

Paediatric Continence Forum – Parent and carer toolkit for lobbying your MP and healthcare commissioners to drive change locally and nationally

Introduction

The Paediatric Continence Forum (PCF) has designed this toolkit to help the parents and carers of children and young people with continence problems to lobby for improvements to NHS paediatric continence services at a local or national level.

The toolkit provides information on:

- how to request a meeting with your local Member of Parliament (MP)
- a brief outline of what you could expect to achieve from this meeting
- a briefing note that you can give to your MP containing more information

The toolkit also outlines ways of approaching the following key organisations to ask for changes on paediatric continence services in your area:

- local commissioners of paediatric continence services (those who decide what services are provided)
- your local Healthwatch organisation (the consumer healthcare champion)

You are not required to contact everyone suggested in this toolkit. You can contact whoever you feel you are most comfortable to approach.

We would be grateful if you could keep the PCF updated of your plans and progress by contacting paediatriccontinenceforum@whitehouseconsulting.co.uk.

Approaching your MP – a step-by-step guide

Background

MPs are expected to make an effort to help anyone living in their constituency who comes to them for assistance. MPs normally hold a ‘surgery’ where they meet with voters – some of which require an appointment whilst others are held on a drop-in basis. You can often find out details of an MP’s surgery on their website, or by phoning or writing to them. MPs will also often attend events within their local constituency – although they are normally in Parliament between Monday and Thursday.

You can also contact MPs offices directly to arrange a meeting. Below is advice on doing this:

1. Identifying your MP

You can find out who your MP is by typing your postcode into www.theyworkforyou.com.

Type in your postcode as below:



You will then receive an overview of your MP. You should only focus on their name and constituency, with their party also being useful for you to know as context:



2. Sending out a meeting request

In the first instance you should write to the MP (preferably via email) rather than call – a customisable letter ([Annex 1](#)) is included near the end of this toolkit. You should include:

- Your name and address so that the MP knows that you live in their constituency
- Your phone number and email address so your MP can contact you

It is best to write to the MP's constituency office, if possible. You can find their contact details on via <http://www.parliament.uk/mps-lords-and-offices/mps/>. Click on the name of your MP and you will see the details.

This is what you should see. If a constituency address is not listed, please use the parliamentary one:

Debbie Abrahams MP

Constituency Oldham East and Saddleworth	Address as Debbie Abrahams	Party Labour
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Contact Details

	Parliamentary House of Commons, London, SW1A 0AA Tel: 020 7219 1041 Fax: 0207 219 2405 Email: abrahamsd@parliament.uk	Constituency Lord Chambers, 11 Church Lane, Oldham, OL1 3AN Tel: 0161 624 4248 Email: abrahamsd@parliament.uk
	Web & Social media Website: www.debbieabrahams.org... Twitter: @debbie_abrahams	

3. Chasing up the meeting request for a response

MPs will normally contact you to acknowledge receipt or to confirm whether they can meet with you, and if so, what time. They receive a large number of requests, but if they do not respond in a few days then please call their office for a follow up.

4. Once you receive a response from your MP

Your MP may invite you to discuss the issue further. [Annex 2](#) of this toolkit – meeting with your MP – outlines how you should go about conducting a meeting, so please check that.

Approaching your local healthcare commissioners – a step-by-step guide

You can contact those who organise health services in your area. You can do this in addition to, or instead of, contacting your MP. Below is an outline of who to approach and how.

What is a clinical commissioning group (CCG) or Health Board?

Your local clinical commissioning group (CCG) or Health Board is responsible for deciding what health care services are offered in your local area. This includes continence problems that cannot be resolved through talking with your school nurse, health visitor or GP. If they do not commission a paediatric continence service, children are often referred for assessment in hospitals. These hospital attendances can be inconvenient for the child and family. It is also very expensive for the taxpayer.

Identifying your CCG/Health Board and their contact details

There are 209 CCGs across England, spread out on a geographical basis, along with 14 Health Boards [in Scotland](#), 7 Local Health Boards [in Wales](#) and 6 Health and Social Care Trusts [in Northern Ireland](#). The services have different names because healthcare is devolved to each of these regions, meaning that the devolved governments – i.e. the Scottish Parliament, Welsh Assembly and Northern Ireland Assembly – have responsibility for deciding health policy in each country.

