Models of Continence Care: What Works Best?
Workshop 27
Tuesday 24 August 2010, 09:00 – 12:00

Time | Time | Topic | Speaker
--- | --- | --- | ---
9:00 | 9:10 | Introduction & General Overview | Cara Tannenbaum
9:10 | 9:35 | Continence promotion in the elderly in outpatients | Susan Orme
9:35 | 10:00 | The long-term care model: barriers and indicators of success | Diane Newman
10:00 | 10:25 | Delivering continence care through a social enterprise model: The Bristol Integrated Continence Service (BICS) | Adele Long
10:25 | 11:00 | Break | 
11:00 | 11:25 | Measuring the outcomes of continence care | Jeffrey Jutai
11:25 | 12:00 | Case studies | Cara Tannenbaum & Jeffrey Jutai

**Aims of course/workshop**

- To review current models of continence care delivery in the context of patient needs.
- To critically appraise the success or failure of various models of care delivery in different countries.
- To present a novel model of integrated continence care.
- To discuss outcome evaluation of continence care delivery at the individual and health systems level.
- To encourage discussion and share lessons learned from around the world.

**Educational Objectives**

This workshop will allow practitioners and service providers to discover and discuss some of the latest research on evidence-based models of continence care. The focus will be on the assessment of patient needs, the process of care delivery and the importance of outcome evaluation. Delegates will learn the advantages and disadvantages of different models of care for meeting patient needs. By the end of the workshop the delegate will be in a position to innovate their own practice if required and will be equipped with a choice of tools to evaluate the outcomes of care delivery. Speakers will also address issues related to different patient populations including patients who self-manage in the community, patients who seek care in the outpatient setting, and patients who reside in long-term care. Translational lessons for improved care across these settings will be highlighted. At the health systems level, new information will be presented on the use of national quality indicators for continence care and cutting-edge triage systems for ensuring appropriate allocation of services. An interactive debate will explore the drivers, enablers and barriers to change in different settings and countries.
WORKSHOP 27

Models of Continence Care: What Works Best?

Chair: Cara Tannenbaum, M.D., M.Sc.
Speakers: Dr Susie Orme, BM BS (Hons) MedSci FRCP
Diane Newman, ANP-C MSN FAAN
Adele Long, MBA(OU) MPhil BSc(Hon) MICR
Jeffrey W. Jutai, PhD CPsych
An overview of different models of continence care

Cara Tannenbaum MD, MSc
The Michel Saucier Endowed Chair in Geriatric Pharmacology, Health and Aging
Associate Professor of Medicine, Université de Montréal

Many different models of continence care exist. An individual with incontinence may attempt to self-manage on their own or choose to engage in a doctor-patient dyad with their primary health care physician. Nurse continence advisors work in tandem with specialty clinics to oversee behavioral pessary interventions. Urology or urogynecology specialist clinics offer second-line surgical interventions. Comprehensive geriatric assessment units integrate a multidisciplinary approach using geriatrician, nurse specialist, physiotherapist and sometimes a pharmacist or social worker. Successful management of incontinence in the hospital or nursing home depends on top-bottom involvement by all personnel from administrators to nursing aides. At the national level, urogynecology triage systems are being implemented.

In order to accurately gauge the effectiveness of each model for improving continence at the individual and/or population level, indicators capturing the full impact of the different continence care delivery methods need to be recorded. The use of multiple indicators may provide a more comprehensive picture of effectiveness than a single indicator alone. However, use of indicators raises certain challenges and highlights the complexity of obtaining valid and sustainable measurements of effective continence care over time.

The most frequently used model of care is the self-management model, whereby individuals with incontinence function on their own behalf to effectively manage bothersome urinary symptoms. Fewer than half of all adults experiencing incontinence seek professional care, with the majority preferring self-help measures to try to control their symptoms (Milne, 2000; Tannenbaum, Drali, Holroyd-Leduc, & Richard, 2009). Evidence-based self-management tools have been created to aid individuals in reducing risk factors for incontinence (see poster #x at ICS). Self-monitoring around pelvic floor muscle exercises, caffeine reduction, weight loss, constipation management and improvement of vision and hearing impairment yields 50% reductions in incontinence in older women with stress, urge and mixed symptoms. A voiding diary is useful as a self-monitoring outcome measure, though improvements in self-efficacy and distress can also be documented using the Geriatric Self-Efficacy Index for Urinary Incontinence and the Urogenital Distress Inventory respectively.
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Nurse-led continence advisor programs appear to have similar efficacy to urology or urogynecology specialty models for conservatively managing incontinence (Borrie, Bawden, Speechley, & Kloseck, 2002; Moore et al., 2003; Williams et al., 2005). Outpatient geriatric assessment units are gaining in popularity (Padros, Peris, Salva, Denkinger, & Coll-Planas, 2008; Tannenbaum, Bachand, Dubeau, & Kuchel, 2001), and report obtainable dryness rates up to 25% and improvement in an additional 45% of frail elderly patients who consult their service (Harari & Igbedioh, 2009).

A number of effective continence interventions are available for nursing home residents, including prompted voiding and correction of reversible precipitating factors (Offermans, Du Moulin, Hamers, Dassen, & Halfens, 2009; Palmer, 2008). However, continence care programs in the long-term care setting are difficult to implement and sustain (Etheridge, Tannenbaum, & Couturier, 2008). Using continence rates as a quality indicator for long-term care may be one way of integrating continence management into mainstream healthcare delivery (Palmer, 2008).

