

**Health Select Committee inquiry into Sustainability and Transformation Partnerships - Response
from the Paediatric Continence Forum**

Executive summary

- The Paediatric Continence Forum (PCF) is an independent group of healthcare professionals and parents that engages with the Government and healthcare organisations, with the aim of improving paediatric continence services across the UK.
- About one in ten children and young people are affected by continence (bladder and bowel) problems – covering bedwetting, daytime wetting, constipation and soiling and toilet training issues. These often cause significant social and psychological pressures, including being bullied at school.
- The PCF campaigns for all children to have access to an integrated, well-resourced community based paediatric continence service, led by a specialist paediatric continence adviser, to alleviate these problems in a timely and appropriate way. Early intervention prevents later and more expensive treatment in secondary care, tying in with the ultimate aims of the STP process.
- This submission will argue that STP leaders should not neglect making improvements to vital areas of NHS care which are often overlooked, including paediatric continence care, due to a focus on efficiency savings or other areas of care.

How effective have STPs been in joining up health and social care across their footprints, and in engaging parts of the system outside the acute healthcare sector, for example primary care, local authorities, public health, mental health and voluntary sector partners? How effectively are they engaging local communities and their representatives?

1. As stated above, appropriate paediatric continence services should be community-based to deliver timely and suitable care to children with continence problems, and to prevent these conditions from worsening and necessitating A&E attendance or secondary care treatment. They should also be delivered in an “integrated” manner as these problems may often be interrelated and require simultaneous treatment – for example, a child’s daytime or bedtime wetting may be caused by untreated constipation. The PCF ascertained in a Freedom of Information (FOI) audit that in England in 2017 that only 89 CCGs provided a full community paediatric continence service, and only 65 delivered this in an integrated manner.¹

¹ *An examination of paediatric continence services across the UK*, p. 7, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2017/10/An-examination-of-paediatric-continence-services-across-the-UK-PCF-August-2017.pdf>.

2. While this is an improvement of around 5% from the PCF's previous FOI audit in 2014, this demonstrates that substantial improvements are still needed to the provision of this type of integrated, community-based service across England. Only 23 CCGs reported have plans to commission a new paediatric continence service, while a further 51 reported plans to review their service provision.² PCF members have expressed concerns that these plans for review could instigate service cuts rather than improvements, indicating that the STP process may not have motivated improvements to preventative care as would be hoped.
3. The PCF includes 15 clinical members who are currently working in NHS services or charities supporting children with bladder and bowel issues, and engages with a further 145 clinical supporters also working with children and young people with these problems. However, it has not been our experience that these clinicians have been engaged with their local STP, either for better or worse.
4. The PCF initially engaged with the STP process at the beginning of 2017, when we sent letters to each STP leader to underline the benefits of commissioning appropriate paediatric continence services. We received responses from five STPs stating they would pass the information provided on to relevant service leads. It should be noted that at this point, it was difficult to ascertain who was the relevant person to contact to raise our concerns and to find correct contact details for them – something which seems counter-productive to a process which has consistently encountered issues with a lack of public and patient engagement.
5. We were also advised to contact NHS RightCare to suggest how improvements to paediatric continence care could be incorporated into transformation triggered by STPs, and we are hoping to pass on resources to NHS RightCare's team of STP Delivery Partners to explain the benefits of commissioning paediatric continence services. We hope that in some cases, CCGs would consider commissioning an STP-wide service if this is cost-effective, but would urge that this service should be adequately resourced for the number of children in the STP area.

What do the available evidence, and experience so far, tell us about the deliverability of STP plans given the financial and workforce pressures across the NHS and local government?

6. The PCF would like to highlight that paediatric continence services have been affected by significant pressures on the school nursing workforce since the transfer of commissioning responsibility for school nursing to local authorities in 2015. Since the change we have received evidence from members indicating that school nurses are sometimes having continence removed from their list of

² Ibid.

responsibilities, removing a vital tier/level one resource of support for children and families encountering continence problems.