You can take the following steps to find out the name of the CCG or Health Board which commissions the services in your area.

England

You can find out the name of the CCG which commissions the services in your area by entering your postcode into [this](#) website. Once you input your postcode and click search, click on the coloured area where the marker is. This should bring up a box saying the name of your CCG.



Once you have found the name of your local CCG, you should go onto their website and note down the postal address, phone number and contact email. A list of CCGs and their websites can be found [here](#); you will want to address your letter to the CCG's clinical lead.

Scroll down until you see your CCG: take a note of the name of the clinical lead and click on the link.

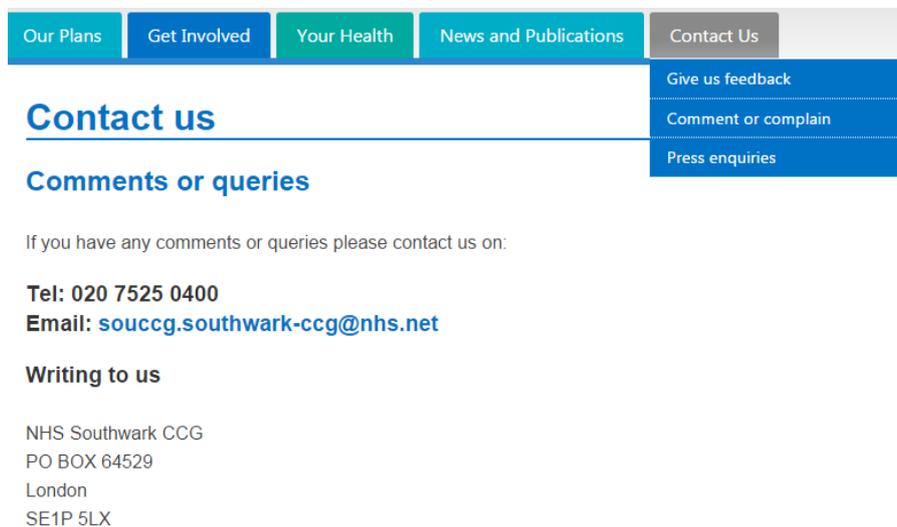
NHS Southwark CCG

Clinical Lead: Dr Amr Zeineldine

Accountable Officer: Andrew Bland

Website: www.southwarkccg.nhs.uk

Once on the CCG's website, you should find the 'Contact us' section. You should see an email address listed, as well as a postal address and phone number. Please keep a record of these.

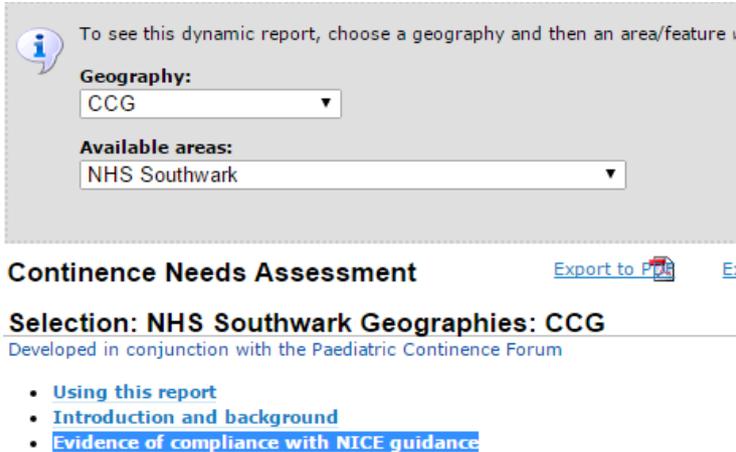


The screenshot shows a navigation menu with 'Contact Us' selected. Below the menu, there are three buttons: 'Give us feedback', 'Comment or complain', and 'Press enquiries'. The main heading is 'Contact us', followed by a sub-heading 'Comments or queries'. Below this, it says 'If you have any comments or queries please contact us on:'. The contact details are: 'Tel: 020 7525 0400' and 'Email: souccg.southwark-ccg@nhs.net'. Under 'Writing to us', the address is: 'NHS Southwark CCG, PO BOX 64529, London, SE1P 5LX'.

