

Cost-effective Commissioning For **Continence Care**



All Party Parliamentary Group For Continence Care Report
A guide for commissioners written by continence care professionals



“When I go to bed, I try to stay awake as long as I can by digging my nails into my hands. I dread waking up in a wet bed....”

Male aged 18 years

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Supported by

The following organisations have given their endorsement to this document:

- Association for Spina Bifida and Hydrocephalous (ASBAH)
- Association for Continence Advice (ACA)
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- Paediatric Continence Forum (PCF)
- Patients Association (PA)
- PromoCon
- Royal College of Nursing (RCN)
- Royal College of Physicians (RCP)
- United Kingdom Continence Society (UKCS)



Baroness Sally Greengross OBE
Chair of the All Party Parliamentary Group for Continence Care

"This timely and useful guide illustrates the importance of continence care and sets out how to commission and deliver a quality integrated service which meets patient's needs and is cost-effective to the NHS. Continence problems can affect any member of the population, young or old. Incontinence can have a profoundly negative impact on a person's quality of life creating isolation, loss of dignity and other health and emotional problems. The wider cost implications of not providing adequate continence care are significant. Patients should be able to expect and receive prompt assessment and care to enable them to carry on living full and active lives. At a time of great change in the NHS we feel it is vital to bring this issue to the attention of all commissioners and policy makers.

This guide has been written and supported by a team of individuals and organisations who are passionate about ensuring quality continence care services are available and effectively delivered. On behalf of all Members of the All Party Parliamentary Group for Continence Care, I congratulate them on an excellent document."

"When the Continence Nurse visited me she found the reason for me always being wet. I now empty my bladder with the small tube (catheter) a few times a day which keeps me dry. My daughters no longer have to take my soaked bedding away every morning and wash it. This has given me back my dignity and that part of my life I had lost."

Female aged 78 years



Dr Clare Gerada
MBE, FRCP, FRCGP, MRCPsych
London-based GP and Chair of Council of the Royal College of General Practitioners

"This document from the APPG is a timely report in an area of healthcare which affects all ages. Incontinence impacts on all aspects of a patient's life and is costly to the NHS if the symptom is not pro-actively identified, diagnosed and treated. I welcome the APPG report and would encourage commissioning bodies to give GP's the option to refer patients to an integrated continence service as described in this commissioning guide."



Tim Harvey
Trustee and Patient Representative of the Bladder and Bowel Foundation

"Incontinence is a degrading symptom for the individual without having to cope with the indignity of poor or inadequate health care. Over the last few years continence care has slipped below the standard of care expected as has been reflected in recent reports identifying the distressing consequences. The comment above on the right highlights the difference access to a specialist Continence Service can make. Please let this report become a benchmark for moving forward."



Dr Julian Spinks
BSc (Hons), MBBS, DGM
Kent-based GP with an interest in continence care

"As GP consortia prepare to take on the commissioning of services for their patients it is vital that they have the right tools to ensure that their decisions result in effective and appropriate services. This report will be an important resource for GP consortia and will enable them to ensure that their population receives the better quality, comprehensive and patient-centred continence services that are so sorely needed."

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This commissioning guide provides a framework for implementing and monitoring a truly integrated continence service. It outlines the essential elements needed during each phase of the commissioning cycle.

Continence care pathways are only effectively delivered through an integrated continence service that is clinically-driven, patient-sensitive and treatment-focused.

Evidence-based clinical pathways can deliver cost savings by reducing:

- unnecessary catheterisations and associated urinary tract infections (UTI)
- pressure ulcers linked to poor continence care
- acute hospitalisations for UTI, urinary retention, renal failure and faecal impaction
- care home admissions precipitated by incontinence
- the use of incontinence products through low-cost interventions such as bladder retraining, pelvic floor muscle training and the appropriate use of medications for incontinence



Planning:

Share data to assess local needs, review current services, identify priorities and avoid duplication. Ensure the Joint Strategic Needs Assessment has at least one indicator for bladder and bowel incontinence. Involve those who will use the service and listen to their views: children, young people and adults, including disadvantaged and vulnerable groups. Forge strong partnerships with providers and the voluntary sector so they know how to access services when supporting someone with continence needs. Access to specialist continence nurses and therapists will promote screening, assessment and treatment practices that take into account the emotional, psychological and mental well-being of patients. There needs to be clarity in the primary / secondary care interface to achieve consistent referral patterns and transition management between paediatric and adult services.

Procurement:

As a minimum, a high quality, cost-effective continence care service requires: an expert clinical leader responsible for strategy, service improvement, education, research and audit activities; one whole time equivalent specialist practitioner per 100,000 population, plus access to designated medical and surgical specialists, investigation and treatment facilities. Define contract criteria to include: on-going education and training of all staff (including pre-registration students and GP registrars); an agreed staff competency level and skills mix; patient choice (e.g., for incontinence pad provision); agreed qualitative and quantitative outcomes. Ensure on-going demands are appropriate. Take account of factors which may affect demand management, such as an ageing population, transfer of secondary care services to the community, price fluctuations of disposable products, and guidelines from organisations such as NICE.

