

EXCELLENCE **in Continence Care**

Practical guidance for
commissioners, and
leaders in health and
social care



NHS England Reader Information Box

Directorate

Medical	Commissioning Operations	Patients and Information
Nursing	Transformation and Corporate Operations	Commissioning Strategy
Finance		

Publications Gateway Reference: 08266

Document purpose:	Strategy
Document name:	Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care
Author:	NHS England
Publication date:	June 2018
Target audience:	CCG Clinical Leaders, CCG Accountable Officers, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, NHS Trust Board Chairs, NHS England Directors of Commissioning Operations, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Directors of Children's Services, NHS Trust CEs, members of the public
Additional circulation list:	N/A
Description:	Practical guidance for commissioners, providers, health and social care staff to put into effect best care
Cross ref:	N/A
Superseded docs: (if applicable)	Excellence in Continence Care: Practical guidance for commissioners, providers, health and social care staff and information for the public (November 2015)
Action required:	N/A
Timing/deadlines: (if applicable)	N/A
Contact details for further information:	NHS England, Quarry House, Quarry Hill, Leeds, LS2 7UE
Document status:	This is a controlled document. Whilst this document may be printed, the electronic version posted on the website is the controlled version. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto a local or network drive but should always be accessed from the internet.

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and practices cited in this document, we have given due regard to:

- Eliminate discrimination, harassment and victimisation, to advance equality of opportunity and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

Contents

Executive summary	4
Reducing healthcare related harm and costs	5
Commissioning for dignity and value	10
References	20



Executive summary

Continence is an important component in a person's health and well-being at any stage of life and is also an important factor in the use of health resources for the following reasons:

- Normal bowel and bladder function is an important part of a child's development and their path to adult and independent living. Failure to acquire control in a timely manner will affect schooling and education.
- Adult incontinence produces marked loss of self-esteem, depression, loss of independence, and can affect relationships and employment prospects.
- In older people, incontinence and associated bladder and bowel disorders may be associated with physical problems such as skin breakdown, falls, urine infection and catheter associated urinary tract infection which in turn often causes confusion. Confusion can result in falls, head injury or femur fractures requiring an acute hospital admission.
- Incontinence or dependence on a urinary catheter significantly increases the level of dependency in frail older people. This may delay discharge from hospital or initiate a move into a residential or nursing care setting.

This guidance is a refreshed and updated e-resource that builds on an earlier publication from November 2015. To help ensure people receive excellent continence care, consideration should be given to:

- Early assessment by an appropriately trained professional allows a patient centred and cost effective care pathway to be followed. After assessment the use of containment products, medication and the level of intervention can be triaged and escalated.
- Effectively resourcing the continence team and its management structure as part of an integrated service.
- How local people may need more specialist assessment which should be provided based on population needs.
- Containment with the use of pads or catheters may be the only realistic option for some people, but this management has associated problems.
- Actively support the individual to participate in the management and treatment of their continence care.
- Simple approaches to care delivery, including electronic and telecommunications, can help people lead healthy lives as well as providing advice and support to implement best practice or services in organisations.

Minimum standards which help build competence and knowledge for the workforce involved in continence care are included in this document. For further supporting information on specific roles and responsibilities go to www.england.nhs.uk/commissioning/continence

This guidance is intended to assist commissioning discussions for those developing high quality community continence services and provides a valuable supporting resource for the wider STP planning process.

Reducing healthcare related harm and costs

The case for change

The NHS Five Year Forward View¹ puts an emphasis on prevention and keeping people well for longer. Prevention is a key part of any strategy to minimise harm and reduce health care costs.

Prevention



The Prevention Pyramid

The All Party Parliamentary Group for Continence Care has designed a Prevention Pyramid showing how risk and costs are reduced where care is underpinned by high quality integrated community continence services. These services not only provide expert treatment within the community but advice regarding self-help strategies. Skills include training colleagues in initial continence assessment and conservative treatments and ensuring that referrals to secondary care are made where appropriate. Movement up the pyramid can be delayed or prevented by an integrated continence service with a traffic light system illustrating the risks and rising costs of untreated continence needs.

In an ageing population, greater prevalence of bladder and bowel problems and the wide range of care groups affected, mean that continence services require a higher priority. Effective community based continence services can save valuable NHS resources whilst restoring dignity to people and improving quality of life².

Incontinence is reported as a significant reason for care home admissions³. Variation in service provision and practice is a particular area of challenge. There appears to be no consistency as to the frequency of continence assessments.

Physical harm related to complications and treatments for continence problems for example pressure ulcers, urinary tract infection, catheterisation and faecal impaction can all lead to admission to hospital and care facilities for extended lengths of stay and sometimes permanently.

Reviewing the evidence

The National Audit of Continence Care⁴ found that many services were not providing services in line with NICE guidance and that the quality of care is worse among older patients over the age of 65 in whom the condition is most prevalent^{5, 6}. Of women suffering from 'moderate' or 'severe' urinary incontinence, fewer than one third were found to be receiving health or social services for their condition⁷.

Towards the aim of reducing healthcare related harm and costs, the Leading Change, Adding Value - a framework for nursing, midwifery and care staff⁸ sets out a systematic way of addressing gaps in services and unwarranted variation across the system. The framework recognises the importance of being able to measure the impact for the improvement of outcomes for local people.

