Paediatric Continence Services in the UK: Results of a Freedom of Information Request

AN EXAMINATION OF PAEDIATRIC CONTINENCE SERVICES ACROSS THE UK

AUGUST 2017

A report by the Paediatric Continence Forum

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Executive summary

• This report provides an analysis of the findings of the Paediatric Continence Forum’s 2017 Freedom of Information (FOI) survey of paediatric continence services across the UK. It is for anyone with an interest in paediatric continence, including commissioners, policymakers, service providers, parents and carers.

• Bladder and bowel dysfunction (continence difficulties) include bedwetting, daytime incontinence, constipation/soiling and toilet training concerns. They affect approximately 900,000 children and young people out of a population of 8,500,000.¹ This translates to about 1 in 10 children in the UK, although this figure is likely to be higher due to under-reporting and the stigma associated with these conditions.

• Provision of comprehensive community continence services for children avoids unnecessary and costly referrals to secondary care, reduces the need for provision of continence containment products (such as nappies and pads, hereafter referred to in this document as ‘products’), and improves clinical outcomes, quality of life and the experience for parents/carers and their children.

• All children and young people from birth to 19 years with bladder and bowel dysfunction, including those with learning difficulties and physical disabilities, should have access to an integrated, community-based paediatric continence service. This service should cover the four areas of continence difficulties “under one roof”, as well as arrange provision of appropriate products for those who are unable to achieve continence. There should be a multi-disciplinary team led by a paediatric continence nurse specialist – to ensure proper diagnosis and treatment for these often-interlinked conditions.

• In January 2017, the Paediatric Continence Forum (PCF) sent out a FOI request to all Clinical Commissioning Groups (CCGs) and Health Boards across the UK, to assess how many CCGs and Health Boards are providing the above service, and compared the results with similar FOI requests undertaken in 2011 and 2014.

• This study identified continued disparities in paediatric continence service provision across the UK despite a small overall improvement over the period: 41.13% of CCGs and Health Boards currently provide all four paediatric continence services and product provision compared to 38% in 2014. England is the only country to demonstrate an improvement in service provision, with 43.2% of CCGs providing services in 2017 compared with 36% in 2014.

Services in the devolved nations have experienced a worrying deterioration. While 53.85% of the devolved Health Boards previously provided the four paediatric continence services as well as products, this has fallen to an average of 24% in 2017 (23.08% in Scotland, 14.29% in Wales and less of a deterioration, 40%, in Northern Ireland).

While these results provide a somewhat worrying picture of paediatric continence service provision in the UK, it was noted that 36.8% of CCGs and Health Boards are intending to review their existing continence service and encouragingly 10.82% plan to commission a new service.

The NICE-accredited Paediatric Continence Commissioning Guide (published by the Paediatric Continence Forum, 2015) provides clear guidance on how to set up and run an integrated, community-based paediatric continence service. Recognition of this Guide among CCGs also offers hope for future improvements to services.

In England, the Carter Review of productivity in NHS hospitals, the NHS RightCare programme and the Sustainability and Transformation Partnership (STP) process all offer the chance to focus on commissioning the most efficient services. As paediatric continence services are clinically and financially effective, commissioning an integrated, community-based paediatric continence service fulfils the aims of these programmes and should be considered by commissioners.

In response to the outcome of the 2017 FOI Survey, the PCF makes the following recommendations:

- Every child and young person in the UK should have access to an integrated, community-based, well-resourced paediatric continence service.

- Health services and local authorities should work collaboratively to ensure that these services are available in every community, recognising that it is their responsibility to work together to provide them, despite recognised clinical and financial pressures.

- Information about the provision of local services should be readily available in health and educational settings – i.e. GP practices and schools. It should also be clear who can refer to these services and how families and young people can contact referrers, e.g. GPs, school nurses and health visitors.
Introduction

Since 2003, the Paediatric Continence Forum (PCF) has closely scrutinised provision of local services for children with bladder and bowel problems – paediatric continence services – in order to highlight instances of good practice and challenge shortcomings in provision. Our analysis has primarily been conducted by submitting Freedom of Information (FOI) requests to Primary Care Trusts (PCTs) and then Clinical Commissioning Groups (CCGs), and Health Boards, in 2011, 2014 and most recently in January 2017. These results have built a picture of the changes to paediatric continence services over time and during a period of substantial upheaval to health services, particularly in England.

