An Examination of Paediatric Continence Services Across the UK

Results of a Freedom of Information Request

June 2022

A report by the Paediatric Continence Forum

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About the Paediatric Continence Forum

The Paediatric Continence Forum (PCF) has campaigned since its inception in 2003 for improvements to children's bladder and bowel services across the UK. The organisation's clinical members include key paediatricians and specialist nurses in the field, with formal representation from the All Wales Continence Forum, Bladder & Bowel UK, The British Association of Paediatric Urology and Continence Nurses, The Community Practitioners' and Health Visitor' Association, ERIC, The Children's Bowel & Bladder Charity, Paediatric Continence Scotland, The Royal College of Nursing, the Royal College of Paediatrics and Child Health, the School and Public Health Nurses Association and from Northern Ireland. The PCF also has four commercial members who support its work: Coloplast UK, Essity Ltd., Kimberly-Clark Europe Ltd, and Norgine Pharmaceuticals Ltd.

Executive summary

- This report provides an analysis of the Paediatric Continence Forum's 2021 Freedom of Information (FOI) survey of paediatric bladder and bowel (continence) services across the UK. It is for anyone with an interest in paediatric continence, including commissioners, policymakers, service providers, parents, carers, children and young people.

- Bladder and bowel dysfunction (continence difficulties) include bedwetting, daytime wetting, constipation/soiling, and difficulties with toilet training. They are thought to affect about 1 in 10 out of a total population of 14,015,000 children and young people in the UK. However, the prevalence is likely to be higher than this, due to under-reporting because of the stigma, shame and embarrassment associated with these conditions, as well as the frequent mistaken assumptions that they are developmental and therefore self-limiting for most and inevitable in those with disabilities.

- Provision of comprehensive integrated community bladder and bowel 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'), hence making better use of restricted NHS resources. This provision also improves clinical outcomes, quality of life and the experience for families and 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 nurse-led paediatric continence service. This service should cover all areas of bladder and bowel dysfunction (constipation and soiling, daytime wetting, bedwetting and toilet training difficulties) as these often co-exist. The service should also arrange provision of appropriate products for those who are clinically assessed as unable to achieve continence. It should be staffed with an appropriate skill mix and be adequately resourced to meet local clinical need. It should be led by a paediatric continence nurse specialist.

- In Autumn 2021, the PCF sent an FOI request to all Clinical Commissioning Groups (CCGs) in England, Health Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland (hereafter, 'NHS organisations') to establish how many of them are providing the above service. The results have been compared to the results with similar FOI requests undertaken in 2011, 2014 and 2017. This FOI request was delayed by one year due to the COVID-19 pandemic.

- This study identified continued disparities in paediatric continence service provision across the UK, despite a small overall improvement over the preceding four years. In 2021, 37.89% of NHS organisations provide integrated services for constipation and soiling, difficulties with toilet training, daytime bladder issues, and bedwetting as well as product provision to those clinically assessed as unable to be continent, compared to 30.74% in 2017. All four nations have shown an improvement in service provision compared to those reported by survey respondents in 2017, although in some areas services are still not at a standard reported in 2014.

- The 2021 survey showed an increase in the number of NHS organisations that are aware of the Children's Continence Commissioning Guide, which provides clear guidance on how to set up and run an integrated, community-based nurse-led paediatric continence service. 72.67% of NHS organisations are aware of the guide in 2021, up from 64.1% in 2017.

- The PCF continues to make the following recommendations:

    - Every child and young person in the UK should have access to a well-resourced integrated, community-based, nurse-led paediatric bladder and bowel service.

    - As provision of appropriate clinical services can produce cost savings, reduce clinical pressures in other parts of heath care, and improve outcomes, statutory bodies that provide for health promotion and clinical should work collaboratively to ensure that integrated children's bladder and bowel services are available in every community for every child or young person that has a clinical need for them. They should recognise that there is a risk in terms of clinical governance to fail to provide these services and it is their responsibility to work together to provide them.

    - Information about the local children's bladder and bowel services should be readily available in all statutory settings (health, education, and social care). It should be clear who can refer children and young people to these services and how families and young people can contact referrers. Services should also be publicised, while ensuring that all children, young people, and their families know how to access them.

Part 1: Introduction

The Paediatric Continence Forum (PCF) was set up in 2003 to increase political awareness of the needs of children and young people with bladder and bowel difficulties, and to improve NHS services in this often-neglected area of child health. This FOI was sent out by the PCF in Autumn 2021 to all Primary Care Trusts in 2011 and to CCGs, Health Boards and Health and Social Care Boards across the United Kingdom to establish the extent of service provision, current gaps and discrepancies as well as plans for changes. Previous FOI requests were sent in 2011, 2014 and 2017, with the recent request delayed from 2020 to 2021 due to awareness of the extraordinary strains on services due to the COVID-19 pandemic.

Bladder and bowel dysfunction (continence difficulties) include constipation, which is often associated with soiling, bedwetting, daytime wetting, and toilet training difficulties. They are thought to affect about 1 in 10 children in the UK out of a population of 14,015,000. However, this figure is likely to be higher due to under-reporting and the embarrassment and stigma associated with these conditions, as well as the frequent mistaken assumptions that they are developmental and therefore self-limiting for most and inevitable in those with disabilities.

Research indicates a clear link between bladder and/or bowel issues and negative social behaviour including bullying, both as perpetrators and recipients, as well as a loss of self-esteem during important formative years. Missed education because of increased toilet visits or time at home due to associated problematic symptoms can have long-term negative effects on educational achievement and attainment, with the impact felt through to adulthood and employment opportunities. Additional costs of washing, drying extra clothing, or bed linen and additional difficulties with child-care for a child who requires intimate care, has a negative impact for all, but a disproportionate effect on those with lower incomes. There is also a link with punitive family responses which may be significant enough to constitute safeguarding concerns or which may escalate to abuse. Furthermore, alongside the increased risk of abuse for the child who is incontinent, abused and looked after children are more likely to be affected by incontinence than the general population.

If continence is actively promoted and if bladder or bowel difficulties are identified early and effectively treated in the community, by a nurse-led integrated bladder and bowel service, symptom escalation is prevented, the risk of expensive paediatric consultant referrals, and unplanned hospital admission or accident and emergency attendance is reduced, as is the need for provision of products to children with disabilities. Timely treatment also alleviates the associated stigma, embarrassment, and stress, radically improving the quality of life for the children and young people concerned and their families.

What should a good and accessible community integrated nurse-led paediatric continence service look like?

A well-resourced, community-based, paediatric continence service should be a single integrated nurse-led service covering all aspects of bladder and bowel care, given that there are clear causal links between conditions affecting different aspects of continence. For example, children with constipation may experience difficulty or delay in attaining or maintaining daytime bladder control, and constipation may also impact on bedwetting. Furthermore, certain continence issues, such as mixed day and night wetting, are more likely to persist into adolescence and less likely to resolve without proactive treatment.

Paediatric continence services should treat children and young people of all ages, from birth to 19 years old. This will avoid delays in treating younger children, which may prevent problems from escalating, and stop those who are older from falling through gaps in provision when they reach a certain age. Effective transition to adult bladder and bowel services for young people with ongoing issues is also important. Additionally, services should not exclude children and young people with additional needs or disabilities who have a bladder or bowel health issue. To do so may be in breach of the Equality Act 2010.

The paediatric bladder and bowel service should have an appropriate skill-mix and should be led by a paediatric continence nurse specialist. There should be clear and effective referral and care pathways to level/tier one (GP, school nursing and health visiting) and level/tier three (secondary care), as well as interdisciplinary working as appropriate to each child, including with early years, education, child, and adolescent mental health services (CAMHS) and social services.

