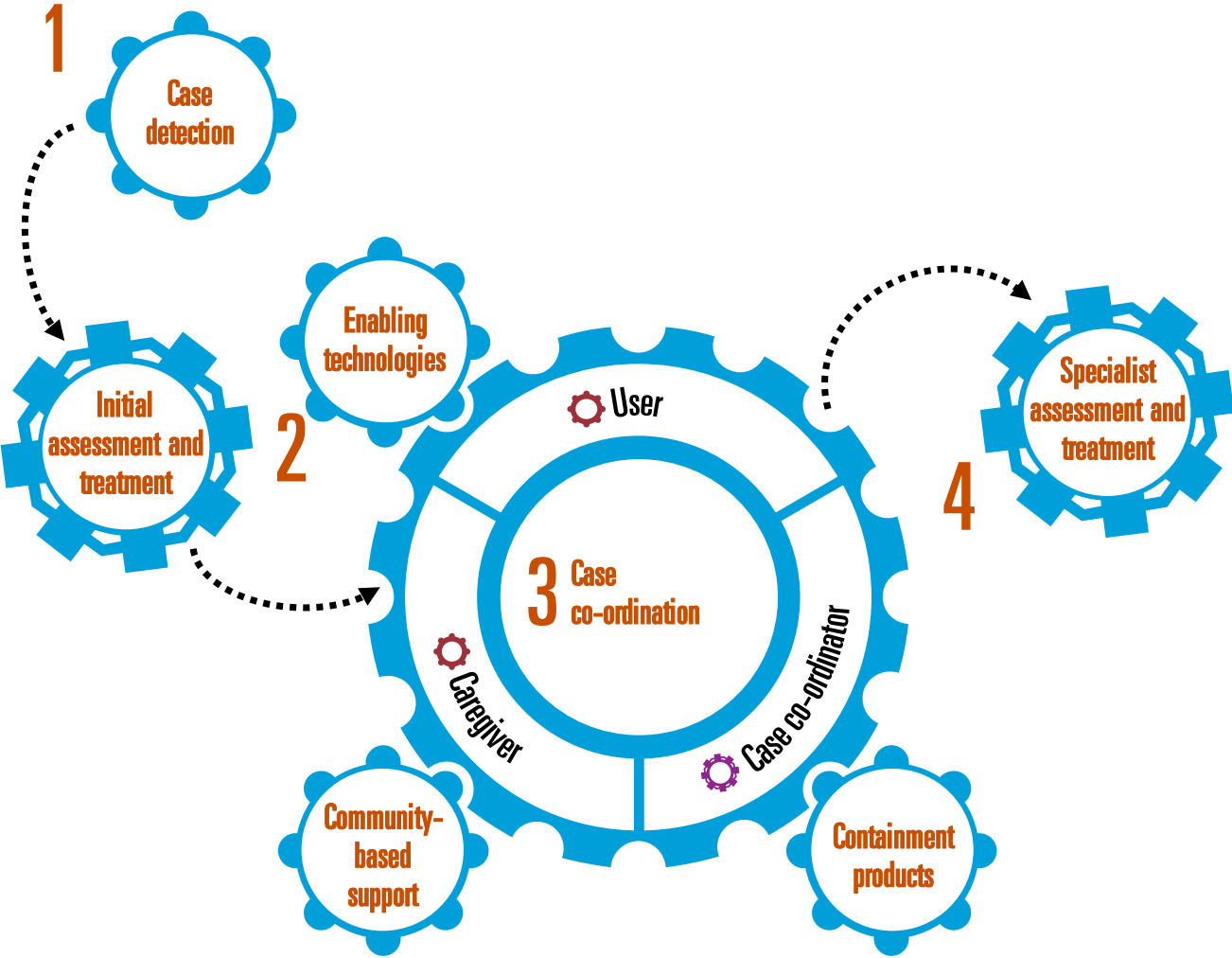


# Summary of Optimum Continence Service Specification

The ideal organisation of care for people with incontinence



## Expert panel

This guide was written by a panel of experts in a variety of fields from across the world:

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## Expert panel statement

This expert panel was convened to consider how we can deliver continence care in a way that can appropriately address the level of suffering and inconvenience experienced by people with incontinence across the world.

It was ambitious to identify a service specification that can be used worldwide: our approach has been to keep to accredited guidance on the creation of service specifications drawn up by the United Kingdom's National Institute for Health and Care Excellence (NICE).

We have placed a priority on achievement of best value for the patient and best value for the commissioner and/or payer of services. This means procuring the optimum healthcare benefit for the cost that the patient and commissioner/payer are willing to take on and implies the need for investing in services in the present, to save costs in the future.

In this summary document we have included the results of a model constructed to assess the expected clinical, quality of life and economic impact of this service specification on people with incontinence, their carers and the healthcare system in the Netherlands.

We intend for this service specification to provide an evidence-based blueprint for payers, providers and clinical professionals on how best to procure, organise and deliver a continence care service. At the very least, this document should provide a useful reference point for discussion and help to promote the issue of incontinence around the world.

## Acknowledgements

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Special thanks to all the interviewees and collaborators who provided input in developing this service specification and validation of the final document.