At the national level, a centrally commissioned clinical audit program to monitor the implementation of evidence-based guidelines across England and Wales found disparate standards of care in the community, hospitals and nursing homes (Wagg, Lowe, Peel, & Potter, 2009; Wagg et al., 2008). The climate is ripe with opportunities to improve appropriate training, skills and access to deliver efficient, high-quality continence care across a variety of settings (Oliver, Thakar, Sultan, & Phillimore, 2009; Stothers, Wilkie, Liebllich, & Wilson, 2008).

Selected references:


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CONTINENCE PROMOTION IN THE ELDERLY IN OUTPATIENTS

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INTRODUCTION AND BACKGROUND:

The concept of “elderly” is an arbitrary one. The diversity within this demographic group is large and the presence of complexity due to coexisting pathologies is not confined to the aged. The prevalence of overactive bladder symptoms and incontinence increases with age. (By their 80s so many percent of patients will have urinary incontinence.) However it is by no means an inevitable consequence of ageing. It is the concept of frailty and biological age that dictates difference in approach to the assessment and treatment of bladder symptoms in this group.

The economic and personal burden of bladder dysfunction and urinary incontinence in the aged is high. The frail elderly rarely present in isolation and the expectations of the carer should be considered. The need for assistance with toileting and hygiene can have a considerable impact on the quality of life of the carer as well as the patient. The presence of urinary incontinence can lead to the carer perceiving the patient in a negative way and is a significant risk factor for admission into long term care.

Nocturia in particular is disabling in the elderly. Disturbed sleep reduces the ability to perform activities of daily living. Getting out of bed at night is a risk for falls and fractured neck of femur.

If the carer needs to toilet the patient and is elderly it is an increased falls risk for both.

“NON BLADDER” CONSIDERATIONS:

The process of toileting is more complex than voiding alone. It also involves the recognition of the desire to void, the motivation to stay dry and finding and mobilising to the toilet. The patient then has to remove lower body clothes. From this it is easy to see that even if the mechanisms of maintaining continence are intact the failure of any of the above processes increases the chances of the patient perceiving their symptoms as more bothersome or rendering the patient incontinent.

From the above the impact of the environment becomes apparent. For example, if the toilet is upstairs and the patient has difficulty climbing the stairs it also increases the likelihood of the patient becoming incontinent. The drive behind toilet mapping is to remove this uncertainty in unfamiliar surroundings.

The presence of severe arthritis, dyspraxia due to stroke or Parkinson’s disease may make it difficult to reach the toilet and undress even if bladder function is normal.
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THE IMPACT OF OTHER PATHOLOGIES:

The impact of chronic medical symptoms can have an impact on the symptoms of bladder dysfunction. Under treated cardiac failure can increase the tendency to nocturnal polyuria and nocturia. The diuresis and urinary frequency associated with diuretics can cause the elderly problems especially if mobility is impaired. Changing to a longer acting loop diuretic such as torasemide can help.

The presence of untreated chronic cough associated with chronic obstructive pulmonary disease can exacerbate stress incontinence episodes.

The impact of constipation on symptoms cannot be overemphasised. Not only does it contribute towards incomplete bladder emptying and recurrent urinary tract infection the constipation itself can increase confusion reducing the desire and motivation to stay dry.

The further difficulty with Parkinson’s disease is the contribution of poor mobility and bradykinesia associated with motor fluctuations and “off” periods. Reviewing movement diaries in relation to symptoms can be helpful if it is under treated Parkinsonism that is the driver behind worsening symptoms.

Hyperglycaemia associated with undiagnosed or poorly controlled diabetes mellitus is associated with a high solute load and polyuria. Again if mobility is impaired the need for frequent toileting means the bothersome of any bladder symptoms will increase.

With multiple pathologies come multiple medications. The impact of polypharmacy on symptoms is important. Many drugs in common use in the elderly especially sedative medication have anticholinergic effects. Not only does this contribute towards incomplete bladder emptying but also exacerbates constipation and cognitive impairment.\(^7,8\) A medication review is therefore recommended as part of the assessment.

ASSESSMENT:

The basis of assessment in the elderly does not differ from that of the young but consideration of the above points is important.

The assessment should therefore include a detailed social history to include ease of access to toileting facilities and ability to attend to lower body hygiene and the perception of carer burden as well as the impact of the patients social functioning. Goal setting should be realistic and both the patient and carers should be fully informed.

An assessment of the ability to perform activities of daily living such as the Barthel Index and an assessment of cognitive function using the Abbreviated Mental Test Score or Folsteins MMSE. This helps guide how realistic the ability to comply with conservative measures such as pelvic floor exercises and bladder drill and also how likely the goals of the patient and carer can be achieved.

The ability to perform personal hygiene is often overlooked and a useful amount of functional information can be obtained by watching how easily the patient can walk over to the examination couch get dressed and undressed. If the clothes are soiled it gives a good indication how the patient is coping with their incontinence.
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Bladder dairies are as useful in the elderly as in the young. However it is often difficult and impractical for the frail to measure urinary volumes and a useful amount of clinical information can be obtained by simply marking when urine is passed when the patient drinks and is incontinent.

