Background to the Paediatric Continence Forum

1.1 The Paediatric Continence Forum (PCF) is an expert group of patient representatives and healthcare professionals campaigning to improve services for children with continence problems (sometimes called bladder and bowel dysfunction, or bedwetting, daytime wetting and constipation/soiling) in all settings across the UK. Established in 2003, it works closely with the national charities ERIC (The Children’s Continence Charity) and PromoCon (Promoting Continence through Product Awareness) and with representation from the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association.

1.2 One of the key goals of the PCF is for every area in the UK to have a proper community-based integrated paediatric continence treatment service, led by an expert paediatric continence professional, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services. Better paediatric continence services will help support NHS England’s Five Year Forward View by delivering savings for the NHS and improvements in the quality of care for children.

1.3 In 2014, the PCF published guidance, accredited by the National Institute of Health and Care Excellence (NICE), for the commissioning of integrated paediatric continence services, which can be found at www.paediatriccontinenceforum.org/resources. This was updated in October 2015.

1.4 UK-wide data suggests that about one in 12 children have a continence problem, with NICE estimating in 2010 that 900,000 children between the age of five and 18 in the UK suffer from bladder and bowel dysfunction. The figure in 2016 is likely to be higher, with academic research finding that referrals for constipation and bedwetting and daytime wetting in one region are overtaking “traditional” health problems like asthma.

Executive summary

2.1 This submission argues that the reductions to the public health budget arising from the Spending Review will negatively impact on the provision of school nurses and health visitors, in turn reducing the number of health professionals delivering first-line paediatric continence treatments in the community. This will undermine the Five Year Forward View by vastly reducing cost-effective treatment in the community in this area of child health and causing additional pressure on general practice, as well increasing incidences of unnecessary and costly treatments at secondary and tertiary level. This submission also seeks reassurances that cuts to the CQC will not impact on its ability to fulfil its functions, including new functions like jointly inspecting local area SEND provision with Ofsted.

2.2 This submission welcomes the frontloading of the £8 billion government funding to address the £30 billion resource gap identified in the Five Year Forward View, particularly the introduction of the sustainability and transformation fund. It argues that commissioners should be actively receptive of

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contributions from the wider health sector on how to deliver these transformations. In particular, it calls for commissioners to utilise the NICE-accredited Paediatric Continence Commissioning Guide, as this will help facilitate transformation and deliver savings required to address the £30 billion resource gap.

**Impact of the cuts to non-NHS England health budgets: public health system – school nurses and health visitors**

3.1 The Spending Review requires the public health system to make “average real-term savings of 3.9% over the next five years”, with ring-fenced funding to expire from 2018-19. This means that local authorities, which assumed full responsibility for public health commissioning in October 2015, will have fewer resources to spend on school nursing and health visiting services. Of particular concern is the £200 million reduction in the public health grant – the equivalent of 6.2% for each local authority.

3.2 Resource restrictions have already prompted Ealing Council to consider implementing 50% funding cuts to school nursing services over the next three years, along with plans to re-allocate public health money elsewhere. London North West Healthcare NHS Trust, which currently provides the service, said that these cuts will lead to job losses for school nurses. The resultant losses will have a direct impact on the development of services for children with bedwetting, especially as Ealing CCG only commissions a product provision service at this time.

3.3 Nationally, budgetary pressures have also prompted local authorities (LAs) to narrow their public health priorities to save money, with many removing continence from the list of school nurse duties. Others have merged their health visiting and school nursing services into a 0-19 healthy child programme service which excludes continence.

3.4 School nurses and health visitors, along with general practice, play an important role in the identification and provision of advice to children, young people and their families on continence problems. Through early intervention, these practitioners can identify and manage continence problems before they become serious – reducing the burden on other NHS services and saving the NHS money in future treatment, not least by reducing the need for expensive containment products such as nappies. Investment in community services can yield significant savings to help the NHS meet its ambition in the Five Year Forward View to address its £30 billion resource gap by 2020.

3.5 The removal of school nurses from the pool of Level 1 continence practitioners has led to an increased burden being placed on general practice – an area that the Five Year Forward View identified as being under particular strain and in need of relief. Anecdotal evidence from the PCF’s clinical members suggests an overwhelming increase in the number of inappropriate referrals to emergency departments, outpatient clinics and tertiary care, which is considerably more expensive and with no better outcomes for children with continence problems. Staff in these settings are less able to cope with the quantity of referrals and do not have the capacity for follow up sessions, nor can they devote the time required – both of which vital for good long term outcomes.