The principles embodied in the NHS Improvement programme Getting it Right First Time⁹ should be applied to continence care as it recognises the importance of access to early assessment and diagnosis and the focus on improving the patient experience.

Towards these aims, pathways of care should be commissioned that ensure early assessment, effective management of incontinence, along with other bladder and bowel problems such as constipation and urinary tract infections and their impact on social, physical and mental well-being and existing comorbidities in order to reduce expensive pad usage, high cost complications and unnecessary hospital and care home admissions.

It is estimated that 14 million men, women, young people and children of all ages are living with bladder problems, roughly the equivalent size of the over 60 population in the UK¹⁰. It is also estimated that 61% of men in the general population experience lower urinary tract symptoms^{11, 12} (LUTS) and around 34% of women are living with urinary incontinence¹³.

In addition, 900,000 children and young people suffer from bladder and bowel dysfunction^{14, 15}. Bowel and bladder problems have more impact than almost any other medical condition on children's self-esteem, education and social relationships, and effective treatment can change children's lives (Dr Eve Fleming, ERIC Trustee).

6.5 million adults in the UK suffer with some form of bowel problem. 1 in 10 of the population are affected by faecal incontinence, with over half a million adults suffering from faecal incontinence, with a negative impact on their lives¹⁶. It is likely that 0.5-1% of adults experience regular faecal incontinence that affects their quality of life^{17, 18}.

Faecal incontinence is closely associated with age (prevalence is about 15% in adults aged 85 years living at home) and is more common in residential and nursing homes¹⁹ (prevalence ranges from 10-60%) (APPG 2011; NICE CG171, 2013).

Urinary and faecal incontinence are conditions affecting one in three people living in residential care and two in three nursing home residents²⁰. Inadequate management of incontinence can lead to escalating costs due to morbidity and unnecessary hospitalisation.

The rate of emergency admissions due to a urinary tract infection (UTI) has almost doubled over the last five years to 60 per 100,000 population placing additional pressure on acute settings which could often be avoided through early continence intervention.

In 2012/13 unplanned admissions for urinary tract infections (UTIs) cost £432 million per year, averaging 2.1 million per CCG²¹. Patients with incontinence are at increased risk of hospital acquired UTI which extends length of stay by 6 days. In 2010, 27,000 men were hospitalised for untreated LUTS²² (NICE CG139, 2012).

Catheter associated urinary tract infections (CAUTI) have significant associated costs of additional bed days and treatment, estimated to cost the NHS up to £99m p.a., or £1,968 per episode. Patients are often catheterised in ways which could have been avoided through good continence care. Nearly one third of urinary catheter-days are inappropriate in medical and surgical inpatients with 26% of catheters inserted in Accident and Emergency having no appropriate indication, suggestive that many catheters are inserted unnecessarily^{23, 24}.

Urinary tract infections are the most common healthcare acquired infection (HCAI), comprising 19% of all HCAIs; 43-56% of UTIs are associated with urethral catheters; approximately 17% of secondary nosocomial bloodstream infections are caused by catheter use, with an associated mortality of 10% (Loveday et al 2014).

Urinary catheters as a source of bacteraemia have seen an increase in both the numbers of cases and as a proportion of cases with source information between 2015/16 and 2016/17 and will require further effort to reduce this^{25, 26}.

Gram negative septicaemia is most commonly caused by UTIs and is considered to some extent to be preventable through good quality continence and medical care. NHS Improvement have mandated that all NHS Trusts have a strategy to reduce incidence by 10% in 2017 and by 50% in 2020^{27, 28}. This will require a collaborative approach across the whole health and social care system to achieve this.

In 2015, GP prescribing data²⁹ illustrates there were 1.1 million prescription items for catheters at a cost of £115.1 million pounds, an increase of 7.1% from 2014.

The 2013 Continence Care Services report for England³⁰ indicated that catheterisation is often a consequence of poor continence care. Continence services working closely with infection teams and GPs is the most effective way to either avoid urinary catheterisation altogether or else to shorten the duration of insertion.

Poor continence care is a contributory factor to pressure ulcers³¹. Nearly 700,000 people are affected by pressure ulcers each year, across all care settings. Each pressure ulcer costs an average of £4,638 - which creates a financial burden on the NHS of between £1.4 and £2.1 billion per year. Savings could be made by reducing the number of people who develop pressure ulcers; good continence care plays an important role in their prevention.

Bowel-related costs

In the period 2010/11, it was reported that 57,000 hospital admissions in England were due to constipation. In 2010, 103 deaths were registered in England and Wales with constipation cited as a contributory factor.



Public Health England publish AMR indicators intended to raise awareness of antibiotic prescribing, antimicrobial resistance, healthcare associated infections, infection prevention control and antimicrobial stewardship. These indicators are available at: <https://fingertips.phe.org.uk/profile/amr-local-indicators>



NHS Improvement published an on line improvement resource to help health and social care economies reduce the number of gram-negative bloodstream infections with an initial focus on Escherichia coli (E.coli) to support the delivery of the national 'Reducing the impact of serious infections (Antimicrobial Resistance and Sepsis)' CQUIN part 2c and 2d. This is available at: <https://improvement.nhs.uk/resources/preventing-gram-negative-bloodstream-infections/>

GP prescribing data (HSCIC 2016) reveals 18.4 million laxative items were dispensed at a cost of £92m per year. Constipation is linked to poor continence management, diet and lifestyle should be considered before drug treatment is initiated.

