

Activity Plan

The Whitehouse Consultancy

The Paediatric Continence Forum

2018

Introduction

This paper sets out the Activity Plan for the Paediatric Continence Forum (PCF) for 2018. It identifies the activities that members agreed need to be carried out this year to meet the aims of the Four Year Strategic Plan (2017-2021).

2016-17 was a year in which the PCF made some progress, but also was forced to engage in “damage limitation” to counteract issues caused by changes within the NHS that worked against our core aim – for every Clinical Commissioning Group and Health Board in the UK to have a proper, integrated paediatric continence service.

Despite these challenges, the PCF was able to meet three out of its five objectives for the year, most notably completing a FOI survey of CCGs and Health Boards to assess the current state of community-based paediatric continence services. This showed an overall small improvement compared to a similar survey in 2014, but with continuing wide disparities in service provision and a worrying deterioration within the devolved nations, particularly in Scotland and Wales. It was encouraging to discover from this FOI survey that over 64% of CCGs and Health Boards are aware of the PCF’s NICE-accredited Paediatric Continence Commissioning Guide and nearly 50% had actively used it in setting up and running their paediatric continence services.

These findings were – and will continue to be – utilised in the PCF’s parliamentary work, such as identifying and lobbying MPs in constituencies with poor services and providing MPs who attended our parliamentary drop-in session the details of service provision in their constituencies, enabling them to write to their CCG/Board Chair as appropriate. Earlier in the year our engagement with Prospective Parliamentary Candidates ahead of the snap General Election ensured that a new generation of MPs were aware of the PCF’s policy concerns.

During the year we were informed by Public Health England that the online Continence Needs Assessment tool – a vital means of measuring how well paediatric continence services are operating – was not going to be transferred across to PHE’s new Fingertips tool. Focussed lobbying by the PCF initially resulted in an assurance from Public Health England that it is their intention to reinstate the Continence Needs Assessment as part of their 2018/2019 business plan. This was reinforced by a similar assurance from the Public Health and Primary Care Minister, Steve Brine, during a parliamentary debate on continence in September 2017. The PCF is continuing to follow up on these promises.

The PCF also worked with the Royal College of Nursing and Bladder and Bowel UK to produce a case study and a financial comparison of optimal and sub-optimal care pathways for a typical child with continence problems. This was submitted to NHS RightCare to demonstrate the considerable savings that can be made by following an optimal care pathway. We understand that it will be considered by their clinical improvement group. Our resources were also disseminated to NHS RightCare Delivery Partners.

The PCF has continued to engage with NHS England and to play an active role in the update of the Excellence in Continence Care document. We have also responded to all relevant public consultations – such as the Nursing and Midwifery Council's nurse proficiencies and education framework consultation; the Welsh Government's Parliamentary Review of Health and Social Care; and NHS England's consultation on items which should not routinely be prescribed in primary care.

The PCF is its membership, so our 143 clinical members are crucial to our work – as are our company members, to whom we are indebted for their support. During the year, the PCF welcomed new representation from the Community Practitioners' and Health Visitors' Association, and we were pleased to start a new parent supporters' forum. The PCF has also begun to recruit clinical members to formally represent the devolved nations, so that we can strengthen our work in these regions.

We remain indebted to the expertise and commitment of colleagues from The Whitehouse Consultancy, who continue to provide the PCF with an efficient advisory and secretariat service.

Dr Penny Dobson MBE

Chair, Paediatric Continence Forum

February 2018

Aims and objectives for the PCF as outlined in the 2017-2021 strategic plan

- a) To increase awareness and understanding within NHS England, its equivalents in the devolved nations, their associated bodies and the Government and MPs, and amongst service commissioners, managers and practitioners of:
 - The need for integrated, community-based paediatric continence services to be available to children and parents nationally and on an equal basis;
 - The principles of good practice and the key elements in the design of such services;

- The savings to be made from running proper integrated services, with improved clinical outcomes; and
 - The effect of decommissioning the role of school nurses who provide continence services at Level/Tier 1.
- b) To improve the level of integration of existing community-based, paediatric continence services nationally and, where necessary, to encourage the establishment of new services to move towards a fully integrated service within each CCG or devolved equivalent.
- c) For paediatric continence to be higher on the agenda of national and local policy-making, as both a clinical and public health need.
- d) For the PCF to be better known nationally and locally amongst commissioners, policymakers and clinical practitioners.
- e) To achieve a NICE clinical guideline on daytime incontinence.

Below we outline the specific objectives we will work towards throughout 2018, what work we will take forward to achieve these, and how this relates to the overall aims set out above.

Specific Objectives for 2018

Building upon past achievements, in addition to pursuing the aims above, our objectives for 2018 will be to:

- Complete an update of the Paediatric Continence Commissioning Guide in conjunction with NICE.
- Continue to engage with Public Health England on the reinstatement of the Continence Needs Assessment tool during 2018/19 and support the update of the data using the PCF's 2017 FOI data.
- Encourage uptake of the reviewed NHS England Excellence in Continence Care commissioning framework, once published and continue to lobby NHS England re the delayed publication of the Commissioning Guide for Children with Complex Needs.
- The Whitehouse Consultancy will continue to provide a professional and efficient secretariat service to PCF members.