Monitoring:

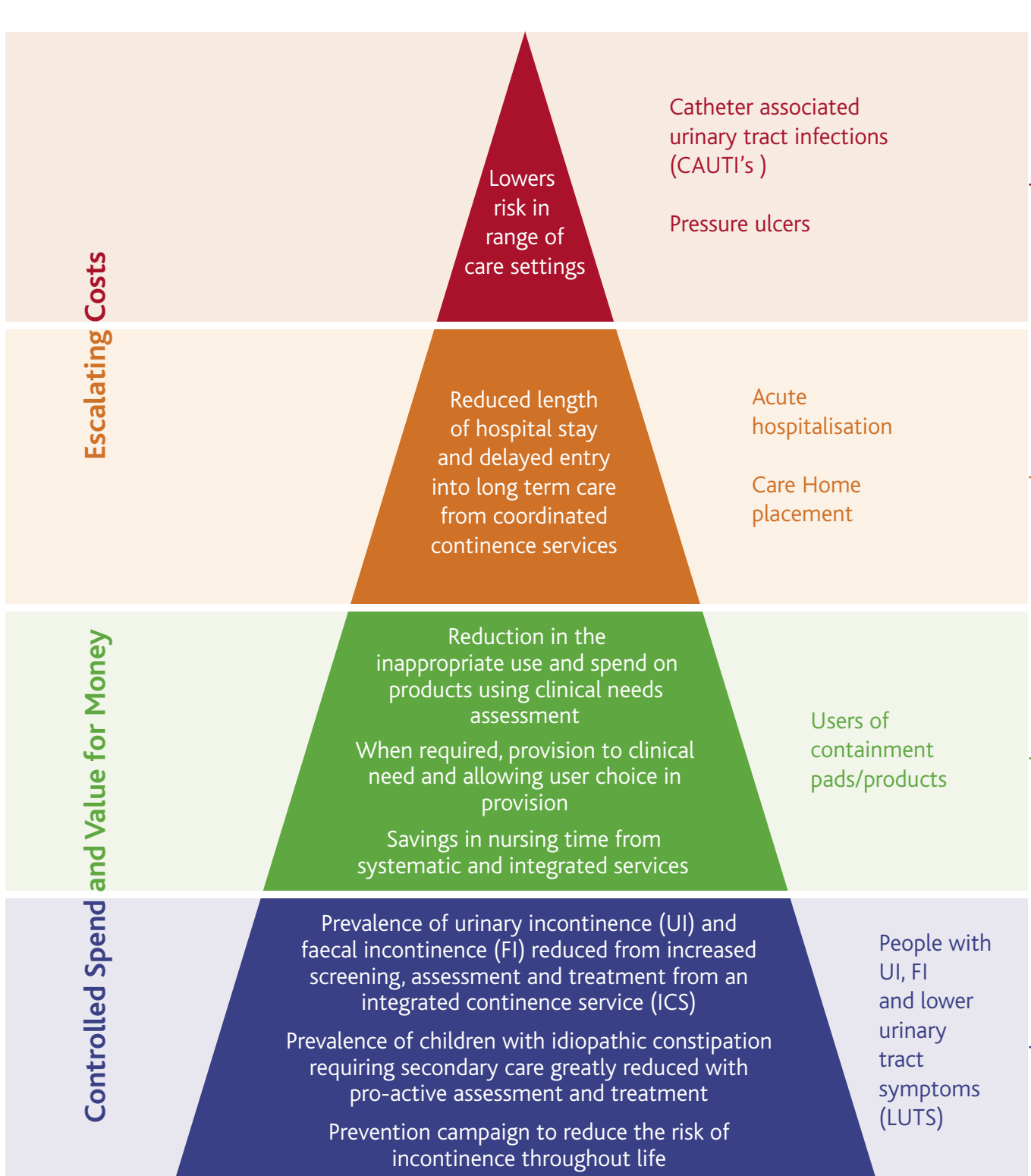
An effective monitoring regime is needed to ensure activities meet the quality and level required. Set performance indicators to ensure contracted continence services are delivered, and determine how these are measured and the frequency of monitoring. Set thresholds to ensure commissioners are alerted of budgetary pressures if patient numbers or treatment costs increase by 5%. As well as monitoring patient pathways and outcomes, performance indicators are also needed for invoicing, data validation and audit.

The fundamental aim of this report is to maintain dignity and relieve physical and emotional suffering in the millions of patients with continence issues. Using individual assessment and appropriate treatment and management regimes, the risk of the costly consequences listed above will be reduced. This is best achieved through the effective commissioning of good quality, evidence-based, integrated continence services.

Prevention Pyramid

How movement up the Pyramid can be delayed or prevented by an Integrated Continence Service

The Prevention Pyramid demonstrates the risks and rising costs of untreated incontinence using the traffic light system, and how an effective integrated continence service can reduce the risks and therefore costs



Implement High Impact Actions to deliver cost savings - CAUTI

- Catheterisation is often a consequence of poor continence care - 25% of catheters are unnecessary: 60% of UTI relate to catheter insertion¹
- CAUTI's are costly (extend length of stay by 6 days), life-threatening (13 - 30% mortality rate for CAUTI bacteraemia), and a national clinical priority¹
- Nurse-led interventions can reduce catheterisation rates (by 42%) and CAUTI (by 57%) and are best delivered within an integrated continence service by daily evaluation of the need for catheterisation and prompt discontinuation when no longer necessary²

Implement High Impact Actions to deliver cost savings - pressure ulcers

- Pressure ulcers are directly linked to poor continence care, costing the NHS £1.4 - £2.1 billion annually, and causing 51,000 hospital admissions (2008/9 HES, England)³
- Pressure ulcers are a national priority as per 2010 Commissioning for Quality and Innovation (CQUIN) with remit to avoid preventable ulcers in both hospital and the community⁴
- Continence care reduces early skin problems leading to pressure ulcers in frail nursing home residents, and prevents pressure ulcers in other high risk groups^{5,6}