School nursing and health visiting should be encouraged to act as tier/level one providers for continence, offering initial assessment, advice and intervention. This, alongside effective referral and care pathways is essential as continence issues may impact different aspects of a child's wellbeing, such as school performance or social interactions, or be associated with other issues including psychological or mental health conditions, which can be risk factors for and impacts of bladder and bowel issues. These issues should be addressed alongside the bladder or bowel problem. There should also be appropriate transition for young people into adult services for those who need it.

The Children's Continence Commissioning Guide, available on the PCF's website, provides more information.

Previous and current PCF FOI surveys: 2011, 2014, 2017 and 2021

The PCF submitted the FOI to all NHS organisations in 2014, 2017 and 2021. The 2017 findings showed a small reduction in the levels of disparity in paediatric bladder and bowel service provision, with 41.13% of NHS organisations providing services for all areas of paediatric continence needs

(constipation and soiling, bedwetting, daytime wetting, delays in toilet training and product provision), compared with 38% in 2014.

Direct comparison with the FOI survey and report for 2011 is limited as it focussed specifically on provision of services for children's bladder and bowel care in England. Consequently, there is not sufficient data to provide full comparisons. Similarly, certain questions in the 2014 FOI were phrased differently, causing gaps in data. Where data from these years is available, it is included and presented comparatively below.

The 2021 results show that just over half (50.93%) of respondents across the whole UK now provide services for all areas of bladder and bowel difficulty, including product provision to children and young people who cannot be continent. This demonstrates a slow but gradual improvement in the overall availability of services for children and young people across the country. However, nearly half of all areas are still not providing access to these cost-effective services that have such a significant positive impact on appropriate use of NHS resources and on quality of life to the child or young person and their family, which remains concerning. Additionally, a mere 37.89% of these services across the UK are integrated (services that provide for all bladder and bowel issues in one place, i.e., constipation and soiling, day and night time wetting, toilet training and product provision).

Previous FOI reports noted a worrying disparity in service levels across the devolved nations, worsening each time. The 2014 results noted that the percentage of NHS organisations with fully integrated services in England, Scotland, Wales and Northern Ireland were 26%, 36%, 29% and 40% respectively. High levels of disparity continued in 2017, with the results in each nation being 31.55%, 23.08%, 0% and 60% respectively. The 2021 results show that despite each nation improving on this front, disparities continue, with the results in each nation being 40.15%, 21.43%, 20% and 80% respectively.

While these figures suggest that England and Northern Ireland have improved slightly on each survey, there remains a long way to go towards achieving comprehensive integrated services. Scotland appears to initially have lost integrated services between 2014, 2017, and 2021. Wales appears to have lost all of its integrated services between 2014, 2017, before returning to 20% in 2021.

However, direct comparisons need to be treated with significant caution. Due to mergers of CCGs, Health Boards and Health and Social Care Boards over the years and boundaries changing, the number of NHS organisations that this survey was sent to has reduced by nearly half between 2017 and 2021. As a result, it is somewhat difficult to make comparisons and paint an accurate picture of improvements or changes in service provision, given that some responses covered multiple areas. An overview of the results of the PCF's 2021 FOI survey is provided below, with the full set of questions asked available in **Appendix 4**.

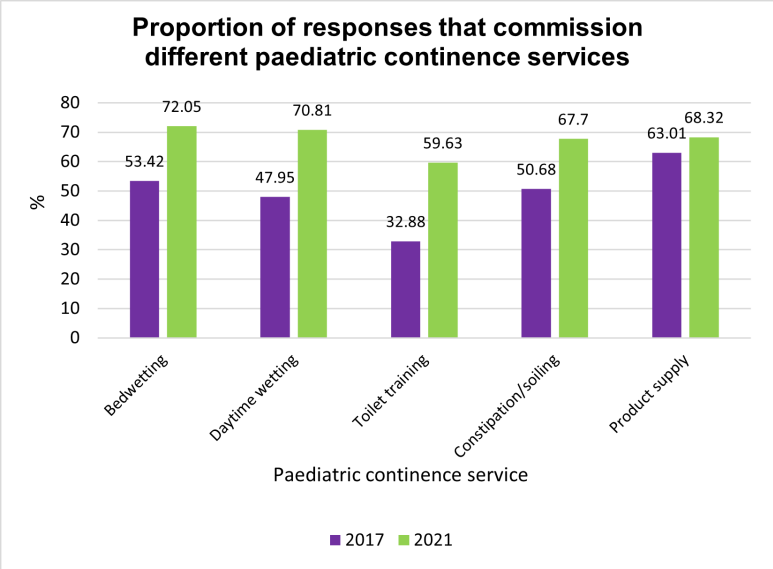
Part 2: NHS Organisations

While comparisons with statistics from previous FOI reports are given, the composition of numerous CCGs has changed since 2017 as a result of mergers, dissolutions, and expansions of various CCGs in England. Some NHS organisations also provided responses according to sub-area or local provider. Therefore, while the comparison across time provides a productive evidence base with which to understand changes in paediatric continence provision, more detailed comparisons by individual commissioner or area are not necessarily as informative. Where feasible, graphs have been formatted to compare results across time. Where more useful, other graphs compare results by UK nation or by specific paediatric continence service offered.

The FOI sent to all NHS organisations in the UK resulted in 159 responses, with some areas providing more than one response having been disaggregated into sub-areas or by local provider. Analysis of these responses demonstrates variation in service provision across the UK nations, including significant change – both positive and negative – since the previous analysis conducted in 2017 and since the first FOI survey in 2011. Responses were received between August and September 2021.

Question 1: Please state whether the following five paediatric continence (bladder and bowel) services are commissioned by your CCG/funded by your Health Board.

Figure 1



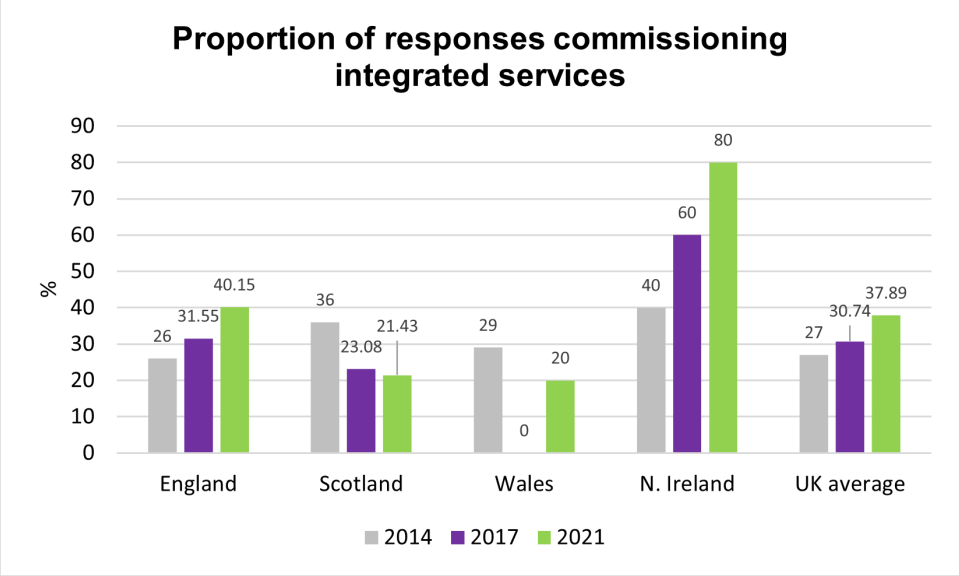
The above results indicate evidence of improvement in provision of all aspects of paediatric continence care that were included in the FOI request – bedwetting, daytime wetting, toilet training, constipation, soiling, and product supply – between 2017 and 2021, with an improvement of almost 20% for

bedwetting and over 20% for daytime wetting. However, despite this improvement, significant and worrying gaps in service provision remain.

