



## **Children's Continenence Commissioning Guide**

### **A handbook for the commissioning and running of children's community continence services**

Sponsoring Organisation: **The Paediatric Continence Forum**

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Document purpose	Guidance
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Description	Guidance to support the commissioning of integrated, nurse-led, paediatric community continence services in all areas of the UK, so that children and young people who have bladder and bowel issues have access to early assessment and cost-effective equitable treatment. This is not a clinical guideline and does not make clinical recommendations.
Cross reference	<p>Excellence in Continence Care (NHS England 2018)</p> <p>Minimum Standards for Paediatric Continence Care in the UK (UKCS 2016)</p> <p>NICE CG 111 Nocturnal enuresis: the management of bedwetting in children and young (2010)</p> <p>NICE QS 70 Nocturnal enuresis in children and young people (2014)</p> <p>NICE CG 99 Constipation in children and young people (2010)</p> <p>NICE QS 62 Constipation in children and young people (2014)</p> <p>NICE CG 148 Urinary incontinence in neurological disease management (2012)</p>
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# Children’s Continence Commissioning Guide

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## Introduction

This second edition of the Children's Continence Commissioning Guide (the Guide) provides the information and tools for commissioners, clinicians and managers across the UK to set up and run integrated, nurse-led, community-based paediatric continence services.

The Guide is based upon the most recent published evidence from:

- NICE (The National Institute for Health and Care Excellence) and their Guidance and Quality Standards
- NHS England's publications: Excellence in Continence Care (2018) and Leading Change Adding Value (2016)
- The principles of NHS RightCare i.e. the right care in the right place at the right time
- The standardization documents from the International Children's Continence Society
- Recent research on the physical and mental impact of incontinence and what children, young people and their families want from continence services

This Guide also fulfils the criteria embodied in the NHS Long Term Plan by:

- Addressing mental health: there are clear associations between childhood continence problems, children's mental health and parental intolerance/child punishment
- Improving the quality of care for children with long term conditions
- Recommending an integrated and collaborative structure to service delivery
- Improving children's involvement/experience of care: The Guide has taken into account the views of children and young people about the kind of services they want
- Reducing emergency department (A&E) attendance: children and young people account for 25% of the total and are the most likely age group to attend A&E unnecessarily. One of the major causes of A&E visits is due to constipation (impaction). This could be radically reduced through prevention, early detection and treatment in the community
- Responding to the needs of all children and young people, including those with learning and physical disabilities
- Ensuring good transition to adult care.

Local commissioning decisions in England will be influenced by new Primary Care Networks, which are being set up to increase collaboration between GPs, their teams and community services. Clinical Networks are to be rolled out from 2019/20 to improve the quality of care for children with long-term conditions (NHS Long Term Plan).

## Executive Summary

1. Bladder and bowel (continence) problems affect more than 900,000 children and young people in the UK (NHS England, 2018), with a negative impact on their health, wellbeing and emotional and psychological development. These children need to be identified and treated at an early stage to prevent attendance at accident and emergency departments for faecal impaction or urinary tract infections, hospital admissions and unnecessary referral to secondary care.
2. All children from birth to 19<sup>1</sup> with continence difficulties (bladder and/or bowel problems and/or delayed toilet training, should have access to a fully integrated Children's Community Continence Service (CCCS)<sup>2</sup> that provides individualised evidence-based care in line with national guidance.
3. The CCCS should consist of an appropriately resourced multidisciplinary team led by a children's continence nurse specialist. It should have clear and effective care pathways from universal (Level/Tier 1)<sup>3</sup> services and to secondary and tertiary care (Level 3 services), as well as to education, social services, child and adolescent mental health services and other services as required.
4. A proper CCCS will result in considerable savings for the NHS. See Section 1.3
5. Key Service Outcomes and their measurement are outlined in Section 2
6. Clinical guidance within this document follows:
  - NICE Clinical Guideline: [CG111 Nocturnal Enuresis: the management of bedwetting in children and young people 2010](#)
  - NICE Quality Standard [QS70 Nocturnal Enuresis \(Bedwetting\) in children and young people 2014](#)
  - NICE Clinical Guideline: [CG99 Constipation in Children and Young People 2010](#)
  - NICE Quality Standards: [QS62 Constipation in Children and Young People 2014](#)
  - NICE Clinical Guideline: [CG148 Urinary Incontinence in Neurological Disease Management 2012](#)

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<sup>1</sup> Practitioners in Community Paediatrics will see young people until the age of nineteen who have special educational needs and are in full time education according to local referral criteria.

<sup>2</sup> See Section 1.5.2 for a full description of a CCCS.

<sup>3</sup> The terms 'Level' and 'Tier' may be used interchangeably, but the term Level will be used in this document. A full description of the Levels is in Section 1.5

# 1. High Value Care Pathway for Children's Continence

## 1.1. Brief description of the condition

Continence is the ability to maintain bladder and bowel control until a socially appropriate time and place to urinate or defecate has been reached. Full control is normally acquired in early childhood as the result of an active learning process. Toilet training should start at 18 months – 2 years, but there is evidence that this is getting later, which causes problems at school entry and an associated increased risk of daytime wetting in primary school children [1].

Continence difficulties include constipation, soiling (faecal incontinence), daytime wetting, bedwetting (enuresis) and problems or delay with toilet training. The majority of these are functional, that is they cannot be explained by anatomical, physiological, radiological or histological abnormalities. Instead it is believed they are caused by a complex inter-relationship of biological, developmental, genetic and environmental factors [2]. Structural (anatomical) or neuropathic causes are rare, but need to be recognised early. The negative impact for the children and their families of any continence difficulty should not be underestimated.

Children and young people of all ages can be affected by continence difficulties. Children with additional needs and those with neurodevelopmental disorders, such as attention deficit hyperactivity disorder and autism are particularly affected, but often neglected in the mistaken assumption that incontinence is part of their wider condition.<sup>4</sup>

Children or young people who experience bedwetting may also have daytime wetting and/or constipation; children and young people with constipation/soiling may also have bedwetting/daytime wetting. There are causal links between these conditions, which require a holistic approach to treatment.

## 1.2 Why an integrated children's continence service should be a priority for commissioners

### 1.2.1 The numbers of children and young people affected

There are about 14,051,000 children under 18 years of age living in the UK [3]. It is estimated that of these about 900,000 have a bladder and/or bowel problem [4]<sup>5</sup>. However, this is likely to be a significant under-estimate due to a lack of reporting because of stigma or embarrassment, or the mistaken belief that the problem will automatically resolve as the child grows and develops.

