

Introduction

Organisational change in NHS is frequent and recurrent. These standards have therefore been written in a generic way in recognition of the different health service structures across England and the devolved nations. The underlying principles of good practice should apply regardless of the organisational context in which they are delivered.

The document makes no attempt to reproduce existing evidence based clinical guidelines (e.g. NICEⁱ / EAUⁱⁱ / SIGNⁱⁱⁱ) which have been developed through a robust process of evidence evaluation.

Process of Project

In order to develop these standards a series of questions were developed, for which structured & systematic literature searches were then performed. No high level evidence was identified in relation to the effectiveness of implementation of service delivery policies.

These audits have regularly showed that there is a real need for an improvement in continence care for people with bladder and bowel problems. The patient advice from the most recent Royal College of Physicians (RCP) audit is available to the public^{iv}. Similar findings on standards were found in the Continence survey from the All Party Parliamentary Group (APPG)^v.

This document has relied on a number of key documents that have described quality standards or guidance for service delivery in the NHS which were used as source material. They are referred to when appropriate in this document.

A meeting of UKCS representatives from specialist nursing, physiotherapy, urogynaecology and urology was convened and met over a period of two days to scope the extent of the proposed document, work collaboratively on initial drafts, and an interactive process of editing then followed over a period of 2 months. This was followed by a period of open review on the UKCS website before final publication.

1 Basic Assessment of Incontinence

Staff

Healthcare professionals should receive a multi-disciplinary education to promote continence awareness^{vi}.

Staff undertaking continence assessments must be trained and accredited in basic assessment techniques including identification of red flag symptoms and reasons for early referral to specialist teams (defined below).

An assessment of continence is undertaken with the goal of making a diagnosis and offering treatment.

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In a minority of cases this goal may be modified to management rather than resolution of symptoms. In these circumstances this change in objective should be actively recorded as this has a significant resource implication that needs to be acknowledged.

Training

Refer to section of training recommendations

Setting

Incontinence is so common that it is logical that initial assessment should occur in the community (including the patient's home) or in acute or long term care settings when patients first present there^{vii}.

Assessment should also take place in assisted care facilities and take account of specific group needs such as elderly mentally infirm and those with special needs.

It should not be necessary to refer a patient to a specialist service in order for a basic assessment of continence to take place and therefore most services should have a basic level of continence awareness and training.

A common assessment process should be feasible irrespective of setting.

Patients

These include adults and children, care and nursing home residents, urinary and faecal incontinence, pregnant women, people with long term mental (including dementia) or physical disabilities, the frail elderly and those where access to healthcare is restricted.

A continence care plan relevant to both the bladder/bowel symptoms and the underlying condition should be formulated^{viii}.

Information

Information about normal and abnormal bladder/bowel function and the basics of self management should be provided at the initial assessment.

A range of information should always be available to health care professionals who are the first point of clinical contact^{ix, x}

A support package for patients and in some cases a key worker should be provided. A defined review should ideally be included.

Equipment / Facilities

Simple assessment tools such as bladder and bowel questions on a holistic nursing assessment, screening questionnaires, symptom questionnaires, frequency volume charts or bladder diaries, and

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knowledge of the application of a bladder scanner should be available for basic assessments.

Facilities for documentation, record keeping, office space and adequate clinical space to discuss embarrassing issues in private should be available.

Supporting Services

Knowledge of available specialist teams (defined below) in locality and a knowledge of referral pathways to those teams.

Workload

No minimum level of workload would be necessary. It is possible for anyone who has initial contact with patients (for instance Health Care Support Workers) to deliver this level of care provided they have appropriate training.

Performance monitoring

Records should be kept of the number of people who have been assessed and the pathways taken e.g.; simple advice given, containment products, referral to specialist team and alignment with national targets for specific groups.

2 Specialist Assessment

Staff

Staff should work as part of a multidisciplinary team with effective links to care providers within a network such that the patient can access a wide range of treatment modalities in a seamless pattern.

The team will include a minimum of continence nurses and specialist physiotherapists as well as gynaecologists, urogynaecologists and urologists, colorectal surgeons and gastroenterologists.