Acute hospitalisations for UTI, urinary retention, renal failure, faecal impaction - costly consequences that can be reduced through proactive continence care

- Annually there are 224,670 admissions for UTI (HES, 2009-2010). These hospitalisations are costly (mean length of stay 9 days), and patients tend to be older (mean age 69 years)⁷
- UI is twice as common in women presenting to GPs with UTI, and 12 times as common in men aged 60+ with recurrent UTI. Addressing continence issues through commissioned services makes clinical and economic sense⁸
- Bowel care via continence services reduces UTI rate in high risk patients (UTI-related costs cut by 66% in spinal cord injured patients)⁹
- Untreated LUTS in men may progress to urinary retention¹⁰ (27,000 hospital admissions HES, 2010)⁷
- Constipation is treatable and preventable but has significant morbidity in youngest and oldest if untreated. Out of 39,643 emergency admissions, 11,093 were aged 0-18 years and 20,710 aged 75+ (HES, 2010)⁷

Care home admission precipitated by incontinence issues

- Incontinence is a significant factor for initiating care home admission¹¹
- In US studies, UI increased likelihood of care home referral two-fold, and faecal incontinence (FI) almost five-fold¹¹
- 50% of care home residents with FI have overflow from constipation. This is a treatable condition¹²

Use of containment products and cost-savings through intervention

- The number of patients requiring costly NHS products is increasing year on year, due to an ageing population and inconsistent delivery of continence care nationally³
- Providing and procuring cost-effective continence products (e.g. alternatives to absorbent pads) to preserve dignity and enable a normal lifestyle is also part of an integrated continence service¹⁴
- Treating overactive bladder in women produces Quality-Adjusted Life Year (QALY) gains and saves money through reduced pad costs¹⁶
- Low cost intervention (continence nurse-led) in community adults can cut pad usage by 50%, even in frail older people^{17,18}
- Professional time in assessment and teaching bladder retraining and pelvic floor muscle exercises is rapidly off-set by a reduction in pad costs¹⁸
- NICE Faecal incontinence guidance states that low cost of conservative treatments are offset by a reduced need for containment products, surgery and social care¹⁹

Paediatric Continence Promotion - improving outcomes and reducing costs

- Lack of specialist paediatric continence promotion services is linked to increased use of disposable containment products and inappropriate referrals to both secondary care and Child & Adolescent Mental Health Services²⁰ (CAMHS)
- Nurse-led interventions in primary care improves treatment outcomes and is cost effective²⁰

Urinary and faecal incontinence in general population - highly prevalent but under-diagnosed and under-treated

- An ICS provides higher quality of care to older people and is dependent upon well-organised services with personnel who have the appropriate training and skills to deliver the care¹³
- Pelvic floor muscle training (PFMT) for stress urinary incontinence (SUI) (up to 64% cure rate), minimally invasive surgical treatment (Tension-free Vaginal Tape 95% cure rate), antimuscarinics in overactive bladder (cost effective in >90% of cases, based on QALY and pad costs)¹⁵
- Prevention in high risk groups (e.g. PFMT for pregnant women, dietary and fluid advice in patients with long-term conditions)²¹
- Continence care pathways - conservative measures will cure the majority of people with incontinence, but proceeding when appropriate to further assessment and possible diagnostics/surgery is only effectively managed through an Integrated Continence Service

"I was in my late 30's when I was diagnosed as being incontinent following a hysterectomy. Making new relationships, especially ones of a sexual nature are almost impossible because of the fear of rejection and ridicule once the condition is known."

Female aged 45 years



Introduction

Commissioning integrated continence services is a dynamic way forward to achieve quality improvement while reducing wasteful and inefficient use of NHS resources²². The NHS Commissioning Board requires commissioners to involve relevant cross-sector health and social care professionals in designing care pathways and packages that meet quality and productivity outcomes.

The NHS outcomes framework²³, NICE quality standards²⁴ and commissioning guidance²⁵ will act as levers to facilitate this in addition to drivers such as the Quality Innovation, Productivity and Prevention (QIPP; 2010)²⁶ challenge and Commissioning for Quality and Innovation (CQUIN; 2010)⁴. Measuring outcomes will form a key indicator of success, and implementing effective care pathways and services is fundamental in achieving this.

This commissioning guide sets out the justification for an integrated continence service and provides a framework for implementation and monitoring. It was prepared by a wide stakeholder group including healthcare professionals and patient associations. The fundamental aim of this publication is to relieve suffering in millions of patients via the commissioning of good quality continence services. It directs commissioners towards the essential elements which make up such a service. An integrated continence service does not exist to give out pads, nor should a GP send patients with incontinence to the 'nurse' just for pads. A dynamic service is one which involves all practice professionals in prevention, recognition, assessment and treatment. According to NICE guidelines, it is the responsibility of primary care to deliver an initial assessment of all patients with incontinence.

Many services relate to patients during specific periods in their lives, but bladder and bowel care is a service which impacts on those of all ages, throughout their lifespan.

Symptoms of bladder and bowel dysfunction affect men, women, young people and children; those without any other disability or illness, and those with varying degrees of learning or physical disability or illness. Lower urinary tract symptoms (LUTS) have a significant impact on men; pregnancy, childbirth and multiparity are some of the contributing factors for women; while constipation and bedwetting can significantly affect children's acceptance at school and their socialising with peers.