Considerable effort has gone into identifying predisposing factors for falls, injurious falls and fractures. Overactive bladder is an important risk factor for falls³². Patients with incontinence are 26% more likely to fall and 34% more likely to fracture³³.

Containment product costs

Significant cost impacts may be achieved as a result of accurate diagnosis, timely and effective treatment as opposed to reliance on products for containment without a full assessment and diagnosis (NICE QS77, 2015; NICE QS45, 2013).

Pad usage and costs can be reduced through good continence care. The monthly costs of pads is estimated at: daytime £34-73, night time £43-64. It is estimated that the NHS spends around £80 million per year on product costs.

Children and young people

More children are starting school without being toilet trained, according to a survey by the Association of Teachers and Lecturers (ATL) and ERIC, The Children's Bowel and Bladder Charity³⁴. 70% of foundation and key stage one staff said more children are now starting school without being toilet trained, compared to five years ago.



PrescQIPP produce evidence-based resources and tools for primary care commissioners, and provide a platform to share innovation across the NHS.
<https://www.prescqipp.info/>

Despite NICE guidance documents, with clear recommendations for the management of children with bedwetting and idiopathic constipation, many areas do not have in place community based services for children with bladder and/or bowel problems (Paediatric Continence Service Commissioning Guide 2014) and there is evidence of increasing referrals of children with constipation and enuresis to paediatric outpatient clinics^{35, 36, 37}.

The cost of assessment and treatment of these problems are:

- Level 1 (by the school nurse) £21.19 per hour
- Level 2 (Specialist paediatric continence advisor) £105 per hour
- Level 3 (secondary and tertiary OPD referrals) £160 to £220 for first appointments and £94 to £123 for follow-up.

NICE assesses that establishing a community based integrated paediatric continence service 'could lead to up to 80% reduction in emergency admissions (for continence problems) and a significant reduction in consultant led outpatient appointments'.

Constipation is common in childhood (prevalence around 5–30% of children) depending on the criteria used for diagnosis.

Symptoms become chronic in more than one third of patients and constipation is a common reason for referral to secondary care. Morbidity may be under-reported as people may not seek advice because they are embarrassed³⁸ (Paediatric Continence Service Commissioning Guide PCF 2014).

Case finding in at risk groups

Case finding and risk stratification are evolving disciplines, important in approaches for local care and business planning, particularly in relation to populations with multi-morbidity and complex needs such as those with continence problems³⁹.

Personalised care and support planning is the key vehicle by which staff work together with people and carers to meet individual care needs, supporting those with complex care needs identified through case finding and risk stratification.



Strengthening commissioning through self-assessment

The continence self-assessment framework supports continence commissioning by CCGs, helping to establish a dialogue with providers in relation to local continence pathways and services and to identify priority areas for action to strengthen commissioning and improve patient outcomes www.bladderandboweluk.co.uk

Commissioning for dignity and value

A key area of challenge is help with the 'how to transform or improve services'. NICE guidance urges commissioners and providers to deliver high quality conservative management of continence care provision delivered in an integrated way. To deliver optimal clinical outcomes an integrated service will benefit from a continence specialist and front-line staff training (HQIP 2010).

Clinical commissioning groups (CCGs) as part of their responsibilities should ensure that clear service level agreements with defined deliverables and standards of care are in place⁴⁰.

Women are at risk of developing bladder and bowel symptoms during pregnancy and post-partum. Regular assessment including by midwives are recommended and national guidelines suggest safe management at this time^{41, 42, 43, 44, 45, 46}.

What good looks like

For all ages the most significant principles to measure progress should comprise of:

- Needs based analysis undertaken and improvement plan developed
- Co production with public, service users and carers and acting on their feedback
- Integration across health, care and education
- Inclusion of the voluntary sector
- Prevention methodologies
- Specialist diagnostics and evidence based treatments including technology solutions
- Public education and awareness strategy
- Training and education of the workforce
- Evidence of people's involvement in decision making and care to improve their experience of the service

- Every patient being offered baseline assessment and timely treatment interventions.

The essential elements of a continence service

The United Kingdom Continence Society (UKCS) has led the design of minimum standards for continence care that provide an overview of the ideal structure of a continence service, not only in relation to staffing and training but also in relation to the settings of services, available resource and minimum workload to maintain expertise across all staff providing bladder and bowel care^{47, 48}.

High quality professional assessment is the foundation of high quality continence care. Many children, young people and adults with continence needs can be cured but where this is not achievable, a robust treatment and management plan can improve the quality of life for most.

NICE guidance makes it clear that once 'red flags' (warning signs of underlying conditions) have been excluded, conservative treatment and care measures should take place.

The initial assessment is best undertaken by staff trained in continence care in a community setting where conservative treatments such as dietary advice, bladder retraining and pelvic floor muscle exercises can be offered. A review by a General Practitioner can identify any medications or medical illnesses that may be having an adverse effect on continence.

Having been assessed, those with more complex problems or who have not responded to treatment, should be referred to a specialist service that can direct individualised treatments e.g. urology, urogynaecology, colorectal surgery, paediatrics, geriatrics or specialist physiotherapy.



