

Excellence in continence care:

Practical guidance for commissioners, providers, health and social care staff
and information for the public



OFFICIAL

NHS England INFORMATION READER BOX

Directorate

Medical	Commissioning Operations	Patients and Information
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance		

Publications Gateway Reference: 03792

Document Purpose	Guidance
Document Name	Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public
Author	NHS England
Publication Date	16 November 2015
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	
Description	Practical guidance for commissioners, providers, health and social care staff and information for the public to put into effect best care and to guide people to the help they need to manage their bladder and bowel problems.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	Implement as best practice and use as advice for self-care.
Timing / Deadlines (if applicable)	
Contact Details for further information	Philippa Potter Head of Nursing NHS England (South) Premier House Caversham Rd Reading philippapotter@nhs.net
Document Status	
This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet.	

Excellence in continence care:

Practical guidance for commissioners, providers, health and social care staff and information for the public

Version number: 1

First published: November 2015

Updated: Not applicable

Prepared by: Philippa Potter, Head of Nursing NHS England (South)

Classification: OFFICIAL

The National Health Service Commissioning Board was established on 1 October 2012 as an executive non-departmental public body. Since 1 April 2013, the National Health Service Commissioning Board has used the name NHS England for operational purposes.

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:

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

Other formats of this document are available on request.

Contents

Contents	4
Glossary of terms	5
Foreword	6
1 Executive summary	7
2 Introduction	7
3 Reducing healthcare related harm and costs	9
3.1 The case for action	9
3.2 Case finding in at risk groups	10
3.3 Who is at risk?	10
4 Commissioning for dignity and value	11
4.1 Prevention	11
4.2 What good looks like	11
4.3 The essential elements of a continence service	12
4.3.1 Adults	13
4.3.2 Children and young people	14
4.4 Empowering people	15
4.5 Delivering and receiving care	16
4.5.1 Management and containment	16
4.6 Developing the workforce	17
4.7 Roles and responsibilities of team members	18
4.8 Measures, drivers, levers and incentives	19
4.8.1 Primary care	20
4.8.2 Commissioning for quality	20
4.8.3 Outcomes based commissioning	21
5 Measuring outcomes	22
6 Next steps	23
7 Contributors	25
8 References	26
9 Resources	28
10 Acronyms	29

Glossary of terms

Topic	Definition
Case finding	A process of identifying people with needs
Children and young people	Includes ages 0-19 years
Clinical Commissioning Group (CCG)	Responsible for the planning and commissioning of health care services for their local area
Constipation	Bowel movements that are infrequent or hard to pass
Containment product	Absorbent products, nappies, toileting aids including e.g. hand-held urinals
Continence	Control of the bladder and / or bowel
CQUIN	A Commissioning for Quality and Innovation payment to a provider: a mechanism for incentivising quality improvement within NHS contracts
Diarrhoea	Loose or liquid bowel movements
Gynaecology	Medical speciality dealing with female reproductive system including the vagina, uterus and ovaries
Hysterectomy	Removal of the uterus (womb)
Lower urinary tract symptoms (LUTS)	Describes a group of signs including e.g. frequency and urgency of urination and incomplete voiding of the bladder (in men involving the prostate gland)
Neurological or neuropathological disorders	Problems of the nervous system
Multi-disciplinary team (MDT)	A multidisciplinary team (MDT) comprises members from different disciplines each providing specific skills to meet the patient's needs. The members collaborate in treatment and care planning
Paediatrics	Medical speciality dealing with the care of children and young people
People / patients	This refers to everyone with continence needs including the whole age range from new born to older age who may or may not be in the health care system
Prostatectomy	Removal of the prostate gland
Provider	Responsible for organising the delivery of care and services
Risk stratification	With case finding, a process of segmenting a population to provide person-centred care to those most in need
Urinary Tract Infection (UTI)	Infection of any part of the urinary tract including the urethra, ureters, bladder and kidneys
Urodynamic studies	Tests of the function of the lower urinary tract
Urology	Medical speciality dealing with the surgical and medical diseases of the male and female urinary tract

Foreword

The Five Year Forward View set us a challenge of refocusing healthcare to prevent ill health and provide people with greater control over their condition and care. It also encourages much greater collaboration between health and social care, working in partnership with the third sector (that includes voluntary and charity groups) and ensuring we maximise the value of resources we spend on healthcare.

This vision underpins what we want to achieve for people living with continence needs who, in the past, have often suffered in silence as higher profile conditions attracted attention and resource.

Over the years, some excellent research and guidelines have been produced for best practice continence care but this work has often stalled as it has not translated into a clear commissioning plan for a local continence pathway.

The Excellence in Continence Care guidance provides a framework that enables commissioners to work in collaboration with providers and others to make a step change to address these shortfalls so that safe, dignified, efficient and effective continence care is consistently provided.

This guidance could not have been produced without our diverse groups of patient and public advocates, clinicians and other partners listed at the back of the document. Their energy, commitment, expertise and determination to ensure that children, young people and adults of all ages, including the most vulnerable in our communities, can rightly rely on excellent continence care is commendable.

One of the most rewarding aspects of developing the guidance has been listening and responding to people using continence services and giving them the opportunity to rebalance power so people can have a greater role in the assessment and management of their continence condition and in service design.