Detailed urodynamic investigation is not routinely necessary in the frail.

TREATMENT:

Whilst containment products may be required the emphasis should be on improvement rather than containment of symptoms. The emphasis should be on improvement of symptoms and attainment of the patients’ goals. Often in the elderly it is the attainment of “social continence.” This involves setting social centred goals based on resumption of social and sexual activity and goals that reduce carer burden. This is the outcome measure recommended By the ICI.9

The cognitively intact will be able to perform pelvic floor exercises and bladder drill. Even the moderately confused can respond to prompted voiding and two hourly toileting regimes. Although dryness may not be achieved significant improvement in incontinence episodes can be expected.

The importance of adequate fluid intake should be stressed. Those who require assistance with making drinks or help with feeding are especially prone to dehydration.

Constipation should be treated appropriately. Heart failure treatment and chronic obstructive pulmonary disease should be maximised. Poorly controlled diabetes should be attended to by appropriate changes to oral hypoglycaemics or insulin.

Rehabilitation and assessment of care needs should be offered where necessary. The provision of aids such as commodes, raised toilet seats and urinals with one way valves can significantly help patients whose continence is in part due to locomotor difficulties.

If incomplete bladder emptying is contributing toward symptoms the elderly will often accept intermittent catherisation by themselves or by carers.

ROYAL COLLEGE OF PHYSICIANS CONTINENCE AUDIT.

It is to audit whether we are applying these standards to continence promotion in the elderly that the Royal College of Physicians UK Continence Audit occurred. England, Wales, Northern Ireland and the Channel Islands are the only countries worldwide to systematically audit continence care against national standards.

The first and second rounds of the National Audit of Continence Care for Older People 2005 and 2006 and the reaudit occurred in 2010.10

Despite some improvements with each year of the audit. It shows that we are not offering treatment for those who are identified as having a urinary or faecal continence problem. Continuing education of those healthcare providers who claim to have an interest in treating the condition and more importantly, those who do not claim to have an interest is the way forward.
CONCLUSION:

Bladder symptoms particularly nocturia and incontinence can be personally and socially disastrous in the complex and frail. Avoiding institutional care by setting realistic goal that take into account the expectations of the patient carer and the impact of coexisting pathologies mean the elderly have more to gain from treatment.

LEARNING POINTS:

1. Frailty and complexity are not confined to the aged and require different approaches to treatment.
2. The process of toileting involves factors other than voiding.
3. Coexisting pathologies, medications and locomotor difficulties increase the burden of bladder symptoms.
4. The frail rarely present in isolation and the perception of burden and expectations of the carer should be considered.
5. No patient should be denied appropriate treatment on the basis of age.
6. In the UK the National audit of Continence Care in Older People indicates the need for continuous improvement and education.

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August 24, 2010; 9:00 – 12:00

THE LONG-TERM CARE MODEL: BARRIERS AND INDICATORS OF SUCCESS

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Objectives:

- Review models for continence care in the long term care (LTC) setting.
- Describe what have been successful and their and specific barriers to implementation.

Prevalence of Urinary Incontinence in LTC

Over 65% of nursing home residents in the U.S. experience some type of urinary incontinence (UI), second only to dementia as a leading cause of placement in an LTC facility (Boylington et al., 2007). DuBeau et al. (2006) demonstrated that prevalent and new or worsening UI decreases QoL even in frail, nursing home residents with functional and cognitive impairments. It is felt by most experts that improving continence care and quality in nursing homes by targeting interventions to those residents most likely to benefit will have an impact on resident QoL. However, despite the fact that UI is highly prevalent in the LTC setting, staff lack knowledge of the causes of UI and do not implement successful interventions.

Overall Prevalence of UI in the Nursing Home Population (Men & Women)
United States

![Bar chart showing prevalence of UI in the nursing home population over time.]

Identified Barriers

There are many barriers to improving continence care in nursing facilities. Restricted mobility is one of the main factors because residents who are placed in restraints or use assistive devices such as a...
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Walker, or who are in a wheelchair, are unable to toilet when needed. Social indifference and cognitive impairment also play a role in implementation of adequate continence care. Staff is also a barrier to providing adequate continence care. It appears as though there is a discrepancy between the goals of residents and those of staff for UI treatment preferences in the LTC environment. (Johnson, Ouslander, Uman, & Schnelle, 2001). Although nursing staff believe that prompted voiding is a more appropriate UI treatment than either absorbent products or more invasive treatments such as catheters, few staff implement and persist with such as program for many reasons as noted below.

Barriers to Continence Care in LTC

- Staff time (2-3 minutes to change and 5-15 minutes for a toilet).
  - Inadequate staff
  - Poor Management Information
  - Poor assessment (few charts have valid assessment of toileting responsiveness
  - Acceptance of condition.