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<sup>4</sup> See Appendix 1 for more details of definitions and terms

<sup>5</sup> See Appendix 2 for more information on prevalence

Of the estimated 8% of children with additional needs, a proportionally higher number have continence difficulties, due either to an associated disorder of the bowel/bladder, or to their physical or intellectual impairment [5]. Delayed toilet training is common for these children and they should be offered an appropriate bowel and bladder assessment and support to achieve their potential. It should be the exception, rather than the rule, that children with additional needs are provided with continence containment products.

Children with day and night time wetting at ages 4 – 9 years are 23 times more likely to have enuresis at 14 years of age and 10 times more likely to have daytime wetting continuing into adolescence [6].

### **1.2.2 The impact of incontinence on the child and family**

Failure to identify and treat continence problems at an early stage can give rise to chronic changes in the bladder or bowel. For example, there is recent evidence that experiencing hard stools in early childhood is a risk factor for later problems with constipation at school age [7]; unrecognised congenital, structural or neuropathic bladder or bowel dysfunction may result in renal deterioration or acute bowel crises, with significant consequences for the child's health. Without treatment problems may persist into adolescence and adulthood [7, 8, 9].

The risk of unrecognised constipation and other underlying pathologies, including undiagnosed urinary tract infections and, more rarely, congenital bladder or bowel problems is greater for those with moderate to severe learning disabilities, cerebral palsy and Down's syndrome. If present and untreated, these conditions may result in renal deterioration or chronic bowel problems [9].

Continence problems occur at a formative time for children and influence their health, wellbeing and emotional development. They are associated with reduced quality of life, affecting peer relationships [10] and cause social isolation and feelings of difference [11]. They are also a cause of reduced self-esteem [10, 12], a sense of social stigma [13], distress and behavioural disorders [2].

Ching et al [14] and Zhao et al [15] found that bullying, either as victim or perpetrator, is associated with increased lower urinary tract symptoms.

Most families are concerned and positively involved. However, lack of understanding and frustration causes some to respond by punishing their children. This can result in a 'vicious cycle' of increased stress, more incontinence, potentially harsher chastisement and the risk of child abuse [16, 17].

There is also evidence that common strategies used by parents to overcome bedwetting in 7½-year-olds are not effective, with some strategies, such as "lifting" and restricting drinks before bedtime, actually increasing the risk of bedwetting [18]. Parents should be encouraged to seek professional advice for their children's bedwetting rather than persist with strategies that may be ineffective.

Effective treatment reduces the cost of extra washing and purchase of additional clothes and bedding. This is substantial and has a disproportionate impact on low-income families.<sup>6</sup>

### **1.3 The cost savings to be made by having an integrated children's continence service**

In areas where there is a well-resourced, integrated community children's continence service, the cost to the NHS of treating childhood incontinence is considerably reduced, due to:

- Less accident and emergency attendances for abdominal pain related to constipation
- Fewer referrals to secondary care for consultant assessment or treatments
- Fewer unnecessary investigations
- Reduced admissions to hospital for disimpaction or treatment of urinary tract infection
- Reduced need for disposable continence containment products, as more children who have the ability to toilet train are identified and become trained with nurse-led support

Optimal versus suboptimal patient journeys demonstrate the above savings, as well as the improvements to the quality of care (Bladder & Bowel UK RightCare patient journeys: [Toby's journey \(enuresis\)](#) [Michael's journey \(constipation\)](#), [James' journey \(intractable constipation\)](#)).

### **1.4 Current practice and why there is scope for improvement**

The transfer of responsibility for commissioning of school nursing and health visiting services from NHS England to Public Health England in 2015 resulted in many Level 1 continence services being decommissioned<sup>7</sup>. This increased the pressure on existing children's continence services and compounded referrals to secondary care in areas where there are no Level 2 services [19].

Level 2 Services are variable across the UK. Where services exist, many are neither comprehensive nor properly integrated. The Paediatric Continence Forum carried out Freedom of Information surveys of Clinical Commissioning Groups and Health Boards in 2014 and 2017 to assess the number and quality of their paediatric continence services.

Key questions were: which of the paediatric continence services (bedwetting, daytime wetting, toilet training, constipation/soiling, product supply) are being commissioned; whether there is a single (integrated) service for all five issues; whether the service is led by a paediatric continence advisor; whether there are plans to commission a new service;

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<sup>6</sup> See section 1.2 and Appendices 2 and 3 for a fuller description of prevalence, risk factors and impact of continence problems on children and families

<sup>7</sup> See Section 1.5 for descriptions of different Levels of service delivery.

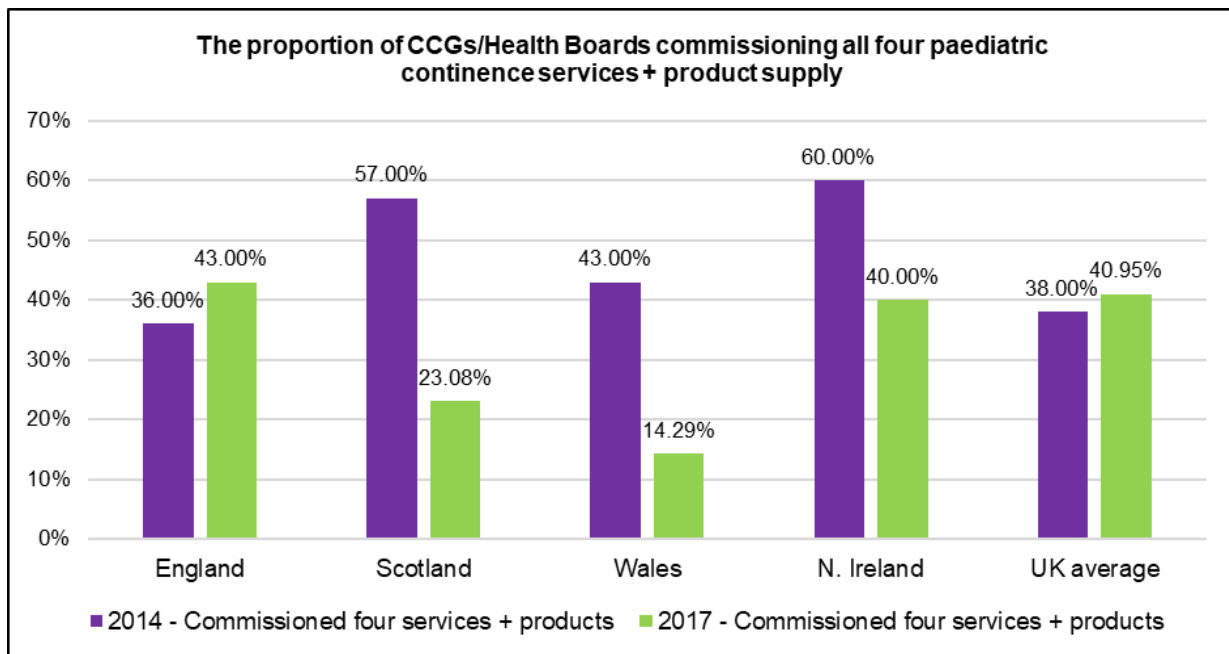


whether there is awareness of, or use of the Paediatric Continence Forum’s Continence Commissioning Guide (2014).<sup>8</sup>