Finding out your local service provision

To find out your local service provision, go to the government run ChiMat website using this [link](#). Under "Geography" click CCG, and then select your local CCG. Once the page has loaded, click on "Evidence of compliance with NICE guidance". Under the bar chart, there is a subsection called "Locally", which outlines provision in your local area.

If the page is as below, click on the highlighted section as scroll down as suggested above:



To see this dynamic report, choose a geography and then an area/feature

Geography:
CCG

Available areas:
NHS Southwark

Continence Needs Assessment [Export to PDF](#) [E](#)

Selection: NHS Southwark Geographies: CCG
Developed in conjunction with the Paediatric Continence Forum

- [Using this report](#)
- [Introduction and background](#)
- [Evidence of compliance with NICE guidance](#)

Contacting and following up with your CCG

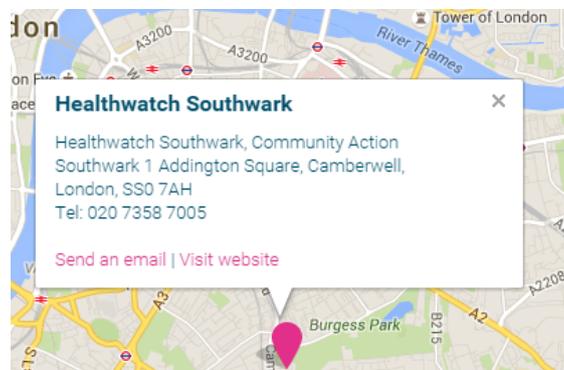
We would suggest contacting your local CCG using the template letter in [Annex 4](#). Although your CCG will be unlikely to meet with you, they are required to respond to you. As with MPs, CCGs are very busy organisations and there may be a delay in responding to you. If after four weeks you have not received a response, then please do contact them by phone to ensure a response.

Approaching your local Healthwatch organisation

Healthwatch England is the national consumer champion for health and social care in England. It is required by law to make sure the health service listens to people's views and experiences and acts on them. Across the country there are a number of local Healthwatch organisations.

You can find your nearest Healthwatch organisation by going to their website, available [here](#), and entering your postcode. This will bring up a postal address, phone number and email address that you can use to contact them.

If you type in SE1 0HS, for example, you should receive this box if you click on the nearby marker.



A template letter for contacting your local Healthwatch organisation can be found in [Annex 5](#). Healthwatch organisations are quite responsive and are likely to respond to you in a couple of weeks.

Wales

To find out the name of the Health Board responsible for commissioning your local services, you can look at the map of Health Boards [on this site](#). As with English CCGs, you will want to address your letter to the Health Board's clinical lead or chief executive.

Scotland

To find out the name of your local Health Board in Scotland, you can use the postcode search [on this website](#). As an example, using the postcode EH99 1SP returns this information on the local Health Board, NHS Lothian.

NHS Lothian

Website

The [NHS Lothian website](#) contains lots of useful information.

NHS Lothian healthy lifestyle

In [these pages](#) you will find information about alcohol, information about smoking, advice on healthy eating and help on getting active.

Patient information centres

Royal Infirmary of Edinburgh
51 Little France Crescent
Old Dalkeith Road
EH16 4SA
Tel: 0131 242 7660
Email: patientinfo@luht.scot.nhs.uk

Anne Ferguson Building
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU
Tel: 0131 536 3176
Email: patientinfo@luht.scot.nhs.uk

St John's Hospital Livingston
Howden Road West
Howden
Livingston
West Lothian
EH54 6PP

Contact information

Details of NHS Lothian's community services, hospitals and making a suggestion or complaint can be found [on their website](#).