Effective management of the bladder and bowel is essential for those with spinal injury, associated congenital disorders, neurological illness, stroke, diabetes, dementia and end-of-life care, to name a few. Many people rely on effective management of symptoms to enable them to work, take part in sport, socialise and lead as normal a lifestyle as possible. Cost savings in effective assessment and treatment will allow for an adequate and appropriate provision of products when required.

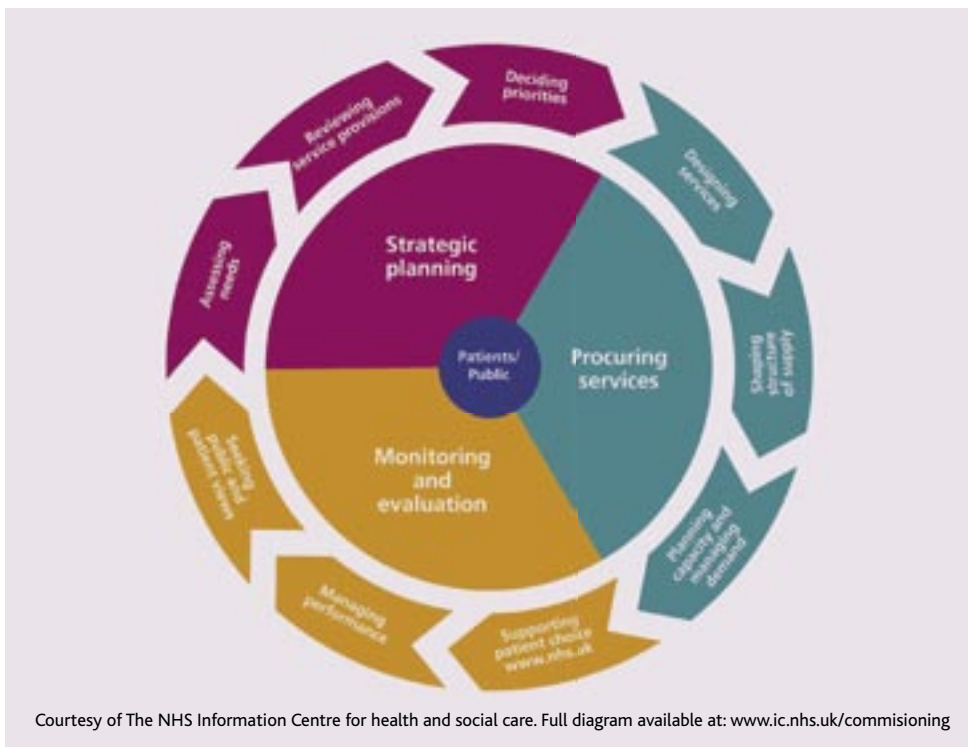
The health and social care challenges associated with an ageing population and the increasing prevalence of treatable incontinence in older people substantiate the need for a vibrant approach to promoting well-being and continence in this group of individuals. Incontinence affects not only people who reside in their own homes, care homes or hospitals, but other vulnerable groups such as the homeless and those in prison, therefore services must be available and responsive to the needs of all.

To reduce significant risk to patient health, promote well-being and demonstrate value for money, some of the benefits of an integrated service include:

- Early identification and treatment of symptoms
- Improved access to specialist assessment, investigation and treatment
- Agreed referral pathways to specialists
- Reduced hospital admissions and re-admissions
- Reduced risk of avoidable pressure ulcers
- Reduction in falls
- Reduced rates of catheter associated infections
- Reduced rates of urinary tract infection
- Cost-savings associated with therapeutic interventions rather than containment
- An improved quality of life, social function and dignity for the patient
- Protection of those most vulnerable in society
- Cost-effective provision of optimal product for management / containment where required

Overall, commissioning an integrated continence service, facilitated by high calibre clinical leadership, will help to improve service quality, patient dignity, patient experience and patient safety, and lead to reduced health and social care costs alongside a reduction in the economic impact of absenteeism and carer burden.





1. Involve people in planning and developing services

It is essential to work closely with those who will receive services, or who are receiving them already, at the planning and designing stages. This includes offering more choice and control about services where feasible, and having honest conversations about what is possible. What is really important is that people are listened to and their views taken into account. This also provides opportunities to talk about the importance of self-care, access to good information and advice to help make the right, informed choices, and aids with self management strategies, making a transparent case for levels of funding and limits on provision.

2. Understanding the needs of populations and individuals

Joint strategic needs assessment by councils and commissioners will promote better understanding of the needs of individuals. Data is crucially important because it helps commissioners identify trends, plan services accordingly, and then govern and monitor those services.

3. Sharing and using information more effectively

Information needs to be used and shared effectively. To achieve this, it must be clear what information can be shared and under what circumstances.

Joining-up the IT systems of front-line practitioners and encouraging individuals and communities to co-produce information will improve care and outcomes. Personalised care planning becomes crucial, as people themselves will hold their care plan, so everyone needs to be involved.

4. Assuring high quality for all

Commissioners should develop effective, strong partnerships with providers and engage them in needs assessment. This includes strong partnerships with other involved parties, such as the voluntary sector, to ensure they know how to access services and provide appropriate information when they are supporting someone with continence needs.