Properly used, the guidance provides a practical means for commissioners to understand the burden of continence needs within their local population. Also, to specify and contract for continence services, effectively measure outcomes and experience and work towards reducing health inequalities.

Now is the opportunity to put into effect the best care and to guide people to the help they need to manage their bladder and bowel problems. Implementation of this framework can bring the beginning of system-wide improvements in the provision of continence care across the country.

Sarah Elliott
Chief Nurse
NHS England (South)

1 Executive summary

NHS England is publishing this guidance to help support best practice in continence care, promoting equal access to services and treatment for all. It is applicable to all children, young people, adults and the elderly, taking into account their diverse needs from assessment, diagnosis and treatment to recovery where possible. The purpose is to promote consistent practice, improve the experiences of people with continence needs drive advances in clinical outcomes and reduce health inequalities.

This guidance will enable Clinical Commissioning Groups (CCGs) and providers to commission and provide healthcare for their population that meets the five domains in the Outcomes Framework 2015/16 (NHS England¹):

- Domain 1 Preventing people from dying prematurely
- Domain 2 Enhancing quality of life for people with long term conditions
- Domain 3 Helping people to recover from episodes of ill health or following injury
- Domain 4 Ensuring that people have a positive experience of care
- Domain 5 Treating and caring for people in a safe environment and protecting them from avoidable harm.

The framework outlines a pathway including assessment, diagnosis and treatment to recovery where possible. The groups of who is at most risk of continence problems are identified and a picture of 'what good looks like' is given to help people understand what a continence service should be delivering with regard to standards and outcomes.

The importance of true empowerment of people is highlighted showing that full partnership in the delivery of person-centred care brings real choice though access to information, advice and treatment: the ability of the workforce to work in a person-centred way is central to this. Minimum standards for the workforce involved in continence are described along with the specific roles and responsibilities of continence team members including the patient, family and carers.

In order to drive change, the metrics and incentives required for this across a whole-system pathway are presented. Outcome measures are recommended that can determine the effectiveness of the actions taken to improve the care and treatment of people with continence needs in the short and longer terms.

Importantly, information is provided to members of the public who may need signposting to services for themselves, friends or family, or with help about aspects of self-care. This short guide and framework brings the potential to improve outcomes, value, experience and quality of life and importantly, to remove the stigma attached to this most basic of needs that can affect us all.

2 Introduction

Robert Francis referred to continence as 'this most basic of needs,' his report highlighting significant concerns in this area of care (Department of Health, 2010). In

OFFICIAL

the 'Hard Truths' report, the Government made a commitment to ensure that the fundamental standards of care that people have a right to expect are met consistently, whatever the setting (Department of Health, 2013.)

Continence is the ability to voluntarily control emptying the bladder and bowels effectively in a socially acceptable and hygienic way.

Recognition of the necessity for nationwide improvements in the care of people with continence problems led to the Excellence in Continence Care programme, the overarching aim of which has been to produce a national framework.

In the UK, there are over 14 million adults who have bladder control problems and six and a half million with bowel control problems (Buckley & Lapitan 2009). In addition, 900,000 children and young people suffer from bladder and bowel dysfunction (NICE¹ 2010). Regular audits by the Healthcare Quality Improvement Partnership (HQIP), the latest in 2010, show that despite the amount of guidance available, the quality of continence care remains variable across the country and poorer overall for the elderly.

Many continence problems can be cured and certainly managed better. People have the right to be heard, receive the right treatment at the right time and live the best achievable quality of life possible. Improving continence care provision through integrated services brings many benefits including:

- a better quality of life and more independence through finding solutions appropriate to individual needs
- less reliance on pads and products by using alternative treatments
- a reduction in admissions to hospitals and care homes
- fewer complications, such as urinary tract infections, faecal impaction and skin breakdown
- a reduction in costs.

HQIP (2010) established that in order to achieve the best clinical outcomes, continence services have to be integrated across primary and secondary care and care home settings. Where this does not occur, children, young people adults and vulnerable at risk groups in particular, continue to suffer with this condition unnecessarily, often in silence and embarrassment.

They also concluded that 'there is an urgent need for improved and equitable practice for all people with bladder and bowel problems' through the development of commissioning frameworks, evidence-based training for health professionals and patient empowerment to increase their expectations of cure.

In their NICE-accredited Paediatric Continence Commissioning Guide (2014, updated 2015), the Paediatric Continence Forum (PCF) stated 'All children and young people from birth to 19 years with bladder and bowel dysfunction (continence

problems) including those with learning difficulties and physical disabilities should have access to an integrated community-based paediatric continence services: the Community Paediatric Continence Service (CPCS).

It is crucial, therefore, that staff involved in commissioning and providing continence services and those affected by continence problems are aware of the resources available to them and the standards that should be achieved.

Implementation underpins all five domains of the NHS Outcomes Framework. It is designed to engage and capture the energies and commitment of medical, nursing and allied health professional leaders who have responsibility for meeting the domain requirements.

This short guide and framework is designed to give clear direction, and when implemented brings the potential to improve outcomes, value, quality of life and the experiences of people with continence needs.