Excellence in assessing need

Evidence for a local needs assessment is available in the Continence Needs Assessment module at Public Health England. Go to: <http://atlas.chimat.org.uk/IAS/profiles/needsassessments>

Children and young people

It is essential that all children and young people with a bladder or bowel problem have a comprehensive bladder and bowel assessment by appropriately trained staff with the correct treatment and management programme put in place. Underlying bladder or bowel problems can otherwise be missed with potentially dangerous results^{49, 50}. It must be the exception, rather than the rule, that children and young people are provided with containment products.

Good information for children and their families is important. Bladder and Bowel UK have a range of free downloadable resources for both healthcare professionals and the general public⁵¹.



The Paediatric Continence Forum: Paediatric Continence Commissioning Guide:

<http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>



Children's Continence Care Pathway

ERIC, the Children's Bowel and Bladder Charity has developed the Children's Continence Pathway which aims to inform parents and professionals about the assessment and intervention a child needs using a series of flowcharts. The pathway also provides a range of resources, including a comprehensive continence assessment form, guidance for its use, which can be used as a teaching aid, and flowcharts detailing the necessary treatment and management of each condition. <https://www.eric.org.uk/childrens-continence-pathway>



The Paediatric Continence Forum together with the UKCS have developed minimum standards for children and young people and are available at:

<http://www.paediatriccontinenceforum.org/wp-content/uploads/2016/07/MINIMUM-STANDARDS-FOR-PAEDIATRIC-CONTINENCE-CARE.pdf>



Guidance for the provision of continence containment products to children and young people: A consensus document published in 2016 was developed by expert clinicians and approved by a number of national organisations including the RCN. It facilitates a consistent and equitable approach to the provision of continence products (such as nappies and pads) to children and young people aged 0-19 and offers impartial advice to ensure all children and young people who have not toilet trained or have urinary or faecal incontinence, undergo a comprehensive assessment and have access to an equitable service.

The Guidance is available to download at:

<http://www.bladderandboweluk.co.uk/wp-content/uploads/2016/12/final-Guidance-Paed-product-provision-doc.pdf>

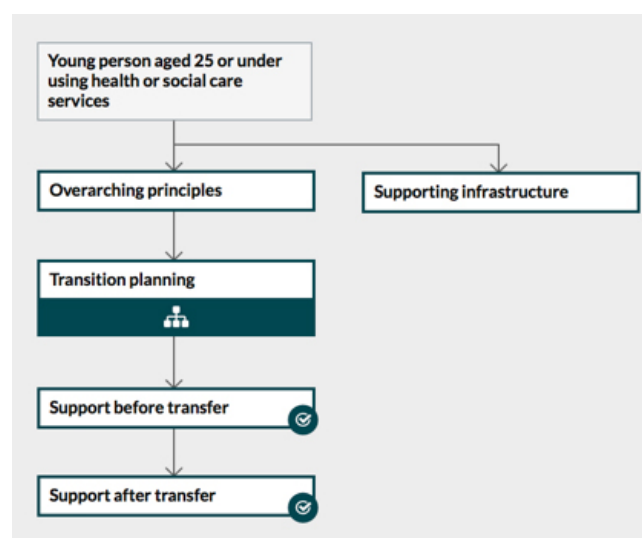
Transition

Transition of a young person's care from paediatric to adult services can be stressful for both the young person and their parents and carers. It is therefore important that it is a sensitively managed process, not an event.

This is addressed in detail in the NICE national guideline 43⁵² 'Transition from children's to adults' services for young people using health or social care services' and the subsequent Quality Standard⁵³. These indicate that the process should begin with planning the move from children's to adults' services at the same time as moving from secondary schooling.

It should include ensuring that a young person, who has moved from children's to adults' services, but does not attend their first meeting or appointment, are contacted by adult services and given further opportunities to engage.

Transition from children's to adults' services for young people using health or social care. (NICE NG43).



Adults

A service to address bladder and bowel problems needs to ensure that people with continence needs are enabled to:

- Identify their need for intervention and self refer
- Access the assessment and treatment interventions they require
- Agree shared goals
- Manage their own care as an active partner in care
- Manage in their own homes wherever possible.

People and their family and carers feel:

- They are treated with empathy and respect, heard and listened to
- Actively involved in decisions about their care
- The provision of services has a person centred approach to care that enables them to manage their condition and keep well for longer, with access to person held records and personal budgets.

People with long term conditions, disabilities or complex needs should be supported to plan their care having:

- A single point of contact
- Proactive planned care with ongoing support

Management of containment products

Products such as absorbent pads or urine collecting devices (sheaths, hand held urinals, faecal collectors) can maintain social continence but treatment must always be the preferred option. Review at regular intervals is required to ensure that the risk of infection is minimised and that products are fit for purpose but that where independence can be regained a return to standard toileting is enabled to promote quality of life.

Containment products can offer security and comfort helping people continue with their normal daily activities. However they are costly, can affect a person's dignity and do not offer a long term solution unless the person has not responded to other treatments.

Urinary catheterisation

It is recognised that indwelling urinary catheterisation is associated with infection which can lead to illness, hospital admission and even death. People living with a long term catheter may find them distressing, uncomfortable and undignified. However for others they may promote independence and prevent kidney damage.