Training

Refer to section of training recommendations

Setting

Specialist assessment will normally occur within a secondary care setting in a dedicated clinical unit.

Patients

These will include patients who have failed initial treatment for UI, men with lower urinary tract symptoms (LUTS), UI or FI co-existing with neurological disease, combined UI and FI, women with pelvic organ prolapse and some patients with voiding disorders.

Information

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Written information on a full range of normal bladder/bowel function, abnormal function and treatment options should be readily available.

Staff should be able to offer appropriate coherent explanation to patients on their condition and support them in their decisions regarding treatment.

Equipment / Facilities

The equipment and facilities as described for the basic assessment of incontinence should be available.

All equipment should be maintained according to manufacturer's standard.

A clinical facility should have space for undertaking a private consultation and intimate clinical examination. All aspects of care should be provided in a compassionate and empathetic manner to ensure all patient needs are met. Healthcare workers should be available to chaperone patients and assist during embarrassing tests and intimate clinical examination^{xi}.

The team must be able to offer advice about containment, products and devices and full storage facilities for these must be available

Supporting Services

Radiology services should be readily accessible.

Specialist teams should streamline patient journey and refer directly into more advanced services eg; Neurourology / paediatrics / Urogynaecology / Urology / Colorectal clinics

Workload

A unit should maintain a minimum workload as recommended in the UKCS minimum standards for urodynamic practice^{xii}

Performance monitoring

Regular audit of outcomes and assessment of performance should be undertaken.

Users and stakeholders should be involved in all aspects of planning and delivery of service and in monitoring for purposes of quality assurance.

3 Behavioural and physical therapies

Staff

Staff should work within a multi-disciplinary team, be appropriately trained, and familiar with relevant evidence based guidance.

Staff will comprise specialist physiotherapists, continence advisors, other health professionals e.g. district nurses or GPs with interest in UI.

Training

Refer to section on training recommendations.

Setting

Male and females with UI or FI should have access to appropriate physical and behavioural treatments within primary and secondary care. Patients in the community should have direct access to these therapies without the need for referral to secondary care.

Patients

Includes all patients identified with a bladder or bowel problem who are at the beginning of the care pathway.

Patients with persistent UI should be referred for further assessment by a gynaecologist/urologist with an interest in female urology to consider surgical options as per NICE guidanceⁱ

All children should be offered assessment by a Paediatric Continence Advisor^{xiii}.

Patients with SUI or MUI should be offered instruction in pelvic floor muscle training by a pelvic floor physiotherapist for at least 3months.

Patients with overactive bladder symptoms should be offered bladder training for a minimum of six weeks by an appropriately trained professional.

Patients with symptomatic pelvic organ prolapse should be offered a specialist gynaecological assessment.

Information

Written information on a full range of bladder function, abnormal function and lifestyle modifications should be readily available.

Staff should be able to provide verbal and written explanation on treatment options such that patients have a realistic expectation on outcomes

Equipment

A continence team should have access to dedicated space and equipment similar to that for undertaking a basic continence assessment.

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Additional treatment modalities such as sacral neuromodulation, biofeedback, and electrical stimulation for male and females with UI should be available.

Workload

There is no recommended minimum workload. Workload and clinical practice should conform to guidance issued by the relevant Royal College or professional body and be sufficient to maintain as a specialist area of practice.

Monitoring Performance

Access to physical and behavioural therapies should be monitored through user and stakeholder involvement.

Outcomes to these therapies should be monitored through PROMs.

Supporting Services

These services should be provided within a continence network to facilitate communication between primary, secondary and tertiary services and seamless referral between health professionals within the network.

- 4 Surgical interventions for uncomplicated incontinence
(Includes primary surgery for stress urinary incontinence and overactive bladder refractory to simple conservative therapies and pharmacotherapy)

Staff

Surgery should be performed by surgeons with specialist training and sufficient workload to maintain expertise.

Surgeons should work in the context of a multidisciplinary team and clinical network.

Supporting health professionals including ancillary and nursing staff.