Despite an established body of knowledge of effective treatment modalities for UI in LTC residents, a number of barriers impede optimal implementation (Newman & Wein, 2009). There is little evidence suggesting that clinicians have adopted and followed previous UI management guidelines, or are aware of current research about the effectiveness of noninvasive programs in the LTC setting (Watson et al., 2003). In addition, many interventions are not implemented correctly and consistently because the success of the UI program relies heavily on the commitment and consistency of caregivers. Prior research has indicated that the two major issues/challenges that need to be overcome to improve urinary continence care in nursing homes are the establishment of appropriate infrastructure and of incentives (Ouslander & Johnson, 2004). The following is a list of possible barriers associated with the delivery of continence care in LTC facilities:

- Inadequate initial staff education on UI and interventions appropriate for this population
- Lack of assessment or evidence of benefit before placing an incontinent resident on a toileting program
- Lack of individualized continence care; rather, care is at the convenience of the staff
- Inadequate staffing
- Poor communication and support from administrative staff regarding expectations
- Lack of financial incentives to keep residents dry

Possible Indicators of Successful Continence Care

However, there is continuing research (a few summarized below) that describes models of continence care that may assist in overcoming current barriers in LTC and this workshop will present these in more details.

Fink, et al., (2008) reported on the efficacy and safety of treatments for nursing home residents with urinary incontinence (UI).

- A systematic review was conducted of randomized controlled trials published from January 1985 through May 2008.
- Treatments included antimuscarinic medications, oral estrogen plus progesterone, and behavioral interventions (e.g., prompted voiding).
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- Efficacy outcomes indicated that neither prompted voiding plus exercise nor prompted voiding plus oral estrogen and progesterone was superior to prompted voiding alone for incontinence management.

Rahman (2010) described a distance learning model designed to help nursing homes implement incontinence management best practices.

- Nurse supervisors from 14 nursing homes in nine states learned how to implement prompted voiding during monthly 60- to 90-min teleconferences.
- Participating facilities assessed a total of 261 incontinent residents and reported maintaining 117 (44.8%) on prompted voiding, for an average of 10 residents per facility.
- Distance learning may be a feasible, effective, and low-cost strategy for translating research into nursing home practice.


- Knowledge and attitude are related to practice but beliefs showed no relation to either practice, or to knowledge, or to attitudes.
- It is worth making an effort to increase nurses’ knowledge about UI assessment via continuing education. In addition, nurses’ and nursing assistants’ attitudes can be positively influenced by cooperation with advanced practice geriatric nurses.

Young (2009) identified risk factors for and time to permanent transition from independent living units to nursing home among residents.

- Prospective cohort study (n=298) among residents at least 75 years of age living independently at baseline.
- Predictive factors were depression, incontinence, impaired cognition and dependence on activities of daily living.
- Prevention and treatment for depression, incontinence, and programs to improve or maintain cognitive function and ability to perform activities of daily living may prolong their independent living life.

Selected References:


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Delivering continence care through a social enterprise model: The Bristol Integrated Continence Service (BICS)

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Objectives
• Highlight key drivers for alternative continence service provision in UK
• Describe the path to setting up an integrated continence service using a social enterprise model

Introduction
The Department of Health (DH) review of continence services in 2000 and paper Good practice in Continence Services (2000) stated that services should be organised and delivered within an integrated model. While this model concentrated on the experience of those who were already in receipt of services through the National Health Service (NHS), there has been more recent discussion describing a more holistic approach to an integrated service that also recognises the role for self-help and use of Third Sector information services and support as an entry point for those experiencing continence problems. This model is already in operation in the United Kingdom (UK) and we wished to explore the feasibility of developing the model to meet the needs of an integrated continence service in Bristol, UK1.

Background
Health services in the UK are delivered predominantly by the National Health Service (NHS) with an increasing proportion going to private health providers. The former ‘free at the point of need’ service is funded primarily through government taxation and is available to all citizens; the latter is funded by private individuals often through insurance schemes.

In recent years health costs have escalated and many governments are concerned as to how these costs will be met. A contributory factor is the increasing older population. Over the last 25 years the percentage of the population aged 65 and over increased from 15 per cent in 1983 to 16 per cent in 2008, an increase of 1.5 million people in this age group. By 2033, it is projected that 23 per cent of the population will be aged 65 and over compared to 18 per cent aged 16 or younger. The fastest population increase has been in the number of those aged 85 and over, the ‘oldest old’. In 1983, there were just over 600,000 people in the UK aged 85 and over. Since then the numbers have more than doubled reaching 1.3 million in 2008. By 2033 the number of people aged 85 and over is projected to more than double again to reach 3.2 million, and to account for 5 per cent of the total population (UK Office of National Statistics, October 2009).

Older people receive a large proportion of health service expenditure. In 2001/02, nearly £32 billion was spent on hospital and community health services in England and 39 per cent of this was spent on people aged 65 and over even though this age group made up only 16% of the population. Those

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1 Bristol is the 7th largest city in England and is situated in the south west of the British Isles (Bristol City Council statistics, 2008).
In patient effective to Statistics, reducing environmental difficulties for appropriate NHS, was entitled to an estimated 62,000 social enterprises in the UK contributing at least £24bn to the economy and one-third of these are in the health and social care sector (Annual Survey of Small Businesses UK 2005-2007).

In 2007 the UK Government introduced financial incentives as part of their plans for stimulating expansion in the role of social enterprise businesses in the provision of health and social care. The £100m social enterprise investment fund (SEIF) was created to facilitate their aim of providing health and social services in a way that is ‘locally responsive, high quality and inclusive, especially in areas of social deprivation’. Funds were made available as loans, grants or for business support and could be used to set up a new service or expand or transform an existing service. A small fund of £20,000 per organisation was also available to explore the feasibility of setting up a social enterprise.

