

All Party Parliamentary Group for Continence Care

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

Meeting

2.00-4.00pm, Thursday 23 November 2017

House of Commons Committee Room 20

MINUTES

Quorum: Madeline Moon MP (Lab Bridgend), Glyn Davies MP (Con Montgomeryshire), Liz McInnes MP (Lab Heywood and Middleton), Baroness Greengross, (CB), Gerald Jones MP (Lab Merthyr Tydfil and Rhymney and Carolyn Harris MP (Lab Swansea East).

Agenda Item 1: Welcome

Glyn Davies MP (standing in for Baroness Greengross) opened the meeting. He declared a personal interest in that he had suffered from incontinence for three years as a result of bowel cancer treatment. He welcomed all the dedicated clinicians and wider ‘continence community’. He passed on the apologies of Rosie Cooper MP (Co-Chair of the APPG) who was unfortunately not able to attend. He welcomed Prof Helen Stokes Lampard, Chair of the Royal College of GPs to the meeting.

He noted that Helen had been ‘recruited’ by her predecessor, Dr Clare Gerada and had been a supporter of the APPG.

Glyn Davies also pointed out that the APPG had briefed Madeline Moon MP ahead of her excellent adjournment debate on 5 September. He informed the meeting that the APPGs Co-Chairs had written to Steve Brine, Health Minister who had responded to the debate with empathy saying *“incontinence is absolutely an issue with which too many suffer in silence and we all need to learn to speak more openly and honestly about it”*. It was also pointed out that the Minister had suggested during the debate that NHS England was exploring the potential for a mandatory data set to provide transparency about continence services commissioned by Clinical Commissioning Groups (CCGs). A response to the above letter is still awaited.

Agenda Item 2: Prof Helen Stokes-Lampard, Chair of the Royal College of GPs (RCGP)

Prof Helen Stokes-Lampard explained that the RCGP was the largest of the medical colleges with 52,000 members. The focus for the RCGP was person-centred care and a holistic approach. She illustrated the approach with a case study of Enid, an 84 year old for whom social isolation, incontinence and frailty were key concerns. She argued for 'Time to care' which was needed to provide space to build up relationships. Helen said she wanted to see 'Enid shaped care' and for a continence service to be readily available. She spoke about the 'just before I leave' topics whereby patients wait until they are leaving to discuss what is often their most important health concern. She also said that many GPs were demoralised with fewer GPs (1000 less than in November 2016) and the problem of reliance on locums along with a nursing shortage. She was keen to have a discussion and take questions.

Agenda Item 3: Dr Satinder Kumar, Hurley Clinic, Kennington, London

Dr Kumar spoke about the progress at the Hurley Clinic in implementing the Excellence in Continence Care Guidelines (EICC). He said there was a multi-disciplinary team with midwives, phlebotomists and admin staff all of whom potentially had the opportunity to ask patients a standardised set of questions including bladder/bowel issues

Steps they have taken include coding people with problems; patient questionnaires, messaging on screen waiting room about continence care and a Patient Participation Group meeting specifically on continence. The PPG, he noted, were very active.

There was a recognition that it was important to detect the problem in patients and to move 'beyond pads'.

The questionnaires provide data to the CCG on bladder (not bowel) and referral to any continence service. He stressed the importance of a holistic approach to continence care which can be linked with falls and affect mood and cause isolation. He mentioned that the GP PMS (Personal Medical Services) contract had a traffic light system of red, green, amber – a fragility score indicating level of care patient requires.

He too pointed out that with GP shortages, they were often reliant on locums who were not always as committed to being proactive on continence care.

But he did mention that that Dr Arvind Madden (also known to Prof Helen Stokes-Lampard) is both a partner in the Hurley Clinic and also Director of Primary Care at NHS England and is taking an interest in continence care.

Dr Kumar pointed out that he had now been Partner in the Hurley Clinic from on 1 December. This afforded him a seat on the Board where he can work to influence the

improvement of continence care across the whole Hurley Group and potentially influence the different CCGs the Hurley Group is linked to.

Questions

Liz McInnes MP (temporarily chairing) asked Prof Helen Stokes-Lampard what the RCGP could do to support greater take-up by CCGs and GPs of the NHS England Excellence in Continence Care Guidelines and whether the RCGP would ensure that its own curriculum includes as part of core competences that GPs should be required to understand how to manage continence care across all age groups?

Helen said she was happy to be supportive on dissemination of APPG and NHS England work in this area. She felt there was leverage via the 'frailty and loneliness agenda' as well as mental health and gave a personal pledge to help.

Regarding the curriculum she suggested that the APPG might exploring opportunities which lie at the exam assessment phase for medical students whereby they take clinics of around 14 patients and that maybe a question on continence care could be sent to the Exams Department.

June Rogers: June Rogers: She stated that School Nurses were not now being commissioned for paediatric continence problems and there was a distinct lack of community based paediatric continence (bladder/bowel) services. The burden of managing these children is now falling on GP's who neither have the time or often the expertise and as a result costs of around £7,000 were being incurred for idiopathic (chronic) constipation requiring hospital admissions, surgery etc. To this had to be added the cost of parents giving up jobs to be at home to change pads and care for children.

Liz Bonner: She questioned whether there was hands-on training for being a member of a CCG/commissioning service. She stated that continence services were being told to refer to GPs for 'mid-stream urine tests' which was a simple procedure and this was causing problems. Helen agreed that in some areas more needed to be done and that it was undeniable that rationing was happening.