**Chart to show outcome of PCF 2017 Freedom of Information requests to CCGs and Health Boards,**

	England		Scotland		Wales		Northern Ireland		UK Total	
	Actual	%	Actual	%	Actual	%	Actual	%	Actual	%
<b>No of CCGs (England), Health Boards (Scotland &amp; Wales), Health and Social Care Trusts (Northern Ireland)</b>	209		14		7		5		235	
<b>Responses received</b>	206	99	13	93	7	100	5	100	231	98
<b>Commission four services and products</b>	89	43	3	23	1	14	2	40	95	41
<b>Commission integrated services</b>	65	32	3	23	0	0	3	60	71	31
<b>Led by a paediatric continence advisor</b>	48	23	1	8	1	14	3	60	53	23
<b>Plan to commission new services</b>	23	11	1	8	1	14	0	0	25	11

**Graph to show comparison of how many CCGs / Health Boards Commission provision of all four paediatric continence services and product provision in 2014 and 2017 (PCF 2014 and 2017 Freedom of Information requests to CCGs and Health Boards)**



The results showed a marked deterioration in services within Scotland, Wales and to a lesser extent in Northern Ireland. Services in England had slightly improved, although this continues to be a less than satisfactory level of service provision.

<sup>8</sup> The full report of the outcome of the Freedom of Information survey is published on the PCF website: [An Examination of Paediatric Continence Services Across the UK](#)

## 1.5 Service descriptions: what ‘good’ looks like

### 1.5.1 Level/Tier 1 services<sup>9</sup>

These are universal services provided by health visitors, nursery nurses and school nurses who play an important role in the early identification of problems with toilet training and the onset of continence difficulties. With knowledge of continence milestones, they are in a good position to provide general advice on toilet training and bladder and bowel health, such as information on fluid intake, dietary advice and the importance of regular toileting.

All children should receive a basic assessment at Level 1 and Level 1 services should know when it is appropriate to refer on to the CCCS at Level 2.

Health visitors lead the Healthy Child Programme (HCP) 0 – 5 years and have a specific responsibility to support children to be ‘ready to learn at two and be ready for school at five’ [20]. School nurses lead the HCP for ages 5 – 19 years. Universal access and early identification of additional needs is included in Public Health Commissioning. Therefore, health visitors and school nurses should provide support with toilet training.

Health visitors and school nurses may also provide first line treatment if commissioned to do so. If not commissioned to do so, this needs to be reflected in Level 2 service provision.

GPs, who also provide Level 1 services, should understand the role of the CCCS and know how to refer. Mechanisms to enable effective communication between Levels 1 and 2 and Primary Care are essential and should be established locally.

### 1.5.2 Level 2: The Children’s Community Continence Service (CCCS)

- Undertakes comprehensive bladder and bowel assessments and treats children and young people from 0 – 19 years with bladder and/or bowel problems and/or delayed toilet training, where universal Level 1 interventions have not resolved the issues
- Consists of an experienced and competent multidisciplinary team led by a paediatric continence nurse specialist
- Has clear and effective referral and care pathways from Level 1 services to Level 3 (secondary and tertiary care), as well as to other professionals and services e.g. paediatricians, education, allied health professionals, child and adolescent mental health services (CAMHS), social care and local voluntary services, as the child’s health, social or psychological situation warrants
- Provides specialist training, education and support to primary and community care staff delivering services at Level 1. This is to ensure that all staff are able to identify continence problems early and offer timely intervention, or refer appropriately if they are not commissioned to provide assessment and treatment. The CCCS should also provide training and support to education staff to raise awareness of continence difficulties that may impact at nursery, school or college and ensure children are supported appropriately

### 1.5.3 Level 3: Secondary or tertiary services

There are some situations where children may require referral for a medical assessment to a paediatrician, or to specialist secondary or tertiary care, as per the local pathway. These

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<sup>9</sup> The terms ‘Level’ and ‘Tier’ may be used interchangeably, but the term Level will be used in this document

include children with ‘red flag’ symptoms indicating a serious underlying disorder, children with recurrent febrile urinary tract infections and children suspected of maltreatment, as well as those children who have not responded to optimal interventions and support at Level 2.

#### **1.5.4 The Children’s Community Continence Service (Level 2): A ‘good’ service has:**

##### **1.5.4.1 Clinical standards**

- Agreed bi-directional care and referral pathways to and from Level 1 and 3 services, with standards and thresholds based on best practice, using available current evidence
- The opportunity for all children and young people referred to have a comprehensive bladder and bowel assessment from an appropriately trained healthcare professional ([UKCS Minimum Standards for Paediatric Continence Care](#) [21]) with appropriate individualised treatment. This should include awareness of the impact of continence on the child’s life and mental health
- Commissioners who are aware that the time required for assessment will vary according to the child’s condition and situation and the amount of follow up required is highly variable; continence difficulties may take months or years to resolve and in some cases may be lifelong

##### **1.5.4.2 Waiting times and access**

- Waiting times for assessment, treatment and review that are reasonable and not in breach of any nationally or locally agreed targets
- Provides assessment and review in a variety of settings that are age-appropriate, meet the needs of the child or young person [22] and complies with Public Health England’s [You’re Welcome quality criteria](#). This may include but not be limited to clinics, homes, special schools and telephone reviews
- Has waiting and treatment areas that are appropriate to the age, development and needs of the children and families concerned [22]
- Provides settings that are geographically convenient with adequate parking and are accessible via public transport