5. Recognising the contribution of all partners

Commissioners can facilitate collaborative approaches with communities to improve advice and support for individuals. This is achieved by fostering the creation of links and resources at a local level, based on agreed universal services and access points. This effectively puts community and local leaders in control and hence accountable for effective delivery

Strategic planning



“I was very impressed by the service and care I received. My treatment was a shining example of the NHS at its best.”

Male aged 41 years

Assessing health needs and capacity planning

Understanding local health demographics will allow an integrated continence service to proactively meet the needs of each individual who is living with bladder and/or bowel incontinence. Commissioners must be clear about the population they are working with and:

- ensure that the Joint Strategic Needs Assessment²⁷ has at least one indicator for bladder and bowel incontinence; for example,
 - number of females over 18 with urinary incontinence
 - number or males over 18 with urinary incontinence
 - number of females over 18 with faecal incontinence
 - number or males over 18 with faecal incontinence
- assess the specific health and social care needs of all patient groups, for example, children, young people and adults, including disadvantaged and vulnerable people

The Good practice in continence services (Department of Health 2000)²⁸ advised that 'continence services provided for a specific population should be organised as integrated continence services. The various professionals providing care at different levels will be employed by different bodies but if services are to be integrated, in line with clinical governance principles, they should all:

- work to common evidence based policies, procedures, guidelines and targets;
- use agreed evidence based policies, procedures and guidelines;
- undertake group audit and review'

In 2011 this translates to requiring clear service level agreements between all providers across the patient pathway, with defined deliverables and standards of care from each sector.

Prevalence

Differences in study populations, definitions, measurements, and survey methods have resulted in a wide range of prevalence rates for urinary incontinence (UI). The EPIC study²⁹ (2006) assessed the prevalence rates of overactive bladder and UI in 19,165 individuals, and 64.3% reported at least one lower urinary tract symptom (LUTS). In the adult female population, prevalence ranges from 5% to 69%, with most studies reporting a prevalence in the range of 25 - 45%.

In the UK for example, 9.4 million men are currently aged over 50 years, of which an estimated 35% experience LUTS³⁵ (ProState of the nation report 2009). This corresponds to an estimated 3.2 million men with clinically significant symptoms³⁵.

Therefore high quality integrated continence services should include:

- A patient-centred, treatment-focused approach to the delivery of services
- Clear clinical leadership
- Screening for bladder and bowel dysfunction e.g. lower urinary tract symptoms in men, women and children; constipation and faecal incontinence
- Assessment, treatment, management and continuing care practices that take into account the emotional, psychological and mental well-being of patients
- Access to specialist continence nurses and therapists
- Responsiveness to people with learning disabilities, mental health problems and those from ethnic minority groups
- Effective and safe provision of care in a range of settings e.g. patient's home, care home, community clinic or hospital
- Evidence-based clinical pathways and access to specialist consultants / surgeons
- Education provision for the patient/carer/ family and for the staff and organisations that support those individuals
- Self-management opportunities
- Transition management between children and adult services; and adult and older people's services
- Ability to produce information on outcomes of care (conservative, pharmacotherapy and surgical interventions), including taking account of patient experiences
- Integrated information systems
- Active monitoring and evaluation of service uptake

Capacity planning

Monitoring information from a range of national and local indicators, together with data on supply, resource use and need, should be considered when designing an integrated continence service. A dynamic understanding of future service demands is also required, using knowledge taken from a range of sources, and built around local outcomes.

Services should:

- Involve direct and indirect stakeholders
- Ensure the workforce has appropriate training, updating, skills and competencies to provide evidence-based continence care
- Urinary incontinence (UI) affects 1 in 3 women aged 18+ (35,000:100,000 women), but less than 20% are actively treated²¹
- Lower urinary tract symptoms (LUTS) affect 2.7% of men aged 18+ and 35% of men aged 60+¹⁰
- UI and / or faecal incontinence affect 50-80% of care home residents¹²

Data in women aged 18+ suggest a 35% overall prevalence of UI, with an estimated 50% of these seeking continence help – approximately 17,500 per 100,000 women aged 18+ per year. Approximately 80% of the population in England is aged 18+, of which 51% are women. So for a practice with a list size of 10,000, the average number of women needing initial treatment for UI would be around 700 per year. The actual number depends on the help-seeking rate of the population, and how proactive practices are at identifying UI in their female patients.

Key questions for commissioners to understand capacity in continence services include:

- How are continence care services organised (including screen / assess / treat policies)?
- What services are provided by primary care, in a community setting or by secondary care?
- Is there duplication of services?
- What do patients, carers and the local community think about continence care services?
- Is there any evidence that some groups are not accessing services and if so, for what reasons?
- Are there any specific gaps in services provided against identified need, including necessary adjustments to ensure equity of access?

Reviewing current provision

In most localities, continence services are already being commissioned and provided. It is important to know:

- where services are delivered/available in the locality
- their current accessibility for the local population
- their current performance against quality indicators
- patient experiences of the service
- staff views of the service
- costs, including benchmarking

Identifying gaps and priorities

The delivery of an integrated service, requires a co-ordinated approach, taking into account the role of other agencies providing care as well as users and their carers/families. Services should:

- Be developed in an integrated fashion with a clear model of care, offering the right care, by the right person, at the right time³⁰
- Be aware of any specific gaps in services provided against identified need in primary, community and secondary care

“I felt there was unnecessary delay in my referral. And there seems to have been a lack of communication between the clinic and the appointments system. This has resulted in my treatment being put back, which means it may now clash with my husband’s operation. If this happens I may be forced to postpone my treatment as one of us needs to be able to cope with everyday things, like Hoovering, shopping etc. and we have no family nearby that could help out.”