Training

Surgeons who undertake continence surgery should have undertaken an approved training programme such as RCOG Subspecialty training or Advanced training skills module in Urogynaecology, Female Urology or equivalent supervised training^{xiv, xv}

Surgeons who undertake procedures that are new or undertake for the first time should adhere to NICE recommendations for clinical governanceⁱ.

Setting

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Second-line conservative treatments and surgery should only occur in secondary care settings.

Surgical options should be discussed at an MDT.

Treatments which are new or have limited evidence on efficacy such as PTNS to be delivered only after discussion by MDT

Botulinum toxin injection to be performed by surgeons trained in lower urinary tract endoscopy

Information

Patients must be provided with information about all treatment options for UUI or SUI or MUI and allowed time to make personal choices

Women should be offered all options and onward referral to another provider should an appropriate treatment not be available locally.

Equipment / Facilities

Resources to teach patients CISC, monitor residuals and bladder training. Facility used to performing endoscopic interventions of lower urinary tract.

Operating facility with full capacity to perform vaginal and abdominal surgery

Inpatient beds and post-operative aftercare available.

Supporting Services

Medical physics, laboratory, radiology, pharmacy support for use of botulinum toxin and support for PTNS .

Centres should be able to demonstrate collaboration with other specialists (Urology/urogynaecology/colorectal) or centres with additional services or expertise

Workload

Interventions for uncomplicated incontinence are usually provided in secondary care setting with enough work to maintain expertise with a population of 250,000 sufficient.

Only surgeons who undertake a sufficient workload should undertake surgery for SUI and OAB. An annual workload of 20 procedures for each primary UI procedure is recommendedⁱ

Surgeons with a caseload of fewer than 5 for any procedure should seek approval through clinical governance committee otherwise a referral pathway should be available through the networkⁱ.

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Recurrent continence surgery is described under the Complex commissioning guide (E10)^{xvi}

Performance monitoring

Surgeons should undertake comparative audit of outcomes and participate in national audits through national databases such as BSUG database^{i, xvii}

Surgeons should be able to present their own personal data for key clinical outcomes for all proceduresⁱ e.g.;

PTNS – response rate

BTX – UTI and Self Catheterisation rates

SUI – validated outcomes at 12 months ,

Surgeons should adhere to the Principles of Good Medical Practice

5 Complex Surgical Interventions

(Includes secondary surgery for female SUI, surgery for male incontinence, incontinence surgery in neuropathic patients, sacral neuromodulation and major reconstructive surgery for intractable incontinence)

Staff

Should be performed by surgeons with specialist training and sufficient workload to maintain expertise. Surgeons should work in the context of a multidisciplinary team

Surgeons will normally be active members of relevant professional groups – eg; BSUG / SFNU

Training –

Specified by Subspecialty training documents in Female Urology, Neurourology and Urogynaecology – see JCST / RCOG websites^{xiv, xiv}

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Setting –

Will usually occur in hospitals serving a large population- probably in excess of 1 million people.

Information

Patients must be provided with information about all treatment options for their particular condition and allowed time to make personal choices

Equipment / Facilities

Ability to teach patients CISC

Advanced operating facility used to performing complex vaginal or abdominal surgery

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Aftercare – patients should be managed peri-operatively on specialised wards who regularly care for patients undergoing complex continence surgery and are able to carry out;

- Vaginal examinations
- IV fluid and electrolyte replacement
- Advanced pain control
- Regular monitoring of drainage

Supporting Services

For BTX – pharmacy support for use of botulinum toxin

For PTNS

For major surgery – Intensive therapy, nephrology, general surgery

Workload

PTNS and BTX - usually provided in secondary care setting with enough work to maintain expertise – population of 250,000 sufficient

Major surgery and SNS require larger populations and more centralised services to support workload.

Performance monitoring

Surgeons should participate in national audits and be able to present key clinical outcomes for all procedures eg;

PTNS – response rate

BTX – UTI and Self Catheterisation rates

Services for Faecal incontinence should comply with the standards outlined by the RCS^{viii}

Recommendations for Service Configuration

Service delivery should be organized through clinical collaboration and agreed local pathways. There should be Regional Clinical Networks which are able to offer the complete range of incontinence therapies and within which it is easy to cross refer patients with service level agreements. They will be comprised of locally based continence teams as well as regional centres able to provide a wider range of treatment options. These arrangements need to be able to transcend transient organisational structures and should be based on strong clinical collaboration.