##### **1.5.4.3 Appointments and follow-up**

- Initial appointments that are face-to-face, with adequate time to complete comprehensive assessments
- The same person to undertake the treatment programme. This person needs to talk to the child or young person directly, using age-appropriate language to develop a trusting relationship with them [22]
- Follow-up at appropriate times and locations to meet individual needs, but with sufficient frequency and appointment time to prevent relapse. Follow-up may be in clinic, at school or home, or via the telephone depending upon the needs of the child and family. The child or young person should always be communicated with directly and involved, unless clearly inappropriate

##### **1.5.4.4 Staffing**

- Staffing should be sufficient to meet the needs of the service. It is recommended that the Children’s Community Continence Service has one whole time clinician post per 100,000 of the total population (all ages) of the area  
Key appointments are:

- The service manager and the lead clinician (a minimum of Band 7). One person may undertake both roles. The lead clinician should be a children's continence nurse specialist – a registered children's nurse, with appropriate knowledge and experience in children's continence
- A consultant paediatrician who is part of, or closely linked to the team
- Sufficient administrative staff to support the service and enable timely communication with other professionals
- The clinical team should have a skill mix to include band 6 and 5 children's nurses and band 4 nursery nurses, as well as occupational therapy hours

#### 1.5.4.5 Resources

- A budget for sufficient equipment and consumables, including telephones, computers, printers, internet access, enuresis alarms, sensors, bladder scanners, uroflow equipment, TENS machines
- Information leaflets, including those directing families to web-based information
- A budget for washable and disposable continence containment products

#### 1.5.4.6 It is the responsibility of the service to:

- Recruit skilled, trained and appropriately qualified personnel in line with the [United Kingdom Continence Society Minimum Standards for Paediatric Continence Care](#)
- Ensure that the specialist nursing staff have the following qualifications: registered sick children's nurse, or registered nurse child branch, or degree level health visitor, or school nurse
- Provide a competency-based training programme to ensure staff have and maintain the required knowledge and skills to practice safely and effectively, including providing care to children with additional needs.<sup>10</sup>
- Ensure that staff work empathetically, promote dignity and respect and empower and encourage patients to self-care
- Encourage non-medical prescribing
- Enable all clinicians to have access to relevant training and education and supervision and attend regular meetings as appropriate, including for peer support. Clinicians should be encouraged to engage with multi-professional networks across the health economy
- Work to NICE guidance and, for conditions where there is no NICE guidance (e.g. daytime wetting, toilet training), to follow high quality, evidence-based practice, within locally agreed pathways, policies and procedures
- Identify a governance lead with responsibility for operations management and anonymous reporting of all clinical incidents to the National Patient Safety Agency (NPSA) and inform all professionals in the service of NPSA medical device and medication alerts
- Be compliant with Health and Safety legislation and the Equality Act 2010
- Adhere to safeguarding policies and procedures

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<sup>10</sup> Training is available from [Bladder & Bowel UK](#), [ERIC](#), [British Association of Paediatric Urology and Continence Nurses](#), [The International Children's Continence Society](#) and [The Association for Continence Advice](#)

## 1.6 Criteria for referral

All children with bladder and bowel dysfunction from birth – 19 years should be eligible for referral to the CCCS. Children should not be excluded due to resource restrictions, or their age, additional need, or due to perceived lack of potential to be toilet trained.

Referral would normally be via the patient's GP, health visitor, school nurse, or other local professional for all patients contracted within the CCG or Health Board area.

### 1.6.1 Exclusion criteria

- Those living outside the geographical boundaries of the of the commissioned service
- Those aged over 18 years of age, if there are no identified additional needs
- Those aged over 25 years if there are identified additional needs, but with local transition arrangements in place [23]

## 1.7 Care pathways

Care pathways should be developed and agreed locally for Level 1 and 2 services to meet the needs of children with any or all continence conditions. There should be local agreement on procedures and pathways for seamless referral to other services as required according to individual need. Any contractual relationships should be the responsibility of the service provider.

[Care pathways for Level 1 and Level 2 services](#), together with supporting [resources for Level 1 healthcare professionals](#) and a [Level 1 assessment tool](#) are available from Bladder & Bowel UK.

A [Children's continence care pathway](#) is available from ERIC that informs parents and professionals about the [assessment](#) and intervention for a child with a bowel or bladder problem.

## 1.8 Discharge and transition to adult services

Discharge should be considered when clinically appropriate. The family should be informed about whom to contact if there is deterioration or if concerns arise after discharge. The service provider should report the patient's clinical progress and discharge management/further treatment plans to the GP within five working days of discharge.

Any plans for transition to adult continence services should be made in advance and organised in a way that the effect for the young person is positive and seamless ([NICE NG 43, 2016](#)). The '[Ready Steady Go](#)' transition programme and [associated resources](#) are an example of good practice that could be adopted by Community Paediatric Continence Services.

## 2. Quality Dashboard for Children's Continence

### 2.1 Measurement of cost savings

Baseline data on hospital admissions for constipation and urinary tract infections for individual CCG areas in England, using Hospital Episodes Statistics (HES Data) enables on-going measurement of some outcome indicators and allows assessment of savings. Costs for provision of continence containment products<sup>11</sup> can also be measured. See Appendix 4 for examples of comparative costs: nurse-led clinics v acute/secondary care.

### 2.2 Service outcomes and key indicators

The key service outcome for integrated CCCS is to help children achieve complete continence, or if that is assessed as not being clinically possible, to manage their condition discreetly and effectively. Key outcomes should cover patient experience, clinical outcomes, process and resource use (as per the Health Foundation's Balanced Scorecard).

#### 2.2.1 Key outcome indicators

- Rates of A&E attendance and hospitalisation for constipation and urinary tract infection
- Rates of referral to secondary or tertiary services for day and night time wetting, constipation, soiling and delayed toilet training
- Percentage of the children referred to the service who are successfully treated without onward referral
- Reduction in costs to the NHS of washable and disposable products to contain incontinence
- Quality of Life assessment from the perspective of the child and/or family<sup>12</sup>

#### 2.2.2 Supporting outcomes

- Children and their families have improved perception and understanding of continence issues and have gained knowledge about how to effectively self-manage
- Effective use of care pathways and toileting programmes

### 2.3 Clinical outcome measures

#### 2.3.1 Enuresis and daytime wetting

There is international consensus on outcome measures for enuresis and daytime wetting available from the International Children's Continence Society [24]:

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<sup>11</sup> Refer to [Guidance on the provision of continence containment products to children and young people](#)

<sup>12</sup> Patient Reported Outcome Measures (PROMs) and Family Reported Outcome Measures (FROMs) can also be used. More specific Quality of Life Tools, tailored for paediatric bladder and bowel dysfunction are outlined in Appendix five.