Toilet training was the least widely reported service to be commissioned or funded in 2021, with only 59.63% of respondents offering this. Although this represents a 26.75 percentage point improvement since 2017, over one third of areas continue to have no access to this support. The PCF are not aware of any area in the UK that is not providing products to children and young people. However, to provide products without a full clinical assessment of bladder and bowel health and the ability to toilet train and providing support to toilet train as appropriate in line with the National Guidance on the Provision of Continence Containment Products to Children and Young People is inappropriate, as it reduces the likelihood of children reaching their potential in this key area of development, and may result in treatable bladder and/or bowel conditions being missed (which is also costly to the NHS).

Question 2a: Is there a single (integrated) service for all the above five problems?

Figure 2

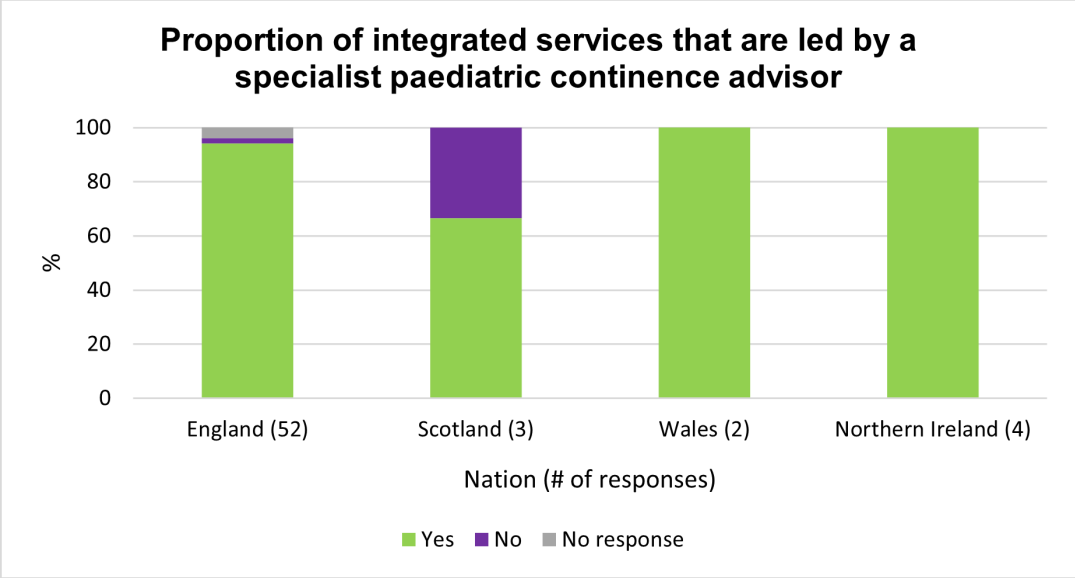


The integration of children's bladder and bowel services (that is, the provision for all issues in one service) by NHS organisations paints a less positive picture, particularly when disaggregated by UK nation. In England, the proportion of responses that recorded an integrated service for all five problems continued an upward trend since 2014, increasing from 31.55% in 2017 to 40.15% in 2021, while responses in Wales increased from 0% to 20% (although not quite returning to 2014 levels) and in Northern Ireland increased to 80%. In Scotland, however, the proportion fell further from 23.08% to 21.43% between 2017 and 2021, following a fall from 36% in 2014. Additionally, in 2021, 17.42% of English responses were unable to provide this information. This is concerning both in terms of a lack of awareness of what areas provide these services, and in anticipation of attempts at future improvements in integration.

Those that do not have an integrated service most frequently cited reliance on health visitors, school nursing, and adult services to provide for the problems listed above. This is concerning, as since 2015 health visitors and school nurses have been employed within a public health role, with continence being seen as a clinical need and therefore beyond the remit for many of them. Adult services are not usually trained, experienced or funded to provide bladder and/or bowel care to children. They therefore often only provide products based on a diagnosis of disability and are unlikely to be ensuring the appropriate assessments of bladder and bowel health or to be providing the required support with individualised toilet training programmes.

Question 2b: Of those that do have a single integrated service, are these led by a paediatric continence advisor?

Figure 3



In 2021, the vast majority of the respondents that had a single integrated service for all issues (constipation and soiling, day and night time wetting, issues with toilet training and product provision to those clinically assessed as unable to become continent), noted that the service is led by a paediatric continence advisor: 49 out of 52 responses (94%) from England, two out of the three integrated services in Scotland, both those in Wales, and all four in Northern Ireland. The 6% of responses in England that did not provide an answer to the question appear as 'no response' on the graph.

In total, 36.54% of all responses, regardless of their level of integration, reported having services led by a paediatric continence advisor – an improvement on the UK average of 22.94% recorded in 2017. However, worryingly, over two thirds of areas continue to lack services led by an individual appropriately trained and experienced in paediatric continence, and who is specifically employed for the role.

Question 4: If you answered yes to any part of question 1, please tell us how many children and young people with continence problems are currently on the caseload of the service?

Figure 4

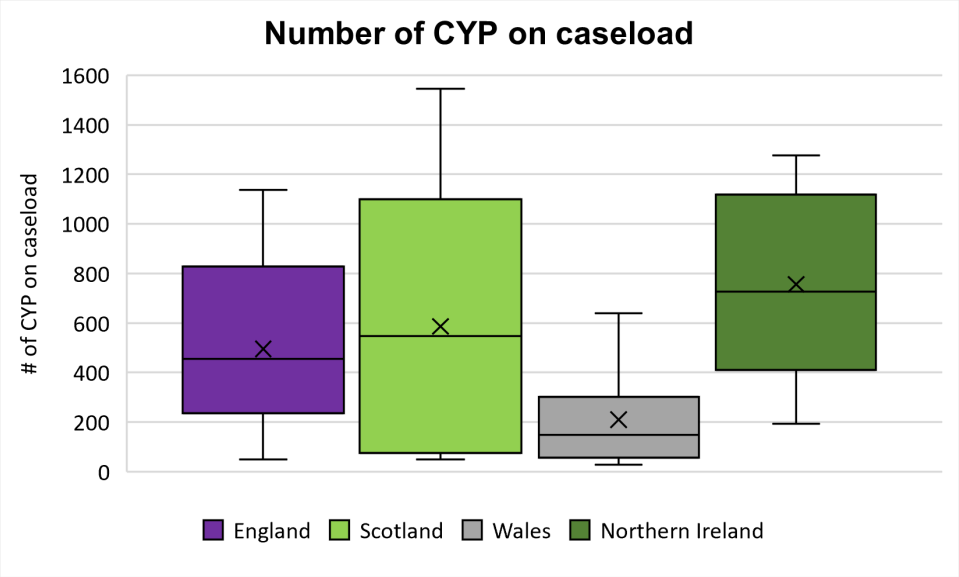


Figure 4 above provides a visual interpretation of the responses regarding numbers of children and young people on the caseloads of children's bladder and bowel services by each country in the UK, where any of constipation and soiling, day or night time wetting, support for delayed toilet training or product provision are provided. The coloured box reflects the interquartile range – the middle 50% range of the data – while the cross represents the mean value and the horizontal black line the median value. It should be noted that one response in England which stated a caseload of 11,011 children and young people has been omitted from the graph to avoid skewing the results, as a significant outlier in the data.