3.6 Although a fairer funding deal for public health services would help halt the decommissioning of school nursing services, the PCF has learnt anecdotally that where services have been

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decommissioned but a CCG commissions a Level 2 service, the Level 2 service is able to absorb the work load normally taken on by school nurses and health visitors. This means that it is crucial that all CCGs are encouraged to commission a Level 2 service to mitigate changes at Level 1.

3.7 An outline of an ideal paediatric continence service can be found in Appendix I at the end of this document, covering the descriptions of each level of a paediatric continence service.

**Impact of the cuts to non-NHS England health budgets: Care Quality Commission**

4.1 The PCF wants assurances that the Care Quality Commission’s 25% budget reduction will not impact on its ability to carry out its duties to inspect health and social care settings, especially given that it will soon be carrying out additional joint inspections with Ofsted on the quality and provision of services for those with special educational needs and disabilities (SEND). We also want the CQC to be effectively resourced to inspect whether providers of services ensure that the continence needs of patients are being attended to.

**Transforming services and delivering savings**

5.1 The PCF welcomes the Spending Review’s reiteration of the Five Year Forward View’s ambition to deliver better, more integrated patient care in a cost effective manner. The PCF particularly welcomes NHS England’s plan to create a sustainability and transformation fund to drive these forward. The PCF is keen for health system leaders – the heads of CCGs, trusts and others – to be receptive of suggestions to improve services from the health sector more broadly – covering patient groups, clinical representatives, industry and so on. In particular, we are keen to see CCGs utilise the NICE-accredited Paediatric Continence Commissioning Guide, endorsed by the Royal College of Nursing, the Royal College of Paediatrics and Child Health, and the Community Practitioners and Health Visitors’ Association. This guidance is intended to help commissioners deliver an integrated (treatment for constipation/soiling, bedwetting, night time wetting and toilet training under one roof) and evidence-based community paediatric continence service.

5.2 Better utilisation of the Commissioning Guide will help satisfy the call for integrated services in the Five Year Forward View, and help address the £30 billion resource gap identified in the strategy as well. Utilisation of the guide will help address the large disparity in treatment costs in secondary care compared to the costs in the community. A secondary and tertiary outpatient referral costs £160 to £220 for first appointments and £94 to £123 for follow-ups, with possible additional financial penalties for failing to meet new to follow-up consultation ratio targets. A&E attendances on average cost £108, with day case treatment costing an average of £693. Meanwhile, assessments in primary care cost on £80 for an assessment appointment and £56 for each follow-up appointment (considerably less for a telephone follow-up).

**Next steps: better funding solutions and utilisation of the Paediatric Continence Commissioning Guide**

6.1 The Health Select Committee should:

- encourage the Department of Health to work with the Treasury to find a more equitable funding arrangement for public health services, given the cost impact that insufficient public health service provision can have on the NHS through an increase in preventable conditions.
- encourage CCGs to commission a Level 2 community based paediatric continence service to mitigate against the changes resulting changes from public health services.
• encourage CCGs to work with stakeholders across the health sector, such as patient groups, clinician groups and industry, to feed into their plans to transform the health system as part of the sustainability and transformation plans.

Appendix I – An ideal three tier paediatric continence service

A paediatric continence service should have three levels, with first line treatments being offered by Level 1 practitioners, with referral being made to other levels should further treatment be required. Below is an example of what a good paediatric continence service should look like, according to the Paediatric Continence Commissioning Guide:

• Level 1 involves the provision of early stage intervention such as advice and support to promote healthy bladders and bowels, resulting in a reduction of the risk of problems such as constipation developing or getting worse. The majority of this service should be carried out by school nurses and health visitors, with GPs also participating. Should problems persist, referral should be made to Level 2.

• Level 2 involves the assessment and treatment of children and young people with daytime wetting and those with special needs and more complex-bladder bowel problems. The assessment is more in depth and includes a full run through of the patient’s health and social history, and possibly a physical examination – abdominal, lower limb neurology and an ultrasound assessment of bladder emptying. This should be carried out by a community paediatric continence service, led by a paediatric continence adviser. This is a specialist continence service that should be commissioned by a CCG, however Freedom of Information (FoI) research conducted by the PCF found that most CCGs (74%) do not commission this service in a ‘joined-up’ (under one roof) manner. Depending on the outcome of the assessment, referral may be made to Level 3.

• Level 3 involves more specialist interventions, and is carried out by paediatricians in the community or specialists secondary care.

22 January 2016

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