#### *Initial success measures*

- No response: < 50 % reduction in symptoms
- Partial response: 50-99% reduction in symptoms
- Complete response: 100% reduction in symptoms

#### *Long-term success measures*

- Relapse: More than one symptom recurrence per month
- Continued success: No relapse in 6 months after interruption of treatment
- Complete success: No relapse in 2 years after interruption of treatment

However, Austin et al [24] recognise that in the clinical setting, the child and their family should decide the criteria for treatment success.

#### *Clinical Indicator*

- Treatment response

### **2.3.2 Constipation/soiling/faecal impaction**

A substantial improvement in the number of children achieving the passage of regular, soft, formed stools at least three times a week with no soiling problems, including those on medication and after the final withdrawal of medication.

#### *Clinical indicator*

- Treatment response

### **2.3.3 Toilet training**

- A reduction in the number of children who receive disposable products for continence containment against the number of children referred to the service with difficulties in toilet training
- The annual cost of washable and disposable products provided to children in the geographical area covered by the CCCS

### **2.3.4 Patient satisfaction**

The service should gather opinions from a cross-section of children with continence difficulties and their families via a self-completion questionnaire. Baseline and end-point data should be collected for comparison. See Appendix five.

### **2.3.5 Quality of life**

The service should make use of validated, reliable and reproducible quality-of-life (QoL) measures developed for children with bladder dysfunction. See Appendix five.

## **3. Audit**

Clinical audit has been described: ‘...as a quality improvement cycle that involves measurement of the effectiveness of healthcare against agreed and proven standards for high quality, and taking action to bring practice in line with these standards so as to improve the quality of care and health outcomes.’ [25] The service and clinical audits should be against the service and clinical outcome indicators as outlined in 2.1 and 2.2.

The CCCS may consider auditing the service against NICE Quality Standards for Bedwetting (QS 70) and Constipation (QS 62). They may also consider auditing:

- Waiting times for the service
- Child and family satisfaction with the CCCS one year after first contact and at discharge
- Time take for written communications to be sent to appropriate professionals and the family
- Referral efficiency between Level 1, 2 and 3 services

## 4. Summary Case Studies: recommendations into practice

Case studies from NHS services are available on the [Paediatric Continence Forum](https://www.paediatriccontinenceforum.org/) website.

## 5. Directory

### 5.1 Patient information

#### Paediatric Continence Forum (PCF)

The Paediatric Continence Forum is an independent national campaign group which was set up in 2003 to improve awareness amongst policy-makers of the needs of children and young people with continence problems and to improve NHS services in this often neglected area of child health. It has strong links with ERIC, The Children's Bowel and Bladder Charity and Bladder & Bowel UK, both registered charities – as well as formal representation from the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the School and Public Health Nurses' Association and the Community Practitioners' and Health Visitors' Association.

The companies, Clos-o-Mat Ltd., Coloplast Ltd., Ferring Pharmaceuticals Ltd., Kimberly-Clark Europe Ltd., Norgine Ltd. and Essity Ltd. actively support the work of the PCF but they have had no input into the contents of this document. The PCF employs the services of The Whitehouse Consultancy, which acts as advisers and provides a secretariat service for the Forum.

**Chair:** Dr Penny Dobson MBE

**Address:** The Paediatric Continence Forum, 225 The Metal Box Factory, 30 Great Guildford Street, London SE1 0HS

**Tel:** 020 7463 0690

**Email:** [paediatriccontinenceforum@whitehouseconsulting.co.uk](mailto:paediatriccontinenceforum@whitehouseconsulting.co.uk)

**Website:** [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org)

#### Bladder & Bowel UK

Working under the umbrella of Disabled Living, Bladder & Bowel UK offers advice and information on all bladder and bowel issues for all age groups, including children, and people with additional needs. Staffed by specialist nurses they have a confidential helpline and provide a range of web-based resources and information leaflets as well as bespoke



training to help children, their parents, carers and professionals to understand bladder and bowel difficulties, promote continence and manage incontinence. They also offer annual education days and symposia for professionals and have a free confidential helpline to support families and professionals.

**Address:** Burrow's House, Priestley Road, Worsley, Manchester M28 2LY

**Helpline:** 0161 607 8219

**Email:** [bbuk@disabledliving.co.uk](mailto:bbuk@disabledliving.co.uk)

**Website:** <https://www.bbuk.org.uk>

### **ERIC, The Children's Bowel & Bladder Charity**

ERIC is dedicated to helping all children and teenagers manage and overcome distressing continence conditions. Whether it is a toilet-training issue, bedwetting, constipation or soiling problem, ERIC provides expert support, information and understanding to children and young people and enables parents, carers and professionals to help them establish good bowel and bladder health. ERIC family support includes a free confidential helpline, parent and family workshops, online resources and information. Support for professionals includes training targeted at the needs of health, education, early years and social care professionals working with children and families and policies, such as for toilet training. Professionals can also access ERIC's free helpline, online tools, resources and information.

**Address:** 36 Old School House, Britannia Road, Kingswood, Bristol BS158DB

**Helpline:** 0808 169 9949

**Email:** [info@eric.org.uk](mailto:info@eric.org.uk)

**Website:** [www.eric.org.uk](http://www.eric.org.uk)

### **International Children's Continence Society (ICCS)**

An international professional organisation, that focuses on progression of research and healthcare. The ICCS has some information leaflets for families available on its website at <http://i-c-c-s.org/parents/>

### **Stopbedwetting.org**

[www.stopbedwetting.org](http://www.stopbedwetting.org) is a national website sponsored by Ferring Pharmaceuticals that provides information and resources to families affected by enuresis.