Care will be delivered at a number of levels

Level 1 - Community based Staff (including staff working in nursing homes)- “Link nurses” (see appendix on basic continence assessment)

All healthcare professionals working should be able to identify sufferers and liaise with providers in their locality.

Primary care should be the first level of care for those suffering with incontinence^{vii}.

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Staff who are based in the community may be trained to be able to provide basic levels of assessment and initial treatment in a community setting^{vi}.

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Good practice should be shared among those undertaking assessments through the development of a wider Continence Specialist team to whom those working apart from the specialist team will link, and have ready access for advice and support and educational resources.

Those working in isolated settings away from the specialist team should attend regular updates and clinical meetings where cases may be discussed.

Patients should be able to be referred directly from the community based practitioner to the specialist team.

Local care pathways and common evidence based policies should be available for management of incontinence in the community.

Users and carers should be involved in the planning, provision and assessment of services within the community^{vii}.

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Level 2 – Specialist Continence teams

A continence specialist team will normally be located in a secondary care facility and will usually comprise; specialist nurses including paediatric nurse specialists, specialist physiotherapists, urologists and/or gynaecologist with particular interest and training in management of incontinence and pelvic floor disorders.

These teams would normally be able to offer basic and specialist assessment, advice on containment and appliances, conservative and drug management and primary surgery for uncomplicated urinary incontinence.

Local continence teams should hold MDT meeting as described in section and undertake regular performance reviews and audit.

The specialist team will provide support, training and ready access for community based “link nurses” as defined above. Patients should be able to access the specialist team directly from the community based link nurses.

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Such a team will normally support a population of more than 100,000^{vi}

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These teams should work to evidence based policies and guidelines for management of lower urinary tract symptoms and other pelvic floor disorders.

These specialist teams should engage with stakeholders and use benchmarking tools to monitor and improve performance^{xi}

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Continence leads in related specialties such as geriatric medicine, midwifery, paediatrics, surgery, gastroenterology and coloproctology should be identified to raise awareness and promote continence.

Surgeons would be expected to have an appropriate workload to maintain surgical skills and work within a multidisciplinary team with expertise in pelvic floor dysfunction.

Surgical teams would be expected to provide evidence of outcomes for their surgical procedures and to provide surgery in line with evidence based practice guidelines (e.g.; NICE, EAU, AUA^{i,ii,iii})

Level 3 – Local Multidisciplinary Teams

Women who have failed conservative management for their UI should have their case discussed with an MDTⁱ. The same principles apply to the management of incontinence in other patient groups.

The multi-disciplinary team should comprise a range of health care professionals who have not had prior involvement in the patient's' treatments and who have sufficient expertise to review all surgical decisions. This would normally include a specialist urologist, urogynaecologist, specialist nurse and physiotherapist and additional input from other specialists such as Care of the Elderly Physicians and colorectal surgeonsⁱ.

All MDTs should operate as a part of a wider regional clinical network who should collectively able to offer the full range of clinical interventionsⁱ.

Patients with complex incontinence problems e.g. failed SUI surgery or failed botox, patients with complex neurological conditions, post-prostatectomy incontinence should routinely be seen and assessed by a regionally based MDT. Much of this will be under specialist commissioning^{xix}

Records should be kept of MDT recommendations, which in turn should be clearly reported to GPs and made available to patients. There should be formal reporting of serious and adverse events

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MDTs should be incorporated into job plans of the individual participants and appropriate administrative support to facilitate record keeping and audit.

The minimum requirement is of 1 session per week dedicated to this specialist work.

MDTs should be working to evidence based common pathways procedures/ policies and guidelines.

Practitioners must be able to show evidence of audit and regular CME related to continence

Teams should have meetings at least once per month.