Northern Ireland

Information on the five Health and Social Care Trusts in Northern Ireland, along with the local council areas they cover, [can be found here](#). You could choose to send your letter to the organisation's chief executive or director of children's services.

Background to the PCF

The PCF is a UK-wide campaign group of healthcare professionals and patient representatives working to improve the quality of paediatric continence services throughout the UK. The PCF engages with policymakers through meeting with MPs and civil servants as well as responding to policy consultations. Over the last couple of years, our primary focus has been the development and dissemination of a 2014 [Paediatric Continence Commissioning Guide](#) – which was updated in October 2015 following its interim

review. This Guide provides information for commissioners (those who decide what health care services are set up in their local area) on how to set up proper integrated paediatric continence services in their areas. The PCF also engaged with NHS England to produce the [Excellence in Continence Care](#) guidance for commissioners, providers, healthcare professionals and the public on improving the care and experience of children and adults with continence issues.

Contact details

For further information on how to use this toolkit, please contact Rhiannon Sanders, PCF Secretariat at paediatriccontinenceforum@whitehouseconsulting.co.uk or on 020 7463 0697.

Annex 1 - Draft meeting request letter or email to your local MP

MP'S NAME

ADDRESS OR EMAIL ADDRESS

DATE

Dear NAME OF MP,

I live in your constituency at [INSERT ADDRESS]. I am also a parent of a child with [INSERT CONDITION(S)], and have experienced problems with the treatment of their condition. I would like to request a meeting to discuss my experiences and discuss ways in which we can move forward to improve the quality and provision of services in our area for paediatric continence problems such as THIS/THESE, so to enable better outcomes for my child [CHILD NAME] and others like them.

More than one in 10 children in the UK are affected by continence problems, such as bedwetting, daytime wetting or constipation and soiling, which cause them significant problems in terms of family relationships, bullying and self-esteem. These problems often occur at a sensitive time of emotional and physical development. [INSERT PERSONAL EXPERIENCE HERE]

Research conducted by the Paediatric Continence Forum (PCF) in August 2014 found that our local CCG of [INSERT CCG NAME] commissions [INSERT CHIMAT SERVICE PROVISION DATA]. Nationally, the research found that 82/211 CCGs (39%) commissioned all four of the main paediatric continence services, with just 26% commissioned in an integrated manner, and 20% led by a paediatric continence advisor. Of the 211 CCGs, 87 (41%) said that they had plans to review their paediatric continence service, with 31 CCGs (15%) stating that they had plans to commission a new service.

I have contacted the PCF, a national campaign group of healthcare professionals and representatives from patient groups, which has informed me that it has produced the NICE-accredited [Paediatric Continence Commissioning Guide](#) - endorsed by the Royal College of Nursing, Royal College of Paediatrics and Child Health, and Community Practitioners' and Health Visitors' Association. This sets out in simple terms how commissioners can support an integrated and effective paediatric continence service. The PCF has also worked with NHS England to produce the [Excellence in Continence Care](#) guidance for commissioners, providers, health professionals and the public to improve the care and experience of children and adults with continence issues. I firmly believe that using these guidance documents will produce better outcomes for my child and others.

I would be most grateful if you would be willing to meet with me to discuss my experiences further, and the work that could be done to ensure that my child and others like them across the UK will be able to access better paediatric continence services. Please do get in touch with me via [EMAIL ADDRESS] so we can set up a date.

Yours sincerely,

NAME

Annex 2 – Meeting with your MP

The most effective meetings with MPs are those with a clear structure and clear set of objectives. The goal of meeting with your MP is to ensure that they are fully aware of your problem and are willing to take action to rectify it. MPs are busy individuals with little additional capacity to fully investigate issues and come up with solutions themselves, so it is best to give them a helping hand where possible.

You will need to establish that your child has a bladder and/or bowel problem that negatively impacts on their life (including socially/educationally) and yours. You will need to highlight that services in your area are not adequate, and that the poor provision of services is quite common across the country. Finally, you will need to state that the PCF has produced guidance to help clinicians set up better paediatric continence services, and that it has other useful materials available on its website: www.paediatriccontinenceforum.org

Objectives

- To ensure that your MP is aware of the impact that bladder and bowel problems can cause a child.
- To ensure that your MP is aware that their constituents are encountering problems with their local provision of paediatric continence services.
- To ensure that your MP takes action to pressure your local CCG to follow the guidance produced by the PCF, and by doing so to improve your local paediatric continence services.