To enable new entrants to the health and social care delivery market, additional guidance was introduced by DH entitled Transforming Community Services: enabling new patterns of provision (2009). This set out the principles underpinning the transformation agenda and the mechanisms by which new providers may emerge, such as the “right to request”. This, combined with financial incentives offered a mechanism for delivering patient care through the creation of a social enterprise model.

**The BICS feasibility project**

**Strategic vision and aims**

In July 2008 the Bristol Urological Institute (BUI) applied to the SEIF for funding to undertake a feasibility study for the delivery of an integrated seamless continence service for patients and carers in which services would range from information and advice to healthcare delivery in the community and at the interface between primary and secondary care.

The vision was to provide people who live in the Greater Bristol area and who experience continence difficulties with a single access point into a clear pathway through information and advice to the most effective and appropriate interventions. This would ensure access to high quality, NHS compliant information for patients and carers, and implement integrated continence care pathways for patients to ensure the most appropriate and timely intervention, reducing unnecessary and repeated referrals between services and reducing dependence on absorbent hygiene products.

In addition, the intention was to integrate training and research into the service with a process of continued evaluation and the opportunity for patients to contribute to research (Exploring Impact: public involvement in NHS, public health and social care research, NIHR Involve, 2009). This would create a virtuous circle of implementation, evaluation and revision in all aspects of continence care and serve to engage providers and users in the process.

The specific aims and objectives of the study were to:
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- model what a fully integrated continence service – starting from the user and carer – would look like and to identify the full range of provision available for individuals to access directly within their communities or which could only be accessed through formal health or social care service providers.
- model what a BICS social enterprise would look like, which could deliver the range of services required and to identify the necessary legal, financial governance and service delivery structures it would need to possess to be viable.
- understand the current provision from third and public sector agencies and to identify the degree to which those agencies would wish to form part of – or become partners in – a new BICS social enterprise.
- understand current levels of relevant health service activity and costs at primary and secondary levels as well as levels of social care services in order to begin identifying the potential cost benefits of a BICS social enterprise.
- analyse the data with a view to identifying the feasibility of creating a Bristol Integrated Continence Service.

Method

The feasibility study was conducted over a period of 6 months from May to October 2009 using a combination of desk research and interviews, visits and meetings. The primary outputs were a report on the feasibility of creating a Bristol Integrated Continence service as a social enterprise and, if deemed viable, develop a business case to take the initiative forward.

The desk research involved the assimilation of relevant background information including national, local and regional strategies and policies, other published and unpublished data on integrated continence services and mechanisms of delivering health and social care through a social enterprise.

The interviews, visits and meetings included individual telephone and face-face meetings and group meetings. Stakeholders were identified; primary care trusts PCTs) and continence service commissioners, Third Sector organisations working at national, regional and local levels, social care service providers, community, nursing and residential care providers and local Member of Parliament who was also the lead for the UK Government All Party Working Group on Continence Services.

The objective would be to assemble the building blocks by which a social enterprise organisation could deliver strong information, advice and support mechanisms through links with the existing community-based organisations, which people turn to for self-help and self-care, whilst working to reconfigure NHS services around a new core continence service which links existing health and social care services in a more meaningful and cost effective format.

To support the preparation of the business plan further data collection was undertaken around the specific topics of:

- setting up a continence information service
- setting up a telephone helpline
- telemedicine and telecare
- evaluation and measuring social return on investment

Findings

By applying medical sociology theories and models of health, culture and care to the local environment of need and service availability for continence care it was possible to identify a continuum of need and the sources of help which individuals or carers currently access. These ranged from self-help in the home drawing
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upon a range of information resources, friends and family, charities such as the Bladder and Bowel Foundation, pharmacies, health and fitness centres etc. to more formal support and medical help from the local continence service and specialist consultants accessed through the family GP.

This continuum of need and sources of help available was plotted into a simple template (Fig 1), which was used to discuss and develop the ideas with key informants and advisors.

Figure 1

<table>
<thead>
<tr>
<th>Continuum of Need and Sources of Help</th>
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<tbody>
<tr>
<td><strong>Self Care</strong></td>
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<tr>
<td><strong>Private</strong></td>
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<tr>
<td>Information Seeking</td>
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<td>Product Purchase</td>
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<td>Self Help</td>
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<td>Carers</td>
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It has been recognised for many years that most of these areas of need and activity operate to a large degree in isolation. We set out to investigate if and how a more holistic approach could be structured and implemented (Fig 2).

Figure 2
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Possible BICS Social Enterprise

Potential services and service providers to deliver the needs

<table>
<thead>
<tr>
<th>3rd Sector Partner</th>
<th>NHS &amp; Social Services Community Continence Services &amp; BUI</th>
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</thead>
<tbody>
<tr>
<td>Information Services &amp; Centre</td>
<td>Advocacy &amp; involvement</td>
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<tr>
<td>Community Drop In Service – advice &amp; products</td>
<td>Self-care and Carers Support</td>
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<tr>
<td>ILS Liaison &amp; DPAs</td>
<td>Assessment &amp; Referral Services</td>
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<tr>
<td>Primary Liaison Services</td>
<td>Community Specialist Services</td>
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<tr>
<td>Patient and Professional Training Services</td>
<td>2ndry Care Liaison Services</td>
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The discussions with stakeholders unveiled a number of blocks and enablers to the realisation of the BICS concept.