Bladder and bowel dysfunction (continence difficulties) include bedwetting, daytime incontinence, constipation/soiling and toilet training concerns. They affect approximately 900,000 children and young people out of a population of 8,500,000. This translates to about 1 in 10 children in the UK, although this figure is likely to be higher due to under-reporting and the stigma associated with these conditions.

Research indicates a link between continence problems and negative social behaviour (including bullying, both as perpetrators and recipients), plus a loss of self-esteem during important formative years. There is also a significant link with parental punishment and child abuse. If continence difficulties are identified early and treated effectively in the community, symptom escalation is prevented and the risk of expensive unplanned hospital admission or accident and emergency attendance is reduced. Early and effective treatment also lifts the stigma and stress associated with these conditions and radically improves the quality of life for the children and young people concerned and their families.

Huge savings are made when children with continence problems are identified early by health visitors, school nurses or community nurses and either treated by them at Level/Tier 1, if the assessment shows the problem is straightforward, or at Level/Tier 2 by the Community Paediatric Continence Service, if the problem does not resolve as expected or is more complex. This thereby prevents expensive

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3 Ibid., p.7.

For further information, please visit www.paediatriccontinenceforum.org.
expenditure on paediatric consultant referrals and acute services. A recent case study compiled by the PCF of “Toby”, a six-year-old boy with bedwetting and underlying constipation, showed that the treatment cost for an optimal pathway was £318 compared to £2,118 for a sub-optimal pathway.\(^4\) Pursuing optimal pathways not only saves money for the NHS, but also improves clinical outcomes and the experience of care for the child and family.

**What should a good and accessible paediatric continence service look like?**

A community-based, well-resourced paediatric continence service should be **one integrated service** covering all aspects of continence, as there are clear causal links between conditions affecting different aspects of continence. For example, children with bedwetting may also experience daytime wetting, and so these issues should be identified and treated simultaneously. The service should treat all children and young people **from birth – 19 years**, to avoid children falling through gaps in provision when they reach a certain age, and should **include all children and young people, including those with additional needs and/or disabilities**.

The paediatric continence service should be run by a **multidisciplinary team** and led by a **paediatric continence nurse specialist**, with clear and effective **referral and care pathways** to secondary care, education, child and adolescent mental health services (CAMHS) and social services. This is essential as continence issues can impact other areas of a child’s wellbeing, such as school performance or social interactions - so these issues should be addressed alongside their bladder or bowel problem.

The NICE-accredited Paediatric Continence Commissioning Guide, available on the PCF’s website, provides more information on this.

**Previous PCF research: 2011 and 2014**

The PCF has previously submitted FOIs to PCTs in 2011, and CCGs and Health Boards in 2014. A summary of the results from both of these surveys can be found in Tables 1 and 2, indicating that PCTs previously offered stronger provision in England than their successor CCGs. 47% of PCTs responded to the PCF’s 2011 survey, of which 88% commissioned all four paediatric continence services (covering bedwetting, daytime wetting, soiling and constipation). When taking into account PCTs which did not respond, this suggests approximately 41% of PCTs were providing all four services in 2011. This then reduced to 39% in 2014 under CCGs. The 2014 survey, which also examined services in the devolved

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nations for the first time, found stronger service provision there than in England on the PCF’s key metric: provision of all four paediatric continence services and product provision.