7. We would therefore strongly urge STPs to plan for increases to the nursing workforce to benefit both paediatric continence and other areas of community care. Many STPs expressed their intention to do this in the plans published towards the end of 2016, but the continuing financial pressures on the NHS may have jeopardised these intentions, as recently suggested by reports that one in ten nurses are leaving the NHS each year.³

Looking across all STPs, are there any major areas where the content of the plans needs to be tested for credibility and realism? Are there any major gaps? For example, are proposals in some plans to reduce bed capacity credible? Are the NHS efficiency estimates in STPs robust? Is the workforce available to enable the implementation of STPs? Or is the timescale for the changes proposed in STPs realistic?

8. The PCF has not seen any suggestion of paediatric continence services being cut as a direct result of an STP decision, but there are widespread concerns in the health sector that the sustainability components of STPs have proposed unachievable cuts to services which would be false economies.
9. The PCF has compiled evidence of the financial benefits of commissioning an integrated, community-based paediatric continence in a case study comparing optimal versus sub-optimal care pathways for children with bladder and bowel problems.⁴ This case study suggests that following an optimal pathway for a typical child could only incur costs of £318, whereas following a sub-optimal pathway could incur costs of up to £2,118. As well as generating significant savings, an optimal pathway provides improvements to the quality of care for the child and family concerned – and we would hope that this would be the prevailing concern for STP leaders rather than possible efficiencies.
10. There are also several resources which can aid commissioners in delivering a suitable paediatric continence service. The PCF has produced a NICE-accredited Paediatric Continence Commissioning Guide⁵, which advises how to commission and run paediatric continence services and is currently being reviewed. NHS England has also published Excellence in Continence Care guidance, which covers

³ 'NHS 'haemorrhaging' nurses as 33,000 leave each year', available at <http://www.bbc.co.uk/news/health-42653542>.

⁴ Children's continence care: sub-optimal pathway versus optimal pathway, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2017/07/PCF-Tobys-sub-optimal-versus-optimal-pathway-14th-March-2017.pdf>.

⁵ Paediatric Continence Commissioning Guide, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>.

continence care for all ages and is also in the process of being reviewed.⁶ The PCF hopes that the publication of this reviewed guidance will be accompanied by an effort to communicate the benefit of appropriate continence care and services for all ages to STP leaders.

What governance, management and leadership arrangements need to be created to enable STP planning and implementation to be carried out effectively? Are additional, or different, arrangements required for areas which are developing ACSs?

11. The PCF would urge STPs to publicise a point of contact for patient groups and members of the public to contact to discuss service delivery issues. The PCF is a national campaigning organisation but cannot attend local STP engagement meetings to discuss these issues in person, and so requires these contact details to be available wherever possible. This will be especially important for those evolving into Accountable Care Systems as they are expected to be at the forefront of transforming the delivery of NHS care, and so should be accessible for patient groups.

What public engagement will be necessary to enable STPs/ACSs to succeed, and how should that engagement be undertaken?

12. It is arguable that at this point in the STP implementation process, there should be a renewed effort on the part of STPs and ACSs to explain their intentions to the communities they affect, and to take on feedback from patients and clinicians on any proposals for service changes that have emerged.

13. There have been indications from STP leaders and Department of Health officials that there have been issues with the implementation of, and communication around, STPs as they were originally envisioned as 'plans' for service change, and have now evolved into 'partnerships' delivering a longer-term vision for service change based on integrating teams and improving working practices. This is largely not the impression of STPs that is held by the public, and if these are the principles now underpinning all STPs this should be communicated to relevant stakeholders to manage expectations of how to measure progress and achievements. This may be an area that the Committee wishes to explore during evidence sessions for this inquiry.

Submitted by the Paediatric Continence Forum, 19/01/2018

For further information, please visit www.paediatriccontinenceforum.org or email paediatriccontinenceforum@whitehouseconsulting.co.uk.

⁶ Excellence in continence care, NHS England, available at <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf>.