All Party Parliamentary Group for Continence Care

"To break the taboo by raising awareness of continence issues for adults and children and to promote costs effective funding for continence services and product provision"

AGM and Meeting

2.00-4.00pm, Wednesday, 29th June 2016, PAL Committee Room 19

Minutes

Agenda Item 1: Election of Officers

Rosie Cooper MP, Co-Chair, moved straight to the election of officers. They were duly elected as follows:

Rosie Cooper MP (Lab West Lancashire): Co-Chair
Baroness Greengross: Co-Chair
Baroness Masham: Officer
Baroness Finlay: Officer
Jason McCartney MP (Con Colne Valley): Officer

The quorum for the meeting (5 MPs/Peers) was as follows: **Rosie Cooper MP, Baroness Greengross, Sir David Alton, Baroness Masham and Jim Shannon MP.**

(NB later the meeting was joined by **Alison Thewliss MP** (SNP Glasgow East) and **Liz McInnes MP** (Lab Heywood and Middleton), who have both joined the APPG. **Paula Sherriff MP** (Lab Dewsbury) sent her apologies due to an urgent constituency matter, but wishes to join the APPG.

Agenda Item 2: Welcome from Rosie Cooper MP

Rosie Cooper MP welcomed everyone. She placed on record her thanks to Baroness Greengross and to her Labour colleague, Judith Cummins MP, who had kindly taken over the organisation of the meeting on 18 November 2015 that she had been unable to attend.

Rosie Cooper MP reminded everyone that the APPG and its dedicated team of clinicians had played a big part in bringing about the publication of NHS England's document: 'Excellence in Continence Care' and that everyone must now work towards ensuring that the guidance is implemented.

Rosie Cooper MP reminded everyone why the APPG was set up:

- To robustly support the need for equitable, accessible, quality continence care services for all age groups
- To demonstrate the benefits of such services to GP commissioners; and
- To break the taboo by raising awareness of continence issues and encourage people to seek medical help to resolve or improve their condition.

She reminded everyone that in the UK there were over 14 million adults with bladder control problems and 6.5 million with bowel control problems. In addition, 900,000 children and young people suffer from bladder and bowel dysfunctions. She called for everyone to work together to improve the lives of all these people.

She said that the focus of today's meeting was to be on **Education and Training**

Agenda Item 3: Update on NHS England's Excellence in Continence Care – Dr Danielle Harari, Consultant Physician in geriatric care and continence lead, Guys and St Thomas' Foundation Trust, Royal college of Physicians

Rosie Cooper MP explained that the author of the NHS England report, Sarah Elliott could not attend as she was at her own retirement function. The update was to be provided by Dr Danielle Harari who is a member of the NHS England Continence Care Board.

Danielle Harari said that Wendy Gray had now taken over from Philippa Potter (a former colleague of Sarah Elliott) and that NHS England planned to take on a senior nurse. Awareness raising was being handled by the NHS England Communications Team (Natalie).

Danielle Harari noted that the previous week had been Continence Care Week and that 12 million retweets had been made on Twitter. She noted that the Internet/social media had brought about greater awareness of continence care along with patients telling their stories.

There is a new CCG Improvement and Assessment Framework for 2016/2017 which replaces the previous CCG Assurance Framework and CCG dashboard.
https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/ccg-iaf-mar16.pdf

Danielle Harari commented that Sarah Elliott's view was that it was about saving many people from ending up in hospital care. She felt the CCGs were now beginning to pick up on this through the CCG Impact and Assessment Framework and the Self-Assessment Framework designed for CCGs. Danielle commented that it was necessary to strongly encourage CCGs.

It was noted that June Rogers and Sharon Eustice (APPG clinicians and continence nurses) were preparing 'pad policy' documents for adults and for children.

Danielle Harari said that Prof Paul Abrams was communicating with the CCGs in relation to CQC inspections, with a view to achieving two or two questions on continence that will be asked as part of the CQC process.

With regard to education of pre-registered nurses, some progress had been made via Jill McLeod-Clarke at Health Education England (HEE), but there are still a huge range of requirements to be met. HEE have a plan for next year and are building a business case for national support and regional support.

It was noted that a social movement covering care homes, primary care and the public is required.

There was talk of virtual commissioning with e-learning and webinars for nurses are carers. E-learning has to be developed further for nurses.

Data was required for a benchmark system, similar to that done for wheelchair uses, and here Danielle called for the simplification of continence metrics.

Nick Madden (PCF): pointed out that they PCF had received a reply from Sir Bruce Keogh (Medical director, NHS England) to say that the Care Quality Commission (CQC) were using a continence standard. It was agreed that this indicates a step in the right direction.