Identified blocks included:

- Profile of continence services with commissioners – broad cross-cutting service that did not feature as a specific priority for change
- PCT providers strongly wished to retain service
- Reticence of PCT staff to move to a social enterprise model
- Current state of flux around commissioning of services
- Impact of recession; public sector cuts and the political impact of a general election in 2010.

Enablers included:

- Strategic fit with policies such as Transforming Community Services, creating Integrated Care Services, the National Care Service, Independent Living Budgets and Personalisation.
- Fit with guidelines and national service frameworks for best practice for continence services
- Strong group of interested stakeholders from a range of sectors representing the continuum of service need and care

We experienced enthusiastic and positive responses from some stakeholders and cautious interest from others. Accessing the necessary financial information from which to derive a business case was difficult and impeded the development of a bid that would deliver all the elements identified. The decision was made to propose a service that could be transformed in stages, allowing for proof of concept through monitoring of the various stages. Among the needs identified for an integrated continence service was that of improved (rather than more) access to meaningful information that empowered patients, their families and carers to benefit from services that were available, either through the NHS or other providers. Representatives from the medical profession were keen to ensure that once patients entered secondary care the professional body was able to direct care. As the infrastructure for Third Sector engagement was already in existence and
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this group had obvious gains, the business case and further funding application focused on the front end of the delivery model, i.e. information services and signposting, advocacy and community drop-in services.

Learning Outcomes

➢ Knowledge of some of primary drivers for integrated continence services
➢ Introduction to social enterprise as a model for service delivery
➢ Understanding of how political and financial implications of service delivery can impact on the model

Co-authors
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MEASURING THE OUTCOMES OF CONTINENCE CARE
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Learning objectives:
As a result of this part of the workshop, participants should be able to:
- Describe a conceptual framework for measuring outcomes.
- Critically appraise an outcome measure.
- Select an outcome measure that best suits their purposes.

What do we need to measure?
Outcomes can be measured at the patient (individual) and service delivery (program) levels. It is important to consider the relationship between these levels of measurement.

Measurement at the Program Level
“A program logic model ... provides a roadmap of your service delivery program, highlighting how it is expected to work, what activities need to come before others, and how desired outcomes are achieved.” (WK Kellogg Foundation Evaluation Handbook, 1998).

The Basic Flow

**Inputs**
This is what we need – staff, facilities, funds, medications, devices, etc.

**Activities**
This is what we will do – actions taken to deliver the treatments and services

**Outputs**
This is what we will deliver – patients treated, patients receiving services (countable)

**Outcomes**
These are the results we expect – derived from the delivery of outputs to patients

**Impacts**
This is the ultimate goal behind the outcomes – Community health, population health

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Outcomes over Time

**Immediate**
- Attitude
- Knowledge
- Prescription
- Device

**Intermediate**
- Targets
- Short Term Goals
- Satisfaction
- Self-efficacy

**Long Term**
- Pop health
- Trends
- New Levels
- Final Results

% of treated patients with positive outcomes ➔ % of targeted patients treated each year ➔ % decrease in doctor visits for continence problems

Strategic Impact: The agency is able to expand the scope of its services

Rules for Good Metrics

1. **Relevant**
   - Does the measurement fit with the performance objective?

   **Objective:** At least 75% of treated patients report good HRQoL
   **Measure:** Reliable and valid measure of HRQoL

2. **Measurable**
   - Can you collect the data and report a measurement that makes sense?

3. **Actionable**
   - Can you act on the measurement in a timely way to correct and improve what is happening?
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Describing Performance

**Numeric**
- Easy to Measure and Report
- May not be very insightful in understanding performance
- Commonly used for inputs and outputs

**Percentages**
- Relatively easy to Measure and Report
- More insightful in understanding performance
- Used for inputs, outputs, and outcomes

**Ratios**
- Relatively easy to Measure and Report
- Very meaningful and useful for comparative benchmarking
- Used for inputs, outputs, and outcomes

**Examples:**
- # of clinical staff
- # of patients treated
- # of prescriptions
- % of time spent on direct care
- % of patients who improved
- Ratio of patients treated to pop. with continence difficulties
- Average treatment cost per patient

*Measurement at the Patient Level*

Despite common misconceptions that UI is inevitable and untreatable, studies have shown that in approximately 70% of patients, UI can be either resolved or improved (Swanson et al., 2002). The evolution of treatment options over the past few decades has resulted in the development of various conservative, pharmacological, surgical and technological treatments. With alternatives comes a responsibility to assess the efficacy and success of the various treatments. There is need to balance scientific rigour with clinical relevance (Tannenbaum & Corcos, 2008).

**Outcomes of interest in continence care:**

"The historical focus on the technical aspects of devices without evaluation of user experiences and the belief that technology benefits must be obvious and easily observable have contributed to a lack of relevant outcome measures" (Fuhrer et al., 2003).

