

# Activity Plan

The Whitehouse Consultancy

The Paediatric Continence Forum

2019

## Introduction

This paper sets out the Activity Plan for the Paediatric Continence Forum (PCF) for 2019. 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).

2018 was another challenging year for the PCF, with the effects of the cutbacks to school nursing and health visitor services in England continuing to decimate the commissioning of paediatric continence services, particularly at Level/Tier 1. All continence services in the devolved nations, with the exception of Northern Ireland, have shown a worrying reduction - although we welcome plans by the Scottish Government to uplift all Health Visitors to a minimum band 7. During the year the PCF has continued to campaign to bring downward trends and their causes to the attention of politicians and civil servants – but the Brexit-effect has made it more of a challenge to get our voice heard.

To complement our early 2017 FOI survey of CCGs and Health Boards, in late 2017 and early 2018 the PCF carried out a Freedom of Information survey of 205 local authorities responsible for public health services in England, Scotland and Wales. There was a good response (93%). However, only 42% said that continence was a listed responsibility for school nurses and 31% for health visitors. There was a poor response to our question “was there a decision taken to remove continence from these (school nurse and health visitor) responsibilities and if so when?”. Overall this confirmed the fragmented nature of paediatric continence services nationally as identified from the PCF’s earlier survey.

We learnt that 42% of local authorities were aware of the PCF’s NICE-accredited Paediatric Continence Commissioning Guide and 22% were using it (this compared to 64% and 50% of CCGs and Health Boards in our earlier survey). Clearly more work needs to be done to inform local authorities of this resource.

The overall aim of the PCF remains: that is: for every Clinical Commissioning Group and Health Board in the UK to have a proper, integrated community-based children’s continence service.

The PCF met 10 of its 25 objectives for the year. Some of the areas not met were due to circumstances beyond our control e.g. a NHS England Commissioning Guide for Children with Complex Needs did not materialize despite our close liaison with NHS England on this matter - and the National Director for Children did not feel that she could add anything to what we were already doing.

On the plus side the PCF was able to raise awareness amongst parliamentarians of the needs of children and young people through a parliamentary launch in February 2018 of a new document called “It Happens to Me Too” This outlined important new research undertaken by the company Coloplast and the University of Bristol about the impact of continence difficulties on the lives of children and

young people - as well as their views on what they want from NHS services. A collaborative project between ERIC, Bladder and Bowel UK, University of Bristol and Coloplast, it was clear that children and young people still suffer huge stigma from these conditions – and that the fragmented nature of continence services is impeding their wish to self - manage their continence problems.

Another positive outcome was that we were able to recruit PCF representatives from our devolved nations in order to strengthen our work to highlight the deficiencies in NHS services to government leaders. We also commenced work on updating the PCF's Paediatric Continence Commissioning Guide - and the PCF's Vice-Chair completed a literature review as a prelude to a further attempt to encourage NICE to undertake a NICE Review on daytime wetting.

On a more challenging note, during 2018 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 in England – was not going to be transferred across to PHE's new "Fingertips" model. Focused lobbying by the PCF initially resulted in an assurance from Public Health England that they intended to reinstate the Continence Needs Assessment as part of their 2018/2019 business plan – and its importance was reinforced by the Public Health and Primary Care Minister, Steve Brine, during a parliamentary debate on continence in September 2017. However, a meeting with PHE's Professor Newton, National Director for Health Improvement in July 2018 failed to change their final decision not to reinstate the tool despite their appreciation of how important it is for the execution of the PCF's Commissioning Guide. We are currently looking for another "home" for this important resource.

During the year the PCF alerted NHS RightCare to case studies that PCF members had put together to demonstrate the cost savings of "optimal" care pathways. Our case was presented to their "topic group" for NHS RightCare prioritisation in April 2018, but it was not passed as a priority as they felt that we already had sufficient resources to aid service implementation.

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, most notably:

- CG148 on urinary incontinence
- CG111 on bedwetting in under 19s

The PCF is its membership, so our 144 clinical members are crucial to our work – as are our company members, to whom we are indebted for their support

We also 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*

*November  
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/carers 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 for young people and higher standards of care;
  - 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 2019, what work we will take forward to achieve these, and how this relates to the overall aims set out above.

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

#### Specific items of work

- Re-publish the Paediatric Continence Commissioning Guide and ensure that it is disseminated among appropriate CCG and Health Board stakeholders.
- Undertake a new project to recognize and promote good practice in the area of transition from children's to adult services, by developing an awards system to recognize the achievements in this area of GP surgeries, community centres, school nurses and hospitals. This seems a very broad group!
- Encourage uptake of the re-published NHS England Excellence in Continence Care commissioning framework.
- 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 appropriate 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 with other appropriate organisations -, such as the Royal College of General Practitioners and the Local Government Association.
- Continue to expand the PCF's clinical supporter group by exhibiting at conferences and via the PCF website and social media
- Identify further opportunities for the PCF to produce content for relevant websites and social media, such as writing pieces for ERIC's blog and BBUK.

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

#### Specific items of work

- Organise meetings with MPs and peers continuing to focus upon 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.
- Continue to consolidate relationships with parliamentarians who attended the 2017 drop-in session and with those parliamentarians who attend Coloplast's youth continence report launch in February 2018.
- Continue to work closely with the APPG on Continence.
- Carry out meetings between the PCF's devolved nation representatives and relevant members from the devolved governments, such as the Cabinet Secretary for Health, Scottish Parliament
- 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

- Find a "home" for a newly updated Continence Needs Assessment Tool
- Undertake a Transition Campaign – to highlight to Government why transition is a major and unaddressed issue, obtain its inclusion within the Government's 10 Year Plan and improve awareness of good practice in this area. As with other areas of work, this will be in conjunction with our company members.
- 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.
- 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

- Advise on parliamentary/policy matters
- 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 twice yearly email updates to PCF Clinical Supporters
- 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.

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