Female aged 80 years



"..incontinence is a hell of a thing, especially when you've had it as long as I have...98% of all nurses are excellent when it comes to care for the incontinence, but as I say, for a lot of them you see it's an extra duty and it puts the pressure on."

Female aged 75 years while in hospital

Privacy and Dignity in Continence Care for Older People research has put patients' voices into a reflective learning tool for clinicians³³. The quotes here and on the opposite page from older patients with incontinence summarise provider-patient ways of communicating that a dynamic continence service would aim to change.

The quote to the left, from an older patient in hospital, illustrates how people with incontinence can feel that they are a burden on healthcare providers.

Improving continence services - including transition

- An increasing number of children and young people with chronic illness are now surviving into adulthood³¹
- Transition into adult services takes place at great change in their lives both physically and emotionally³²
- Without appropriate support there is potential for poor concordance to treatment which is risky for those with serious bladder and bowel problems
- The need for adequate preparation for transition of young people requiring long term follow up into adulthood is well recognised
- In order to understand long term outcomes of treatment, e.g. bladder augmentation carried out in childhood, it is vital to follow their progress through to adulthood

Example of good practice

Collaboration between Alder Hey Children's NHS Foundation Trust and Aintree NHS Foundation Trust has resulted in the development of a structured and fully integrated Adolescent and Reconstructive Urology Service which oversees the care of urology patients before, during and after the transition of their care to adult services. At Alder Hey age boundaries are loosely applied, with adolescent urological care tailored to the maturity, readiness and awareness of the individual patient. The age range spans from 11 to 19 years with a great deal of flexibility. It is important to foster a high degree of independent thinking and to involve the patient at the centre of decision making. The following case example of a young person can help illustrate the role of the transitional urology team in managing young people's care, ongoing health and continence needs.

Case study

David was born with spina bifida and has been cared for by the urology team at Alder Hey since birth. At fourteen years old he saw the Adolescent Urologist at Alder Hey and a good rapport was developed between David, his family and the consultant. Developing an integrated model of care allowed David the opportunity to start taking on responsibilities for his own care and well being. Over time David began to lead the discussion in consultations and the team supported his parents in stepping back from being his direct care providers and also 'managers'.

During the process, and within dedicated transition clinics, David had the opportunity to meet local higher education teams and explore opportunities for training, education and employment. In a familiar clinical environment he met the adult team of nurses from Aintree as well as community staff, such as physiotherapists and community continence teams. His transitional needs as a young adult were addressed and new links were built which focused around his ongoing care, independence and need to learn new problem-solving skills. During this transition process David and his consultant completed documentation together which addressed his physical, emotional, sexual and relationship healthcare needs.

We believe our approach complements the Department of Health philosophy of transitional care which is centred on helping to prepare young people and their families for the significant uncertainties and changes which accompany the move to adult healthcare.

(For confidentiality the patient name has been changed)



Designing and redesigning services

In designing the service (and any subsequent redesign) commissioners need to be aware of the various components of an integrated continence service. This is well described in the DH Good practice in continence services (2000)²⁸. This guidance was used as the gold standard for service organisation by the Royal College of Physicians National Audits of Continence Care for older people 2005, 2006 and National Audit of Continence Care 2010³⁴. The 2010 audit included over 18,000 cases and the majority of hospital trusts, PCT's and Mental Health Care Organisations in England and Wales. In the 2010 audit only 4 participants reported that they met all the elements for an integrated continence service. Analysis of the audit data from 2006 showed that the better integrated a service was organisationally, the higher the standards of clinical care. The NICE commissioning guides (UI in women, LUTS in men, children and young adults) also give information on the essential elements of an effective service. It is therefore inherent on commissioners to ensure that services meet national guidance to ensure appropriate and effective care for their local population groups.

Services for patients in the community do not only consist of direct patient care. The majority of community nursing led services also have a role in provision of incontinence products. This part of the service is one of the main non-pay expenditures for community services and costs are rising due to increasing demands as well as product costs related to global increases in raw materials such as oil and fluff pulp. Sustainability in procurement however should not be at the expense of innovation.

Commissioners must remain aware of the financial impact that incontinence products will have on their budgets, and ensure their service design allows the most efficient and effective use of financial resources without compromise to the client's dignity.

The model of an integrated continence service team will depend on local requirements However, at a minimum the service requires:

- An expert clinical leader who is responsible for strategy, service improvement, education, research and audit activities, including proper resources and linkages to academic institutions; high-level collaborative working and the development of care pathways across the health and social care community
- One whole time equivalent specialist practitioner per 100,000 population in order to cover the broad population in need (children, young people, adults, patients with disability, care home residents etc)
- Access to designated medical and surgical specialists, investigation and treatment facilities (as per NICE recommendations)

Commissioners need to be particularly mindful of:

- Providing effective, evidence based care so the patient's experience delivers the best possible experience in terms of value and quality
- Measuring service outcomes to ensure patients receive high level care provided by the most appropriate professional
- Avoiding duplications in local services, especially with new ways of provision where a number of providers might have similar care packages
- Maintaining economies of scale and a critical mass to deliver care
- The need to investigate innovative ways of providing incontinence products that preserve dignity and autonomy while remaining cost-efficient
- Supply of incontinence products should include an appropriate range of cost effective products for all patients, enabling patient choice where possible
- Commissioning both clinical continence services and product services taking local demographics and their impact on future delivery into account
- Together with other relevant criteria, tendering processes should take into consideration value-added services such as educational materials and training



“Over the years, my body and home have become shrines to plastic to protect my skin and my furniture. The medical profession explain to me that this (incontinence) is a common condition affecting many thousands of people. Why then do I feel dirty, isolated and alone? A common condition yes, but one that condemns the long-term sufferer to a 'half-life' ruled by it.”