Rosie Cooper MP asked what Parliamentarians could do to help further raise awareness, Danielle responded that PQs may be helpful, Rosie Cooper agreed these should be around NHS assessment and treatment and cost effectiveness.

Baroness Greengross said that integration of health and social care was key and proposed that the APPG contact Health Watch, and Health and Wellbeing Boards. She felt it was important to determine at what level to campaign at local level.

Tony Brooks (Chair of RCN Continence Forum): People enquire if the RCN offer continence/bladder/bowel education and training as they cannot access it elsewhere, the Trusts are not offering education, which means that nurses are not able to correctly assess new patients. He said it was about education first, and that simply relying on catheters and pads is not the answer. He noted that /Health Care Assistants (HCAs) should also be trained. Social Services were raised as a key potential resource for the group to explore, it was agreed that this should be part of the picture. The new model in Manchester was referred to, this being an area in which the budget for local health services is held by the Greater Manchester Authority.

Baroness Greengross proposed that the group seeks to communicate with Manchester regarding their integrated health and social care system in relation to continence.

Mark Stott (Consultant Urologist) spoke about the frail elderly, and how effective continence care could reduce the length of hospital stay, and reduce the need to get up in the night thus avoiding unnecessary falls. He concurred that there is a real need to link with Social Services but that this seems to be difficult.

Baroness Greengross proposed that the APPG should re-connect with Dr Sarah Wollaston MP, Chair of the Health Select Committee, to see if she would be willing to take another look at discussing continence care in her Committee. (She had previously supported the notion of proposing a two-day inquiry.) It was also noted that new contacts should be established with

the new Policy Lead for Long Term conditions at NHS England, following Martin McShane's departure.

Tracy Stewart (APPG Secretariat) spoke of the need for cost modelling and supportable figures. She asked Mandy Fader and Prof Cottenden what figures and examples would be meaningful, and how we might inspire an independent academic to take on this work. Would it be possible to produce a bench mark to demonstrate the cost effectiveness of improved care? Mandy noted that some work had been conducted on all associated costs to get a better idea of what the overall costs of incontinence care. Mandy and Alan will give this consideration. Alan advised it is better to focus on a number of key aspects rather than the entire costs. Sue Hatton advised that Health Education England may be able to provide good examples of such work. And that she would forward these. It was suggested the NHS England Board could also be approached in this regard.

Danielle Harari referred people to the cost pyramid in the APPG guidance for commissioners which spelt out the right approach.

Karen Tomlin (Nurse) pointed out that infographics are a good way to communicate important points to commissioners.

Liz Bonner spoke about ChiMat (Child and Maternal Health Observatory) which was a source of countrywide data.

Robert Dixon (Bladder & Bowel Foundation) referred to the models already produced by his organisation, and that duplication of work should be avoided. Note: since the meeting B&BF has announced it is no longer operational. It is hoped that there may be a transfer of its work to another organisation.

Pat Murtagh (APPG Secretariat) said she agreed with him and that the APPG meetings such as this were inclusive in order to share information at such meetings.

Agenda Item 4: Education and training

Liz Bonner, (**Lead Nurse, Haringey Bladder and Bowel Service**) spoke about the stigma of incontinence and the social isolation it brings. She said there were simple interventions that could help.

She said that work by the APPG which had let to the development of the NHS England Group, and its subsequent report, 'Excellence in Continence Care', as well as the related section in the Report of the Chief Medical officer published last year, and work being done by other groups had produced a beneficial 'pincer movement.'

She emphasised the importance of continence/bladder/bowel/education in pre-registered training, this currently is not included in the pre-registered curriculum. The National Midwifery Council (NMC) are currently revising the 2018 curriculum. Liz said that '***bladder and bowel care is not an extra but an essential,'*** and we must press for its inclusion.

She further called for mandatory basic foundation training for private care agencies as their workers are providing personal care and are not able to offer advice, other than to change pads.

Liz Bonner also noted that Trusts should ensure that people with continence problems are identified, assessed, and get the treatment they need.

The independent inquiry into care at Mid Staffs (Francis, 2010) highlighted that, of the 33 cases of oral evidence presented, 22 (67%) raised significant concerns about continence, including bladder and bowel care. This area of care was singled out for complaint more frequently than any other, indicating just how important dignified continence care is to overall standards

2014 The United Kingdom Continence Society (UKCS) recognised lack of training was leading to inappropriate referrals and poor bladder and bowel care. The UKCS funded a multi-disciplinary task and finish group led by Mr Phil Tooz Hobson to produce minimum standards for continence care in the United Kingdom – Adults

The document was developed to address the issue of poor education and training for all health and social care professionals caring for people with continence needs. The document recommends minimum standards of continence training for all staff working across primary, secondary and tertiary care.