The MDT also has an important role in promoting awareness of incontinence services and the availability of treatments

Services should serve populations of approx 250000. A level of one specialist nurse per 100000 population has been recommended by the APPG.

Level 4 - Regional expert Multidisciplinary teams

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Every regional network should include a regional team who can provide a wider range of expertise and therapies.

They should be able to deal with:

- Women with failed stress incontinence therapy
- Women with failed first line surgery for UII (including major reconstructive surgery)
- Patients with complex neuropathy
- Men with postprostatectomy UI(including male slings and AUSs)
- Patient with combined urinary and faecal incontinence
- Women with prolapse and urinary incontinence

There should be access to expertise in anorectal function. This includes the involvement of a colorectal specialist and access to investigations with anorectal physiology, defaecating proctography and endoanal ultrasound. Treatments should include access to biofeedback and rectal irrigation. These should include reconstructive surgery

Regional centres will normally be active in clinical or basic science research in the field of incontinence and will provide specialist training for both medical and nursing personnel.

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Regional teams will normally support populations of over 1M people

Some services may only be feasible at a supraregional level e.g. vesicovaginal fistula, sacroneuromodulation). These teams would normally support populations of several million people i.e.; the number of such teams within the UK will be relatively few. These services will be commissioned as specialist services^{xix}

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Governance Arrangements

Multi-agency Advisory Groups

Urinary incontinence spans the whole of the health and social care sector and services should be organized through collaboration of the multiple agencies involved. At a local and regional level there should be strategic groups with the following representation:

- primary care
- specialist continence services
- acute and mental health care directorates
- longterm care (high prevalence of UI)
- voluntary sector (high prevalence of UI)
- education sector (because of enuresis. soiling)
- private care sector (residential homes with high prevalence of UI)
- social services
- service users
- designated leads for relevant specialties

These groups must have board level support and will advise on planning and configuration of continence services at a regional or sub-regional level^{vii}

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One important role of this group is to advise and set standards for toilet provision and access within care facilities in all sectors.

Further points for Consideration^{vi}

To be able to deliver the service described above and in accordance with the GCP document one may need to consider the following points as additional factors alluded to in the text above, but not expressly expanded on:

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- Need for informal network of continence providers –
- Need for networks to embrace those working in isolation
- People working in isolation must be linked to local or regional support networks.
- Developing a Service lead from within the network, who has responsibility to ensure that services are integrated. This role is probably

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best served by someone based in the community rather than secondary care.

- Resources for attendance backfill and administrative support, equipment and consumables.

ⁱ <http://guidance.nice.org.uk/CG171>

ⁱⁱ <http://www.uroweb.org/guidelines/>

ⁱⁱⁱ <http://www.sign.ac.uk/guidelines/fulltext/88/index.html>

^{iv} <http://www.rcplondon.ac.uk/sites/default/files/keeping-control-2011.pdf>

^v <http://www.appgcontinence.org.uk>

^{vi} http://www.rcn.org.uk/_data/assets/pdf_file/0010/78598/002224.pdf

^{vii} Department of Health (2000) *Good Practice in Continence Services*.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005851

^{viii} http://www.healthcareimprovementscotland.org/previous_resources/process_documentation/nhs_qis_nice_advice.aspx

^{ix} <http://www.bladderandbowelfoundation.org>

^x <http://www.disabledliving.co.uk/PromoCon/About>

^{xi} <https://www.gov.uk/government/publications/essence-of-care-2010>

^{xii} http://www.ukcs.uk.net/docs/joint_statement.pdf

^{xiii}

<http://www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp>

^{xiv} <http://www.rcog.org.uk/education-and-exams/postgraduate-training>,

^{xv} <http://www.rcseng.ac.uk/surgeons/training/curriculum>

^{xvi} <http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-e/e10/>

^{xvii} <http://www.bsug.org.uk>

^{xviii} <http://www.rcseng.ac.uk/healthcare-bodies/docs/Commissioning%20guide%20for%20faecal%20incontinence%20open%20for%20consultation%2013%20May%20-%202010%20June%202013.pdf/view?searchterm=faecal+incontin>

^{xix} <http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-e/e10/>

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