

AGM and Meeting of the APPG for Bladder and Bowel Continence Care

Tuesday, 25 April 2023, Portcullis House, Room O, 16.00-17.00

Election of Chair, Co-Chair and Officers

The AGM of the APPG took place earlier on Tuesday, 25 April 2023. The following officers were elected:

Andrew Selous MP, Chair

Baroness Finlay, Vice-Chair

Ruth Jones MP, Officer

Nick Fletcher MP, Officer

Baron Watson of Wyre Forest

(Quorum at the AGM: Andrew Selous MP, Andrea Leadsom MP, Martin Vickers MP, Fiona Bruce MP, Gary Streeter MP)

Attendance:

Andrew Selous MP

Ioan Bishop, Policy and parliamentary affairs officer, Care England

Daphne Colpman, clinical nurse specialist – continence, UCLH

Lubna Latif Curtis, Health influencing senior officer, Prostate Cancer UK

Sohier Elneil, Consultant Urogynaecologist and Uro-neurologist, UCLH

Jacq Emkes, Patient Advocate

Hannah Gagen on behalf of the Urology Trade Association

Dr Satinder Kuman, Hurley Clinic, London

Nikesh Thiruchelvam, Consultant Urologist, Cambridge University Hospitals NHS Trust

Ali Wileman, RCN Bladder and Bowel Forum/Specialist Nurse Bladder & Bowel UK

Tracy Stewart, APPG Secretariat

Pat Murtagh, APPG Secretariat

Welcome and Introductions:

- Andrew Selous MP was initially absent due to voting. In his absence, Pat Murtagh commenced the meeting acknowledging the significant contribution made to the APPG by the late Baroness Masham.

Update from Prostate Cancer UK (PCUK)

Lubna Latif Curtis, Health Influencing Senior Officer at PCUK, spoke about the work on the '**Boys need Bins**' Campaign to put sanitary bins in men's toilets:

- Two surveys were being undertaken – one for organisations and one for individuals
- A report is due to be launched at an event in September to include MPs and patient voices
- Prostate Cancer UK developed a template letter for supporters which has reached 532 MPs representing 82% of MPs - positive responses from: Margaret Ferrier MP, Carla Lockhart MP, and Sarah Olney MP.
- A major pub restaurant chain is due to announce it will be installing bins across all its venues
- Winchester Council has installed bins in local authority toilets
- PCUK plan to contact local councillors

- Hygiene company, PHS, is running a '**Dispose with Dignity**' campaign using Whitehouse Consulting as lobbyists and aim to secure a debate in June
- Leeds City council is running a pilot
- Railway Stations Director in Wales is interested in assisting
- World Continence Week will be on 21 June 2023 – an article will run in the Local Government Association Newsletter in June.

Inequalities for ethnic minority groups around bladder and bowel health

Nikesh Thiruchelvam – Consultant Urologist, Cambridge University Hospitals NHS Trust:

- Pat Murtagh congratulated Nikesh on his appearance on BBC Surgeons 'On the Edge of Life; Series 5, Episode 5 which made key points about the impact of incontinence
- NHS Race Observatory findings are that GPs are less likely to send ethnic patients on pathways for continence care and that class did not make a difference
- Proposed to work with the Nuffield Trust to gather more data
- Sohier Elneill, Consultant Urogynaecologist and Uro-Neurologist, UCLH, suggested that Female Genital Mutilation (FGM) patients needed bladder and bowel services but there was an issue of trust and take up was slow. A patient advocacy group would help as women are scared to come forward
- Ali Wileman, Royal College of Nursing (RCN) Bladder & Bowel Forum, suggested champions were required such as an ethnic TV personality
- Tracy Stewart, APPG Secretariat, said contact had been made with two equalities groups and further input was awaited
- It was agreed that a focus group meeting would be beneficial – Tracy to discuss with APPG chair and other attendees

National Bladder and Bowel Project

- **Jacq Emkes**, APPG patient advocate, provided an update on the 'Excellence in Continence Care' project – which has now become the National Bladder and Bowel Health Project
- There are three workstreams – bladder, bowel and paediatrics/transition
- They are looking for evidence-based pathways to seek a gold standard which is mandatory and measurable
- Jacq called for: 1) Leadership to deliver the long term plan (2) raise the profile of bladder and bowel health and 3) remove the postcode lottery
- It is estimated that up to 50% of patients are catheterised unnecessarily at an annual cost of £150 - £331m in urinary tract infections. Nikesh pointed out that UTIs represented one of the main reasons people were hospitalised and UTIs were indeed costing the NHS a large amount of money.
- Cornwall has developed a very interesting model by providing an out-of-hours specialised care system in the form of a '**Continence Car**' in which clinicians visit homes to unblock catheters and prevent hospital admissions. The service has evolved to also deal with wounds. They are seeing roughly 300 patients a month with a 'leave at home rate' of around 80-90% and the others safely referred elsewhere. A massive achievement preventing hospital admissions.
- Jacq also reminded others of her personal story: after an injury during surgery she had to undergo 3 bladder reconstructions, 2 spinal surgeries and a kidney transplant. She now uses a disposable catheter in order to be able to live a full life.

General Discussion:

A pilot project in a Leicester hospital whereby patients were offered decaffeinated drinks as the default option has resulted in an 80% decline in falls as people visit the toilet less frequently. The APPG has received feedback that this is being replicated in other Trusts and care settings.

Care England

Ioan Bishop of Care England, who heard about the caffeine free drinks pilot at the last APPG meeting in November 2022, said they had held a webinar for their members and are hoping to see similar pilots and that they would be collecting data. The NHS spends huge resources each year dealing with falls.

Ioan commented that numerous ideas from the APPG meeting in November had been taken back to Care England and that there is a new focus on bladder and bowel continence.

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