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 (bladder and bowel dysfunction) 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. In 2014, the PCF published NICE-accredited guidance for the commissioning of paediatric continence services, which can be found at www.paediatriccontinenceforum.org/resources.

1.3 UK-wide data suggests that around one in 12 children have a paediatric continence problem, with the National Institute of Health and Care Excellence (NICE) estimating in 2010 that 900,000 children between the age of five and 18 in the UK suffer from idiopathic constipation, bedwetting and night time wetting\(^1\). The figure in 2015 is likely to be higher, with academic research finding that the number of referrals for constipation and enuresis are overtaking “traditional” health problems like asthma\(^2\).

School nurse commissioning handover, April 2015 – Impact on paediatric continence

2.1 Public health practitioners like school nurses and health visitors play an important role in the identification and provision of advice to children, young people and their families on continence problems like nocturnal enuresis (bedwetting), constipation, soiling and toilet training. 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 is likely to yield savings in subsequent years.

2.2 The transfer of school nurse commissioning from Public Health England (PHE) to local authorities (LAs) in April 2015 led LAs nationwide to remove continence from the list of school nurse duties. This has meant that children who would normally receive treatment and advice on continence problems from school nurses must go elsewhere for treatment. This has created a gap in public health service provision, resulting in additional burdens on GPs, as well as increases in expensive referrals to tertiary care – exactly what effective public health functions should prevent.

2.3 Budgetary pressures have worsened the situation. Ealing Council is set to implement 50% of funding cuts to school nursing services over the next three years, along with plans to re-allocate public health money elsewhere\(^3\). London North West Healthcare NHS Trust, which currently provides

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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.

2.4 This submission illustrates that commissioning changes have limited the preventative functions of public health in areas including continence. It outlines that local authorities have not received sufficient guidance from PHE on commissioning school nursing services, leading to misunderstanding with clinical commissioning groups (CCGs) on what services should be commissioned – a ‘commissioning gap’. It argues that further reductions will be brought about by cuts to local authorities. It warns that the changes have prompted workforce reorganisation which will exacerbate the problem.

2.5 We suggest that the Health Select Committee uses the impact of public health commissioning changes on continence provision as a case study for further analysis.

Withdrawal of school nurses from continence – Impact on the delivery of public health functions

3.1 Public health practitioners such as school nurses and health visitors form part of the base element (Level 1) of an effective community-based paediatric continence service. The removal of school nurses from the pool of Level 1 continence practitioners has led to an increased burden being placed on the remaining elements – particularly GPs. Unable to cope, tertiary clinics are now reporting an increase in the number of referrals from GPs for continence problems. An overview of an ideal community-based paediatric continence service can be found below:

- 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.

3.2 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.

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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.

3.3 Limitations in the capacity of local authorities to fulfil their public health functions is very expensive to the NHS. 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. This is compared to a specialist nurse in primary care – which school nurses and health visitors refer more complex cases to – which costs on average £80 for an assessment appointment and £56 for each follow-up appointment (considerably less for a telephone follow-up).

Local authority delivery of public health functions – Narrow definitions of public health

4.1 Local authorities have adopted a very prescriptive description of public health, erroneously listing continence exclusively as a clinical need rather than a public health need. This is due to guidance on school nurse commissioning issued by PHE in 2014, Maximising the school nursing team contribution to the public health of school-aged children: guidance to support the commissioning of public health provision for school aged children 5-19, not referring to continence. With CCGs not taking adequate action to commissioning integrated paediatric continence services, as evidenced in the PCF’s Fol research, a ‘commissioning gap’ has developed.

4.2 PHE must issue updated guidance which acknowledges continence as a public health need. Moreover, local authorities must look beyond the guidance and recognise that public health practitioners such as school nurses have been treating and providing advice on continence problems as a public health issue for many years. Additionally, local authorities should adopt a broader approach when determining commissioning priorities, and also recognise that:

- The National Child and Maternal Health Intelligence Network (ChiMat), which provides authoritative public health data, considers continence as a public health need.
- The Atlas of Variation in Healthcare for Children and Young People also lists childhood constipation and childhood UTI admissions as public health indicators.
- The International Continence Society identifies continence as a public health problem.
- The Welsh Government is in the process of passing the Public Health (Wales) Bill, which recognises continence problems and good toilet provision as public health issues.

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4.3 Poorly managed continence problems can impact more broadly on children, for example through an increased risk of urinary tract infection, acute or non-acute hospital admissions for treatment of constipation, skin problems due to avoidable use of nappies, as well as social and schooling problems such as impaired school performance and bullying\(^{10}\).

### Public health spending – Cuts leading to a withdrawal of continence services

5.1 The £200 million reduction in the public health grant – the equivalent of a 6.2% reduction for each local authority – will likely result in more local authorities removing continence from the list of school nursing duties to save money. Funding reductions have caused directors of public health to re-evaluate how much they are spending and what they are spending it on, with conditions such as continence suffering as a consequence of this. The Community Practitioners and Health Visitors Association has already warned that LAs will start to withdraw nurses from non-statutory services and where commissioning overlaps with NHS England\(^{11}\).

### The public health workforce – developing an integrated 0-19 Health Child Programme Service

6.1 Many local authorities are now considering merging school nursing services with health visiting services, which they assumed commissioning responsibility for in October 2015, into a single 0-19 Healthy Child Programme Service (HCPS). This has resulted in local authorities withdrawing Level 1 continence services, with job losses for school nurses and other community practitioners – a loss of valuable expertise.

### Solutions: more joined up working and utilisation of the Paediatric Continence Commissioning Guide

7.1 Local authorities and CCGs must take action to ensure that there are adequate Level 1 and Level 2 services in place to prevent increases in direct referrals to Level 3 services. Some of these actions require joint working, whilst others require action to be taken individual by each set of bodies. Bladder and bowel dysfunction is an issue that requires close liaison between health and social care, but ongoing developments have fractured this relationship.

#### Local authorities

7.2 Local authority directors of public health should consider reversing changes to school nursing services, recognising continence as a public health need. They should ensure that Level 1 practitioners are available in sufficient quantity, trained and enabled to carry out their Level 1 functions. These practitioners include school nurses, health visitors, as well as new HCPS practitioners.

#### CCGs

7.3 PCF clinical members have reported that areas with good Level 2 services are better able to accommodate the withdrawal of school nurses from Level 1 services. This means that CCGs should consider commissioning Level 2 services as a priority, given the developments affecting Level 1


services. This should involve the utilisation of the NICE-accredited Paediatric Continence Commissioning Guide (available at www.paediatriccontinence.org/resources) to help ensure better clarity in commissioning arrangements, with local authorities aware of the need to commission good Level 1 services and CCGs clear on the need to commission good Level 2 services to support Level 3 services.

7.4 The Paediatric Continence Commissioning Guide has been accredited by NICE and endorsed by the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association. It was developed in close coordination with clinical experts, with feedback from patient groups like ERIC and PromoCon. Forthcoming resources, such as a sample care pathway, will be available on the PCF’s website in due course.

Joint action

7.5 Local authority directors of public health should work with CCG leaders to address the ‘commissioning gap’, should local authorities decide not to reverse their decisions on school nurse commissioning. This should involve ensuring that the remaining elements of a Level 1 services, such as GPs or newly commissioned 0-19 practitioners, are well trained to identify continence problems, and are well equipped with care pathways to refer them onwards for further treatment if necessary. Should a specialist paediatric continence care pathway not exist, then CCGs and LAs should work with organisations like the PCF to develop them.

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