

Activity Plan 2020

The Whitehouse Consultancy

The Paediatric Continence Forum

This paper briefly reviews year 2019 and sets out the Activity Plan for the Paediatric Continence Forum (PCF) for 2020. It identifies the actions that members agreed need to be carried out to meet the aims of the Four Year Strategic Plan (2017-2021).

The PCF's Vision is for every Clinical Commissioning Group and Health Board in the UK to have a proper, integrated community-based children's continence service. In reviewing how far the PCF achieved the year's objectives towards this goal, the PCF fully met 9/21, partly met 5/21 and did not meet 7/21 of its objectives. Some of the "not met" objectives were due to the political climate, in which meetings with MPs were delayed or denied due to the Brexit agenda; the objective of gaining a NICE guideline on daytime wetting was again not achieved due to a poor evidence-base.

Despite these constraints, the past year was a productive one for the PCF. For example, in September 2019, the PCF updated and re-published its Children's Continence Commissioning Guide; the author was Davina Richardson, Children's Specialist Nurse with the organization Bladder & Bowel UK and its editor the PCF Chair, Dr Penny Dobson MBE; many clinical PCF members participated as part of the independent Guide Development Group. The update included a full literature review undertaken by the PCF's Vice-Chair, Mr Nick Madden. The updated guide was circulated to chief executives of all clinical commissioning groups and NHS trusts.

Also during the year, the PCF highlighted best practice in the transition from child to adult continence services through the launch of a Transition Awards Scheme; this was led by our Vice-Chair and undertaken in conjunction with clinical members and the company Essity.

In addition to direct PCF activities carried out by our clinical and company members, an important role of the PCF is to enable members to share their own work - and for the PCF to contribute, where appropriate, towards the dissemination of new initiatives and good practice.

One example is the work that member organization Bladder & Bowel UK are doing, with support from Ferring, to improve services in Northern Ireland, as well as making positive links with colleagues in Wales and Scotland. ERIC too contributed by running training seminars for health professionals in these regions and the PCF's Chair undertook some direct work with the Isle of Man government. To strengthen our devolved nation representation on the PCF we have welcomed new clinical members from Northern Ireland and Scotland, as well as representation from the new paediatric "arm" of the All Wales Continence Forum.

Another example of shared enterprise was in April 2019 when the PCF arranged a meeting with Gill Jones, Deputy Director for Early Education at Ofsted. This was to support the work that ERIC was doing to highlight shortcomings in early years setting and schools in managing the needs of children with continence problems. At the request of Ofsted, ERIC put together some Top Tips for Ofsted Inspectors (all educational settings), to help Inspectors identify standards in; identifying children in early years settings who are not toilet trained and

the policy to address this; access to fresh drinking water and toilet facilities; the quality of washroom and toilet facilities; the procedure for children and young people to disclose continence problems.

ERIC and Bladder & Bowel UK published their guidance “Managing Bladder and Bowel Issues in Nurseries, Schools and Colleges” in September 2019, which the PCF helped to disseminate; to all schools in the UK, all Directors of Children’s Services and all Members of the House of Commons with the request that they share the information with their local schools and Local Education Authorities. A media release relating to the publication was widely circulated by the PCF, securing good coverage, including in The Times Education Supplement.

The PCF also drafted and facilitated an Early Day Motion being tabled by Rosie Cooper MP, the Chair of the All-Party Parliamentary Group on Continence Care to highlight the worrying results of a research study on pupils’ access to toilet facilities while in school, carried out by Essity. The relationship between PCF and Ms Cooper has been maintained and several written parliamentary questions were put down in the House of Commons to promote PCF issues. A relationship with Baroness Masham of Ilton, a Vice Chair of the same All-Parliamentary Group was also established and led to the tabling of questions in the House of Lords.

Rosie Cooper also wrote to the Minister for Children and Families to promote awareness of the PCF and of the work of ERIC and Bladder & Bowel UK in producing the schools’ guidance; and the Minister responded proposing a meeting with a senior official further to discuss these matters.

During the year, the PCF continued to support and disseminate research from the University of Bristol that increases our understanding of the psychological impact of continence problems on children. These important messages have been incorporated into our Commissioning Guide and to publications from member organisations. The PCF also gave feedback on a new University of Bristol - initiated App to help children with day time wetting manage their treatment and has participated in a University of Exeter study evaluating the effectiveness of NHS practice on children and young people with neurodisability and incontinence.

PCF clinical members have actively contributed to NHS England’s new National Bladder and Bowel Health Project as members of the Excellence in Continence Care Programme Board, both contributing to the specific workstream on “paediatrics and transition” as well as to some of the other workstreams. It is anticipated that the outcome will be a series of evidence-based and patient –focused care pathways for continence, which we hope will be a “must do” for commissioners.