3 Reducing healthcare - related harm and costs

3.1 The case for action

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 life (All Party Parliamentary Group for Continence Care (APPG), 2011).

Not all costs are financial and there is a large body of evidence about the effect of continence problems not just on the system but on people's lives. There can be considerable psychological impact, affecting personal relationships, body image, sex and romantic lives. Physical harm related to complications and treatments for continence problems e.g. 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.

Commissioners are well-placed to focus on transforming the care of people with continence needs, reducing duplication, driving healthcare closer to home and focusing on primary and secondary prevention as set out by NHS England in the Five Year Forward View (2014).

It is the duty of commissioners to take action in promoting equality and reducing health inequalities. When commissioning, implementing and evaluating continence services, commissioners need to take into account the duties placed on them under the Equality Act (2010) and the Health and Social Care Act (2012). Service design and communications must be appropriate and accessible to meet the needs of diverse communities, that includes people with physical disabilities, the elderly, people with learning disabilities or communication needs, those who are isolated or live alone, are in care or hospitalised long-term and those with specific religious requirements.



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.

Go to:

<http://www.disabledliving.co.uk/DISLIV/media/promocon/Useful%20Reports%20-%20Other%20Organisations/self-assessment-framework.pdf>

3.2 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 problems (NHS England² 2015).

Case finding is a systematic way of identifying people with particular needs from a larger population for a certain purpose e.g. pregnant women needing treatment for continence problems.

Risk stratification is a process that can be used for commissioning as it divides a population into different groups and estimates the levels of clinical threat for a specific outcome e.g. number of unscheduled admissions to hospital.

These concepts are increasingly important processes that are essential to meeting the core objectives in the NHS England Business Plan (2015²): to involve people with long term conditions, to strengthen primary care as the foundation for personalised NHS care and to provide modern integrated services.

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.

People with continence needs are often too embarrassed and / or poorly informed about the possibility of improvement and even cure. Continence problems can be frequently overlooked by providers in all settings and for this reason NICE recommends case finding in all at risk groups.

3.3 Who is at risk?

At risk group
Children and young people
Pregnant women
Women who have had children
Women undergoing the menopause
Women who have had a hysterectomy
Men who have had a prostatectomy

At risk group
People with chronic constipation
People with dementia
People with diabetes
People with diarrhoea
People with heart failure
People with learning disability
People with mental health problems
People with musculoskeletal problems e.g. arthritis
People with neuropathological problems e.g. dementia, Parkinson's, spina bifida, multiple sclerosis, stroke
People who are obese
People with spinal injury
People with urinary tract infections (UTIs)
Older people (65+)

4 Commissioning for dignity and value

The strategic outcome

Applicable to all, the most crucial aim is to help those with continence needs achieve complete continence, or to manage the condition discreetly and effectively if full control is not possible (PCF 2014).

4.1 Prevention



The Prevention Pyramid

The All Party Parliamentary Group for Continence Care has designed a Prevention Pyramid (2011) 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.

Go to: <http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf>

4.2 What good looks like

Defining 'what good looks like' helps people understand a service and what it should be delivering with regard to standards and outcomes in a simple but meaningful way. Applicable to services commissioned for adults, children and young people, the most significant measurable principles comprise:

1. Organisational leadership of continence
2. A needs analysis relevant to adults, children and young people

3. A continence service provision design that meets the needs analysis, incorporating:
 - a. Evidence of public, user and carer involvement
 - b. Integration across primary, secondary and tertiary services, health, education and social care
 - c. Inclusion of the voluntary sector
 - d. Prevention methodologies
 - e. Baseline assessment for all sufferers
 - f. Specialist diagnostics
 - g. Evidence-based treatments
 - h. Public education and awareness strategy
 - i. Training and education of the workforce
4. Use of technology
5. Improvement plans in place where indicated
6. An evaluation strategy incorporating people's feedback

People need to be able to report:

- Their involvement in decision-making and care
- Being offered baseline assessment and treatment interventions in a timely way
- Having the best possible experience.



Excellence in 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. It is a powerful and proven way of improving patients' experience of services. The approach was designed for and within the NHS to develop simple solutions that offer patients a better experience of treatment and care, which the evidence shows is very much needed in continence care.

Go to: <http://www.kingsfund.org.uk/projects/ebcd>

4.3 The essential elements of a continence service

The United Kingdom Continence Society (UKCS) has led the design of minimum standards for continence care (2015). These 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 in specialist services. Implementation can drive improvements in the standard of continence care across the country.

Where commissioners are aiming to secure innovation or deliver more choice for people, a service specification for a community continence service supports commissioners to deliver in partnership (NHS 2012).

An overview of a service specification for a paediatric continence service is provided in the Paediatric Continence Commissioning Guide (2014). The national Child and Maternal Health Intelligence Network (CHIMAT) is part of Public Health England and publishes a needs assessment report on continence in children and young people. Providing national and local data in context of evidence and national guidelines, it is intended to help local areas to undertake needs assessments as part of planning for children and young people.



Excellence in assessing need

Evidence for a local needs assessment is available in the Continence Needs Assessment module (Public Health England 2015).

