Activity Plan
The Whitehouse Consultancy

The Paediatric Continence Forum
2017
Introduction

This paper sets out the Activity Plan for the Paediatric Continence Forum (PCF) for 2017. It identifies the activities needed to carry out the aims of the Four Year Strategic Plan (2017-2021).

2015-16 was another busy and productive year in which the PCF fully or partly met two thirds of its year objectives. This included organising a joint letter with a range of other organisations to NHS England's Chief Executive, Simon Stevens - to highlight the deterioration in community-based paediatric continence services following the transfer of school nurses from Public Health to Local Authority control. As a result Public Health England (PHE) included continence in a new commissioning guide for children with additional needs and continence was included as part of PHE’s digital “week of action” to showcase the important role that school/other community nurses play in the lives of children and young people aged 5-24 years.

Work has also continued with NHS England as part of their Excellence in Continence Care (EICC) working group and on updating the 2015 EICC guidance. During the year, the PCF also completed new UK Minimum Standards of Care for continence, due to be published shortly by the UK Continence Society (UKCS). There has also been a good level of parliamentary activity throughout the year, with a parliamentary drop-in session hosted in July and ten written parliamentary questions tabled on the needs of children and young people with continence difficulties.

We were delighted to recruit three new company members; Abena UK, Laborie and SCA – and three new clinical members representing Bladder and Bowel UK (formerly PromoCon), the School and Public Health Nurses Association (SAPHNA) and the Royal College of Nursing (RCN). We also attracted a further 80 PCF clinical supporters, and have started an equivalent supporters group for parents.

It was heartening to hear while exhibiting at the ACA and ERIC Conferences that the PCF’s Commissioning Guide is being put into practice. The challenge for 2017 is to ensure that this process continues – towards the ultimate goal of each Clinical Commissioning Group (and the equivalents for the devolved nations) using the Guide as a template for local service delivery.

PCF objectives for the previous activity plan that were not met – largely due to circumstances outside our control – will be added to our plans for 2017.

Dr Penny Dobson MBE
Chair, Paediatric Continence Forum
January 2017
Aims and objectives for the PCF as outlined in the 2017-2021 strategic plan

- To increase awareness and understanding within the Commissioning Board and its equivalent in the devolved nations, the Government and amongst service commissioners, managers and practitioners of:
  - The need for integrated, well-resourced, community-based paediatric continence services to be available to all 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 properly integrated and resourced services, with improved clinical outcomes; and
  - The effect of decommissioning the role of school nurses who provided continence services at Level/Tier 1.

- 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 and adequately resourced service within each CCG or devolved equivalent.

- For paediatric continence to be higher on the agenda of national and local policy-making as both a clinical and public health need.

- For the PCF to be better known nationally and locally amongst commissioners, policymakers and clinical practitioners.

- To achieve a NICE clinical guideline on daytime incontinence.

Objectives for 2017

Building upon past achievements, our objectives for 2017 will be to:

- Increase the PCF’s profile within the health and children’s sectors;
- Increase the parliamentary profile of children’s continence and the work of the PCF;
- Develop the role of the PCF as a policy leader in delivering policy change; and for
- The Whitehouse Consultancy to continue to provide a professional and efficient secretariat service to PCF members.
Increase the PCF’s profile within the health and children’s sectors

Relevant strategic plan aims

- To increase awareness and understanding within NHS England and its equivalent in the devolved nations, the Government and amongst service commissioners, managers and practitioners of:
  - The need for integrated, well-resourced, community-based paediatric continence services to be available to all 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 properly integrated and resourced services, with improved clinical outcomes; and
  - The effect of decommissioning the role of school nurses who provided continence services at Level/Tier 1.
- For paediatric continence to be higher on the agenda of national and local policy-making as both a clinical and public health need.
- For the PCF to be better known nationally and locally amongst commissioners, policymakers and clinical practitioners.

Over the next 12 months, we plan to consolidate the above relationships and increase our presence within other areas of the health and children’s sectors, to enable us to:

- Take forward the School Nursing Campaign;
- Promote the use of the PCF’s Commissioning Guide;
- Encourage uptake of NHS England’s Excellence In Continence Care (EICC) commissioning framework; and
- Increase awareness and uptake of the UKCS document.