Female aged 64 years

Case Study

Liverpool Community Health NHS Trust has a lead Paediatric Continence Adviser, who works across primary and secondary care to provide a comprehensive service that includes assessment, treatment, awareness raising and training for all staff. This has transformed the service from a fragmented continence-supply ('free-nappy') service to a fully integrated Paediatric Continence Promotion service in line with NICE guidance²⁰.

The outcome is that health visitors and school nurses are more confident in dealing with children and young people with wetting and soiling problems, such as bedwetting and constipation. They are proactive in instigating first line treatments and appropriately refer on to the Paediatric Continence Service in a timely fashion. Since the service was introduced in 2005 there has been a drop in the number of children and young people receiving free nappies from nearly 700 to less than 300 per year. The need to refer children and young people with idiopathic constipation to secondary care has also been virtually eliminated.

Defining contracts

Recent findings from the Royal College of Physicians National Audit of Continence Care 2010³⁴ suggest that the majority of hospital services were commissioned as a block, including gynaecological and urology services. Community services were also block commissioned (by activity), however, there was little detail about the exact services to be delivered and the majority of commissioning organisations had little idea of what service levels they were contracting for.

Contracts need to have defined criteria:

- Education and training to ensure that all staff, including pre-registration students and GP registrars, keep up to date
- Defined competencies for all staff linked to evidence based practice
- A set skill mix that commissioners are willing to pay for
- Qualitative and quantitative outcomes
- Highly refined activity data
- Descriptions of patient's choice in their care
- Outlines of any tendering processes that need to occur e.g. for incontinence pad provision

Procuring a 'fit for purpose' continence service

When procuring appropriate services, a number of recommendations need to be considered to ensure the provision of high quality, cost effective continence care. As well as considering quality through CQUIN⁴ and the new NHS Outcomes Framework²³ other recommendations specific to continence care need to be considered. NICE quality standards²⁴ are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

NICE has made a number of recommendations regarding the implementation of their guidelines and it may be useful to consider procurement of new contracts for specific services such as Paediatric Continence Promotion to provide services in an improved, cost effective way.

Managing demand

In managing the demand for continence services it is important to take note of factors which can affect demand such as:

- An ageing population
- The opening of new-build, large care homes who will require a steady supply of expertise and products
- The transfer of some secondary care services to the community e.g. LUTS assessment services for men
- Potential price fluctuations of disposable product as a result of external factors such as raw material / transport costs
- The optimum use of care pathways and treatment plans which can help control the inappropriate use of products and ensure appropriate use of resources and services
- Guideline treatment recommendations from organisations such as NICE



Monitoring activity and quality

An effective monitoring regime is needed to ensure that all activities are of the quality and level required. Thresholds to alert commissioners to possible effects on the budget when the volume of activity increases (for example through a rise in new referrals) must also be included.

Activity

Performance indicator	Indicator	Threshold	Method of measurement	Frequency of monitoring
Number of funded patients agreed as per contract / service level agreement (SLA) for a treatment pathway	Number of patients with a care pathway	If number increases by 5% commissioners to be alerted to cost pressure	Clinical outcome measures: discharged, cured, referred to secondary care	Quarterly
Number of funded patients agreed as per contract / SLA for the supply of disposable / reusable products	Number of patients with a care pathway	If number increases by 5%, commissioners to be alerted to cost pressure	Number of patients receiving products and cost per patient per day	Quarterly
Number of children and young people funded as per contract / SLA to have on-loan bed wetting alarms	Number of children with a care pathway requiring an alarm to have prompt access to equipment	If cost increases by 5% commissioners to be alerted to cost pressure	Number of alarms issued quarterly	Quarterly
Cost of prescription only items e.g., catheters, anal irrigation and medications	Total prescriptions per item	If cost increases by 5% commissioners to be alerted to cost pressure	Medicines management to monitor prescription costs	Quarterly
Urodynamic and flowmetry studies	Number of urodynamic and flowmetry studies referred to community and / or secondary care	If cost increases by 5% commissioners to be alerted to cost pressures	Data report	Quarterly
Clinical audit using NICE Quality Standards / Essence of Care Benchmark	Audit plan including audit tools in place	One adult and one paediatric audit completed annually	Audit report	Annually
Competency frameworks for bladder and bowel problems in place for adults, children and young people	Bladder and bowel assessment, treatment and management. Catheterisation and care. Bowel care, digital rectal examination, anal irrigation and toileting programmes	100% staff have completed competency frameworks	Data report	Annually