Go to: <http://atlas.chimat.org.uk/IAS/profiles/needsassessments>

4.3.1 Adults

A service to address bladder and bowel problems needs to ensure that:

- People with continence needs are identified and supported to:
 - identify their need for intervention
 - agree shared goals
 - self-refer
 - access the assessment and treatment interventions they require
 - manage their own care as an active partner in care via an holistic approach
 - if necessary, manage in their own homes wherever possible, and their conditions (or that of dependents) as successfully as possible
 - have a good experience of receiving care.
- People and their family and carers feel:
 - they are treated with empathy and respect, listened to and heard
 - actively involved in decisions about their care
 - services have a person-centred approach to care, including the provision of:
 - * person-held records
 - * access to personal budgets where appropriate
 - * education and information to protect their own health, prevent ill health and to manage their condition.
- People receive a service that is integrated, well organised and coherent, providing:
 - timely access to help
 - expert assessment and diagnosis
 - effective treatment
 - self-management where possible
 - referral to more specialist services where necessary.

- People with long term conditions, disabilities and complex needs are supported to plan their care and treatment, having:
 - a known single point of contact
 - an identified care coordinator
 - proactive planned care with on-going support.

Simple approaches to care delivery, including electronic and telecommunications, can facilitate this.

4.3.2 Children and young people

In addition, a service for children and young people needs to provide:

- treatment for all children and young people (from birth to 19 years old), including those with learning difficulties and physical disabilities
- one community - based service for children and young people with all wetting (daytime and bedwetting), constipation and soiling problems
- leadership via a paediatric continence nurse specialist with input from a multi-disciplinary team (NHS England⁴)
- clear and effective referral and care pathways to secondary/tertiary care, education, Child and Adolescent Mental Health Services (CAMHS) and to social services.



My story

A mother of teenage twins has worked hard to give her girls the best possible life. Although before they were born 15 years ago, Clare was told there would be problems with her babies: it was only around 6 or 7 years of age that the twin girls' problems with continence began to be taken seriously by a health professional and even then the problem continued to be seen as part of developmental delay. Now, both girls use bowel irrigation, twice a day.

'A learning disability nurse helped us get a special school nurse visit and from then on we entered a series of experiments to try to identify what could help my girls go to the toilet. They are much more comfortable after the procedure and they actually ask to have it.'

Arranging this daily care hasn't been easy: at times, talk of a stoma operation was proposed as a resolution. However, with learning disabilities, diabetes, a heart valve problem in one twin and learning disabilities and milder health problems in the other, Clare wants to make sure the quality of life for her girls is the best it can be.

'Between residential school-care half the week and home care for the rest of the week, we manage. The girls are doing well at school and we are hopeful that now we have good support for continence, we can manage the issue better. That said, it isn't without its problems; making sure there is a consistent understanding between

different health care professionals who come into contact with the girls is a battle, and whether or not there is something fundamentally wrong with the structure of my daughters' bowels is a nagging question.'

What Clare would like you to understand: My family's experience of continence highlights how important it is to have specially trained health care professionals. It was only after receiving specialist advice that the right investigations were done and my daughters' problems seen as more than developmental delay. The initial options we were given for my twins didn't work and later became more dramatic and restrictive. We were often worried for their future and we still feel like that from time to time.

4.4 Empowering people

Care needs to be integrated across health, care and education settings so people do not have to repeat often embarrassing stories to each part of the service. For example, parents of a child with wetting and soiling problems often have to travel to different clinics and tell the same story to different professionals. This results in fragmented care for conditions that are intrinsically interrelated. As well as improving experience of care, integrated services deliver better clinical outcomes (HQIP 2010).

People with bladder and bowel problems should be supported to self-manage their condition as, in many cases, the issue can be completely resolved. Their awareness of the potential for improvement and / or resolution of the problem with treatment are central to this.

The Bladder and Bowel Foundation (BBF) found that an analysis of calls to their helpline suggests that up to half the people with a continence problem have never spoken to a health care professional about it (2015). Only one in three families seek help for children and young people with continence problems (Butler et al 2005). This is because of the social stigma associated with their condition and poor signposting to services.

Where help is sought, a third of parents reported they were not always involved in decisions about their child's care (CQC 2015), demonstrating the need for more active involvement of patients and families not just in decision-making but also in service review and design.

As full partners in the design and delivery of person-centred care, voluntary organisations can significantly extend the range of support that is available. Working alongside CCGs, these partnerships offer the opportunity to consider new and innovative ways to include a user perspective in commissioning decisions. With the aim of ensuring delivery of holistic care including advocacy, information, advice, education and peer support, collaboration can effectively design services where the needs and preferences of local people and service users are reflected in commissioning plans.

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. This enables an optimum quality of life, independence and personal dignity.

4.5 Delivering and receiving care

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. Where appropriate, these should be taken prior to referral to either a specialist continence service or secondary care for more in-depth diagnostics and / or surgical intervention if indicated.

A review by a General Practitioner can identify any medications or medical illnesses that may be having an adverse effect on continence. First line medication for continence or constipation can be prescribed in the primary care setting. This can mean that some people do not need referral to a specialist.

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.

This step-wise approach, from health care professional via specialist services as necessary, to secondary care ensures that the person is assessed by the right individual in the right place at the right time, all reducing inappropriate referrals and improving outcomes and experience.