The mean number of children and young people on the caseload of services was recorded as 495.1, 586.1, 209.4, and 756.4 for England, Scotland, Wales, and Northern Ireland respectively (omitting the large outlier in England). The range of responses across all the devolved nations, however, represented by the vertical black lines on the graph, indicates a wide dispersion – with caseloads varying from a minimum of 50 to a maximum of 1,546 in Scotland, and from 50 to 11,011 in England (including the anomaly, or 50 to 1,138 excluding it). The ranges for Wales and Northern Ireland were 40 to 639 and 192 to 1,276, respectively.

Large caseload numbers may suggest cause for concern in terms of resourcing of services. However, caseload numbers can only be meaningfully considered alongside information about the number of whole time equivalent (WTE) staff in each service, their skill-mix, and the level of need of individual children. Occasionally, conditions may resolve after two or three appointments, while most will require longer-term support and follow up. Some may need this for many months. All children and young

people require timely support and interventions, individually tailored to need. It is difficult to see how this can be provided in the context of such high caseload numbers in many areas.

Table 1 below cross-references the mean caseload number of children and young people in each UK nation with the mean number of whole time equivalent (WTE) staff. The information on staff numbers was provided in responses to question 6 in the FOI survey (see Appendix 4). Note that the averages given only consider those survey responses that were able to provide this information. The comparison presents a worrying picture of a minimal number of WTE staff resourced for very high caseload numbers. Such sparse staffing inevitably restricts the quality, responsiveness, and effectiveness of paediatric continence services for children and young people that need it.

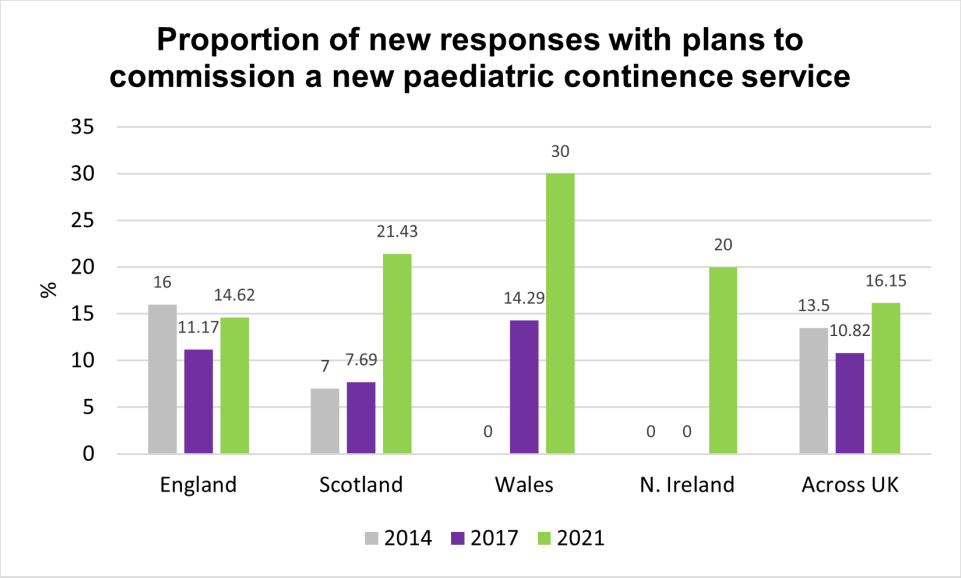
Table 1

	England	**Scotland**	**Wales**	**N. Ireland**
Mean caseload number	495.1	586.1	209.4	756.4
Mean number of WTE staff	1.85	1.31	1.16	2.32

It is equally striking that 73 out of the 113 respondents from England (64.6%) and one of fifteen (6.66%) from Scotland were unable to provide information about caseload numbers. This lack of information is concerning, suggesting that commissioners are unaware of the needs of children with bladder and bowel dysfunction, or in some cases, of what is being provided. The wide range in the size of caseloads also warrants research to try to understand the reasons for this.

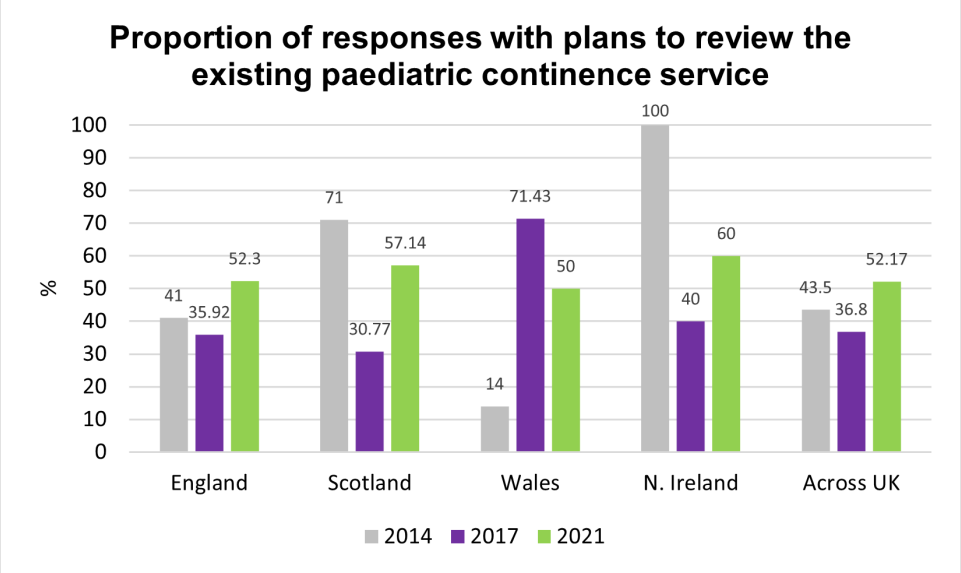
Question 5: Do you have any future plans to commission/provide a new paediatric continence service, or to review the existing paediatric continence service?

Figure 5a



As shown in Figure 5a, the 2021 data indicate an increase in the number of NHS organisations that are planning to commission or provide a new paediatric continence service, increasing from 11.17% to 14.62% (19 of 130) in England between 2017 and 2021 (but failing to meet the level in 2014), from 7.69% to 21.43% (3 of 14) in Scotland, from 14.29% to 30% (3 of 10) in Wales, and from 0% to 20% (1 of 5) in Northern Ireland. That said, only 16.15% of responses across the whole UK reported intentions to commission new services, against a backdrop of 38.36% across the UK currently having an integrated children's continence service (see Figure 2).

Figure 5b



At least half of responses from all four UK nations (52.3%, 57.14%, 50%, and 60% for England, Scotland, Wales and Northern Ireland respectively) indicated that they plan to review their existing paediatric continence service, amounting to 52.17% of responses from across the UK. Several of those intend to restructure their services to create a more integrated regional provision; for example, pan-Dorset, pan-Staffordshire or across Liverpool and Sefton CCGs. Wales was the only devolved nation to indicate a fall in the number of responses with plans to review the existing service. Additionally, of the total responses across the UK that indicated a lack of such plans, five have only recently commissioned new services, so would not be expected to be reviewing services imminently.

It must also be noted that plans for service review may not be positive. The question does not ask whether there are plans for improvement, just for review. Review could be undertaken with the idea of diverting resources to other areas of health provision that are considered to have higher priority of need. Furthermore, plans for review may not result in the review being undertaken or improvements being seen if other priorities intervene.

Part 3: Local Authorities

An FOI request was also sent to all local authorities in the UK between August and September 2021. 90 out of a total 429 local authorities (20.98%) responded to the request. Percentages provided below are based both on the total number of authorities and on those that responded, as indicated.

Does your local authority provide a dedicated children's continence clinic?