The numerous effects of urinary incontinence on a person’s psychological and social wellbeing make it challenging to measure the relative success of a particular treatment. For example, it is prudent to ask oneself if reducing the number of leakage episodes constitute a better treatment success than a client’s own perception of dryness. The former is an objective measure, acquired by using a pad weight test (for example), while the latter is a subjective measure. Unlike objective measures, subjective questionnaires are highly versatile in their production and administration. But versatility raises concerns about accuracy. In order to eliminate bias, questions such as “who should ask the questions”, “to whom questions should be asked”, “what questions should be asked” and “when should they be asked” need to be considered when determining the efficiency of a questionnaire (Baseman & Lemack, 2001). A combination of both subjective and objective measures is most likely the best way to assess the efficacy and effectiveness of UI treatments.
## Outcome Vantages (Perspectives)

<table>
<thead>
<tr>
<th>Effectiveness</th>
<th>Social Significance</th>
<th>Subjective Well-being</th>
</tr>
</thead>
</table>
| 1ICF Functioning  
2Body Functions  
3e.g., Psychological Functioning  
4(objectively assessed)  
5Activities and Participation | 3Caregiving  
4Amount of supervision (vigilance)  
5Level of assistance from others | 3Psychological Functioning  
4(subjectively assessed)  
5Psychosocial impact of device |
| 1ICF Contextual Factors  
2Environmental Factors  
3Facilitators  
4Barriers | 3Cost  
4Service sector  
5ADT user and family  
6Other sectors | 3Quality of life  
4Activities  
5Participation |
| User Longevity | 3Residential Care Placement  
4Home vs. Long-term care/ Nursing home | 3Satisfaction  
4Device satisfaction  
5Life satisfaction  
6Satisfaction with care giving |
| | 3Service Utilization  
4Hospital readmission  
5Doctor & other health professional visits | |
| | 3Device utilization  
4Frequency of use  
5Duration of use  
6Manner of use  
7Rate of use | |

Note: 1Part; 2Component; 3Domain; 4Category

Outcome measurement tools designed specifically for continence/incontinence:
- Bristol Female Lower Urinary Tract Symptoms Questionnaire
- Geriatric Self-Efficacy Index for Urinary Incontinence (GSE-U1)
- Incontinence Impact Questionnaire (IIQ-7)
- Incontinence Outcome Questionnaire
- Incontinence Quality of Life Questionnaire (i-QOL)
- International Consultation of Incontinence Questionnaire Urinary Incontinence Short Form (ICIQ-UI-SF)
- Kings Health Questionnaire
- Male Urinary Symptom Impact Questionnaire (MUSIQ) and Male Urogenital Distress Inventory (MUDI)
- Urogenital Distress Inventory (UDI-6)
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Psychometric evaluation of outcome measures – a case example

**Incontinence Impact Questionnaire (IIQ)**

The IIQ consists of 30 questions that assess the following 4 domains: physical activity, travel, social relationships, and emotional health. The IIQ was developed by Shumaker et al. in 1998 and is still commonly used today to assess the impact of urinary incontinence on activities and emotions in women.

<table>
<thead>
<tr>
<th>Appropriateness</th>
<th>• Data suggests that the IIQ is better able to differentiate among UI patient groups, and is more highly correlated with measures of condition severity, than the generic measure.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reliability</td>
<td>• <em>Internal consistency</em>: Shumaker et al. analyzed Cronbach’s alpha coefficients for each subscale: Physical Activity ($\alpha=0.87$), Travel ($\alpha=0.87$), Social ($\alpha=0.90$), and Emotional ($\alpha=0.90$). Harvey et al. reported a Cronbach score of $\alpha=0.95$ adding that items had low to moderate correlation with each other ($0.24-0.66$).</td>
</tr>
<tr>
<td></td>
<td>• <em>Test-retest</em>: Wyman et al. using similar scales reported values in the range of 0.52-0.70 and a total score correlating 0.71, with a one week interval between tests.</td>
</tr>
<tr>
<td>Validity</td>
<td>• <em>Construct validity (convergent)</em>: Shumaker et al. extensively correlated IIQ scores with scores on several generic measures, including the RAND 36-item Health Survey, the Centers for Epidemiologic Studies Depression Scale, the Medical Outcomes Study measure of Social Support 1992 and the Profile of Mood States. Scores were found to be statistically significant ($p &lt; 0.05$ or below) on all but one of the 15 correlations. Correlations ranged from 0.37 to 0.52 (mean = 0.37). Moderate correlations with the generic instruments indicate that the IIQ measures more than general health status.</td>
</tr>
<tr>
<td></td>
<td>• <em>Construct validity (convergent)</em>: Shumaker et al. reported further comparisons between the total and subscale scores for the IIQ and several clinical indices of UI severity, including a UI diary and pad tests since they both exhibited high test-retest reliability. The number of incontinent episodes reported in the diary correlated significantly with IIQ total scores (0.32) and all symptom and impact subscales except the Obstructive Discomfort symptom subscale. The pad test results correlated significantly with IIQ total scores (0.27) and all symptoms and impact subscales except the Stress Incontinence symptom subscale. Parallels between the clinical measures with the general health and social variables were minor.</td>
</tr>
<tr>
<td></td>
<td>• <em>Construct validity (divergent)</em>: Minimal correlation between age and IIQ total and subscale scores demonstrates that increasing age would not act as a confounding variable.</td>
</tr>
</tbody>
</table>
|                 | • *Criterion Validity (known groups)*: In a pilot study, 162 patients
were diagnosed by an attending physician who was blind to their responses on the survey. Of the 162 patients, 104 were diagnosed with genuine stress incontinence (GSI), and the remainder with detrusor instability with or without stress incontinence (DI + GSI). Scores from participants in both groups were assessed using two tailed t-tests. In order to do that, t values were converted to

correlations using the formula $r = \frac{t^2}{t^2 + df}^{1/2}$ (t's based on equal within-group variances were used for conversion). The results indicated that the only significant difference was lower scores on the Travel subscale for DI + GSI patients. No significant relationships between the generic health measures and diagnosis were present. The data provided good evidence of the ability of the I1Q to discriminate effectively between known UI clinical groups.