4.5.1 Management and containment

Should the person fail to respond to treatment, various management options should be available:

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 (Hicks et al 2007). It must be the exception, rather than the rule, that children and young people are provided with containment products.

Adults

Assessment to ascertain the need for containment products such as absorbent pads, pants and hand-held urinals can meet a person's continence needs in the short-term. Reassessment at regular intervals is then required to ensure not only that products remain fit for purpose, but that where independence can be gained, a return to standard toileting is enabled for a quality of life with freedom from leakage and odour.

Containment products can offer security and comfort helping people continue with their normal daily activities and so improving quality of life. However they are costly, can affect a person's dignity and do not offer a long-term solution. Therefore, they should not be offered in the long term unless the person has not responded to other treatments.

Indwelling urinary catheters are associated with infection that can lead to illness, hospital admission and even death, with up to 30 percent mortality for catheter related blood infections: they are also distressing for people who have to live with them. Catheters should be removed as soon as possible and this is optimally done within an integrated continence service. The service can, for example, teach patients how to self-catheterise intermittently.

The need for other prescription products such as sheaths and faecal collectors must also be reassessed to reduce potential problems that can be caused, for example the risk of infection.



Impartial product advice

Go to: <http://www.continenceproductadvisor.org/>

4.6 Developing the workforce

The NHS is defined by its staff: developing and supporting the workforce within a culture of safety and compassion is crucial to ensuring the best outcomes for people. The correct education and training helps us all understand the importance of the need to embrace the right skills, values and behaviours for the benefit of all those with continence needs who touch our services.

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 2015). This includes:

- Education at undergraduate level for physiotherapists, nurses and medical students

- Continuous Professional Development (CPD) 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.

The underlying principles of good practice apply regardless of the organisational context in which they are delivered. Meeting these standards can ensure that people with continence needs are identified, assessed and treated accordingly by an appropriately trained person, all helping to promote consistency in practice.

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 recommended.

Those commissioning and providing education have the talents and ability to develop and make accessible a variety of learning packages and study methodologies to enable maximum uptake. Those developing curricula and supporting certification are also guided in syllabus design and the relevance and application of the resulting award.

The Paediatric Continence Forum is currently developing UKCS minimum standards for children and young people.



Excellence in workforce design

Go to: UKCS Minimum standards for continence care in the United Kingdom (2015)
www.ukcs.uk.net

4.7 Roles and responsibilities of team members

Team member	Specific responsibilities
All staff in health and social care	<ul style="list-style-type: none"> • Implement the Excellence in Continence Care framework • Demonstrate compassion and dignity to de-stigmatise bladder and bowel problems • Provide information to people seeking help and advice, working with them in making decisions about their care • Liaise with colleagues • Complete training and education relevant to the role
Educators	<ul style="list-style-type: none"> • Provide targeted training and education programmes • Widen access to learning methodologies e.g. e-learning

OFFICIAL

Administrative staff	<ul style="list-style-type: none"> • Provide professional and welcoming contact and communication • Support day-to-day management of continence services • Route queries and concerns appropriately
Commissioning leaders	<ul style="list-style-type: none"> • Lead and manage a service that is accessible to all • Review risk groups and promote prevention • Increase case finding • Review service annually with providers, public and service user involvement • Allocate resources • Procure patient, carer and public feedback • Consider implementation of NICE and other recommendations
Provider leaders	<ul style="list-style-type: none"> • Lead and deliver a service that is accessible to all • Promote prevention within all risk groups • Increase case finding • Review service annually with commissioners, public and service user involvement • Apply resources for best outcomes, value and experience • Procure patient, carer and public feedback • Consider implementation of NICE and other recommendations
Public, service users, patients, carers and families	<ul style="list-style-type: none"> • Self-assess and manage where able • Seek information and advice from e.g. the chemist or NHS Direct • Consider information provided and ask questions • Contact GP for further help if needed • Provide feedback and participate in service improvement reviews
Nursing staff and allied health professionals	<ul style="list-style-type: none"> • Assess need • Prescribe and treat within sphere of competence • Refer for specialist advice and treatment
General Practitioners and medical staff	<ul style="list-style-type: none"> • Provide clinical assessment and treatment • Prescribe medication and treatment with appropriate review • Provide antibiotic stewardship • Refer to specialist staff • Commence pathway in line with local and national clinical guidance • Provide clinical advice • Assess and review policies and practices: make recommendations for change • Evaluate clinical outcomes
Specialist continence staff	<ul style="list-style-type: none"> • Provide clinical leadership of continence services • Provide advanced clinical assessment and treatment • Advise about the design and delivery of services • Develop clinical guidelines and pathways • Endorse best practice by teaching • Guide and correct practice where necessary • Assess and review policies and practices: make recommendations for change • Evaluate clinical outcomes

4.8 Measures, drivers, levers and incentives

Commissioners are well placed to focus on transforming the care of people with bladder and bowel problems causing continence needs. As set out in the Five Year Forward View, focusing on primary and secondary prevention, reducing duplication of effort and ensuring services are provided closer to home are the main priorities.

The emphasis needs to be on commissioning for health to achieve improved outcomes and value. To drive this, partnership working is required with local authorities, primary care, acute care, community and mental health providers via Health and Wellbeing Boards to align metrics and contracting requirements across a whole-system pathway.