Specific items of work

- Continue project work with NHS England as a member of the EICC working group, and with Public Health England as a contributor to their Children with Complex Needs Board and the Commissioning Framework and other resources arising from this.
- Reinforce existing relationships with the Departments of Health and Education through periodic meetings and email exchanges.
- Engage with the Children’s Commissioner for England, Anne Longfield - emphasising how recent developments such as changes to school nursing have impacted on children with continence problems.
- Build relationships with charities such as Crohn’s and Colitis UK and Shine, to help disseminate the PCF’s local lobbying toolkit.
• Develop partnerships with organisations such as the Royal College of General Practitioners, the British Medical Association, the Association of Directors of Public Health and the Local Government Association.

• Engage with the National Clinical Director for Children, Dr Jackie Cornish/Strategic Health Authorities as a means of enabling the PCF’s Commissioning Guide to receive publicity via the Commissioning Board.

• Achieve formal clinical representation on the PCF committee from the devolved nations and set up a parent supporters group. Continue to expand the PCF’s clinical supporter group through exhibiting at conferences and via email.

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

**Relevant strategic plan aims**

- To increase awareness and understanding within NHS England and its equivalent in the devolved nations, the Government and amongst service commissioners, managers and practitioners of:
  - The need for integrated, well-resourced, community-based paediatric continence services to be available to all 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 properly integrated and resourced services, with improved clinical outcomes; and
  - The effect of decommissioning the role of school nurses who provided continence services at Level/Tier 1.

- For paediatric continence to be higher on the agenda of national and local policy-making, as both a clinical and public health need.

**Specific items of work**

- Consolidate existing relationships with MPs through meetings and further PQs, taking advantage of the contacts generated through the parliamentary event being hosted by Coloplast. Host another parliamentary event in late 2017, showcasing the updated Freedom of Information results collected in early 2017, considering how to make an event engaging for parliamentarians.

- Secure the interest of new parliamentarians and use new relationships to ensure parliamentary activity, such as written questions, oral questions and letters to the minister.

- Secure an adjournment debate on the School Nursing Campaign.

- Strengthen our relationship with the Continence Care APPG and encouraging collaboration with and publication of the work of the PCF.
Implement the local lobbying toolkit – encouraging parents and carers to write to their MPs and local Healthwatch organisations to urge improvements to local services. Draft new versions of the toolkit assisting parents who are facing service closures; parents who need to campaign for services to be created; and to create concise versions of the toolkit.

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

Relevant strategic plan aims

- 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 and adequately resourced service within each CCG or devolved equivalent.
- For the PCF to be better known nationally and locally amongst commissioners, policymakers and clinical practitioners.
- To achieve a NICE clinical guideline on daytime incontinence.

As well as continuing to take forward our work with policy stakeholders and parliamentarians, we will continue to engage with the health service to improve the quality of paediatric continence services. The PCF will use the data from a 2017 survey of paediatric continence services nationally to identify areas of poorer service provision, as well as identifying and disseminating good models of practice.

Specific items of work

- Undertake a review of the Paediatric Continence Commissioning Guide in conjunction with NICE.
- Carry out a repeat FOI survey of Clinical Commissioning Groups and their equivalents in the devolved nations, and secure media coverage to highlight what the results demonstrate about service provision since the last survey in 2014.
- Carry out a new FOI survey of Local Authorities to provide a full geographical picture of service provision across the UK.
- Upload the results of the FOI surveys on to ChiMat’s Continence Needs Assessment tool.
- Identify and engage with poorly functioning CCGs in this area and publicise good quality services on the PCF website, with service specifications and business plans demonstrating examples of best practice.
- Complete and publicise data on the relative costs of an appropriate versus inappropriate patient journey.
• Recruit more consultants to support CCGs in setting up or adjusting paediatric continence services, to meet the standards of the PCF’s Commissioning Guide.

• Continue to support good links with NICE, including engaging with the development of any relevant guidance or quality standards.

• Launch the minimum standards for paediatric continence document and work to ensure good uptake amongst clinical practitioners.

• Prompt NHS England, through direct and political pressure, to encourage NICE to produce a clinical guideline on daytime incontinence.

• Undertake a literature review as a prelude to submitting an application to NICE for a clinical guideline on daytime incontinence.

• Respond to relevant government consultations or parliamentary select committee inquiries, both to make the case for policy change and to ensure that we highlight the role of the PCF as the key authority in this area.

• Attend policy events relevant to the PCF’s aims and objectives.

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 its smooth operation.

Specific items of work

• 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.

• Organise membership meetings three times a year.

• Continue to identify potential new members for the PCF and work with the Chair to make these approaches.

• Keep the PCF website updated on an ongoing basis, and maintain the PCF’s Twitter account.

• Organise the finances of the PCF, including invoicing and expenses.

• Organise formal terms of reference for the PCF.