Sharon Eustice: How can we get commissioners to get a grip on continence issues? She asked what the appetite was for the Health Select Committee to take up this issue was and asked if the APPG could re-connect with Dr Sarah Wollaston. Helen Stokes-Lampard offered to support the approach and connect with Dr Sarah Wollaston MP. Pat Murtagh added that the APPG had sent in a Pitch for a short Inquiry on Continence Care to Dr Wollaston some time ago. Although she was personally supportive no time had yet been found. It was agreed that a further approach should be made.

Jacqueline Emkes: She commented that GP visits were problematic and that there needed to be some training for GP receptionists. There was an issue with things like urine sample pots

which were rationed but patients could not take their own which caused problems. Helen suggested contacting the Royal College of Pathologists and she acknowledged there was a problem with pots as they needed to fit the pathway to the lab and its machinery which meant private purchase was not practical.

Danielle Harari: Would a mandatory data set on continence trigger outcome driven primary care? Helen spoke about the fact that QOF (quality outcomes framework) was currently frozen. There was consultation at the moment which was whole person centred with measurement of quality indicators.

Dr Helen Meese: She asked what could industry do from a technology perspective? Helen said that GPs were not used to working with industry but there was a clinical research group at the RCGP.

Agenda Item 4: Wendy Gray, Head of Nursing Regional Nursing Directorate, NHS England (South)

Wendy Gray thanked all the Board, including those present, for all their hard work. She said that the current revision of the EICC guidelines was subject to the 'NHS England Gateway procedure' of internal review before it could be published. As this was a revision and not an entirely new document then she hoped approval could be granted to be able to publish by end December.

The revision reflected the need to address the transition from children to adult services, a section on care homes, improved bowel care, and 'what does good continence care look like' with case studies. Wendy said they will link externally through social media for a better launch as the last EICC document was published in November 2015 just when the media was covering with the terrorist attack in France. They plan to use e-learning and blogs.

Nick Madden: Mentioned that the revised EICC document contains figures demonstrating that poor continence care increases the risks of pressure sores and falls, which are then costly to treat.

Questions

Baroness Greengross asked about the dementia pathway and mandatory data collection? Wendy Gray replied that a minimum data set is work in progress and that the 'Right Care programme is a vehicle that informs and educates Commissioners. Wendy also said that if the APPG wanted to contact anyone at NHS England to push the agenda then the right contact was Jane Cummings. However, Wendy clearly felt that everything was currently being done and that now might not be the right moment for APPG to press NHS England.

Sharon Eustice: Asked about the role of clinical directors and whether they could assist in implementation? Wendy said yes and that nurses and midwives can also help through their. She said that Directors of nursing have robust quality networks

Liz Bonner said that residential/nursing homes are excluded from bowel and bladder services and asked whether EICC revision included care settings?

Penny Dobson suggested that the Public Health England document on paediatrics could be meshed with the revised EICC guidelines.

Agenda Item 5: Anne Trotter, Assistant Director, Education and Standards – Nursing and Midwifery Council (NMC)

Anne Trotter provided an update on the Education Standards Consultation that the APPG had responded too in September. She said it looked at what people needed from a nurse in the future from 2017 to 2030. Revised Standards are due to be published in April 2018 and the responses were at the analysis stage.

Tracy Stewart proposed that the NMC could make use the combined expert group of the APPG consisting of academia, industry experts – the latter had been used to providing post-registration training for decades.

Liz Bonner asked about whether other disciplines including physiotherapists should be included.

Tracy Stewart suggested that the retail sector is large and it could include pharmacists in terms of staff training.

Baroness Greengross suggested that Boots might also be a good contact.

Danielle Harari said that ‘nurse empowerment’ was important as nurses don’t feel able to remove catheters.

Agenda Item 6: Dr Penny Dobson, Paediatric Continence Forum (PCF)

Penny spoke about Youth Incontinence and a forthcoming publication “*It Happens to Me*” which looks at breaking down the barriers faced by children and young people with bladder and bowel problems. It will be launched in the House of Commons in early 2018.

The report ‘It Happens to Me’ is a cooperation between the Paediatric Continence Forum (PCF), ERIC, the University of Bristol, Bladder and Bowel UK and the company Coloplast Ltd, bringing together research. The report’s purpose is to:

- Raise awareness of how continence problems can ruin young lives, causing isolation and lack of confidence
- Reassure young people that they are not alone and that help is available
- Highlight the importance of early diagnosis and intervention with the key role of the school nurse

- Highlight the current state of paediatric continence services
- Confirm the importance of good transitional arrangements to adult services
- Support the implementation of NHS England's Excellence in Continence Care Guidelines and the PCF's Nice-accredited Paediatric Continence Commissioning Guide.

Agenda Item 7: General discussion on future priorities (AOB)

Dr Helen Meese (Institution of Mechanical Engineers) announced that a White Paper on Incontinence Engineering Innovation to Enhance Quality of Life had been published. This looked at public awareness, innovation including academic, technology, manufacturing and clinical expertise. She called for inclusion of incontinence technology engineers within NHS Trusts to ensure innovation with continence care and procurement mechanisms.

Tracy Stewart suggested that a number of attendees might be interested to hear more about this and offered to help coordinate a stakeholder group contact list.

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