Commissioning levers include CCG duties to reduce health inequalities in access and outcomes, as defined in the Health and Social Care Act (2012), raising the profile of user experience and the Joint Strategic Needs Assessment (JSNA). The Local Government and Public Involvement in Health Act (2007) requires CCGs and local authorities to develop a JSNA of the health and well-being of their local community. This in turn, supports better targeting of interventions to reduce the health inequalities for people with bladder and bowel problems and improves quality.

4.8.1 Primary care

Changes to the GP contract require case management of patients, personalised care planning and care coordination and these will support greater awareness of needs. Movement away from the Quality and Outcomes Framework (QOF) will give GPs opportunities to focus on real quality improvements including:

- case finding of patients with bladder and bowel problems
- self-support
- the identification of the requirement for domiciliary care and nursing home support.

Primary care commissioners must ensure that the needs of people with bladder and bowel problems are identified and managed ensuring continuity of care and including suitable medical support to care home residents.



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. In defining bother, it becomes possible for clinicians to measure improvements as a patient reported outcome. Where people are unable to communicate their symptoms, this score and other patient centred outcome measures should be obtained from family, relevant others or carers or through observation.

Go to: http://www.baus.org.uk/userfiles/pages/files/Patients/Leaflets/ICIQ-UI_Short_Form_UK_English_.pdf

4.8.2 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 (JSNA) data set to establish current and future local health needs and organisational self- assessments
- Use of audit results such as those by HQIP (2010)
- Improvement in case finding in at risk groups.

A Commissioning for Quality and Innovation (CQUIN) payment to a provider is a mechanism for incentivising quality improvement within NHS contracts (NHS England⁵ 2015). Setting a range of CQUINs with providers at critical points of the continence pathway will help resource and embed service redesign.

CQUINs relating to bladder and bowel care should be based on recognised evidence. There are three CQUINs in the NHS Contract pick list relating to bladder and bowel:

- Improving Urinary Continence Care (find, assess, investigate and refer)
- Urinary Catheter Care
- Management of Faecal Incontinence.

They can be found here: <http://www.appgcontinence.org.uk/>

CQUINs can also be developed that encompass:

- 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.

4.8.3 Outcomes based commissioning

Aligning metrics, incentives 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.

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 peoples' 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 the following categories:

- **Patient experience**
where patients have provided feedback on the quality or effectiveness of the service they have received
- **Patient Reported Outcome Measures (PROMS)**
patients are able to quantify quality of life after contact with health services
- **Harm reduction**
where outcome measures indicate whether harm to patients has occurred
- **Systems supporting continence care**
whether system-related measures support improvements in care
- **Financial**
where indicators demonstrate any savings released as a result of pathway changes: examples include:
 - Commissioning for Value such as prescription costs
 - urgent emergency care cost e.g. blocked catheter
 - the Right Care programme.

The primary objective for Right Care is to maximise value:

- the value that the patient derives from their own care and treatment
- the value the whole population derives from the investment in their healthcare.

To build on the success and value of the Right Care programme, NHS England and Public Health England are taking forward the Right Care approach through new programmes to ensure that it becomes embedded in the new commissioning and public health agendas for the NHS.



Commissioning for value

Go to: <http://www.rightcare.nhs.uk/>

5 Measuring Outcomes

Measuring outcomes is an essential mechanism to check the best outcomes, experience and value are being realised for people. The following indicators are helpful for commissioners to incorporate within their contract schedules.

Outcome	Measures
Increased identification	There is a record of the continence needs of high risk people e.g.

OFFICIAL

Outcome	Measures
	<ul style="list-style-type: none"> • people with any long term condition (see 3.3) • older people (65+) • pregnant women
Improved evidence-based commissioning	<p>A local continence service is in place informed by peoples' choice and satisfaction levels. The service specification covers recording and reporting of the number of people with continence needs and the assessment, diagnosis and treatment plus on-going treatment, care and support. Levels of management:</p> <ul style="list-style-type: none"> • Level 1: GP and nurse • Level 2: specialist nurse (continence, urology, urogynaecology, geriatrics) or physiotherapist • Level 3: secondary care consultant • Level 4: tertiary care
Improved patient experience	<ul style="list-style-type: none"> • Reduced bothersome score • Personalised care plan documents patient-defined goals, is based on shared decision-making and is reviewed at regular intervals until goals achieved • Improved patient reported experience • Carer burden and strain
Baseline continence assessment for all who need it	<p>Assessment of all of any age in all settings: 'Do you ever have difficulty getting to the toilet quickly enough?' Those who screen positive have three simple tests:</p> <ul style="list-style-type: none"> • Urine test • Symptom history +/- bladder/bowel diary • Examination for retention +/- bladder scan
Improved Quality of Life following treatment	<ul style="list-style-type: none"> • PROMS improvement • Ability to self-manage and self-care • Increased social interaction • Improved continence post-surgical procedure e.g. radical prostatectomy or pelvic floor repair.
Reduced Emergency Department visits and / or unplanned hospital admissions	<ul style="list-style-type: none"> • Reduction of urinary tract infection • Reduction of blocked catheter • Reduction in constipation or impaction
Reduced harm	<ul style="list-style-type: none"> • Reduction in acquired pressure ulcers • Reduction in falls and fractures • Reduction in inappropriate or unnecessary catheterisation • Reduction in Catheter Associated Urinary Tract Infection (CAUTI)
Reduced cost	<ul style="list-style-type: none"> • Reduction in prescriptions for catheters • Reduction in containment cost (pads) • Reduction in out-patient appointments • Reduction in surgical interventions