## **5.2 Professional information and education**

### **Association for Continence Advice**

Tel: +44 (0) 1506 811077 Email: [aca@fitwise.co.uk](mailto:aca@fitwise.co.uk) website: [www.aca.uk.com](http://www.aca.uk.com)

### **BAPU (British Association of Paediatric Urologists)**

Contact via email: <http://www.bapu.org.uk/contact/contact-access-request/>

Website: <http://www.bapu.org.uk>

### **BAPU-CN (British Association of Paediatric Urology and Continence Nurses)**

Operating under the umbrella of BAPU. Contact via email: [Jo.Searles@nhs.net](mailto:Jo.Searles@nhs.net)

### **Bladder & Bowel UK**

Email: [bbuk@disabledliving.co.uk](mailto:bbuk@disabledliving.co.uk) Website: <https://www.bbuk.org.uk>

**ERIC, The Children's Bowel & Bladder Charity**  
Email: [info@eric.org.uk](mailto:info@eric.org.uk) Website: [www.eric.org.uk](http://www.eric.org.uk)

**International Children's Continence Society**  
Website <http://i-c-c-s.org> Paediatric continence care e-learning course is available from <http://i-c-c-s.org/e-learning/>

**NHS Health Education England Mind-Ed e-learning for health.** Modules on paediatric continence wetting and soiling problems – Available from:  
[https://www.minded.org.uk/Catalogue/Index?HierarchyId=0\\_36391\\_36845\\_36857&programmeld=36391](https://www.minded.org.uk/Catalogue/Index?HierarchyId=0_36391_36845_36857&programmeld=36391)

**United Kingdom Continence Society**  
Website <http://www.ukcs.uk.net> International Children's Continence Society Paediatric Continence Care E-Learning course, available from <http://i-c-c-s.org/e-learning/>

## **5.3 Additional information, guidelines and practical guidance for Commissioners**

NICE Clinical Guideline: [CG111 Nocturnal Enuresis](#): the management of bedwetting in children and young people (October 2010)

NICE Quality Standard: [QS70 Nocturnal Enuresis \(bedwetting\) in Children and Young People](#) (September 2014, reviewed 2017)

NICE Clinical Guideline: [CG99 Constipation in Children and Young People](#) (May 2010)

NICE Quality Standard: [QS62 Constipation in Children and Young People](#) (May 2014)

NICE Clinical Guidance [CG43 Transition to adult's services for young people using health and social care services](#) (2016)

NICE Clinical Guidance [CG148 Urinary incontinence in neurological disease: assessment and management](#) (August 2012)

NICE [Assessing the resource impact of implementing NICE guidance](#)

NHS England: [Excellence in Continence Care: practical guidance for commissioners and leaders in health and social care](#) (2018)

NHS England: [NHS Long Term Plan](#)

Department of Health [Improving Children and Young People's Health Outcomes: A System Wide Response](#) (2013)

United Kingdom Continence Society (UKCS) [Minimum Standards for Paediatric Continence Care in the UK](#) (2016)

Bladder & Bowel UK [Guidance for the Provision of Continence Containment Products to Children and Young People](#) (2016 reviewed 2019)

Bladder & Bowel UK: [Understanding bladder and bowel co-morbidities in children and young people with additional needs: the importance of assessment](#) (2018)

[Report of the Children and Young People's Health Outcomes Forum](#) (2013)

All Party Parliamentary Group [Cost Effective Commissioning for Continence Care](#) (2011)

## 6. Further information

### 6.1 Guide development

NICE accredited the original publication of this Guide in 2014 under their 'single guideline' category. This update has gone through the same regulatory process, including a full literature review, although NICE no longer have the resources to accredit this category of guideline. The current update was directed by the following independent body of experts, the Guide Development Group (GDG). See below:

<b>Sue Affleck</b>	Head of Nursing and Clinical Nurse Specialist, St. George's Hospital London
<b>Elaine Baptiste</b>	Specialist Paediatric Continence Nurse, Waltham Forest. Representative from the Community Practitioners' and Health Visitors' Association
<b>Brenda Cheer</b>	Paediatric Specialist Continence Nurse and ERIC Nurse
<b>Dr Penny Dobson MBE</b>	Chair and Founder of Paediatric Continence Forum. <b>Editor*</b>
<b>Ingrid Ecklekamp</b>	Team Lead, Specialist Children's Services, Greater Glasgow
<b>Dr Tim Fooks</b>	General Practitioner, Pulborough Medical Group, West Sussex
<b>Jayne Hill</b>	Head of North Yorkshire Children and Young People's Commissioning Team
<b>Sharon Holroyd</b>	Lead Clinical Nurse Specialist, Calderdale Bladder and Bowel Service. Representative from the Royal College of Nursing
<b>Dr Carol Joinson</b>	Reader in Developmental Psychology, School of Social and Community Medicine, University of Bristol*
<b>Mr. Nicholas Madden</b>	Paediatric Surgeon/Urologist, Chelsea and Westminster Hospital (retired). Vice-Chair, Paediatric Continence Forum. <b>Lead literature reviewer 2019*</b>
<b>Lorna Montgomery</b>	Parent representative. Chair of the Management Committee ERIC
<b>Juliette Rayner</b>	Chief Executive, ERIC, The Children's Bowel and Bladder Charity
<b>Rhonda Reilly</b>	Children's Continence Nurse, Western Health and Social Care Trust, Northern Ireland

<b>Davina Richardson</b>	Children's Nurse Specialist, Bladder & Bowel UK and ACA Executive Committee member. <b>Lead author 2019 update*</b>
<b>June Rogers MBE</b>	Children's Nurse Specialist, Bladder & Bowel UK
<b>Dr Sameena Shakoor</b>	Consultant Paediatrician, Kent Community Health NHS Trust. Representative from the Royal College of Paediatrics and Child Health
<b>Sharon White OBE</b>	CEO, School and Public Health Nurses Association
<b>Dr Anne Wright</b>	Consultant Paediatrician, Guy's and St Thomas' NHS Foundation Trust*

\*Members of the Literature Review Sub-Group. Research recommendations from this sub-group were approved by the GDG in 2019

There were no conflicts of interest for Guide Development Group members.

## 6.2 Literature review

A full literature review was carried out for the 2014 Guide. This 2019 update was supported by a further review of literature published between the years 2014 and 2019. Details of the 2019 literature review is available on the Paediatric Continence Forum website: [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org).

## 6.3 Barriers to implementation

- Adequate funding for personnel and equipment
- Insufficient professional training courses for the post registration qualification of a paediatric continence nurse specialist
- Adequate time to win the "hearts and minds" of local agencies for integrated working
- Lack of understanding of the impact of continence problems on the individual child or young person and the affect upon their mental health
- Poor signposting of services

# Appendix one

## Summary of definitions and terms

The definitions of continence conditions below are based, where possible, upon the International Children's Continence Society (ICCS) 'Standardization of Terminology of Lower Urinary tract Function in Children and Adolescents' [24].

**Bedwetting** Also known as enuresis, or nocturnal enuresis. It is defined as a symptom and condition of intermittent incontinence that occurs during periods of sleep. It relates to children over five years of age, where it occurs more than once a month for more than three months. Enuresis is further classified as 'frequent' if it happens four or more times a week or 'infrequent' if it is happening less than four times a week [24]. The term bedwetting is suitable for all children, but the term 'enuresis' is applicable to children from their fifth birthday [24].