Catheters should be:

- Avoided where possible
- Removed as soon as possible
- Be regularly reviewed
- Care and product usage should be tailored to the individual.

Where bowel management programmes are already in place (e.g. patients with spinal cord injury) it is essential that these are continued following admission to any care setting/hospital. Providers must ensure adequate and timely access for patients to appropriately trained staff/carers to carry out these procedures, including evenings and weekends.



NHS Improvement Patient Safety Resource Alert

"Resources to support safer care for patients at risk of automatic dysreflexia without interventional bowel care":

<https://improvement.nhs.uk/resources/patient-safety-alerts>



Guidance for the provision of containment products for adult incontinence: A consensus document published by the Association for Continence Advice provides impartial advice to ensure all adults who suffer with urinary or faecal incontinence undergo a comprehensive assessment and have access to an equitable service. The Guidance is available to download at: https://www.aca.uk.com/files/8415/1350/9577/Guidance_provision_of_incontinence_products_V12.November_2017.pdf

Care homes

It is estimated that more than 50% of care home residents have urinary incontinence. People living in care homes are entitled to the same access and level of NHS services as those living in their own homes. Care homes and commissioners should collaborate with each other to ensure adequate provision and funding of products.

Commissioning for Patient Experience, Engagement and Empowerment

True empowerment of people brings choice: not just a choice of a provider, but choice of what they feel is appropriate for them. This may mean turning down a particular treatment option. Empowerment means having access to information, advice and treatment and brings the understanding that people have the right to continent living, whenever this is achievable as, in many cases, the issue can be completely resolved.



NICE Clinical Guideline 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. <https://www.nice.org.uk/guidance/cg138>



Excellent partnership working Experience Based Co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways in partnership.

Further information is available from the Point of Care Foundation: <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>

As full partners in the design and delivery of person centred care, third sector organisations can radically extend the range of support that is available and can work collaboratively with commissioners to provide services that deliver holistic care (e.g. advocacy, information, advice, education, peer support). Commissioning plans should reflect the needs and preferences of local people who use continence services. Service users' views must be reflected through shared decision making in commissioning decisions.

Personal Health Budgets

Services should work toward a person centred approach to care via a shared decision making process, including person held records, personalised care and support plan and personal health budgets. The NHS England policy and vision for personal health budgets⁵⁴ is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the healthcare and support they receive. Personal health budgets are one way of helping people to be more involved in discussions and decisions about their care.

This directly involves containment products which must be chosen to best suit individual needs. With the appropriate support, informed choice and access to up to date advice, those with continence problems can be helped to live life with dignity, self-esteem and independence. This is a cost saving in itself and reduces wastage of inappropriate or over supply of items.

Procurement officers are best placed to make and evaluate choices. Patients are best placed to know individual requirements. Collaboration and understanding patient reported outcomes, in addition to cost, make for economic decision making process.

Developing the workforce

To ensure that outcomes are improved, risks to people are minimised and that they are cared for appropriately, it is the responsibility of all staff to be familiar with NHS England priorities in relation to continence and be able to identify their role in meeting these.

Endorsing a service provision framework and in order to drive improvements in continence care, minimum standards for education, training and service configuration exist for all grades of staff at every level across primary, secondary and tertiary care via a modular approach (UKCS 2014; 2016). This includes:

- Education at undergraduate level for physiotherapists, nurses and medical students
- Continuous professional development for postgraduates if they care for patients with continence needs or are in a position to identify people with continence problems
- Fundamental continence care education for others such as care assistants in care homes and hospitals.

Health and social care staff working with people with continence needs will be aware of their responsibilities in relation to the skills and competencies they require to work in a person centred way to support people in making decisions which sometimes may not be the ones recommended⁵⁵.



The Royal College of Nursing has developed an on line resource for registered nurses, nursing students, healthcare assistants (HCAs) and assistant practitioners working in any healthcare setting or specialism designed to help support people who have incontinence or bowel and bladder problems. <https://rcni.com/hosted-content/rcn/continence/home>

People with continence needs should be seen at the most appropriate time by the most appropriate professional. Trained specialist continence nurses have an important role in initial assessment and treatment, supplementing doctor-led provision models⁵⁶.

Any workforce planning led by Health Education England (HEE) around STPs needs to address the shortfall in specialist nurses and the need to train non specialists in primary care, hospitals and care homes as services are delivered closer to home or in the patient's home. This will require further discussion and agreement locally.

Physiotherapy has a vital role to play in continence care and needs to be considered as part of any remodelled provision or workforce planning. Evidence has shown pelvic floor muscle training can be more effective than pharmaceutical management⁵⁷. Patients require specialist assessment to maximise conservative measures, and a multidisciplinary team benefits from the expertise of nurses, physiotherapists and occupational therapists⁵⁸.



