

# **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, Wednesday 18 July 2018**

**Council Room, Church House**

## **MINUTES**

### **Agenda Item 1: Welcome**

Baroness Greengross opened the meeting and apologised for the change of venue due to activities in Parliament. She welcomed Susan Williams from the Royal Hospital Chelsea to her first APPG meeting and stated that Rosie Duffield MP had wished to attend but was at another meeting in the Commons but wanted to participate in the future. In view of the Room switch, it would not be possible to hold the AGM which had to be held on the parliamentary estate. Baroness Greengross gave the floor to Jo Gander, Director of Clinical and Product Assurance, NHS Supply Chain to update the APPG on changes in Procurement who had limited time.

### **Agenda Item 2: Procurement**

Jo explained that she was recently appointed to CaPA (Clinical and Product Assurance). Her role as Director of Clinical and Product Assurance meant that she oversaw all of the eleven Category Towers for different products. There would be greater clinical involvement in purchasing decisions using research and GIRFT (Getting it Right First Time). The goal was to tackle ‘unwarranted variation’ on an evidence base. She said that it would be based on the “cost of pathway and total pathway”. There were six people in product assurance. They were aiming to be open and transparent and said anyone with clinical concerns could write to CAPA at [CaPa@DH.gsi.gov.uk](mailto:CaPa@DH.gsi.gov.uk).

She mentioned the National Wound Care Strategy and the Excellence in Continence Care Guidelines as examples of stakeholder engagement. (Jo was able to stay for an hour to listen to the concerns of others).

## **Agenda Item 1: Welcome and update contd:**

Baroness Greengross pointed out that the last AGM was held on 5 July 2017 and the previous meeting of the APPG on 23 November 2017. She updated the meeting on activities of the APPG with regard to the General Medical Council. Following on from excellent work with the Nursing and Midwifery Council, which had led to improving and clarifying the standards required for continence care, the work with the GMC was now progressing.

The APPG submitted views in December 2017 to a GMC Consultation on ‘Outcomes for Graduates’. This included an Appendix on Practical Procedures for Doctors. The APPG recommended that ‘carry out a continence assessment’ be included as one of the ‘practical procedures’. Following an exchange of letters with the GMC, representatives were called to a meeting in the House of Lords on 5 April where the case was made that the APPG viewed this as very important indeed.

Baroness Greengross placed on record how grateful the APPG was to its supportive clinicians Dr Kumar and Joanne Hoyle for attending this meeting along with Anne Trotter from the NMC.

The GMC is to carry out a full scale review of the Appendix on Practical Procedures and the APPG was the first to be consulted. Specific wording has now been submitted for consideration and Dr Kumar has been invited to sit on the GMC’s expert working group.

**The anticipation is that a document will be ready by the autumn and the intention is to invite the GMC to the next APPG.**

Dr Kumar made the point that these standards from the GMC are very important and the equivalent of ‘tablets of stone’ handed down to the Medical Schools who then devise the curriculum. **(Action: Dr Kumar to sit on GMC Expert Group. GMC to be invited to next APPG meeting in November.)**

## **Agenda Item 3: Excellence in Continence Care Guidelines**

Baroness Greengross placed on record the thanks of the APPG to Wendy Gray who had led the review of the guidelines for NHS England and has now moved to a new job. Her place has been taken by Sue Doheny who couldn’t attend the APPG.

Members of the Board present said the revised document was within the ‘Gateway’ at NHS England and awaiting imminent publication. It was a much shorter document with the case-studies in an appendix which would be available separately online. They were developing ‘levers’ and ‘drivers’.

NHS England were currently considering how best to publicise the Guidelines and were looking for a suitable peg and even ‘champions’ amongst CCGs. They had missed the peg of ‘continence week’. All agreed that this document was still very important in pushing for better continence care – though concern was expressed as to whether the services would be

available in secondary care to deliver the much hoped for better care. The possibility of the APPG assisting with NHS England's communications plan was raised.

Baroness Greengross asked whether there would be any mandatory obligation to collect data. **(Action: Tracy to offer support, where possible, to Sue Doheny for their Communications Plan).**

#### **Agenda Item 4: Nursing and Midwifery Council**

Anne Trotter (NMC) said that on 13 July they became the official regular for nursing associates. The consultation closed on 2 July on nursing associate standards. The idea is for a registered nurse to do the primary assessment and formulate the Plan and nursing associate to follow the plan. However, responses did query capability of nursing associates to do this given different training and differing skill set. She pointed out the Regulation just covered England. Standards would be published in October. And the outcome made clear at the NMC Conference in September.

#### **Agenda Item 5: Health Advice on Packaging**

Baroness Greengross explained that there had been two approaches to the APPG regarding health advice and labelling on packs and in advertising. Whilst a shift to promotion of retail products has helped shift the taboo and has encourage people to buy correct products (rather than substituting with femcare for example), there is concern that without health advice ie to seek medical help, the condition is being 'normalised'.