Of the 90 local authorities that submitted a response, only nine (10% of respondents, or 2.1% of total) indicated that they provide a dedicated children's continence clinic. 20 (22.22% of respondents, or 4.66% of total) indicated that they do not, while 1 did not answer. The remaining 60 local authorities that responded to the FOI request indicated that the service is provided by CCGs/Health Boards (45.56% of respondents, or 13.99% of total), by Healthcare Trusts or NHS Foundation Trusts (8.89% of respondents, or 1.86% of total), or by other providers (5.56% of respondents, or 1.17% of total). Examples of such other providers include not-for-profit service Achieving for Children in the Royal Borough of Kingston upon Thames and the Royal Borough of Windsor and Maidenhead or Evelina London in the London Borough of Lambeth.

Which of the five continence services are covered by the dedicated continence clinic?

None of the local authorities that provided a response indicated that all five continence services are provided. Six indicated that they provide four out of five services: Brighton and Hove City Council, Cambridgeshire County Council, Leicestershire County Council, Monmouthshire Council, Northumberland County Council, and Peterborough City Council. Of those, the most common service not provided was product supply (three of six), followed by daytime wetting (two of six) and toilet training (one of six).

Individually, the most commonly provided service of the local authorities that responded was bedwetting (8 of 90, 8.89%), followed by constipation or soiling services (7 of 90, 7.78%). Five local authorities (5.56% of respondents, or 1.17% of total) indicated that toilet training is covered by a dedicated continence clinic, while only four indicated that daytime wetting or product supply are provided (4.44% of respondents, or 0.93% of total).

Is the amount of time dedicated to service provision in this clinic determined by the number of children and young people being referred to the clinic each week, or regulated in another manner?

Three local authorities (3.33% of respondents, or 0.7% of total) indicated that the amount of time dedicated to service provision is determined by the number of children and young people referred each week. Six (6.67% of respondents, or 1.41% of total) indicated that this was not the reason. Of those that responded it was not, methods of regulation vary from depending on the needs of the child or young person being assessed (London Borough of Waltham Forest), to assessments limited to ad hoc provision for children requiring product assessments (Leicestershire County Council), to no cap at all

on the amount of time dedicated (Northumberland County Council). 13 local authorities (14.44%, or 3.03% of total) either could not answer or did not provide the information.

Is continence a listed responsibility provided by your local authority for professions including school nurses, health visitors, or other healthcare professionals?

Eight local authorities had continence as a listed responsibility for school nurses (8.89% of respondents, or 1.86% of total), while six had it as a listed responsibility for health visitors (6.67% of respondents, or 1.41% of total). Five local authorities recorded that it was a listed responsibility for other healthcare professionals (5.56% of respondents, or 1.17% of total); these were either assistant or associate practitioners (Brighton and Hove City Council, Cambridgeshire County Council and Peterborough City Council) or alternative services such as that which is part of broader regional health and care services (London Borough of Sutton) or with an in-house specialist nurse (London Borough of Waltham Forest).

That continence is not explicitly included in the Health Visiting and School Nursing Framework (May 2021) as a responsibility is of grave concern. It is likely that this is reflected in the low numbers stating that continence is listed as a responsibility for health visitors. Given that a key part of their role is supporting early development and ensuring that children are ready for school, they are in a unique position to be able to support toilet training and to be able to help identify issues such as constipation, where the incidence is highest in toddlers and per-school children.

Do you have any future plans to commission/provide a new paediatric continence service or to review the existing service?

Of the 28 local authorities that responded to the question about whether they have future plans to commission or provide a new service, 26 said that they do not (92.86% of 28 respondents, or 6.06% of total), while only one – Cambridgeshire County Council – said that they do (3.57% of 28 respondents, or 0.23% of total). One – Leicestershire City Council – indicated that the question was not relevant for the local authority.

22 local authorities (5.13% of total) responded that they do not have plans to review the existing paediatric continence service, while three (0.7%) said that they do. Of those three, Leicester City Council said that a review will be “heavily discussed with partners as part of the S75 work to see how they can move and shape their services offer so it aligns as tightly as possible with the Public Health Offer”; the London Borough of Waltham Forest said that a revised business plan has already been submitted to Commissioners; and Suffolk County Council said they had plans for a review but could not provide further detail.

Are you aware of the Children's Continence Commissioning Guide?

Of 28 responses, 15 local authorities (53.57% of respondents, or 3.51% of total) said they were aware of the Guide while nine (32.14% of respondents, or 2.11% of total) indicated that they were not. Two said the information was not held and two did not provide an answer.

Of the 15 that indicated they were aware of it, nine said that the services commissioned or provided by the local authority actively use the Guide. There was a common response that the local authority uses it to commission the "universal elements" of the service, or those which the local authority provides itself, while specialist elements are the responsibility of the CCG/NHS. Responses that indicated this included Peterborough City Council, Scottish Borders Council, West Dunbartonshire, and Suffolk County Council.

Part 4: Looking forward

The Health and Care Bill, which was introduced in the House of Commons in July 2021 and achieved royal assent in May 2022, covers England and takes forward recommendations for legislative reform published in the NHS Long Term Plan (January 2019) and the White Paper, Integration and Innovation: working together to improve health and social care for all, (February 2021). This Bill abolishes clinical commissioning groups in England and replaces them with integrated care boards (ICBs) to commission hospital and other health services. It also establishes integrated care partnerships (ICPs) to bring together ICBs and local authorities to produce an integrated care strategy for their geographical areas. All 42 Integrated Care Systems (ICSs) are expected to be fully operational by July 2022.

The PCF has worked with other organisations that represent children and young people to ensure that children and young people's needs are met, and that their needs receive equal priority within ICSs, while also campaigning for ICSs to consider the voices of children, young people and parents/carers. This will provide leadership, ensuring that children are prioritised within ICSs and that the distinct services and workforce that support them are represented. The PCF has also campaigned to ensure that services for children and young people are appropriately represented within ICPs and, in particular, for the new system to ensure that there is a single, integrated, community-based, nurse-led paediatric continence service within each area. ICPs will be required to produce an integrated care strategy, and local authorities would be required to have regard to it in exercising their functions.

Once the ICSs have been established, which is anticipated to be in July 2022, the PCF will ensure that they are made aware of the Children's Continence Commissioning Guide, so that they have appropriate information about how to commission and run integrated, community-based, nurse-led, paediatric continence services that are clinically effective, improve the lives of children and their families, and generate significant cost savings for the NHS.

Information on current service provision in each of the ICS areas can be found in Appendix 3. This table also shows which of the areas stated that they have plans to review their current service or commission a new service, and which areas have no plans to do so. Plans to review a service might be positive if these intend to increase effectiveness of the service and to make sure that fully integrated services, delivered by a nurse-led clinical team led are in place, including bedwetting, daytime wetting, constipation, soiling, delayed toilet training and product provision for children unable to toilet train.

Conversely, service review could also be about reducing service provision. The PCF advocates that fully integrated services provide better value for money, and in the long-term will lead to cost savings as well as better patient outcomes. Reduced services will add costs to other parts of the health system such as paediatric outpatient referrals, attendance at A&E, unplanned admissions and products for children with disabilities who have the potential to toilet train. The integrated care systems provide a

great opportunity for commissioners and providers to review and plan wholistically to deliver high-quality, cost-effective services.

Furthermore, if a service has recently been reviewed, or has no plans to review, and is already well resourced and functioning effectively, then a review may not be necessary.

Question 7: Are you aware of the Children's Continence Commissioning Guide? If so, do the services commissioned in/provided by your CCG or Health Board use it?