On the publicity front, the PCF’s Chair gave presentations on the work of the PCF at two study days organized by Bladder & Bowel UK and was also invited by BBC Wales (TV and radio) to speak about the poor level of paediatric continence services there, as identified by our 2017 FOI Survey. The PCF also publicised World Bedwetting Day, organized by Ferring. The PCF web-site is regularly updated with key publications and information; and key updates are promoted through its Twitter account.

When NHS England announced plans to prohibit the routine prescription of items for minor and infrequent ailments, the PCF responded by calling for child continence medicines, such as laxatives, to be exempt from the prohibition. NHS England subsequently published guidance in which it said that “Laxatives are not recommended for children unless they are prescribed by a GP.” The PCF also responded to the NICE consultation on the social, emotional and mental wellbeing in primary education (May 2019) and the Ministry of Housing, Communities and Local Government Consultation on Changing Places Toilets (July 2019).

The PCF is its membership, so our 19 clinical members are crucial to our work – as are our company members, to whom we are indebted for their support. Our “eyes and ears” remain our 186 clinical supporters.

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

Dr Penny Dobson MBE

Chair, Paediatric Continence Forum

November 2019

[Aims of the PCF as outlined in the 2017-21 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 school nurses being moved from from a clinical to a public health agenda, resulting in the decommissioning of Level one children’s services in many areas.

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 2020, how we will achieve these, and how these relate to the overall aims set out above.

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

Objectives

- Encourage the commissioning of services that follow the 2019 Children's Continence Commissioning Guide (where there are no services, services that are under-resourced or not fully integrated)
ACTION: Publicity and political activity, highlighting the clinical and financial benefits. Encourage practitioners to share their experiences of putting the Guide into practice through case studies on the PCF website. Additionally, to engage with the Association of Directors of Children's Services and other professional bodies; as well as key players in primary care networks, clinical commissioning groups and NHS trusts. Contribute to NHSE's National Bladder and Bowel Health Project
- Assess how far community-based NHS children's continence services have improved since the PCF FOI surveys in 2017/2020 and how far the 2019 Children's Continence Commissioning Guide is being used as a template
ACTION: Carry out a FOI Survey of Clinical Commissioning Groups and Health Boards and evaluate and publicise the results.
- Increase awareness of good practice in the transition of children and young people to adult services
ACTION: Publicise and promote good practice, including through the Association of Directors of Children's Services, the Association of Directors of Public Health and the Local Government Association.
- Increase awareness amongst staff in nurseries, schools and colleges of the importance of putting the 2019 "Managing Bladder and Bowel Issues" guidance into practice
ACTION: Continue to share the guidance with nurseries, schools and colleges, plus trade associations and other relevant groups such as NAHT and Teach First.
- Increase the awareness of Ofsted about the impact of continence problems on children and young people in early years, school and college settings and encourage Ofsted inspectors to assess according to ERIC's "Top Tips".
ACTION: Correspondence and meetings with Gill Jones, Deputy Director for Early Years at Ofsted and her team
- Achieve childhood continence being designate as a long term condition within the CYP Transformation Programme under NHS England's Long Term Plan. Also use the new structures within the LTP eg the Primary Care Networks to effect positive change
ACTION: Liaison with NHSE and Primary Care Networks
- Achieve a NICE Clinical Guideline on day time incontinence
ACTION: Resubmit to NICE

- Encourage the sharing of/identify further opportunities for the PCF to produce content for relevant websites and social media.

Increasing 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; the results of the 2017 and 2020 FOI surveys of CCGs and Health Boards, the 2018 local authority FOI survey and the publication of the 2019 Commissioning Guide; the 2019 Guidance for Schools to ensure parliamentarians are aware of the work of the PCF and its allied organisations
- 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 work closely with the APPG on Continence Care, and a range of other, similar groups focusing on children's health and well-being, and life sciences.
- 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. Liaise with and support the All Wales Continence Forum in their contact with the Welsh government
- 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

- Contribute to NHSE's National Bowel and Bladder Health project – as a member of the Excellence in Continence Care Forum and the NBBHP workstreams
- Promote research outcomes and identified good practice on the PCF website and on social media
- Publish a business plan demonstrating how to present the case for an appropriate, integrated paediatric continence service and disseminate this among poorly functioning CCGs to publicise the required standard of services
- Respond to appropriate policy consultations to ensure the PCF's views are represented at all levels of government
- Enhance the public profile of the PCF in key policy and specialist practice - focused media by continuing to identify and seize opportunities for media comment and the positioning of articles on current policy challenges.

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
- Carry out a 2020 UK-wide FOI survey of paediatric continence services
- 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
- Explore new ways to enable communication with and between PCF members.

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