

PCF Activity Report : July – October 2018

Activity

Developing the Parliamentary supporter base

The PCF has continued to develop its Parliamentary supporter base. Using the information from the 2017 Freedom of Information Request (FOI) audit, Whitehouse has begun targeting those MPs where paediatric continence services in their constituencies appear to be poor or non-existent.

A meeting with Emma Hardy MP (Labour, Hull West and Hessle) has been planned, and Toby Perkins MP (Labour, Chesterfield) has also registered an interest in meeting.

Whitehouse will continue to engage with MPs and Parliamentarians who support the aims of the PCF. In July, we contacted Paula Sherriff MP after her comments on the need for additional Changing Places toilet facilities.

Whitehouse will now continue to target the worst-performing STPs directly. Many are undergoing service reviews, and representation from the PCF will increase pressure on local health providers and services to restore, protect and increase funding for paediatric continence care.

The PCF has sent our FOI results to support clinical member June Rogers MBE who is making representation to the Welsh health service to raise the profile of continence services. The PCF has also made contact with Neil Gray MP (SNP, Airdrie and Shotts) to ask him to write to the Scottish Cabinet Sec for health and Sport, Jeanne Freeman OBE.

Whitehouse has also contacted the Hon David Ashford MHK. In charge of health services on the Isle of Man following a meeting the PCF chair had with clinical colleagues there.

Developing relationships with key policymakers

The PCF has submitted a formal letter to Sir Simon Stevens, Chief Executive of NHS England, to respond to the NHS Ten Year Forward Plan. The letter highlighted the deteriorating state of paediatric continence services - particularly as an unintended consequence of the 2015 transfer of health visitors and school nurses to local authority control. We feel let down by the Government. We asked Simon Stevens what he was going to do to redress this situation as part of his Forward Plan.

The letter was submitted in August and will now be reviewed by the Forward Plan committee, who are outlining and devising the policy priorities on the NHS's Ten Year Forward Plan.

The PCF has also contacted Professor Russell Viner, President of the Royal College of Paediatrics and Child Health, indicating the concern about the current underinvestment in paediatric continence care.

In July the PCF Chair and Vice Chair held a meeting with Professor Newton, National Director of Health PHE and Dr Helen Duncan, Director of Child and Maternal Intelligence, PHE. It was clear that PHE are unable to reinstate the Paediatric Continence Needs Assessment Tool on their new Fingertips website. Professor Newton subsequently wrote to his counterpart at NHSE – but this did not prove successful either. We are now in touch with Dr Duncan to explore the feasibility of transferring the tool to another provider. This would ensure that, in the future, paediatric continence outcomes would continue to be measured.

All-Party Parliamentary Group for Continence Care

The PCF attended the All-Party Parliamentary Group for Continence Care on the 18th July. The following is an account of some of the items covered at this meeting.

The Chair, Baroness Greengross thanked Wendy Gray in her absence for leading the review of NHS England's Excellence in Continence Care guidelines and to her successor, Sue Doheny. There was a discussion about the importance of publicising this new document.

Jo Gander, Director of Clinical & Product Assurance at NHS England, gave a presentation on Category Towers and the Supply Chain Coordination Limited (SCCL). Category Towers have been set up by the NHS to streamline the purchase of goods by NHS Trusts and hospitals. There will be greater clinical involvement in purchasing decisions using research and GIRFT (Getting it Right First Time). The goal is to tackle "unwarranted variation" on an evidence base. CAPA is at CaPa@DH.gsi.gov.uk

There was a discussion about men's washrooms and the importance of disposal bins in men's washrooms. It was agreed that men should have the same provision as women in the workplace and in all public toilets. The meeting also discussed the campaign by Paula Sherriff MP and the need for additional Changing Places facilities.

There was also a discussion about the importance of health advice on packaging. Tenor, as major brand, has decided to introduce health advice on all its products and Boots will be running a campaign calling on people to seek medical advice. There were concerns that some continence, bladder and bowel issues were being "normalised"

At the meeting, PCF Chair stressed the need for properly trained school nurses, noting that the shift to local authority oversight has been detrimental to Level/Tier 1 paediatric continence services. This view was shared by the group. The APPG has produced a document for NHS England on costs associated with not delivering an incontinence service.

Policy Development

Responding to consultations

The PCF has established new Working Groups to work on consultation responses as and when they are published by Government and NICE. This streamlined way of approaching consultations seems to be working well, with the Forum now in a position to respond in a more planned way to consultation requests. The PCF responded to the NICE Guideline CG111 Review on Bedwetting in under 19s on the proposal **not to update**. The PCF did not agree with the proposal not to update the guideline'.

The PCF also responded to NICE Guideline CG148 consultation on urinary incontinence in neurological disease but was unable to submit at this "topic expert" stage. We will submit our comments once it comes out for stakeholder review.

The PCF responded to a more general consultation by the Scottish Government on Supporting Disabled Children, Young People and their Families.

Promoting the Work of the PCF

Website and Publicity

PCF members played a key role in the publication of NHSE updated Excellence in Continence Care Guidelines The PCF subsequently promoted the document on both the PCF website and social media, where there were high levels of engagement from clinical supporters, families and those with continence and bladder and bowel issues. The PCF has created a new "Parliamentary Activity" page on its website, listing the campaigns it has been a part of and the written parliamentary questions and references in debates the Forum had a part to play. The Forum has also listed the benefits of becoming a corporate member to encourage interest. In the past three months, the website has had 1,250 visits – a rise

Of about 5% from the previous quarter. If the number of views continues at its current rate, 2018 will have seen the highest number of visitors to the website since 2015.

Monitoring

Whitehouse has continued to monitor development in Westminster, Whitehall and the devolved administrations.

We have provided weekly analysis on issues such as: NHS funding, the healthcare workforce, and developments in continence and paediatric continence provisions in the health and education sectors.