6 Next steps

There are eight important steps to take to implement this guidance:

1. Ensure commissioning intentions include a focus on continence needs for people of all ages and includes both bladder and bowel.
2. Ensure that commissioners and providers have a full understanding of local need relating to continence care through effective engagement with the public, service users, patients, carers and families.
3. Implement a baseline assessment of local provision of continence care considering all best practice guidelines.
4. Develop continence care pathways that meet local need.
5. Ensure outcome measures are in the contracting, quality assurance and performance monitoring of commissioned services.
6. Monitor and evaluate the outcomes of commissioning intentions for continence care.
7. Deliver continuous improvements in continence care via an improvement trajectory.
8. Ensure the commissioning process provides integrated services that are community based.



What it means to me

Name: Jacqueline Emkes

Location: Bedford

Occupation: Maths Teacher

Jacq began to have recurring bladder infections following a hysterectomy operation in 2009. In 2010 she was diagnosed with an obstructed ureter. Two major operations resulted in continued pain and infection and left her with no sensation in her bladder.

‘Before this happened to me, the number of days I’d had off work probably amounted to a few hours a year. When I developed bladder problems and was subsequently given self-catheterisation as a means to manage the problem, it became a huge burden during working hours. I avoided using the catheter in school or public places, which meant I suffered more infections. It took me ages to find out how to get help locally. It would help so many people if GPs and nurses had more training and could direct people to the right place, so they could get help quickly.’

In 2013, Jacq found that she met the criteria for a Sacral Nerve Stimulator, which helped stimulate the bladder to empty better and meant that the need to self-catheterise reduced greatly during daytime hours.

Today, Jacq is recovering from further bladder reconstruction surgery, which took place in August 2015. She is also attending a pain clinic, as back problems and many infections have left her with almost constant pain. She is also on a waiting list to receive a stimulator in the spine to help reduce pain.

'My life and that of my family has been greatly affected by my illness. I am left with limited working capacity and feel very disappointed to have had to reduce my career in such a way. To have a social life and do normal day-to-day tasks has been very challenging at times. However, I am grateful for the support I have had. My GP, urological surgeons, the nurses and a specialist bladder and bowel physiotherapist have helped me enormously through the last few years. I have also found great strength through support networks for one use Clean Intermittent Self Catheterisation (CISC). I am now looking forward to better health and trust that my recent operation will prove successful.

What Jacq would like us to understand: 'I'd urge anyone with early signs of bladder and / or bowel problems to seek help without delay: literally thousands of people suffer in silence. Although it hasn't been straight forward for me, the support and expertise I have had from the health professionals that have looked after me has had an enormously positive impact on me.'

7 Contributors

Name	Title	Organisation
Paul Abrams	Professor of Urology, Head of Bristol Urological Institute - Teaching and Research LUTS Expert Group Chair	University of Bristol
Angela Billington	Independent Nurse Consultant	
Katie Breeze	Senior Communications and Engagement Manager	NHS England South (South Central)
Tony Brooks	Chair	RCN Continence Forum
Melissa Davies	Consultant Urologist	Salisbury NHS Foundation Trust
Robert Dixon	CEO	Bladder and Bowel Foundation (B&BF)
Penny Dobson MBE	Chair	Paediatric Continence Forum (PCF)
Sarah Elliott	Chief Nurse	NHS England (South)
Jacqueline Emkes	Patient Advocate	
Sharon Eustice	Nurse Consultant Bladder and Bowel Specialist	Peninsula Community Health
Richard Fluck	National Clinical Director (Renal)	Derby Hospitals NHS Foundation Trust
Danielle Harari	Consultant Physician and Senior Lecturer, Department of Ageing and Health	Guy's & St Thomas' NHS Foundation Trust Kings College, London

OFFICIAL

Name	Title	Organisation
	Royal College of Physicians Continence Programme Lead	Royal College of Physicians
Julie Jenks	Urology Clinical Nurse Specialist	British Association of Urological Nurses (BAUN)
Nicholas Madden	Vice-Chair	Paediatric Continence Forum (PCF)
Natalie McEwen	Communications and Engagement Manager	NHS England South (South Central)
Philippa Potter	Head of Nursing	NHS England (South)
Angie Rantell	Lead Nurse Urogynaecology Nurse Cystoscopist	King's College Hospital NHS Foundation Trust
Debbie Rigby	Deputy Director of Quality, Patient Safety and Governance	NHS Somerset CCG
June Rogers MBE	Paediatric Continence Specialist	PromoCon Disabled Living
Dawn Stobbs	Personalisation and Control Specialist	NHS England
Helen Stokes-Lampard	Honorary Treasurer	Royal College of General Practitioners (RCGP)
Nikesh Thiruchelvam	Consultant Urologist	British Association of Urological Surgeons (BAUS)
Catherine Thompson	Head of Patient Experience	NHS England
Cath Williams	Business Manager Specialist Services	Association for Continence Advice (ACA)
Tara Willson	Patient Advocate	
John Young	National Clinical Director (Frailty and Integrated Care)	NHS England