An overview of the results of the PCF’s 2017 FOI survey is given in Table 3, with the full set of questions asked available in the Appendix. This includes results for a question not asked in 2014, on awareness and use of the Paediatric Continence Commissioning Guide (PCCG) among CCGs and Health Boards.
Table 1: Results of PCF Freedom of Information requests to Primary Care Trusts, 2011

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>England (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Primary Care Trusts (England)</td>
<td>152</td>
<td>-</td>
</tr>
<tr>
<td>Responses received</td>
<td>72</td>
<td>47.36%</td>
</tr>
<tr>
<td>Commission four services</td>
<td>63</td>
<td>88.00%</td>
</tr>
<tr>
<td>Children offered washable and disposable products</td>
<td>60</td>
<td>83.00%</td>
</tr>
<tr>
<td>Commission integrated services</td>
<td>37</td>
<td>26.00%</td>
</tr>
<tr>
<td>Led by a paediatric continence advisor</td>
<td>18</td>
<td>25.00%</td>
</tr>
<tr>
<td>Plan to commission new services in line with NICE guidelines</td>
<td>18</td>
<td>25.00%</td>
</tr>
</tbody>
</table>

Table 2: Results of PCF Freedom of Information requests to CCGs and Health Boards, 2014

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>England (%)</th>
<th>Scotland</th>
<th>Scotland (%)</th>
<th>Wales</th>
<th>Wales (%)</th>
<th>Northern Ireland</th>
<th>Northern Ireland (%)</th>
<th>UK total</th>
<th>UK total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of CCGs (England), Health Boards (Scotland and Wales), Health and Social Care Trusts (Northern Ireland)</td>
<td>211</td>
<td>-</td>
<td>14</td>
<td>100.00%</td>
<td>7</td>
<td>100.00%</td>
<td>5</td>
<td>100.00%</td>
<td>237</td>
<td>100.00%</td>
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<tr>
<td>Responses received</td>
<td>211</td>
<td>100.00%</td>
<td>14</td>
<td>100.00%</td>
<td>7</td>
<td>100.00%</td>
<td>5</td>
<td>100.00%</td>
<td>237</td>
<td>100.00%</td>
</tr>
<tr>
<td>Commission four services</td>
<td>82</td>
<td>39.00%</td>
<td>8</td>
<td>57.00%</td>
<td>4</td>
<td>57.00%</td>
<td>3</td>
<td>60.00%</td>
<td>97</td>
<td>40.90%</td>
</tr>
<tr>
<td>Commission four services and products</td>
<td>76</td>
<td>36.00%</td>
<td>8</td>
<td>57.00%</td>
<td>3</td>
<td>43.00%</td>
<td>3</td>
<td>60.00%</td>
<td>90</td>
<td>38.00%</td>
</tr>
<tr>
<td>Commission integrated services</td>
<td>54</td>
<td>26.00%</td>
<td>5</td>
<td>36.00%</td>
<td>2</td>
<td>29.00%</td>
<td>2</td>
<td>40.00%</td>
<td>63</td>
<td>27.00%</td>
</tr>
<tr>
<td>Led by a paediatric continence advisor</td>
<td>43</td>
<td>20.00%</td>
<td>5</td>
<td>36.00%</td>
<td>2</td>
<td>29.00%</td>
<td>2</td>
<td>40.00%</td>
<td>52</td>
<td>21.10%</td>
</tr>
<tr>
<td>Plan to review service</td>
<td>87</td>
<td>41.00%</td>
<td>10</td>
<td>71.00%</td>
<td>1</td>
<td>14.00%</td>
<td>5</td>
<td>100.00%</td>
<td>103</td>
<td>43.50%</td>
</tr>
<tr>
<td>Plan to commission new service</td>
<td>34</td>
<td>16.00%</td>
<td>1</td>
<td>7.00%</td>
<td>0</td>
<td>0.00%</td>
<td>0</td>
<td>0.00%</td>
<td>35</td>
<td>13.50%</td>
</tr>
</tbody>
</table>
Table 3: Results of PCF Freedom of Information requests to CCGs and Health Boards, 2017