Increase the PCF's profile within the health and children's sectors

Specific items of work

- Update the Paediatric Continence Commissioning Guide and ensure that it is disseminated among appropriate CCG and Health Board stakeholders.
- Explore undertaking a new School Nursing Campaign in cooperation with SAPHNA, to ensure schools, local authorities and Multi Academy Trusts (MATs) are aware of the dangers of children “slipping through the net” if school nurses are no longer providing level/tier 1 assessment and treatment on continence problems in the area.
- Encourage uptake of the reviewed NHS England Excellence in Continence Care commissioning framework, once published.
- Continue to lobby NHS England on the delayed publication of the Commissioning Guide for Children with Complex Needs.
- Consolidate and build relationships with appropriate contacts within the Department of Health and Social Care and Department for Education, pressing for a cross-departmental approach to be taken to ensure the promotion of issues relating to paediatric continence.
- Continue to engage with organisations such as the Children and Young People's Nurse Academics UK and build new contacts with groups such as the PSHE Association and the Association of Young People's Health.
- Strengthen partnerships with our representative organisations and build new alliances with organisations such as the Royal College of General Practitioners, the British Medical Association and the Local Government Association.
- Engage with the National Clinical Director for Children, Dr Jackie Cornish.
- Continue to expand the PCF's clinical supporter group by exhibiting at conferences and via social media and email updates and extend our parent supporters group.
- Identify further opportunities for the PCF to produce content for relevant websites and social media, such as writing pieces for ERIC's blog.

Increase the parliamentary profile of children's continence and the work of the PCF

Specific items of work

- Organise meetings with MPs and peers focusing on the results of the 2017 FOI survey of CCGs and Health Boards, the 2018 local authority FOI survey and the publication of the updated Commissioning Guide, to ensure parliamentarians are aware of the PCF's latest work.
- Secure parliamentary activity including written questions and letters to relevant ministers.

- Seek an adjournment debate on gaps in children’s public health services, with a focus on paediatric continence but allowing contributions on other areas of child health to encourage its uptake and boost attendance.
- Consolidate relationships with parliamentarians who attended the 2017 drop-in session and with those parliamentarians due to attend Coloplast’s youth continence report launch in February 2018.
- Encourage the promotion of the reviewed Commissioning Guide by the Continence Care APPG and continue to strengthen our relationship with the APPG’s officers and secretariat.
- Carry out meetings between the PCF’s devolved nation representatives and relevant members from the devolved governments, such as the member of the Scottish Parliament Alex Cole-Hamilton, who has been pushing for a national continence strategy in Scotland.
- Collaborate with partners such as ERIC and Bladder & Bowel UK to promote World Bedwetting Day in Parliament and on social media.

Developing the PCF’s role as a policy leader and delivering policy change

Specific items of work

- Complete an update of the Paediatric Continence Commissioning Guide in conjunction with NICE.
- Finish the FOI audit of local authorities, and secure pre-agreed coverage in the Nursing Times to promote what the results highlight about gaps in service provision across the UK.
- Continue to engage with Public Health England on the reinstatement of the Continence Needs Assessment tool during 2018/19 and support the update of the data using the PCF’s 2017 FOI data.
- Publish a business plan demonstrating how to establish an appropriate, integrated paediatric continence service, and disseminate this among poorly functioning CCGs to publicise the required standard of services.
- Explore promoting the PCF’s consultancy service through creating a page on the PCF’s website to list consultants available to support CCGs with their paediatric continence services.
- Maintain our link with NICE and discuss the production of a guideline on daytime incontinence with NICE and NHS England.
- Undertake a literature review as a prelude to submitting an application to NICE for a clinical guideline on daytime incontinence.
- Respond to appropriate policy consultations to ensure the PCF’s views are represented at all levels of government.

Providing a professional and efficient secretariat service to PCF members

As well as the policy and parliamentary work outlined above, Whitehouse will also continue to provide the PCF with an efficient secretariat service which ensures smooth organisational operation.

Specific items of work

- Proactively identify possible new company members for the PCF and produce a briefing for the Chair to circulate to these to highlight the PCF's work and benefits of company membership.
- Organise membership meetings three times a year.
- Provide effective communication with the membership, keeping them updated on relevant developments through the weekly monitoring document and more frequently when developments are particularly relevant.
- Provide regular email updates to the PCF's clinical supporters.
- Set up a Facebook page for the parent supporters' group.
- Keep the PCF website updated on an ongoing basis and maintain the PCF's Twitter account.
- Exhibit at appropriate conferences and meetings with clinical members.
- Organise the finances of the PCF, including invoicing and expenses.
- Assist the Chair with succession planning.