The United Kingdom Continence Society (UKCS) has developed a series of Minimum Standards for continence care, covering all aspects of adult care from female incontinence to neuropathic bladder and including specific information relating to continence services for children and young people. The UKCS Minimum Standards for continence care in the United Kingdom are available at: www.ukcs.uk.net



The Royal College of General Practice and Public Health England's Primary Care Unit have developed a free e-learning managing urinary tract infections course that explains the importance and appropriateness of diagnostics and offers advice on how to assess and treat patients with a range of urinary symptoms. <http://www.rcgp.org.uk/TARGETAntibiotics>

Measures, drivers, levers and incentives

Commissioning levers include STP opportunities, CCG duties to reduce health inequalities in access and outcomes, as defined in the Health and Social Care Act⁵⁹, raising the profile of user experience and the Joint Strategic Needs Assessment (JSNA). The Local Government and Public Involvement in Health Act (2007) require CCGs and local authorities to develop a JSNA of the health and well-being of their local community. This in turn, improves quality and supports better targeting of interventions to reduce the health inequalities for people with bladder and bowel problems.

Of particular relevance to continence care is NHS England's 2017/19 Quality Premium, designed to incentivise service improvements in CCGs. The Quality Premium emphasises the importance of reducing the number of E.coli bacteraemia infections across the whole health economy, with a significant proportion of these due to poor catheter care.



Bothersome rating

The bothersomeness of symptoms and the embarrassment caused is increasingly used to measure the effect of people's symptoms. The ICIQ-UI Patient Perception Bothersome rating asks people to rate the effect of their current bladder / bowel problems.

For further information: https://www.health.harvard.edu/newsletter_article/urinary-symptoms-of-bph-how-bothersome-are-they

Commissioning for quality

Commissioners can use various contract levers with providers to support improvements including:

- Evaluation of user experience
- Ensuring care pathways are effective
- Using Joint Strategic Needs Assessment data set to establish the current and future health needs of the local population and organisational self assessments
- Use of audit results such as those by HQIP
- Improvement in case finding in at risk groups.



International Consultation on Incontinence Modular Questionnaire (ICIQ)⁶⁰

The ICIQ-UI short form provides a brief and robust measure to assess the impact of symptoms of incontinence on quality of life and outcome of treatment.

For further information: <http://iciq.net/index.html>

To deliver clinical quality improvements and drive transformational change underpinned by the NHS Five Year Forward View, organisations will move to more place based commissioning, geared towards transforming services to deliver better quality standards for patients.

Commissioners might want to consider the following as a way of monitoring local continence pathways of care within service agreements:

- Establishment of case-finding questions e.g. 'Do you ever have problems getting to the toilet on time?'
- Assessment of patients using three simple tests: urine test/ bladder/bowel diary and bladder scan
- Assessment of all people for continence problems, over the age of 75 in primary care, at hospital admission and in the community setting
- The training of the domiciliary sector in simple assessment and the establishment of referral pathways, by community services.

Outcomes based commissioning

Measuring outcomes forms a key indicator of success and implementing effective continence care pathways and services is fundamental in achieving this.

Outcome measures are of great importance, but process and balancing measures should not be excluded. These can be very useful in determining effective change and action in the short term, especially where outcome measures can take a long time to determine.

In the true meaning of person centred care and involvement, what is commissioned is informed by people's choices and satisfaction levels, not just on any clinically identified need.

It is recommended that measures to evaluate Excellence in Continence Care pathways are based on existing data collection in the following categories:

Patient experience

Patient experience insight data including for example complaints, comments and suggestions, Friends and Family, Patient Reported Outcome Measures.

Safety data

Safety data including for example reduction in pressure ulcers and continence-related dermatitis, catheter associated urinary tract infections and mortality due to constipation and urosepsis.

Delivering quality and value

Where indicators demonstrate any savings released as a result of changes to the pathway.

Examples include:

- Commissioning for value such as prescription costs
- Reduced urgent emergency care cost
- Increased identification and prevention
- Improved evidence-based commissioning
- Baseline continence assessment for all who need it.

The primary objective for NHS RightCare is to maximise the value that the patient derives from their own care and treatment and the value the whole population derives from the investment in their healthcare.



NHS RightCare scenario
Getting the dementia pathway right.

This scenario highlights continence care and support, good practice and where practice could be improved across the patient journey. <https://www.england.nhs.uk/wp-content/uploads/2017/04/toms-story-full-narrative.pdf>

Aligning metrics, using incentives as levers and contracting requirements across a whole system pathway including primary as well as acute, community and social care providers, will help drive system changes.

Measuring outcomes forms a key indicator of success and implementing effective continence care pathways and services is fundamental in achieving this.

This document can assist commissioners and providers of services towards these aims.

For further supporting information including case studies go to <https://www.england.nhs.uk/commissioning/continence/>