**Responsiveness**
- Women from three clinical studies, regardless of study assignment or treatment group, were required to fill out the I1Q at baseline, then at a 12-week follow-up participant visit. A correlation between the scores at baseline and the scores from the follow up displayed statistically significant changes over the three-month period for all variables except the pad test. The data indicated that the incontinence condition specific measures of the I1Q are responsive to changes in the target population.

**Other Formats**
- I1Q-7- Shorter form consists of 7 items. Validated by correlating scores with long form scores in addition to clinical data.

**Precision**
- Responses are presented based on the degree to which urinary incontinence affects each activity or feeling ranging from 1 = not at all to 4 = greatly.

**Acceptability**
- The strong psychometric qualities of the I1Q in comparison to well validated measures such as the RAND 36-Item Health Survey, explain why it is highly accepted among both patient groups and health care providers. The questionnaire’s high face or content validity generally appeals to the latter group.

**Feasibility**
- The I1Q effectively represents the health related quality of life of the specific patient population and reliably assesses the effects of treatment on their health related quality of life. With the development of the short forms, feasibility has increased, but nevertheless, patients had no difficulty answering either one.

**Conclusions about outcome measures:**
- There are reasonably well researched instruments available which were designed principally to assess the health-related quality of life impact of incontinence symptoms.
- They have not been used consistently or extensively in device effectiveness research.
- Their validity for evaluating the effectiveness (especially the psychosocial impact) of assistive devices is unknown.
- None of the measures completely and thoroughly assess stigma.
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Psychosocial impact:
UI has been associated with humiliation and elevated levels of stress (Farage, Miller, Berardesca, & Mailbach, 2008), feelings of powerlessness (Hägglund & Ahlström, 2007), and isolation and depression (Vikstrup, Koke, Burgio, Ouslander, 2005). Psychosocial factors are important but understudied. Placebo treatment of UI in RCTs has resulted in reductions in incontinence episodes ranging from 32% to 65% (Van Leeuwen et al., 2006). In many societies, UI acts as a cultural symbol of frailty, increasing dependency, old age and incompetence (Mitteness & Barker, 1995). In the social imagination, there is a link between incontinence and incompetence.

Van Brakel (2006) recommended that forthcoming measures of stigma incorporate an assessment (ideally in the format of an interview) of five components of health related stigmas:

a) attitudes of members of the community and specific groups (e.g., health care providers) towards people who possess stigmatizing health conditions;
b) discriminatory services and legislation;
c) actual experiences of discrimination (i.e., enacted stigma);
d) fear of discrimination (i.e., felt stigma); and
e) an assessment of internalized stigma, psychosocial issues such as self-esteem and dignity, fear, shame, guilt (i.e., self-stigma).

None of the measures completely and thoroughly assess stigma in the manner proposed by Van Brakel. However, an examination of the stated objectives for each measure reveals that several of the questionnaires address fundamental aspects of UI stigma. For example, several of the questionnaires assess the emotional impacts of UI (e.g., MUDI-MUSIQ, IQOL, Kings Questionnaire, IQ). Clearly, the stigma associated with UI is likely to have emotional impacts. Furthermore, some of the questionnaires focus on the social ramifications of UI (e.g., MUDI-MUSIQ, IQ, IOC-UI-SF, and King’s Questionnaire). Again, stigma is a social construct (i.e., stigma occurs in social settings) thus, the stigma associated with UI is likely to have social impacts.

While several measures address issues that are both pertinent to UI and to the stigmatizing nature of UI, it is our belief that the questionnaire format alone cannot adequately assess the stigma associated with UI in a manner consistent to that proposed by Van Brakel. A combination of subjective and objective measures is most likely the best way to assess the efficacy and effectiveness of UI treatments.

Goal Attainment Scaling (GAS)

- Originally developed in the 1960s as an outcome measure in community mental health services.
- Since that time it has been used with many diagnostic groups including acquired brain injury, the elderly, pediatric learning disability, stroke, and chronic pain.
- In addition, GAS has been used to evaluate client outcomes in generic programs such as occupational therapy services in the community and social work services in a hospital.
- Measures achievement of treatment or intervention goals.
- Can be used with persons with different kinds of treatment issues.
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- Can be used with persons with different numbers of treatment goals.
- Produces a Goal Attainment Score (GAS) which allows you to track progress.

Although there are very few publications on its use, GAS is a promising approach for UI (Milne et al., 2009).

References:


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Other Resources
Flow Charting Tools for Drawing Logic Models:
http://www.rff.com/
http://www.igrafx.com/Products/flowcharter/
http://www.smartdraw.com/exp/dia/home/
http://www.patton-patton.com/
http://www.polarsoftware.com/index.asp

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