8 References

All Party Parliamentary Group (2011) Cost-effect Commissioning for Continence Care <http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf>

Bladder and Bowel Foundation (2015) Unpublished analysis of calls to their helpline

Buckley BS & Lapitan MCM (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 2009; 63(4): 568-573

OFFICIAL

Butler R, Golding J, Heron J and the ALSPAC Study Team (2005) Nocturnal enuresis: a survey of parental coping strategies at 7 1/2 years (ALSPAC Study) Child Care Health Dev, 31 (6), 659-667

CQC (2015) Children and young people's inpatient and day case survey 2014
[http://www.cqc.org.uk/search/site/Children and young people %20and%20young%20people%E2%80%99s%20inpatient%20and%20day%20case %20survey%202014?location=&sort=default&la=&distance=15&mode=html](http://www.cqc.org.uk/search/site/Children%20and%20young%20people%E2%80%99s%20inpatient%20and%20day%20case%20survey%202014?location=&sort=default&la=&distance=15&mode=html)

Department of Health (2010) Independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009, Volume 1, Chaired by Robert Francis QC
[https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658 Cm 8777 Vol 1_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658_Cm_8777_Vol_1_accessible.pdf)

Department of Health (2013) Hard Truths: the journey to putting the patient first
<https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response>

Equality Act (2010)
<http://www.legislation.gov.uk/ukpga/2010/15/contents>

Health and Social Care Act (2012)
<http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

Healthcare Quality Improvement Partnership (HQIP) & Royal College of Physicians (2010) National Audit of Continence Care: Combined Organisational and Clinical Report
<https://www.rcplondon.ac.uk/sites/default/files/full-organisational-and-clinical-report-nacc-2010.pdf>

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.

Joint Strategic Needs Assessment
<http://www.hscic.gov.uk/jsna>

Local Government and Public Involvement in Health Act (2007)
<http://www.legislation.gov.uk/ukpga/2007/28/contents>

NHS England (2014) Five year forward view
<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS England¹ (2015) Outcomes Framework 2015/16
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385749/NHS_Outcomes_Framework.pdf

NHS England² (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>

NHS England³ (2015) Building the NHS of the Five Year Forward View – The NHS England Business Plan 2015-2016
<http://www.england.nhs.uk/wp-content/uploads/2015/03/business-plan-mar15.pdf>

NHS England⁴ (2015) MDT Development: Working toward an effective multidisciplinary/multiagency team
<http://www.england.nhs.uk/wp-content/uploads/2015/01/mdt-dev-guid-flat-fin.pdf>

NHS England⁵ (2015) Commissioning for Quality and Innovation (CQUIN): Guidance for 2015/16
<http://www.england.nhs.uk/wp-content/uploads/2015/03/9-cquin-guid-2015-16.pdf>

NICE Clinical guideline 49 Faecal incontinence: The management of faecal incontinence in adults (2007) (reviewed 2014)
<http://www.nice.org.uk/guidance/cg49>

NICE Paediatric Continence Service: Commissioning Guide Implementing NICE guidance Commissioning (2010)
<https://www.nice.org.uk/guidance/cg99/resources/paediatric-continence-service>

Paediatric Continence Forum (2014) (Updated 2015) Paediatric Continence Commissioning Guide: A handbook for the commissioning and running of paediatric continence services
<http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>

Public Health England (2015) Needs assessments reports
<http://atlas.chimat.org.uk/IAS/profiles/needsassessments>

UKCS (2015) Minimum standards for continence care in the United Kingdom
<http://www.ukcs.uk.net/>

9 Resources

Bladder and Bowel Foundation
<https://www.bladderandbowelfoundation.org/>

ERIC (The Children's Continence Charity)
<https://www.eric.org.uk>

National Institute for Health and Care Excellence (NICE)
<https://www.nice.org.uk/>

PromoCon Disabled Living
<http://www.disabledliving.co.uk/PromoCon/About>

Paediatric Continence Forum

<http://www.paediatriccontinenceforum.org/>

United Kingdom Continence Society

<http://www.ukcs.uk.net/>

10 Acronyms

Acronym	Meaning
APPG	All Party Parliamentary Group for Continence Care
BBF	Bladder and Bowel Foundation
CAUTI	Catheter Associated Urinary Tract Infection
CHIMAT	Child and Maternity Health Information Network
CPCS	Community Paediatric Continence Service
CPD	Continual Professional Development
CQC	Care Quality Commission
CQUIN	Commissioning for Quality and Innovation
EBCD	Evidence Based Co-Design
HQIP	Healthcare Quality Improvement Partnership
ICIQ	International Consultation on Incontinence Questionnaire
JSNA	Joint Strategic Needs Assessment
NICE	National Institute for Health and Care Excellence
PCF	Paediatric Continence Forum
PROMs	Patient Reported Outcome Measures
QOF	Quality Outcomes Framework
UKCS	United Kingdom Continence Society