<table>
<thead>
<tr>
<th>Number of CCGs (England), Health Boards (Scotland and Wales), Health and Social Care Trusts (Northern Ireland)</th>
<th>England</th>
<th>England (%)</th>
<th>Scotland</th>
<th>Scotland (%)</th>
<th>Wales</th>
<th>Wales (%)</th>
<th>Northern Ireland</th>
<th>Northern Ireland (%)</th>
<th>UK total</th>
<th>UK total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>209</td>
<td>-</td>
<td>14</td>
<td>-</td>
<td>7</td>
<td>-</td>
<td>5</td>
<td>-</td>
<td>235</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Responses received</td>
<td>206</td>
<td>98.56%</td>
<td>13</td>
<td>92.86%</td>
<td>7</td>
<td>100.00%</td>
<td>5</td>
<td>100.00%</td>
<td>231</td>
<td>98.30%</td>
</tr>
<tr>
<td>Commission four services</td>
<td>89</td>
<td>43.20%</td>
<td>3</td>
<td>23.08%</td>
<td>2</td>
<td>28.57%</td>
<td>2</td>
<td>40.00%</td>
<td>96</td>
<td>41.56%</td>
</tr>
<tr>
<td>Commission four services and products</td>
<td>89</td>
<td>43.20%</td>
<td>3</td>
<td>23.08%</td>
<td>1</td>
<td>14.29%</td>
<td>2</td>
<td>40.00%</td>
<td>95</td>
<td>41.13%</td>
</tr>
<tr>
<td>Commission integrated services</td>
<td>65</td>
<td>31.55%</td>
<td>3</td>
<td>23.08%</td>
<td>0</td>
<td>0.00%</td>
<td>3</td>
<td>60.00%</td>
<td>71</td>
<td>30.74%</td>
</tr>
<tr>
<td>Led by a paediatric continence advisor</td>
<td>48</td>
<td>23.30%</td>
<td>1</td>
<td>7.69%</td>
<td>1</td>
<td>14.29%</td>
<td>3</td>
<td>60.00%</td>
<td>53</td>
<td>22.94%</td>
</tr>
<tr>
<td>Plan to review service</td>
<td>74</td>
<td>35.92%</td>
<td>4</td>
<td>30.77%</td>
<td>5</td>
<td>71.43%</td>
<td>2</td>
<td>40.00%</td>
<td>85</td>
<td>36.80%</td>
</tr>
<tr>
<td>Plan to commission new service</td>
<td>23</td>
<td>11.17%</td>
<td>1</td>
<td>7.69%</td>
<td>1</td>
<td>14.29%</td>
<td>0</td>
<td>0.00%</td>
<td>25</td>
<td>10.82%</td>
</tr>
<tr>
<td>Aware of the PCCG</td>
<td>130</td>
<td>63.11%</td>
<td>8</td>
<td>61.54%</td>
<td>5</td>
<td>71.43%</td>
<td>5</td>
<td>100.00%</td>
<td>148</td>
<td>64.07%</td>
</tr>
<tr>
<td>Use the PCCG</td>
<td>104</td>
<td>50.49%</td>
<td>4</td>
<td>30.77%</td>
<td>3</td>
<td>42.86%</td>
<td>4</td>
<td>80.00%</td>
<td>115</td>
<td>49.78%</td>
</tr>
</tbody>
</table>

For further information, please visit www.paediatriccontinenceforum.org.
Analysis of 2017 findings

The 2017 survey included an additional question on awareness and use of the Paediatric Continence Commissioning Guide, to try to measure the impact of the PCF’s work since the last survey in 2014.

Question 1: Please state whether the five paediatric continence services have been commissioned by your CCG/Health Board.

These figures present two key findings. Firstly, there is markedly different performance between the devolved nations and England in both surveys, but with service provision in Northern Ireland remaining comparatively strong. Performance in England and Northern Ireland contribute to a slight improvement of 2.95% in overall UK service provision between 2014 and 2017. However, in all areas of the UK, there is also vast room for improvement – in England only 43% of CCGs now provide all four paediatric continence services and product provision, while they are provided by less than 15% of Health Boards in Wales.

Provision in England has not substantially improved from that historically offered by PCTs: while approximately 41% of PCTs commissioned all four paediatric continence services in 2011, the most directly comparable figure for CCGs fell to 39% in 2014, and only marginally increased to 43.2% in 2017.