Performance indicator	Indicator	Threshold	Method of measurement	Frequency of monitoring
Continence Specialist Nurse or Physiotherapist	Number of pelvic floor pathways for men and women commenced by nurse or physiotherapist in the community and secondary care	If cost increase by 5% commissioners to be alerted to cost pressures	Data report	Quarterly
GP to code all patients with bladder/bowel conditions	All patients coded	100%	Data report	Quarterly
Number of new referrals seen and assessed in primary care	Patients referred have a full continence assessment that identifies the type of bladder and / or bowel problem; a care plan including treatment, management and / or containment	100%	Audit / Report	Quarterly
Access to Occupational Therapist, Speech and Language Therapist or Dietician	Number of referrals related to bladder or bowel conditions to each Allied Health Professional	100% of referrals reported	Data report	Quarterly
Secondary and tertiary referrals for bladder and bowel conditions	Number of referrals; length of bed days	100%	Hospital Episode Statistics Report (HES)	Monthly/ Quarterly
Patient reported experience	Patient survey	10% to complete annually	Patient satisfaction audit report	Annually
Quality of Life following treatment	Questionnaire	100%	Quality of Life following treatment report	Annually
Unplanned hospital admissions for urinary tract infection, retention of urine, constipation and pressure ulcers	Number of admissions	100% to be reported	Hospital Episode Statistics Report (HES)	Monthly/ Quarterly
Acquired pressure ulcers	Number of acquired pressure ulcers in community and acute settings associated with incontinence	100% to be reported	High Impact Indicator (HES) (data being collected by nursing), CQUIN	
Infection control: number of urinary catheters in situ	Monthly nursing indicators report	100%	Number of catheters in situ for under 29 days and over 28 days	Quarterly

Invoicing, data validation and payment

Performance indicator	Indicator	Threshold	Method of measurement	Frequency of monitoring
Commercial invoices paid within 30 days	% of outstanding invoices	5%	Reports from accounts payable	Quarterly
Standing Financial Instructions (SFI)	Organisation compliant with SFI	100%	Audit	Annually
CQUIN payment framework	Organisation compliant with CQUIN	100%	Audit	Annually

User and local authority views; patient choice

Performance indicator	Indicator	Threshold	Method of measurement	Frequency of monitoring
Service user-group	Terms of reference, membership list. Evidence of users involved in service change, development and patient choice	2- 4 meetings per year	Minutes / notes of meetings	Annually
HealthWatch, Local Involvement Networks (LINKs), Health and Wellbeing Boards	Membership of service user group; monitoring complaints and service concerns	2- 4 meetings per year	Minutes / notes of meetings	Annually
Information for all stakeholders	Service website / newsletter; services accessible to black, minority and ethnic groups	90% for debate	Audit of communication network	Annually
Self-help groups and associated charities	Information available for service users for example: ERIC, B&BF, PromoCon, RADAR and other associated charities	100%	Audit	Annually

Feedback on activity quality and projected budget outturn

Performance indicator	Indicator	Threshold	Method of measurement	Frequency of monitoring
NHS Commissioning Boards returns	Quarterly and annual reports; meetings to monitor quality and cost; service specific	100%	Minutes, financial reports, audit reports	Annually

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32. Transition: getting it right for young people http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145
33. Privacy and Dignity in Continence Care http://www.bgs.org.uk/pdf/cms/reference/privacy_in_continence_toolkit.pdf
34. Royal College of Physicians National Audits of Continence Care for older people 2005, 2006 and National Audit of Continence Care 2010 <http://www.rcplondon.ac.uk/resources/national-audit-continence-care>
35. ProState of the Nation Report (2009) <http://www.prostateaction.org.uk>

Others suggested sources of information

The Expert Patients Programme
www.expertpatients.co.uk/

Patient Choice
<http://www.dh.gov.uk/en/Healthcare/PatientChoice/index.htm>

Equity and excellence: Liberating the NHS White Paper 2010 (and associated documents)
<http://www.dh.gov.uk/en/AdvanceSearchResult/index.htm?searchTerms=Liberating+the+NHS>

The Mid-Staffordshire NHS Foundation Trust Inquiry 2010
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113018

The National service frameworks
Older people 2001
Long-term conditions 2005
Children, Young People and Maternity Services 2004
National Stroke Strategy 2007
www.dh.gov.uk

Implementing the Next Stage Review visions: the quality and productivity challenge (QIPP) 2009 (letter)
http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_104239

Essence of Care 2010
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119969

Map of Medicine
<http://healthguides.mapofmedicine.com/choices/map/index.html>

Constipation in children and young people: costing report 2010
<http://guidance.nice.org.uk/CG99/CostingReport/pdf/English>

Spending Review HMS Treasury 2010
www.hm-treasury.gov.uk/spend_index.htm



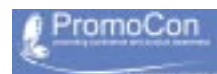
Abbreviations

AHPMA	Absorbent Hygiene Product Manufacturers Association
APPG	All Party Parliamentary Group
CAMHS	Child and Adolescent Mental Health Services
CAUTI	Catheter associated urinary tract infection
CAUTI's	Catheter associated urinary tract infections
CQUIN	Commissioning for Quality and Innovation
FI	Faecal incontinence
GP	General Practitioner
HES	Hospital episode statistics
ICS	Integrated Continence Service
LUTS	Lower urinary tract symptoms (in men)
NICE	National Institute for Health and Clinical Excellence
PFMT	Pelvic floor muscle training
QALY	Quality-adjusted life year
QIPP	Quality, Innovation, Productivity and Prevention
SFI	Standing financial instructions
SLA	Service level agreement
UI	Urinary incontinence
UTI	Urinary tract infection

All Party Parliamentary Group For Continence Care Report

Officers of the All Party Parliamentary Group for
Continence Care are:

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Lord McColl of Dulwich, Vice-Chair
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