Structure

- Introduce yourself and explain that your child has a bladder and/or bowel problem.
- Provide an overview of how your child's problem affects their life and yours.
- State your experiences with the existing provision of services.
- Emphasise that paediatric continence problems are not uncommon and affect more than one in 10 children.
- Emphasise that the majority of paediatric continence services in the UK are not integrated, meaning that there is not a single point of access for each of the four paediatric continence services (bedwetting, night time wetting, toilet training, and constipation/soiling). This means that accessing services is difficult, time consuming, involves continually repeating your story and results are poor.
- State that the PCF, a group of healthcare professionals and patient representatives, has produced guidance for commissioners on how to commission an integrated paediatric continence service, which it has sent to all CCGs.
- State that you would like to see your MP put pressure on your local CCG to ensure that the guidance is read and adhered to.
- State that in addition to the guidance, the PCF can provide your MP with a template letter to send to their CCG. Note that the PCF has also drafted parliamentary questions on a range of issues for them to ask the relevant government departments.
- Ask whether your MP would be willing to write to their CCG and would be willing for the PCF to send them a draft letter.
- State that, if so, the PCF will follow up with their office in a few weeks' times.

After your meeting has concluded, please do contact Rhiannon Sanders at the PCF via paediatriccontinenceforum@whitehouseconsulting.co.uk or on 020 7463 0697 to let us know how it went.

Annex 3 – Briefing note for parliamentarians from the PCF

Introduction

More than one in 10 children and young people are affected by continence problems, causing them significant difficulties in terms of family relationships, bullying and self-esteem. The Paediatric Continence Forum (PCF) was set up to ensure that there was sufficient focus on this vital issue.

The PCF is a national group of healthcare professionals working with the Government and healthcare organisations to improve paediatric continence services nationally. Formed in 2003, it has close links to the charities ERIC (The Children’s Continence Charity) and PromoCon. Its membership includes paediatricians and specialist nurses, with formal representation from the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association (CPHVA). It also has links with the British Association of Paediatric Urologists.

This briefing provides an overview of paediatric continence services within the UK and suggests policy changes which would both improve the quality of services provided and save the NHS money.

We are asking parliamentarians to:

- Advocate better quality, community-based continence services which are “joined-up” and run by dedicated paediatric continence professionals, as well as draw attention to the recently published commissioning guidance for paediatric continence services and other useful materials.
- Investigate the quality of paediatric continence services in their own constituency and advocate measures which would lead to higher quality services.
- Consider the role of paediatric continence services when discussing issues relating to childhood health, disability and education.

Paediatric continence is a serious problem

Continence problems, such as bedwetting, daytime wetting or constipation and soiling, occur at a sensitive time in a child’s emotional and physical development. These can cause low self-esteem and social isolation, contributing to family stress and bullying by peers, which impacts on their social and educational opportunities. The PCF advocates prevention, early detection and effective intervention.

Poor quality services lead not only to children and parents “dropping out” of treatment, but also increase the rate of unnecessary and high cost referrals to secondary care. A secondary and tertiary outpatient referral costs £160 to £220 for first appointments and £94 to £123 for follow-ups. This is compared to a specialist nurse in primary care, which costs on average £80 for an assessment appointment and £56 for each follow-up appointment (considerably less for a telephone follow-up).

The PCF has produced the [Paediatric Continence Commissioning Guide](#), a tool accredited by the National Institute for Health and Care Excellence (NICE) and endorsed by the RCN, the RCPCH and the CPHVA. The Guide provides clear advice to commissioners and healthcare professionals on how to commission integrated, community-based paediatric continence services. It outlines that early identification and intervention saves children from unnecessary emotional distress and saves NHS resources by reducing the possibility of hospital admissions for complications such as chronic constipation/impaction.