For further information, please visit www.paediatriccontinenceforum.org.
Question 2: Is there a single service for the above five problems?

When considering the proportion of areas which commissioned a single paediatric continence service (indicating the service is integrated), Northern Ireland experienced a 20% increase in the proportion of Health Boards commissioning integrated services – but this only constitutes one more Health Board. Northern Ireland has nearly twice the proportion of Health Boards commissioning these than the next best nation, England. England has shown a 5.55% increase in the percentage of CCGs offering integrated services between 2014 and 2017, indicating further room for improvement.

Provision of integrated children’s continence services in Scotland and Wales also gives cause for concern. In Scotland, 7% fewer Health Boards offer integrated services than the national average, and there was a 13% reduction (i.e. two fewer Health Boards) in the number providing integrated services since the 2014 survey. The complete loss of integrated services in Wales is especially alarming. However, this provides an opportunity for service providers to re-evaluate their services and there are indications that they are doing so (highlighted in the answers given to question 7).
Question 2: If these services are integrated, is this service led by a paediatric continence advisor?

The proportion of areas with services led by a paediatric continence advisor has marginally increased across the UK, from 21.1% in 2014 to 22.94% in 2017. There was a 20% increase in Northern Ireland and a 3.3% increase in England, compared with a 28.3% reduction in Scotland and a 14.71% reduction in Wales. The key role of the specialist paediatric continence nurse, as the senior clinical lead to the integrated Paediatric Continence Service, cannot be underestimated.

Question 3: If the answer to question 2 is no, please list the services that are commissioned to handle these problems and the designation of each of the service leads.

The PCF also asked CCGs and Health Boards for information on alternative services provided to treat bladder and bowel conditions in children and young people. As demonstrated in table 4, school nurses were the most common alternative source of care in England, with 32.52% of CCGs naming school nurses; while in Wales it was broadly defined as “community based care” (71.4%) and in Scotland health visitors were the most common (38.46%). It should be noted that many CCGs and Health Boards listed more than one type of alternative provision.

Table 4: The proportion of CCGs and Health Boards listing types of alternative provision to paediatric continence services, 2017

<table>
<thead>
<tr>
<th>Type of alternative provision to paediatric continence services (2017)</th>
<th>England</th>
<th>N. Ireland</th>
<th>Scotland</th>
<th>Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>School nurses</td>
<td>32.52%</td>
<td>20.00%</td>
<td>15.38%</td>
<td>28.57%</td>
</tr>
<tr>
<td>Health visitors</td>
<td>23.30%</td>
<td>20.00%</td>
<td>38.46%</td>
<td>28.57%</td>
</tr>
<tr>
<td>Primary care/GPs</td>
<td>9.71%</td>
<td>0.00%</td>
<td>15.38%</td>
<td>0.00%</td>
</tr>
</tbody>
</table>
Health professionals such as school nurses, health visitors and GPs are crucial resources for this area of child health. They can play an important role in the early identification of continence problems and straightforward treatment (at Level/Tier1) with a pathway to the Level 2 Community Paediatric Continence Service if required – and are often the first point of reference for families with concerns about their child. However, these professionals have stretched workloads and cannot always provide the guidance needed. Additionally, many school nurses were affected by the transfer of commissioning for school nursing to local authorities in 2015, which has resulted in continence being removed from their remit in many areas.

Health visitors normally only work with children up to the age of 5, while school nurses may be more likely to focus on teenagers, with suggestions that in some areas of the UK this is leaving a large number of children aged 5-11 vulnerable to slipping in between services. GPs too have heavy workloads and receive only minimal or no training on continence issues. Clear signposting to local continence services is therefore essential for effective assessment and treatment.

**Question 4: For each of the above five services, please state how many people aged from birth to 18 years were referred to the service in each of the last five years.**

| Community care | 21.84% | 0.00% | 30.77% | 71.43% |
| Community nurses | 8.25% | 20.00% | 0.00% | 42.86% |

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Finally, each CCG and Health Board was asked how many children were referred to each of the above five services over the last five years, to try and gain an understanding of whether referrals have increased or decreased over this time. However, when analysing the results for England – chosen as it is the country with a particular divide in responsibility for providing continence services since the transfer of commissioning for school nurses to local authorities – there was a startling lack of information provided for this question.