References

- ¹ NHS Five Year Forward View (2014) <https://www.england.nhs.uk/publication/nhs-five-year-forward-view>
- ² All Party Parliamentary Group (APPG) for continence (2011) Cost-effective commissioning for continence care. <http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf>
- ³ Kings Fund (2014) Admission to a nursing home can never become a 'never' event. <https://www.kingsfund.org.uk/blog/2014/08/admission-nursing-home-can-never-become-never-event>
- ⁴ Healthcare Quality and Improvement Partnership (HQIP) (2010) National audit of continence care. <https://www.rcplondon.ac.uk/projects/outputs/national-audit-continence-care-nacc>
- ⁵ Harari D, Husk J, Lowe D, Wagg A. (2014) National audit of continence care: Adherence to National Institute of Clinical Excellence (NICE) Guidance in older versus younger adults with faecal incontinence Age ageing. Nov;43(6):785-93
- ⁶ Wagg A, Gibson W, Ostaszkiwicz J, Johnson T, Markland A, Palmer A, Palmer M.H., Kuchel G, Szonyi G, Kirschner-Hermanns R. (2014) Urinary incontinence in frail elderly persons: Report from the 5th International Consultation on Incontinence. <http://onlinelibrary.wiley.com/doi/10.1002/nau.22602/full>
- ⁷ National Institute for Health and Clinical Excellence (2013) Urinary incontinence in women: management. (CG171) <https://www.nice.org.uk/Guidance/CG171>
- ⁸ NHS England (2016) Leading change adding value. A framework for nursing, midwifery and care staff. <https://www.england.nhs.uk/wp-content/uploads/2017/06/leading-change-adding-value-summary.pdf>
- ⁹ NHS Improvement (2017) Getting it right first time. <https://improvement.nhs.uk/news-alerts/getting-it-right-first-time-recruits-new-clinical-leads/>
- ¹⁰ Buckley, B. S., & Lapitan, M. C. M. (2009) Prevalence of urinary and faecal incontinence and nocturnal enuresis and attitudes to treatment and help seeking amongst a community-based representative sample of adults in the United Kingdom. International journal of clinical practice, 63(4), 568-573.
- ¹¹ National Institute for Health and Clinical Excellence (2010) Lower urinary symptoms in men: management. (CG97) <https://www.nice.org.uk/Guidance/CG97>
- ¹² National Institute for Health and Clinical Excellence (2013) Lower urinary tract symptoms in men. (QS45) <https://www.nice.org.uk/Guidance/QS45>
- ¹³ In Contact Bladder Campaign <http://ww38.incontact.org/>
- ¹⁴ National Institute for Health and Clinical Excellence (2010) Bedwetting in under 19s. (CG 111) <https://www.nie.org.uk/guidance/cg111>
- ¹⁵ National Institute for Health and Clinical Excellence (2014) Bedwetting in children and young people. (QS70) <https://www.nice.org.uk/guidance/qs70>
- ¹⁶ Age UK (2017) Later life in the United Kingdom http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf
- ¹⁷ National Institute for Health and Clinical Excellence (2007) Faecal Incontinence in Adults: Management. (CG49) <https://www.nice.org.uk/Guidance/CG49>

- ¹⁸ National Institute for Health and Clinical Excellence (2014) Faecal incontinence in adults. (QS54) <https://www.nice.org.uk/Guidance/QS54>
- ¹⁹ Roehrborn, C. 2007 'Male lower urinary tract symptoms - epidemiology, terminology and pathophysiology'. European Urological Review, (1):64-6).
- ²⁰ British Geriatrics Society. (2010) Continence care in residential and nursing homes. <http://www.bgs.org.uk>
- ²¹ The Medical Technology Group (2015) Media Release: NHS could slash emergency admission costs with better use of medical technology. <http://www.mtg.org.uk/wp-content/uploads/2016/07/Admissions-of-Failure-report-release-FINAL-131115-1.pdf>
- ²² National Institute for Health and Clinical Excellence (2012) Healthcare-associated infections: prevention and control in primary and community care (CG139) <https://www.nice.org.uk/guidance/cg139>
- ²³ Loveday HP, Wilson JA, and Pratt RJ (2014) Epic3: national evidence-based guidelines for preventing healthcare associated infections in NHS hospitals in England. Journal Hospital Infection 86 (1 Suppl): S1–70
- ²⁴ Feneley R, Hopley IB, Wells PNT (2015) Urinary catheters: history, current status, adverse events and research agenda. J Med Eng Technol 39(8): 459-70.
- ²⁵ National Institute for Health and Clinical Excellence (2014) Infection, prevention and control. (QS61) <https://www.nice.org.uk/guidance/qs61/chapter/quality-statement-4-urinary-catheters>
- ²⁶ Public Health England (2017) Urinary tract infection: diagnosis guide for primary care. <http://www.gov.uk/government/publications/urinary-tract-infection-diagnosis>
- ²⁷ Department of Health (2016) Reducing infections in the NHS. <https://www.gov.uk/government/news/reducing-infections-in-the-nhs>
- ²⁸ NHS Improvement (2017) GNBSI letter to the system. https://improvement.nhs.uk/documents/1337/2017-06-28_GNBSI_letter_to_system_-_final_TvRv5iK.pdf
- ²⁹ Health and Social Care Information Care (2016) Prescriptions dispensed in the community: England 2005 - 2015 <http://digital.nhs.uk/catalogue/PUB20664>
- ³⁰ All Party Parliamentary Group (APPG) Continence Care (2013) Cost effective commissioning for continence care: A guide for commissioners written by continence care professionals. <http://www.appgcontinence.org.uk/>
- ³¹ Public Health England (2015) All Our Health: personalised care and population health. Guidance pressure ulcers: applying All Our Health. <https://www.gov.uk/government/publications/pressure-ulcers-applying-all-our-health/pressure-ulcers-applying-all-our-health>
- ³² Szabo SM, Gooch KG, Walker DR, Johnston KM, Wagg AG. (2017) The association of overactive bladder and falls and fractures: A systematic review.
- ³³ Soliman Y, Meyer R, Baum N. (2016) Falls in the elderly secondary to urinary symptoms. Reviews in urology.; 18(1):28-32
- ³⁴ ERIC and the Association of Teachers and Lecturers (2016) Survey of 699 school staff, 110 (18), 20-22.
- ³⁵ Pal E, Liu D, Sutcliffe J. (2016) Surgical Clinic Use for Chronic Idiopathic Constipation. European Journal of Paediatrics 175.(11), 1727-1728