Figure 6

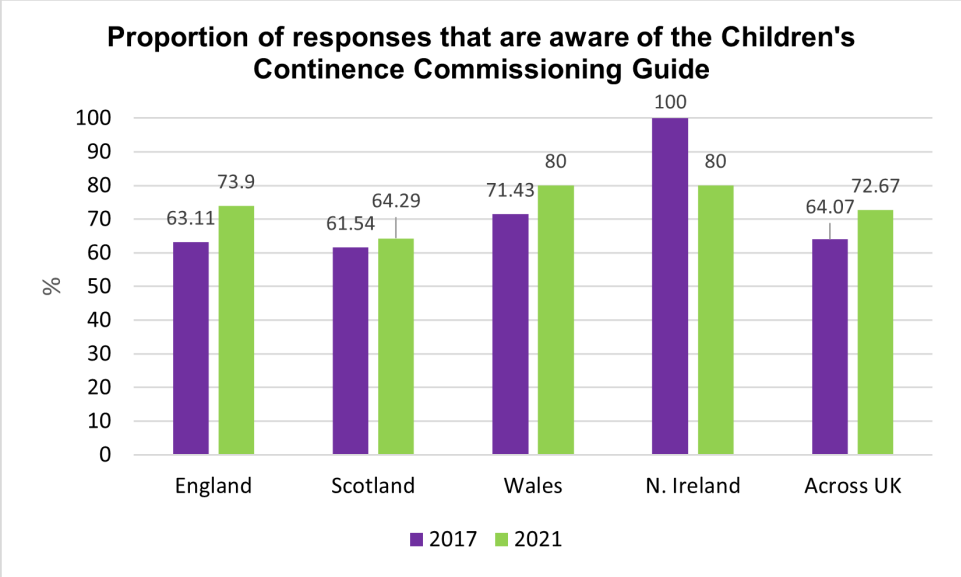
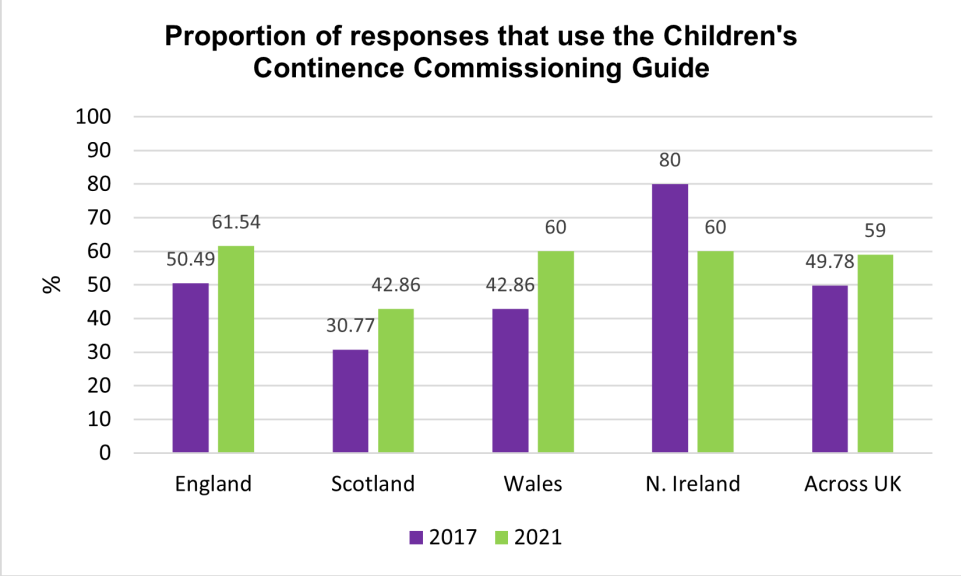


Figure 7



Figures 6 and 7 above visualise the proportion of responses that have heard of and that use the PCF's Children's Continence Commissioning Guide ('the Guide') in 2017 and 2021. Note that the Guide was first published in 2014, hence this data was unavailable any earlier than 2017, the first report since its publication.

Together, the graphs indicate that the already strong indication of the awareness and utilisation of the Guide across the UK has improved further between 2017 and 2021. Almost three quarters (72.67%) of responses across the UK in 2021 indicated that they had heard of the Guide, while over half (59%) said that they use it – up from 64.07% and 49.78% respectively in 2017. When disaggregated by UK nation, England, Scotland and Wales all recorded an increase both in the proportion of responses that have heard of and that use the Guide. Interestingly, the proportions of responses that have heard of or use it has decreased in Northern Ireland. While this may be due to changes in the composition of some Health and Social Care Trusts, the PCF is aware that commissioners in Northern Ireland have done a substantial amount of work to set up new services recently; in such instances, it is possible that these new services will not require use of the Guide again imminently.

Recommendations

In light of the findings of this report, the PCF 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, nurse-led and well-resourced children's bladder and bowel service. Not only will this improve quality of life for the child or young person and their family, but also has the potential to realise significant cost-savings for the NHS.

- All organisations providing health care (i.e., CCGs and subsequent ICBs and ICPs in England, Health Boards in Wales and Scotland and Health and Social Care Trusts in Northern Ireland) should work collaboratively to ensure that these services are available in every community. They should also recognise the need for an adequate minimum of paediatric continence services in light of the clear cost and health benefits for children, and given that material costs of care in the long run are far greater than prevention or early diagnosis. For example, diagnosing and treating a problem before hospital admission is required saves an average of £56 per patient, while each successive paediatric appointment is an average of a further £133 per patient.

- When reviewing service provision, consideration should be given to ensure that resourcing is sufficient to meet local need and to maximise effectiveness and efficiency of the services. Reviews should be mindful that lessons have been learnt during the pandemic, with some positive innovation, such as increased use of remote consultations, with the caveat that these

are not appropriate for everyone and there is unequal access to the required technology. Negative impacts of the pandemic include increased wait times between referral and initial appointment, increased times between reviews, as well as acknowledgement that examinations cannot be undertaken remotely, and that in-person appointments give increased opportunity to engage the child or young person and provide additional context, particularly where there may be safeguarding issues.

- Information about the provision of local services should be readily available to the community and to statutory organisations. 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

For further information on the issues discussed in this report, please contact us at paediatriccontinenceforum@whitehousecomms.com. The PCF recommends the **PCF Continence Commissioning Guide** available from: http://www.paediatriccontinenceforum.org/wp-content/uploads/2019/12/PCF-Childrens-Continence-Commissioning-Guide-Dec-2019.pdf

The PCF also recommends the following further resources:

- **Excellence in Continence Care** (2018): Practical guidance for commissioners, providers, health and social care staff and information for the public, developed by NHS England.
- **NICE guidance on bedwetting in under 19s** (published 2010).
- **NICE quality standard on bedwetting in under 19s** (published 2014).
- **NICE clinical guideline on constipation in children and young people: diagnosis and management** (last updated 2017).
- **NICE quality standard on constipation in children and young people** (published 2014).
- **UK Continence Society minimum standards for paediatric continence care in the UK** (published 2017).
- **Paediatric Continence Scotland Survey Report** (2021)
- **Bladder and Bowel Health in Children learning module** (2021): developed by health professionals for Paediatric Continence Scotland in association with the Scottish Government.
- **Paediatric Continence Scotland Continence Network Proposal** (2020)

For direct support and information for children, young people and their families and carers please contact:

- **Bladder & Bowel UK**
  https://www.bbuk.org.uk/
  Helpline telephone: 0161 607 8219

- **ERIC, The Children's Bladder & Bowel Charity**
  https://www.eric.org.uk/
  Free Helpline: 0808 169 9949 or https://www.eric.org.uk/Listing/Category/our-helpline