The graph above indicates how CCGs answered this question, including where they suggested redirecting the question to. Only 4% of CCGs could give figures to answer the question, while a majority of CCGs (43%) said the information was not held, and 31% redirected the question to the Trust. This suggests a potential lack of accountability in some areas for assessing both service performance and whether services are appropriately resourced. Statistics on service referrals and contacts need to be readily available to providers and commissioners to justify the resources required for a paediatric continence service.

**Question 5a: Do you have any future plans to commission a new paediatric continence service?**

The numbers of CCGs and Health Boards reviewing the service provision in their areas may be a cause for optimism. The answers to questions 5a and 5b of the FOI survey identified that 10.82% of health authorities across the UK are planning to commission new services, and 36.8% are intending to review their service provision in the future. Declines in existing provision in Wales were particularly recognised in answers to these questions: 71.43% of Welsh Health Boards said they would be reviewing their existing bladder and bowel services, a 57% increase in the proportion expecting to do so in 2014.
Question 5b: Do you have any future plans to review the existing paediatric continence service

CCGs and Health Boards with plans to review their existing paediatric continence service

<table>
<thead>
<tr>
<th></th>
<th>2014 - Plans to review existing service</th>
<th>2017 - Plans to review existing service</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>41.00%</td>
<td>35.92%</td>
</tr>
<tr>
<td>Scotland</td>
<td>71.00%</td>
<td>30.77%</td>
</tr>
<tr>
<td>Wales</td>
<td>14.00%</td>
<td>71.43%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>40.00%</td>
<td>43.50%</td>
</tr>
<tr>
<td>UK average</td>
<td>36.80%</td>
<td>100.00%</td>
</tr>
</tbody>
</table>
Looking forward

In England, the period between the PCF’s 2014 and 2017 FOI surveys saw substantial changes to community health services. These include the transfer of school nurse commissioning from CCGs to local authorities in April 2015; and the drive to make efficiency savings to meet the ambitions of the NHS’s Five Year Forward View. It is encouraging therefore to see that overall there appears to have been a slight improvement in service provision.

For the devolved nations, especially Scotland and Wales, long periods of continuity in government and comparatively fewer changes to health service provision have not been reflected in the availability of paediatric continence services. This is certainly a cause for concern for the PCF and we hope to engage with the devolved governments over the coming years to understand how this problem can be addressed.

While these results provide a somewhat worrying picture of paediatric continence service provision in the UK, many respondents noted in their answer to question 5 plans to either commission new services or review their existing services. The PCF hopes that this will result in improvements rather than further cutbacks. Additionally, many respondents, particularly in England, reported having recently reviewed and commissioned new services, possibly in line with the commissioning cycle underpinning STPs.

Every area of the UK is currently examining how to make the best use of limited resources in the public sector and how to make health care sustainable on restricted budgets. In England, the Carter Review of productivity in NHS hospitals and the NHS RightCare programme have simultaneously brought focus onto the most efficient ways to procure and deliver services. Alongside the advent of STPs, this offers the opportunity to examine existing provision and make decisions to invest in preventative health services that will direct children and young people away from secondary care and result in long-term savings.

Paediatric continence services are an example of services which can deliver this sort of transformation, as they are clinically and cost effective, reducing unnecessary spending on unplanned hospital admissions, paediatric outpatient referrals and accident and emergency department attendances. STPs are also encouraging collaborative working across health economies and could result in existing CCG boundaries blurring, suggesting that services could be commissioned for multiple CCGs if it would benefit the whole STP.

In areas where CCGs or Health Boards are failing to commission proper community-based paediatric continence services, there is no indication that other providers – such as the local authority or acute trusts – are stepping in to fill gaps in provision. Even if this does happen, it presents a picture of
fragmented, less effective and more costly provision, in which children will continue to fall through the net.