The PCF has also worked with NHS England to produce the [Excellence in Continence Care](#) guidance for commissioners, providers, healthcare professionals and the public to help improve the care and

experience of children and adults with continence issues. NHS England is currently working to ensure that this guidance is used by all the intended parties.

The quality of paediatric continence services in the UK

The PCF achieved its first success in 2004, securing the inclusion of continence services within the national service framework for children.

Despite this success, the provision of children's continence services continues to be unsatisfactory. Services vary in quality nationally – in most cases there is not a single, integrated, community-based service led by a specialist paediatric continence adviser. A Freedom of Information (FOI) survey conducted by the PCF in August 2014 revealed that clinical commissioning groups (CCGs) in England are failing to provide proper integrated paediatric continence services. All 211 CCGs provided a response, with only 39% responding that they commission all the four main continence services (covering bedwetting, daytime wetting, toilet training, constipation/soiling) – with just 26% of responding CCGs commissioning services that are fully “joined up”.

This picture shows little progress since CCGs took over responsibility from primary care trusts (PCTs) in April 2013. A similar study by the PCF in 2011 showed that 25% of PCTs commissioned the four main services, with 12% of these described as “joined-up”. This represents only a 10% improvement.

Most CCGs (59%) have no plans to review their existing service provision or commission a new service, suggesting a reliance on universal services, such as school nurses and health visitors to handle continence problems. **However, the school nurse resource is now depleted as a result of local authorities taking over responsibility for their employment from public health. We are very concerned that many local authorities have since dropped continence from the school nurse remit (because continence issues are categorised as a ‘clinical’ rather than a ‘public health’ need).** This puts even more pressure upon already fragmented community-based continence services.

It is more important that policymakers are mindful of the need to improve standards, given the significant changes to service commissioning in the last few years. These changes have allowed wider range of service providers, some of which have excluded continence from their services.

The PCF's vision for high quality, integrated paediatric continence services

The PCF is engaging with NHS England and its associated bodies, the Departments for Health and Education and supportive parliamentarians to raise political awareness of the need to improve the quality of paediatric continence services. Our NICE-accredited paediatric continence commissioning guide is a practical tool to aid the commissioning of improved and cost effective services.

The PCF would like to see every Clinical Commissioning Group provide the four main paediatric continence services: bedwetting, daytime wetting, constipation/soiling and toilet training. It calls for these services to be “joined-up” and run by dedicated paediatric continence professionals, as recommended by recent NICE guidance.

Contact details

For further information please contact the PCF's secretariat via ben.chiu@whitehouseconsulting.co.uk or on 020 7793 2537. Further information: <http://www.paediatriccontinenceforum.org/>

Annex 4 - Draft letter to your local clinical commissioning group

NAME OF CCG CLINICAL LEAD
ADDRESS OR EMAIL ADDRESS

DATE

Dear NAME OF CCG CLINICAL LEAD,

I live in [INSERT TOWN/CITY] and I am also a parent of a child with [INSERT CONDITION(S)]. I have recently learnt that research conducted by healthcare campaign group the Paediatric Continence Forum (PCF) found that our local CCG of [INSERT CCG NAME] commissions [INSERT CHIMAT SERVICE PROVISION DATA].

The research is [SURPRISING/NOT SURPRISING] given the experience that my child, [CHILD NAME], and the rest of our family have encountered when accessing paediatric continence services in our area. [INSERT PERSONAL EXPERIENCE HERE].

According to the PCF's research [CCG NAME] is performing [BETTER/WORSE] than the national average, which found that 82/211 CCGs (39%) commissioned all four of the main paediatric continence services, with just 26% commissioned in an integrated manner, and 20% led by a paediatric continence advisor. Of the 211 CCGs, 87 (41%) said that they had plans to review their paediatric continence service, with 31 CCGs (15%) stating that they had plans to commission a new service.

I was recently informed that following the transfer of school nursing services to local authorities in April 2015, many local authorities no longer require with school nurses to provide support for children with continence problems. In places where there is no commissioned paediatric continence service, school nurses took on extra responsibilities to treat children. With school nurses now gone, children are now being sent to hospitals for care that could easily be offered in the community for significantly less expense to the NHS and equally good outcomes.