Appendix 1: Results by Year

Table 1: Summary of Results 2021

		England (#)	England (%)	Scotland (#)	Scotland (%)	Wales (#)	Wales (%)	Northern Ireland (#)	Northern Ireland (%)	UK total (#)	UK total (%)
FOI Responses	**Number of CCGs (England), Health Boards (Scotland and Wales), and Health and Care Social Trusts (Northern Ireland)**	106	--	14	--	7	--	5	--	**131**	**--**
	Responses received	130	97.7%	14	100%	10	100%	5	100%	**159 of 161**	**98.76%**
Question 1	**Commission bedwetting**	92	70.8%	12	85.71%	8	80%	4	80%	**116**	**72.05%**
	Commission daytime wetting	91	70%	11	78.57%	9	90%	3	60%	**114**	**70.81%**
	Commission toilet training	77	59.2%	8	57.14%	7	70%	4	80%	**96**	**59.63%**
	Commission constipation/soiling	87	66.0%	10	71.43%	8	80%	4	80%	**109**	**67.7%**
	Commission product supply	86	66.2%	9	64.29%	10	100%	5	100%	**110**	**68.32%**
	Commission all 4 services + product supply	68	51.1%	4	28.57%	6	60%	4	80%	**82**	**50.93%**
Question 2	**Commission integrated services (all in one place)**	52	40.15%	3	21.43%	2	20%	4	80%	**61**	**37.89%**
	If so, led by a paediatric continence advisor	49 of 52	94.2%	2 of 3	66.66%	2 of 2	100%	4 of 4	100%	**N/A**	**N/A**
Question 4	**Mean number of children on caseload of service (excl. anomalies)**	495.1	--	586.1	--	209.4	--	756.4	--	**N/A**	**N/A**
Question 5	**Plans for new service**	19	14.62%	3	21.43%	3	30%	1	20%	**26**	**16.15%**
	Plans to review service	68	52.3%	8	57.14%	5	50%	3	60%	**84**	**52.17%**
Question 7	**Aware of the Guide**	96	73.9%	9	64.29%	8	80%	4	80%	**117**	**72.67%**
	Use the Guide	80	61.54%	6	42.86%	6	60%	3	60%	**95**	**59%**

Note: the number of responses does not equate to the number of CCGs and Health Boards across the country; in certain instances, commissioners disaggregated their response by sub-area or by local provider. The small number of responses in the devolved nations, compared with England, should also be factored into any comparison of the percentages given.

Table 2: Summary of Results, 2017

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

Table 3: Summary of Results, 2014

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

Appendix 2: Results by Nation

Table 4: Summary of Results in England (2014, 2017, 2021)

	2014		2017		2021	
	#	%	#	%	#	%
Number of CCGs	211	N/A	209	N/A	106	N/A
Responses received	211	100%	206	98.56%	130	97.70%
Commission four services	82	39%	89	43.20%	69	53.08%
Commission four services and products	76	36%	89	43.20%	68	51.10%
Commission integrated services	54	26%	65	31.55%	52	40.15%
Led by a paediatric continence advisor	43	20%	48	23.30%	49	36.70%
Plan to review service	87	41%	74	35.92%	68	52.30%
Plan to commission new service	34	16%	23	11.17%	19	14.62%
Aware of the PCCG	N/A	N/A	130	63.11%	96	73.90%
Use the PCCG	N/A	N/A	104	50.49%	80	61.54%

Table 5: Summary of Results in Scotland (2014, 2017, 2021)

	2014		2017		2021	
	#	%	#	%	#	%
Number of CCGs	14	-	14	-	14	-
Responses received	14	100.00%	13	92.86%	14	100.00%
Commission four services	8	57.00%	3	23.08%	6	42.86%
Commission four services and products	8	57.00%	3	23.08%	4	28.57%
Commission integrated services	5	36.00%	3	23.08%	3	21.43%
Led by a paediatric continence advisor	5	36.00%	1	7.69%	2	15.38%
Plan to review service	10	71.00%	4	30.77%	8	57.14%
Plan to commission new service	1	7.00%	1	7.69%	3	21.43%
Aware of the PCCG	N/A	N/A	8	61.54%	9	64.29%
Use the PCCG	N/A	N/A	4	30.77%	6	42.86%

Table 6: Summary of Results in Wales (2014, 2017, 2021)

	2014		2017		2021	
	#	%	#	%	#	%
Number of Health Boards	7	-	7	-	7	-
Responses received	7	100.00%	7	100.00%	10	100.00%
Commission four services	4	57.00%	2	28.57%	5	50.00%
Commission four services and products	3	43.00%	1	14.29%	6	60.00%
Commission integrated services	2	29.00%	0	0.00%	2	20.00%
Led by a paediatric continence advisor	2	29.00%	1	14.29%	2	20.00%
Plan to review service	1	14.00%	5	71.43%	5	50.00%
Plan to commission new service	0	0.00%	1	14.29%	3	30.00%
Aware of the PCCG	N/A	N/A	5	71.43%	8	80.00%
Use the PCCG	N/A	N/A	3	42.86%	6	60.00%

Table 7: Summary of Results in Northern Ireland (2014, 2017, 2021)

	2014		2017		2021	
	#	%	#	%	#	%
Number of Health and Social Care Trusts	5	-	5	-	5	-
Responses received	5	100.00%	5	100.00%	5	100.00%
Commission four services	3	60.00%	2	40.00%	3	60.00%
Commission four services and products	3	60.00%	2	40.00%	3	60.00%
Commission integrated services	2	40.00%	3	60.00%	4	80.00%
Led by a paediatric continence advisor	2	40.00%	3	60.00%	4	80.00%
Plan to review service	5	100.00%	2	40.00%	3	60.00%
Plan to commission new service	0	0.00%	0	0.00%	1	20.00%
Aware of the PCCG	N/A	N/A	5	100.00%	4	80.00%
Use the PCCG	N/A	N/A	4	80.00%	3	60.00%

Appendix 3: Future integrated Care Systems

Have stated there are plans to commission a new service and/or review their current service
No plans to renew current service or commission a new service
Unknown

Future ICS	Response to FOI	Number of services commissioned (out of bedwetting, daytime wetting, toilet training, constipation/soiling/product provision)
Bath and North East Somerset, Swindon and Wiltshire	NHS Bath and North East Somerset CCG	UNKNOWN
	NHS Swindon CCG	4
	NHS Wiltshire CCG	4
Bedfordshire, Luton and Milton Keynes	NHS Bedford CCG	5
	NHS Luton and South Bedfordshire CCG	1
	NHS Milton Keynes CCG	1
Birmingham and Solihull	NHS Birmingham and Solihull CCG	3
The Black Country and West Birmingham	NHS Black Country & West Birmingham CCG	UNKNOWN
Bristol, North Somerset and South Gloucestershire	NHS Bristol, North Somerset and South Gloucestershire CCG	3
Buckinghamshire, Oxfordshire and Berkshire West	NHS Berkshire West CCG	5
	NHS Buckinghamshire CCG	5
	NHS Oxfordshire CCG	5
Cambridgeshire and Peterborough	NHS Cambridgeshire and Peterborough CCG	0
Cheshire and Merseyside	NHS Cheshire CCG	5
	NHS Halton CCG	5
	NHS Knowsley CCG	5
	NHS Liverpool CCG	3
	NHS South Sefton CCG	5
	NHS Southport and Formby CCG	5
	NHS St Helens CCG	5
	NHS Warrington CCG	UNKNOWN
	NHS Wirral CCG	UNKNOWN
Cornwall and the Isles of Scilly Health & Social Care Partnership	NHS Kernow CCG	0
Coventry and Warwickshire	NHS Coventry and Warwickshire CCG	0
Cumbria and North East	NHS Newcastle Gateshead CCG	4
	NHS North Cumbria CCG	5