The Nursing and Midwifery Council (NMC) governs the pre-registration curriculum for nursing. Nurses have to complete 150 hours of practice over three years yet, within this time, there is no standalone provision made for the practice for bladder and bowel care. The level of experience of bladder and bowel care gained during training is completely random. Some universities such as Glasgow Caledonian have developed a module that pre-registration nurses may choose to take during their third year but this is optional.

The All Party Parliamentary Group for Continence Care 'Cost-effective Commissioning for continence Care' (2011) identified how risk and costs are reduced where care is underpinned by high quality integrated community continence services. These services not only provide expert treatment within the community but advice regarding self-help strategies.

Skills include training colleagues in initial continence assessment and conservative treatments and ensuring that referrals to secondary care are made where appropriate. Movement up the pyramid can be delayed or prevented by an integrated continence service with a traffic light system illustrating the risks and rising costs of untreated continence needs.

Education provision is essential for the patient/carer/ family staff and organisations that support people with bladder and bowel care problems.

Education and training should be mandatory if staff are dealing with people with bladder bowel care problems, including pre-registration students and GP registrars,

There is a desperate stigma, social isolation and physical impact of incontinence that affects self-esteem and cause depression Margaret Macaulay Research Nurse / Project Manager Continence & Skin Technology Group, UCL

www.continenceproductadvisor.org

Today is an important day where we seek to influence curriculum development for undergraduate nurses, physiotherapists, occupational therapists and advanced practitioners of the future. It is vital for the dignity and well-being of people who suffer bladder and bowel incontinence that staff are properly trained using the Minimum standards for continence care which can be adapted for any staff grade.

Nick Madden (PCF) commented that a secondary and tertiary outpatient referral costs the NHS £160 to £220 for first appointments and £94 to £123 for follow-ups. This is compared to referral to a specialist nurse in primary care costing on average £80 for an assessment appointment and £56 for each follow-up appointment (considerably less for a telephone follow-up). Additionally, there is an increased likelihood of avoidable A&E attendances costing on average £114 and the risk of admission. This demonstrates the benefits of access to local services and expertise, and the need to ensure that there is training for such staff.

Similarly, is was noted that paediatric urologists are less expensive at £160 than Community Paediatricians at £220.

Robert Dixon (Bladder & Bowel Foundation) commented that the B&BF had some training programmes available to nurses.

Sue Hatton (**Health Education England)** spoke about the new Nursing Associate role and how they hoped to have 1000 staff in position by January 2017. It was noted that there is a real opportunity to appeal for the new role to include continence training.

Other points that were noted were: NMC should be addressed regarding the curriculum, the need to get continence care into the Core Care Certificate.

Kath Williams (Association for Continence Care - ACA) noted a lack of knowledge across associated professions including occupational therapy, physiotherapy as well as nursing. ACA is focussing on occupational therapists and together with The International Continence Society (ICS) they are working to create on-line learning.

Professor Charles Knowles (Colorectal Surgeon) said the same problems exist in his sphere, particularly relating to pelvic floor health

Agenda Item 5: Continence Care Provision, Policy Document from UCL, Professor Mandy Fader, Professor of Continence Technology

Mandy Fader emphasised that the undergraduate curriculum was outcome based but there was a lot of concern currently regarding the switch to bursaries and concern as to whether enough nurses would want to train. She predicted a nurse staffing crisis in 2017 as a result of the change.

She commented that she had a role in the NMC Reform Group. She said that CPD budgets had been cut for already qualified staff and there was a legacy of under-trained nurses.

She described it as a complex picture but not one without hope.

With regard to the provision of pads she had looked at a project for Prostate Cancer UK. It revealed that all men didn't receive pads; there was no definition of 'need' in the provision of continence pads; no equality of treatment compared to those with stoma needs and that all in all continence pad provision was inequitable. This reinforces the indignity, she said.

Wendy Colley commented that nurses were afraid to advise patients on what they should use so as not to over influence their choice

Agenda Item 6: **Hurley Group – update – postponed until next meeting**

Agenda Item 7: AOB and Next meeting

Rosie Cooper MP said that the APPG intended to meet up again sometime in November 2016.

There was no other business

Action Points Arising from the Meeting

1. Prepare some possible PQs particularly related to education and training of nurses and other professions with a view to the APPG campaigning for mandatory continence care in all care settings
2. APPG to contact Health Watch
3. APPG to renew contact with Chair of Health Select Committee
4. APPG to contact Health Education England with regard to influencing the curriculum to ensure continence care is mandatory for all nurses, nursing associates etc.
5. APPG to make new contacts with NHS England, following the departure of Dr Martin McShane with a view to ensuring delivery of the NHS England Excellence in Continence Care document
6. Explore options for cost modelling.
7. Liaise with the Hurley Group with a view to demonstrating an effective model for integrated continence care.

12 July 2016