- ³⁶ Scarlett A, Chin-Goh K, Choudri M, Madden N, Rahman N, Farrugia M-K, de Caluwe D. (2015) Referral patterns for wetting children to a paediatric urology center: Who should see what? Poster Presentation at 26th ESPU/ICCS Congress, Prague
- ³⁷ Thompson E, Todd P, Ni Bhrolchain C. (2010) The epidemiology of general paediatric outpatients referrals: 1988 and 2006. *Child: Care, Health & Development*.39(1):44-9
- ³⁸ National Institute for Health and Clinical Excellence (2010) Constipation in children and young people: diagnosis and management.(CG99) <https://www.nice.org.uk/Guidance/CG99>
- ³⁹ NHS England (2015) Using case finding and risk stratification: A key service component for personalised care and support planning. <http://www.england.nhs.uk/wp-content/uploads/2015/01/2015-01-20-CFRS-v0.14-FINAL.pdf>
- ⁴⁰ National Institute for Health and Clinical Excellence (2015) Urinary incontinence in women. (QS77) <https://www.nice.org.uk/guidance/qs77>
- ⁴¹ National Institute for Health and Clinical Excellence (2008) Antenatal care for uncomplicated pregnancies. (CG62) <https://www.nice.org.uk/Guidance/CG62>
- ⁴² National Institute for Health and Clinical Excellence (2014) Intrapartum care for healthy women and babies. (CG190) <https://www.nice.org.uk/guidance/cg190>
- ⁴³ National Institute for Health and Clinical Excellence (2006) Postnatal care up to 8 weeks after birth. (CG37) <https://www.nice.org.uk/guidance/CG37>
- ⁴⁴ Royal College of Obstetricians and Gynaecologists (2015) Female genital mutilation and its management (Green-top Guideline No. 53) <https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg53/>
- ⁴⁵ WHO (2017) Guidelines Management of health complications from FGM. <http://www.who.int/reproductivehealth/topics/fgm/management-health-complications-fgm/en/>
- ⁴⁶ Department of Education (2015) Mandatory reporting of female genital mutilation: procedural information. <https://www.gov.uk/government/publications/mandatory-reporting-of-female-genital-mutilation-procedural-information>
- ⁴⁷ United Kingdom Continence Society (2016) Minimum standards for paediatric continence in the UK. <http://www.ukcs.uk.net/newsletter-downloads/downloads/policy-documents-downloads/>
- ⁴⁸ United Kingdom Continence Society (2014) Adult minimum standards document. <http://www.ukcs.uk.net/newsletter-downloads/downloads/policy-documents-downloads/>
- ⁴⁹ Hicks JA, Carson C, Malone PS (2007) Is there an association between functional bladder outlet obstruction and Down's syndrome? *Journal of Paediatric Urology* 3(5):369-74. <https://www.bladderandbowel.org/bladder/>
- ⁵⁰ Rogers J. (2012) Working with families to boost children's continence. *Nursing Times*. 2012 Dec 11- 2013 Jan 14; 108(50):16, 18.

- ⁵¹ <http://www.bladderandboweluk.co.uk/children-young-people/children-resources/>
- ⁵² National Institute for Health and Clinical Excellence (2016) Transition from children's to adults' services for young people using health or social care services. (NG43) <https://www.nice.org.uk/guidance/ng43>
- ⁵³ National Institute for Health and Clinical Excellence (2016) Transition from children's to adults' services. (QS140) <https://www.nice.org.uk/guidance/qs140>
- ⁵⁴ NHS England Personal Health Budgets <https://www.england.nhs.uk/personal-health-budgets/>
- ⁵⁵ National Institute for Health and Clinical Excellence (2012) Patient experience in adult NHS services.(QS15) <https://www.nice.org.uk/guidance/qs15>
- ⁵⁶ Wagg, A. (2015) Improving Continence around the World. Nursing Times <https://www.nursingtimes.net/clinical-archive/continence/improving-continence-care-around-the-world/5085280.article>
- ⁵⁷ Imamura M, Abrams P, Bain C et al (2010) Systematic review and economic modelling of the effectiveness of non-surgical treatments for women with stress urinary incontinence. Health Technology Assessment 14:1–118, iii–iv
- ⁵⁸ Imamura M., Jenkinson D., Glazener C., Vale L (2010) Effectiveness of non-surgical interventions for women with stress urinary incontinence: Systematic review and meta-analysis of randomised controlled trials. Neuro-urology and Urodynamics. 29,6. 907-908
- ⁵⁹ Health and Social Care Act. (2012) <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>
- ⁶⁰ Abrams, P., Avery, K., Gardener, N., Donovan, J., & Board, I. A. (2006). The international consultation on incontinence modular questionnaire. The Journal of urology, 175(3), 1063-1066. www.iciq.net



Contributors

NHS England is grateful to members of the EICC board past and present for their work and contributions to this refreshed and updated publication, the many professionals who shared their good practice and a special acknowledgement to the people with lived experience.