	NHS County Durham CCG	5
	NHS North Tyneside CCG	5
	NHS Northumberland CCG	0
	NHS Tees Valley CCG	5
	NHS South Tyneside CCG	UNKNOWN
	NHS Sunderland CCG	0
Joined Up Care Derbyshire	NHS Derby and Derbyshire CCG	5
Devon	NHS Devon CCG	5
Dorset	NHS Dorset CCG	5
East London Health & Care Partnership	NHS Barking and Dagenham, Havering and Redbridge CCG	5
	NHS City and Hackney CCG	5
	NHS Newham CCG	5
	NHS Tower Hamlets CCG	UNKNOWN
	NHS Waltham Forest CCG	5
Frimley Health & Care ICS	NHS East Berkshire CCG	5
	NHS North East Hampshire and Farnham CCG	3
	NHS Surrey Heath CCG	5
Gloucestershire	NHS Gloucestershire CCG	5
Greater Manchester Health and Social Care Partnership	NHS Bolton CCG	5
	NHS Bury CCG	5
	NHS Heywood, Middleton and Rochdale CCG	0
	NHS Manchester CCG	3
	NHS Oldham CCG	3
	NHS Salford CCG	0
	NHS Stockport CCG	5
	NHS Tameside and Glossop CCG	3
	NHS Trafford CCG	4
	NHS Wigan Borough CCG	5
Hampshire and the Isle of Wight	NHS Isle of Wight CCG	0
	NHS North Hampshire CCG	3
	NHS Portsmouth CCG	5
	NHS South Eastern Hampshire CCG	3
	NHS Southampton CCG	5
	NHS West Hampshire CCG	3
Herefordshire and Worcestershire	NHS Herefordshire and Worcestershire CCG	4
Hertfordshire and West Essex	NHS East and North Hertfordshire CCG	3
	NHS Herts Valleys CCG	4
	NHS West Essex CCG	5
Humber, Coast and Vale	NHS East Riding of Yorkshire CCG	3
	NHS Hull CCG	3
	NHS North East Lincolnshire CCG	5
	NHS North Lincolnshire CCG	0
	NHS Vale of York CCG	5

Kent and Medway	NHS Kent and Medway CCG	0
Healthier Lancashire and South Cumbria	NHS Blackburn with Darwen CCG	5
	NHS Blackpool CCG	5
	NHS Chorley and South Ribble CCG	0
	NHS East Lancashire CCG	4
	NHS Fylde and Wyre CCG	5
	NHS Greater Preston CCG	0
	NHS Morecambe Bay CCG	5
	NHS West Lancashire CCG	0
Leicester, Leicestershire and Rutland	NHS East Leicestershire and Rutland CCG	4
	NHS Leicester City CCG	5
	NHS West Leicestershire CCG	4
Lincolnshire	NHS Lincolnshire CCG	0
Mid and South Essex	NHS Basildon and Brentwood CCG	5
	NHS Castle Point and Rochford CCG	5
	NHS Mid Essex CCG	5
	NHS Southend CCG	5
	NHS Thurrock CCG	5
Norfolk and Waveney Health & Care Partnership	NHS Norfolk and Waveney CCG	5
North London Partners in Health & Care	NHS Barnet CCG	UNKNOWN
	NHS Camden CCG	5
	NHS Enfield CCG	0
	NHS Haringey CCG	5
	NHS Islington CCG	5
North West London Health & Care Partnership	NHS North West London CCG	5
Northamptonshire	NHS Northamptonshire CCG	3
Nottingham and Nottinghamshire Health and Care	NHS Nottingham and Nottinghamshire CCG	5
Shropshire and Telford and Wrekin	NHS Shropshire, Telford and Wrekin CCG	3
Somerset	NHS Somerset CCG	5
Our Healthier South East London	NHS South East London CCG	5
South West London Health & Care Partnership	NHS Croydon CCG	UNKNOWN
	NHS Kingston CCG	4
	NHS Merton CCG	5
	NHS Richmond CCG	1
	NHS Sutton CCG	5
	NHS Wandsworth CCG	1
South Yorkshire and Bassetlaw	NHS Barnsley CCG	4
	NHS Bassetlaw CCG	0
	NHS Doncaster CCG	0

	NHS Rotherham CCG	4
	NHS Sheffield CCG	5
Staffordshire and Stoke on Trent	NHS Cannock Chase CCG	5
	NHS East Staffordshire CCG	5
	NHS North Staffordshire CCG	5
	NHS South East Staffordshire and Seisdon Peninsular CCG	5
	NHS Stafford and Surrounds CCG	5
	NHS Stoke on Trent CCG	5
Suffolk and North East Essex	NHS Ipswich and East Suffolk CCG	UNKNOWN
	NHS North East Essex CCG	UNKNOWN
	NHS West Suffolk CCG	2
Sussex and East Surrey	NHS Brighton & Hove CCG	5
	NHS West Sussex CCG	5
	NHS East Sussex CCG	5
Surrey Heartlands Health & Care Partnership	NHS Surrey Heartlands CCG	5
West Yorkshire and Harrogate (Health & Care Partnership)	NHS Bradford District and Craven CCG	5
	NHS Kirklees CCG	5
	NHS Calderdale CCG	UNKNOWN
	NHS North Yorkshire CCG	UNKNOWN
	NHS Leeds CCG	5
	NHS Wakefield CCG	5

Appendix 4: FOI Request

Freedom of Information Request

Dear (Name),

I am writing to make a Freedom of Information request to (org name) on behalf of the Paediatric Continence Forum (PCF).

The PCF is a group of health professionals, patient representatives and companies that campaign to raise awareness of childhood bladder and bowel (continence) problems through proactive engagement with the Government.

To assess the current situation for children's continence (bladder and bowel services) in the United Kingdom, please would you answer the following questions:

1) Please state whether the following five paediatric continence (bladder and bowel) services are commissioned by your CCG/funded by your Health Board:

   a. Bedwetting *(Yes/No)* If yes, for ages __ to __
   b. Daytime wetting *(Yes/No)* If yes, for ages __ to __
   c. Toilet training *(Yes/No)* If yes, for ages __ to __
   d. Constipation/soiling *(Yes/No)* If yes, for ages __ to __
   e. Product (nappy/pad/washable pants) supply for paediatric continence problems *(Yes/No)*

   If yes, for ages __ to __

   If any of the above services are not commissioned/funded and delivered by your CCG/Health Board, does anyone else provide any of these services? (Yes/No)
   If yes, please provide details of which partner organisation provides them, which service(s)they provide and the age ranges:

2)
   a. Is there a single (integrated) service for all the above five problems? *(Yes/No)*
   b. If the answer to 2a is yes, is this service led by a paediatric continence advisor? *(Yes/No)*
   c. If the answer to 2a is no, please list the services that are commissioned/provided and the designation of each of the service leads:

3) If the answer to 2a is yes, please could you tell us:
   a. How many children and young people are on the waiting list for this service?
   b. How long has the child currently at the top of the list had to wait?

4) If you answered yes to any part of question 1, please tell us how many children and young people with continence problems are currently on the caseload of the service?

5) Do you have any future plans to:
   a. Commission/provide new paediatric continence service? (Yes/No)
   b. Review the existing paediatric continence service? (Yes/No)
   If so, please provide details _____

6)
   a. How many full-time equivalent staff specialising in paediatric continence are currently employed by the services commissioned by your CCG/provided by your Health Board? ____

   Please specify whether they:

b. Are registered children's nurse? (No/Yes, some of them/Yes all of them)
c. Have had specific training in paediatric continence management (Yes/No)

7)

a. Are you aware of the Children's Continence Commissioning Guide? (Yes/No)
b. If yes, do the services commissioned in/provided by your CCG or Health Board use it? (Yes/No)

I would like a response by email to paediatriccontinenceforum@whitehousecomms.com. Should you have any queries about this request, please email or phone me on 020 3855 5760.

With thanks and kind regards,

Jordan Newfield

Secretariat, Paediatric Continence Forum