Tracy updated the APPG that Tena, a major brand, had decided to introduce health advice on all its products including in Europe. Boots would be running a campaign calling on people to seek medical advice. Nikesk Thiruchelvan, Consultant Urologist at Addenbrookes questioned whether labelling should be mandatory. It was pointed out that Tena's decision was a major leap forward and others would be likely to follow.

June Rogers said she had concerns about TV advertising emphasising Ooohs moment. Tracy explained the Advertising Standards Authority guidelines on short ads.

There followed a discussion about supply of products and services. More products are now being sold in retail as NHS Trusts limit supply of products and in some cases plan to withdraw them altogether. There will be stricter criteria for provision in the future.

Liz Bonner pointed out that in London hospital three pads were being offered for a 24 hr period which wasn't enough for many people. Liz in discussion with Jo Gander (CaPA) expressed continued concern over the cost of delivery charges from NHS Supply Chain which meant she couldn't afford as many products. Liz was assured that these charges would cease. (to be clarified).

Charles Knowles (Colo-rectal surgeon) pointed out that the problem with the NHS providing services for 'chronic' conditions is that they were not 'profitable' and didn't attract tariffs. He said that these services were being cut and that waiting times were increasing. This was exacerbated by the problems which had surrounded the vaginal mesh implants with some areas such as Oxford ceasing to offer operations. He said that this meant that more women with stress incontinence would go untreated. He pointed out that an enormous number of admissions to hospitals were caused by catheter associated infections.

June Rogers and Penny Dobson also added to Charles Knowles' view saying that it wasn't just a problem with products but about the decimation of services, including children's services. There would be costs for inaction which would still fall on the NHS.

It was pointed out that the APPG had produced a document for NHS England on Costs associated with not delivering an incontinence service. (**Action: It was agreed to send this to Jo Gander by way of background information**).

The APPG discussed beginning a campaign highlighting the concerns about the decimation of services and that a letter should be sent from the APPG to the new Secretary of State for Health and Social Care, Matt Hancock who was appointed on 9 July. (**Action: Charles Knowles to send some key points to Pat Murtagh who will draft a letter to Matt Hancock from the APPG.**)

## **Agenda Item 6: Implementing the EICC Guidelines at the Hurley Clinic, Kennington**

Dr Kumar explained that the Hurley Clinic was part of a bigger Group of 14 practices. The Hurley Clinic serviced 13,000 patients of whom 10% were over 60 years of age. The 14 practices had in excess of 100,000 patients. Dr Kumar commenting on the concerns about services said it was important that primary care needed to have the services delivered by secondary care.

Work was progressing at the Hurley Clinic on identifying the scale of the incontinence problem by using opportunities such as registration, ante-natal checks up and other opportunities to gather data. He said that there was an obligation to assess over 60s and other opportunities presented themselves through home visits. The collection of data was crucial. Charles Knowles said this data would be very interesting. It is hoped the Hurley Clinic would have the data by Dec 2018. Dr Clare Gerada, former Chair of the Royal College of GPs is also a partner and very supportive of Dr Kumar's work in this field.

## **Agenda item 7: Men's Washrooms**

There has been extensive coverage recently of single use plastic which pollute our waste water treatment and oceans. Incontinence products must be disposed of by the solid waste treatment system and NOT flushed down the toilet which leads to sewer blockages.

It is estimated that 11% of men between the ages of 60-64 have frequent urinary incontinence and around 30% report infrequent urinary incontinence.

Being able to dispose of products correctly and discreetly outside the home is just as important for men as for women. Yet astonishingly there is no requirement for bins to be placed in men's washrooms. The only mandatory requirement is for bins in women's workplace toilets.

Baroness Greengross said the APPG should call for men to have the same provision as women in the workplace and in all public toilets?

Tracy explained that this idea was gaining widespread support and that she had recently raised it during an evidence session at County Hall for the London Assembly who had said they would act to change this.

Liz Bonner said that she had given 'radar' keys to male patients which allow access to disabled toilets so they could dispose of products. This had led to some of her male patients being abused by people as when they emerged from toilets they didn't look disabled.

It was noted that Paula Sherriff MP was campaigning for Changing Places which called for proper Changing Places to be made compulsory in all public buildings which were suitable for disabled adults and children.

Charles Knowles was very keen to support this idea and felt the Prostate cancer charities and other bowel charities would get right behind this and had facebook pages etc. He also said the charities had links to Armitage Shanks and wondered if they might be approached to assist re advertising perhaps on bins. **(Action: Tracy to liaise with Charles over links to charities and consider next steps including inviting to next APPG)**

## **Agenda Item 8: Any other Business**

Charles Knowles mentioned MASIC Foundation. This looks at incontinence in women with severe birth injuries. He felt they might like to attend a future APPG meeting. Baroness Cumberlege is a key supporter. He said there were three key charities including the Bowel Disease Research Foundation, Bowel and Cancer Research and MASIC

**The next meeting likely to be on Monday 12 November 2018, 1.00-3.30pm, House of Lords Committee Room G.**