**Children and young people** Any person from birth to the age of 19 years. This document relates to all children and young people and does not exclude those children and young people who have learning of physical difficulties or disabilities or sensory or processing disorders, or chronic illnesses. For simplicity all children and young people aged 0 – 19 years are referred to as children.

**Children's Community Continence Service (CCCS)** A service provided in the community for children and young people (aged 0 – 19 years) that provides care for all bladder and/or bowel conditions as well as difficulties with toilet training (see section 1.5.2).

**Chronic constipation** Constipation that has persisted for more than eight weeks.

**Constipation** Decreased frequency of bowel movements, often associated with hard or large stools that may be painful and/or difficult to pass.

**Continence** The ability to control bladder and bowels until a socially acceptable time and place is reached to pass urine and/or faeces. The term "continence" is often used interchangeably with "bladder and bowel difficulties" "bladder and bowel dysfunction" or "bladder and bowel problems".

**Continence difficulties** Any problem(s) maintaining bladder or bowel continence, or any bladder or bowel symptom, or issue with toileting that affects day-to-day living.

**Daytime wetting** Incontinence of urine during waking hours.

**Disability** A long term impairment of physical functioning (physical disability) or intellectual functioning (learning disability).

**Encopresis** This term is now obsolete. However, it is still sometimes used to describe the passage of normal stools in inappropriate places. It was used to distinguish children who were soiling due to mental health, behavioural or psychological problems, from those who

were soiling due to chronic constipation. It has been replaced by the term non-retentive faecal incontinence.

**Enuresis** Intermittent urinary incontinence during periods of sleep (see bedwetting above).

**Faecal incontinence (Soiling)** Passage of stools in an inappropriate place. It may be due to neurological damage or congenital abnormality, but is most often functional or idiopathic in origin and is usually associated with chronic constipation.

**Faecal impaction** A quantity of faeces in the rectum or colon that is so large that the child is unlikely to be able to pass the faeces spontaneously without treatment.

**Incontinence** The loss of control of bladder or bowels resulting in uncontrolled wetting or soiling in a child who is old enough to have been toilet trained.

**Integrated** In this document refers to a CCCS (see above) that provides assessment and treatment for all bladder and bowel symptoms in the same clinic (see section 1.5.2).

**Intractable Constipation** Chronic constipation that does not respond to optimum medical management.

**Learning difficulty** Someone who has a problem with a specific area of learning e.g. dyslexia.

**Learning disability** Someone who has an IQ of lower than 70 and is intellectually delayed in every aspect of their life. Learning disabilities can be mild, moderate, severe or profound.

**Level/Tier 1 services** All universal healthcare services. This includes general practitioners, practice nurses, children's community nurses, health visitors and school nurses.

**Level/Tier 2 services** Specialist services in the community. Within this Guide Level 2 services refer to the integrated Children's Community Continence Service.

**Level/Tier 3 services** Services provided by secondary or tertiary care. These include paediatricians, paediatric gastroenterologists, paediatric urologists and paediatric surgeons, as well as inpatient facilities and accident and emergency departments.

**Lower urinary tract symptoms** Includes both storage and voiding symptoms, such as incontinence, increased or decreased voiding frequency (having to go to the toilet more or less often than normal to pass urine), urgency (sudden, unexpected and immediate need to pass urine), hesitancy (difficulty starting to pass urine when there is a need to do so), straining (having to make an effort to start or continue passing urine), weak stream, intermittency (stopping and starting when passing urine), and dysuria (pain when passing urine). Other symptoms include holding manoeuvres to prevent urine being passed, feeling of incomplete bladder emptying, urinary retention (being unable to completely empty the bladder), post-micturition dribbling (incontinence of urine immediately after finishing passing urine on the toilet) and splitting of the urinary stream (urine is passed as a spray or split stream, rather than a single discrete stream) [24].

**Nocturnal enuresis** The word ‘nocturnal’ is no longer recommended for use to describe enuresis or bedwetting. See bedwetting above.

**Physical disabilities** A long-term impairment of a person’s physical functioning, affecting any aspect of daily living. Physical disabilities include conditions that limit stamina, mobility, dexterity as well as problems such as respiratory disorders, blindness and epilepsy.

**Soiling** Incontinence of faeces in a child who is old enough to have been toilet trained, or whom has previously toilet trained. It is often associated with constipation.

**Urinary tract infection** A bacterial infection of the upper or lower urinary tract (kidneys, ureter, bladder and/or urethra) that causes illness in children. It can be associated with lower urinary tract symptoms, urinary and/or faecal incontinence.

## Appendix two

### Prevalence of continence difficulties in children and young people

#### A2.1 Children and young people with bedwetting

Prevalence of bedwetting in children by age in years	
5	16.1%
6	12.95%
7	10.1%
8	6.14%
9	3.14%
10	2.63%
11	2.17%
12	2.02%
13	1.55%
14	1.49%
15	1.28%
16	1.65%
17	2.0%
18	2.19%

Yeung et al [26]

At age 5 years, 55.7% of affected children were wetting less than three nights a week, 30% were wetting 3 – 6 nights a week and 14.3% were wetting seven nights a week. At age 19 years, only 10.3% of affected young people were wetting less than three nights a week, 41.4% were wetting 3 – 6 nights a week and 48.3% were wetting every night. This strongly suggests that those children with the most severe symptoms are more likely to have

enuresis that persists into adult life and should therefore be offered interventions at a younger age [26].

## A2.2 Children and young people with daytime urinary incontinence

Age of children in years	Prevalence of daytime urinary incontinence	Number of children in study	Study author
6 – 13	18%	4250	Sarici et al [27]
10 (median age)	6.7% (plus 4.1% with day and night time wetting)	416	Akil et al [28]
5 – 17	13.8%	827	Sampio et al [29]
4.5	15.5%	10,819	Swithinbank [30]
9.5	4.9%		
5 – 17	3.3% (plus 1.8% with day and night time wetting)	482	Loening Baucke [31]

Heron J et al [6] found that 8.6% of children from a sample of almost 9,000 children aged 4 – 9 years, were delayed in attaining bladder control in the day and/or night; 5.8% of children had daytime wetting alone (i.e. without bedwetting); 15.6% had bedwetting alone, and 7% had persistent (day and night) wetting.

