he agreed to speak to Nikki and Wendy

Ends