I have contacted the PCF, a national campaign group of healthcare professionals and representatives from patient groups, which has informed me that it has produced the NICE-accredited [Paediatric Continence Commissioning Guide](#) - endorsed by the Royal College of Nursing, Royal College of Paediatrics and Child Health, and Community Practitioners' and Health Visitors' Association. This sets out in simple terms how commissioners can commission an integrated and effective paediatric continence service. The PCF has also worked with NHS England to produce the [Excellence in Continence Care](#) guidance for commissioners, providers, health professionals and the public to improve the care and experience of children and adults with continence issues. I firmly believe that using this guidance will produce better outcomes for my child and others.

I would be most grateful if you willing to take a look at these documents, which are available on the PCF's website at www.paediatriccontinenceforum.org, and consider whether the CCG could utilise them in any manner. Given my situation, the results from the PCF, as well an increasing number of children being referred to hospitals rather than community care, I would like to know what [CCG NAME] is doing, or plans to do in the future, to improve access to better paediatric continence services.

Please do get in touch with me by post, or ideally on [\[EMAIL ADDRESS\]](#) so you can update me on any developments.

I look forward to hearing from you.

Yours sincerely,

NAME

Annex 5 - Draft letter to your local Healthwatch organisation

LOCAL HEALTHWATCH ORGANISATION NAME

ADDRESS

DATE

Dear LOCAL HEALTHWATCH ORGANISATION NAME,

I live in [INSERT TOWN/CITY] and I am also a parent of a child with [INSERT CONDITION(S)]. I have recently learnt that research conducted by healthcare campaign group the Paediatric Continence Forum (PCF) found that our local CCG of [INSERT CCG NAME] commissions [INSERT CHIMAT SERVICE PROVISION DATA].

The research is [SURPRISING/NOT SURPRISING] given the experience that my child, [CHILD NAME], and the rest of our family have encountered when accessing paediatric continence services in our area. [INSERT PERSONAL EXPERIENCE HERE].

According to the PCF's research [CCG NAME] is performing [BETTER/WORSE] than the national average, which found that 82/211 CCGs (39%) commissioned all four of the main paediatric continence services, with just 26% commissioned in an integrated manner, and 20% led by a paediatric continence advisor. Of the 211 CCGs, 87 (41%) said that they had plans to review their paediatric continence service, with 31 CCGs (15%) stating that they had plans to commission a new service.

I have contacted the PCF, a national campaign group of healthcare professionals and representatives from patient groups, which has informed me that it has produced the NICE-accredited [Paediatric Continence Commissioning Guide](#) - endorsed by the Royal College of Nursing, Royal College of Paediatrics and Child Health, and Community Practitioners' and Health Visitors' Association. This sets out in simple terms how commissioners can commission an integrated and effective paediatric continence service. The PCF has also worked with NHS England to produce the [Excellence in Continence Care](#) guidance for commissioners, providers, health professionals and the public to improve the care and experience of children and adults with continence issues. I firmly believe that using this guidance will produce better outcomes for my child and others.

I was recently informed that following the transfer of school nursing services to local authorities in April 2015, many local authorities no longer require children with school nurses to provide support for children with continence problems. In places where there is no commissioned paediatric continence service, school nurses took on extra responsibilities to treat children. With school nurses no longer having continence as part of their remit, children are now being sent to hospitals for care that could easily be offered in the community for significantly less expense to the NHS and a better experience for the child.

I would be most grateful if you willing to contact [CCG NAME] to raise the issues that I have identified in this letter. I would also much appreciate it if you would be willing to advise them to look at the Commissioning Guide and the NHS England Excellence and Continence Care guidance, which are available on the PCF's website at www.paediatriccontinenceforum.org, as a way of addressing these issues.

Please do get in touch with me by post, or ideally on [\[EMAIL ADDRESS\]](#) so you can update me on any developments.

I look forward to hearing from you.

Yours sincerely,

NAME