## A2.3 Children and young people with faecal incontinence

Age of children in years	Prevalence of faecal incontinence	Number of children in study	Study author
4 – 17	4.4%	482	Loening-Baucke [31]
13 – 18	2.6%	1,807	Rajindrajith [32]
6	1.6%	2,079	Equit et al [33]

## A2.4 Children and young people with constipation

Age of children	Prevalence of constipation	Number of children/mothers in study	Study author
0 – 3 years	18.5%	1255 mothers with children aged 0-18 years	Robin et al [34]
4 – 18 years	14.1%		
4 – 17 years	18%	482 children	Loening-Baucke [31]
0 – 12 months	16.1%	1231 children aged 0 – 48 months	Chogle et al [35]
13 – 48 months	26.8%		
8 – 18 years	15.6%	212 children	Timmerman et al [36]

Koppen et al [37] conducted a systematic review of data for functional defecation disorders in children. They included 35 studies that detailed prevalence of functional constipation in children aged 0 – 18 years and found a reported prevalence of 0.5 – 32.2%, with a pooled prevalence of 9.5%.



## **A2.5 Further information about prevalence and impact on long-term prognosis**

Children with persistent (day and night) wetting at 4 – 9 years old are 23 times more likely, than those with normal development of bladder control in childhood, to experience bedwetting at 14 years of age [6]. Where children have persistent (day and night) wetting from 4 – 9 years, or delayed bladder control (attainment of bladder control after age 6), they are between seven and ten times more likely to have daytime wetting in adolescence.

It is known that urinary incontinence in adulthood has been linked to urinary incontinence in childhood. Kuh D et al [38] found that wetting in the day, or several nights a week at age 6 years was associated with severe incontinence in women at age 48 years.

These statistics, together with the increase in population in the UK in recent years, suggests that the number of children with continence difficulties is significantly higher than the 900,000 previously estimated.

## **Appendix three**

### **The impact of incontinence on children and their families**

1.2.6 Cross-sectional studies have found strong evidence that incontinence in school-age children is associated with high rates of emotional and behavioural problems. These children are also more likely to be bullied or be the perpetrators of bullying [14, 15, 39].

Children and adolescents with incontinence have increased levels of psychological problems [40]. It is, however, unclear from these studies whether psychological problems are a cause or a consequence of incontinence. Psychological distress might emerge when children become aware that continence problems are abnormal for their age, or in the face of negative reactions from their parents or peers. There is some evidence for improvements in psychological functioning following successful treatment for continence problems. Building a trusting relationship with the treating clinician is important to the child or young persons' engagement with the treatment programme [22].

Recent prospective cohort studies have found evidence that psychological problems in early childhood are risk factors for incontinence at school age [40]. Moreover continence problems in primary school-age children are risk factors for psychological problems in adolescence [18].

It is known that the prevalence of stressful life events, including abuse, is higher in children with functional defaecation disorders than in healthy children [41].

## Appendix four

### Comparative costs

#### *Costs if children are seen in primary care*

- The hourly rate of nursing top band 6/ mid band 7 £18.20 (before any on costs)

Source Royal College of Nursing, Pay rates 2017 – 18 (<https://www.rcn.org.uk/employment-and-pay/nhs-pay-scales-2017-18>)

#### *Costs if children are seen in acute/secondary care:-*

- The average cost of a paediatric first appointment is £236 and a follow-up appointment is £189 if the child has been admitted to hospital. If they have not required admission, the cost of a follow up appointment is £133
- The average cost of a community paediatric first appointment is £407 and a follow-up appointment is £265 if the child has not been admitted to hospital
- The average cost of a paediatric gastroenterology first appointment is £267 and a follow up appointment is £216 where the child has not been admitted to hospital
- The average cost of a paediatric urology first appointment is £119 and follow up is £102
- The average cost of a first appointment with an occupational therapist is £82 and a follow up appointment is £63
- The cost of a specialist continence nurse face-to-face appointment is £102 and non-face-to-face is £77
- The average cost of an A&E first attendance is £148

Source: National Schedule of Reference Costs Year: 2016-17 - All NHS trusts and NHS foundation trusts – Outpatient Attendances Data

## Appendix five

### Surveys and proformas for service audit

There are a number of questionnaires which have been used in children with continence problems and are available on-line and/or in published papers.

#### **Quality of Life**

The PedsQL is a more general questionnaire, which is commercially available on-line (<http://www.pedsq.org/>) and has been used in relation to childhood continence in a study of faecal incontinence [42] and one of school children with constipation [43].

A similar, slightly simpler 12-question assessment, the DCGM -10 has been used for children with continence and other chronic health problems [44].

Detailed questionnaires relating to bowel problems are the FIC QOL. These are available online using the link: [https://www.ucdmc.ucdavis.edu/urology/specialties/pediatric\\_urology](https://www.ucdmc.ucdavis.edu/urology/specialties/pediatric_urology) where they can be found under 'pediatric urology information handouts', with the titles 'Bowel care survey for caregiver' (the 'Caregiver' referring to the fact that the questionnaire is to be administered by adults) and 'Bowel care survey for patients (adolescents)'. They include useful questions regarding symptoms in addition to the quality of life elements [45].

The CINCY-FIS is a reliable and valid assessment for paediatric faecal incontinence-specific quality of life and parenting stress [46]. The QQVCFCA is a validated quality of life questionnaire for children and adolescents with faecal incontinence, Hirschsprung's disease or anorectal malformation [47].

The PinQ included children aged 6 – 17 years old with daytime urinary incontinence and enuresis in its development [48].

### **Symptom Scores**

The Dysfunctional Voiding Scoring System [49] and Dysfunctional Voiding and Incontinence Symptom Scoring System [50], provide symptom scoring systems for urinary problems in the same way as the FIC QOL; in the former the questions are predominantly directed to the child, the latter is addressed to the parents. The Child Bladder and Bowel Dysfunction Questionnaire (CBBQ) [51] is a self-administered tool, developed with children aged 5-12 years and is suitable to use prior to seeing a health care professional.

### **PROM / FROM**

Patient and family reported outcomes can be assessed using the Experience of Service Questionnaire (ESQ) produced by the Commission for Health Improvement (now the Healthcare Commission) and available on the [Child Outcomes Research Consortium](#) website. ESQ (formerly CHI-ESQ;) is available in three versions: one for parents/carers, one for young people aged 12 – 18 years and one for children aged 9 – 11 years.

# Appendix six

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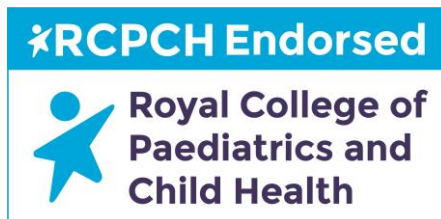
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