**Question 7: Are you aware of the NICE-accredited Paediatric Continence Commissioning Guide? If so, do the services commissioned in your CCG/Health Board use it?**

The PCF’s NICE-accredited Paediatric Continence Commissioning Guide is one of the key tools to facilitate commissioning of children’s continence services. It was extremely encouraging to discover that so many CCGs and Health Boards are aware of the Guide (64.07%) and nearly half have used it in their local services (49.78%), as displayed in the chart above. We hope that the PCF’s supporters will be able to spread information about this Guide further, to ensure that as many health economies as possible have access to information on why and how to commission appropriate services.

**Recommendations**

In light of the findings of this report, the PCF would like to make the following recommendations to policymakers and service providers:

- Every child and young person in the UK should have access to an integrated, community-based, well-resourced paediatric continence service.

- Health services and local authorities should work collaboratively to ensure that these services are available in every community, recognising that it is their responsibility to work together to provide them, despite recognised clinical and financial pressures.
• Information about the provision of local services should be readily available in health and educational settings – i.e. GP practices and schools. It should also be clear who can refer to these services and how families and young people can contact referrers, e.g. GPs, school nurses and health visitors.

Further information and resources

The PCF’s clinical members are leading authorities on paediatric continence in the UK and can provide advice on creating a business plan for a paediatric continence service. If your CCG or Health Board would like to discuss this further, please contact us at paediatriccontinenceforum@whitehouseconsulting.co.uk.

For further information on the issues discussed in this report, the PCF would recommend the following resources:


• NICE guidance on bedwetting in under 19s, available at https://www.nice.org.uk/guidance/cg111.

• NICE Quality Standards on bedwetting in under 19s, available at: https://www.nice.org.uk/Guidance/QS70.


For support relating to personal or family experiences of bladder and bowel problems, please contact:

• ERIC, The Children’s Bowel & Bladder Charity  
https://www.eric.org.uk/
Helpline: 0845 370 8008* (Calls to the Helpline cost 9.6p per minute plus service provider charge)

- **Bladder & Bowel UK** (formerly PromoCon)
  
  [http://www.bladderandboweluk.co.uk/](http://www.bladderandboweluk.co.uk/)

  Helpline telephone: 0161 607 8219

The PCF has for many years worked with ChiMat (the National Child and Maternal Health Intelligence Network, or ChiMat, now part of Public Health England), to compile an online **Continence Needs Assessment Report**. This provides estimates of the numbers of children in CCGs and top level local authorities with bedwetting; daytime wetting; unplanned admissions to hospital for UTIs and constipation; and the PCF’s FOI data on service provision for 2014. The tool can be accessed at this link, but it should be noted that it may be archived in future as ChiMat’s online data is being moved to Public Health England’s new “Fingertips” tool. It may be at least a year before the Continence Needs Assessment report will be fully re-instated and updated.
Appendix

2017 research: Freedom of Information requests to CCGs and Health Boards

1. Please state whether the following five paediatric continence services have been commissioned by your CCG/Health Board:
   a. Bedwetting;
   b. Daytime wetting;
   c. Toilet training;
   d. Constipation/soiling;
   e. Product supply for paediatric continence problems.

   If any of the above services are not commissioned by your CCG/Health Board, please let us know which partner organisation does commission the service.

2. Is there a single service for the above five problems? If the answer is yes, is this service led by a paediatric continence advisor?

3. If the answer to question 2 is no, please list the services that are commissioned to handle these problems and the designation of each of the service leads.

4. For each of the above five services, please state how many people aged from birth to 18 years were referred to the service in each of the last five years.

5. Do you have any future plans to:
   a. commission a new paediatric continence service; or
   b. review the existing paediatric continence service?

   If so, please provide details.

6. How many nurses specialising in paediatric continence are currently employed by the services commissioned by your CCG/Health Board? Please specify whether they have had specific training in:
   a. Children’s nursing;
   b. Paediatric continence management.

7. Are you aware of the NICE-accredited Paediatric Continence Commissioning Guide? If so, do the services commissioned in your CCG/Health Board use it?