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## Executive summary

Global demographic, lifestyle and clinical trends suggest the incidence of those suffering from incontinence (both urinary and faecal) is likely to continue to rise sharply in the coming years. In many countries of the world, patient and caregiver expectations of the availability and quality of continence care continue to increase. In parallel, the increased need to constrain health and social care spending has forced payers to reconsider the overall structure and extent of provision in health and social care. Yet, at the organisational level, there is limited evidence to provide guidance to payers and providers about how care might best be configured to deliver cost-effective, evidence-based, and high-quality patient-centred care.

Against this backdrop, an expert professional panel from a wide range of disciplines and geographies was convened. Its aim was to define an 'optimum' service specification for continence care for community-dwelling adults based on best available evidence. Furthermore, given incontinence's global prevalence, the panel aimed to design a specification that was able to take account of local variations in practice, resource and culture. With that in mind, the panel collected and considered evidence from a range of sources including published peer-reviewed journal articles, 'grey' literature and interviews with key opinion leaders, patient groups and payers around the world.

## Key findings

- incontinence is a healthcare issue with significant impact on the lives of both people suffering from incontinence and their caregivers, with serious implications for local health economies in terms of provision of health and social care;
- continence care is not currently a priority for health system administrators; the recent trend is for a reduction in the resources made available to provide continence care;
- where there is evidence, it indicates that the best-performing healthcare services are locally-derived and led by motivated individuals with specific interests and skills;
- basic continence care is often not delivered well by generalist healthcare professionals either in the identification of cases or in the adherence to evidence-based recommendations;
- there is a lack of healthcare professionals trained in continence care, both in terms of generalists with basic training and specialists with more comprehensive training;
- initial assessment and treatment is optimally delivered by a dedicated local nurse-led continence service, situated either in the community or adjacent to a specialist clinic;
- the interaction of health and social care needs in people with continence problems is often overlooked, with significant negative implications for the overall well-being of both sufferer and caregiver;
- the use of containment products is often inconsistent and insensitive to the needs of patients and caregivers;
- there is a lack of emphasis on self-management, which should be used to empower sufferers and reduce costs in the longer term. In particular, advancements in technology have not been used optimally to enhance standard care.

## Key recommendations

Using consensus methodology, the expert group concluded that continence services need to be redefined to improve the identification, assessment and treatment of incontinence. We have therefore presented in this document the essential core components of an effective continence service.

Our key recommendations on how best to deliver these core components are:

- Ensure ease of access by the establishment of robust referral pathways from detection of incontinence through to appropriate assessment and treatment

Cases can be “detected” through a variety of means e.g. self-referral to a primary care physician or incidental discovery during an unrelated hospital admission. Robust referral pathways linking case detection to appropriate assessment and treatment are important to ensure patients receive timely and effective care.

- Shift the responsibility of basic continence care away from primary care physicians to continence nurse specialists in primary care, where available

Where continence nurse specialists are unavailable, train existing healthcare professionals such as primary care-based nurse practitioners, community nurses, physician’s assistants, or, in developing countries, local community healthcare workers, to provide evidence-based continence care;

The quality of continence care provided can be highly variable between different healthcare professionals. The initial visit, clinical assessment, and treatment for a patient with incontinence should be provided by a dedicated nurse-led continence service. Nurses have the requisite training and are capable of managing and treating incontinence more effectively than primary care physicians, while many primary care physicians are unaware of clinical guidelines or find them difficult to adhere to for a variety of reasons. Nurses are also able to triage and manage independently a significant proportion of patients referred for specialist care, and there is evidence that patients appreciate the good communication skills provided by nurses.

- Where possible, use a case co-ordinator to ensure collaborative working, especially to help delay or prevent admission of patients to permanent care settings; given the general trend to more integrated clinical pathways, in particular concerning patients with multiple morbidities, it is necessary to strike a balance between specialisation and holistic case management approaches

Case co-ordination is important for providing ‘patient-centred’ care and ensuring patients do not ‘fall through the gaps’ between providers. A single point of contact for patients is needed to co-ordinate the multiple agencies involved in providing continence care to ensure that all health and social care elements are delivered smoothly and in a timely fashion. These case co-ordinators can improve the quality of care and reduce costs by minimising overlaps in care provision.

- Promote use of self-management tools and techniques; provision of information on the use of containment products; use of enabling technologies; an emphasis on shared decision-making between healthcare provider and patient/caregiver; and educational campaigns on the nature of the illness and treatment strategies

Patients and their caregivers wish to be at least well-informed and prefer to have an active role in treatment decision-making. The case co-ordinator allows for them to discuss their options with a health practitioner who is knowledgeable and available. Training for formal caregivers and advice and information on appropriate containment products for informal and formal caregivers are all also recommended;

- Specialists should be well integrated with other parts of the care pathway. They play a key role in quality governance, training and the dissemination of best practice

It is important that specialists such as urologists, gynaecologists and colorectal surgeons are integrated with other components of the service via the case co-ordinator and through collaboration in developing services. Specialists hold key insights and knowledge that will be

invaluable to other providers in the areas of quality governance, training and dissemination of best practice.

- Use a comprehensive assessment of user, product, and usage-related factors to assess the needs of patients and caregivers with regards to containment products. This process should be standardised, valid and easily reproducible. The final decision regarding choice of product should remain with the end-user: the patient and/or the caregiver

The international standard for the evaluation of containment products (ISO 15621:2011) recommends consideration of factors separated into the categories: user-related, product-related, and usage-related factors.

In the prescription or recommendation of containment products, a standardised assessment should be used to reduce variation in provision and to avoid a narrow focus on absorption or product-related technical factors alone. The needs of each patient can then be reassessed periodically to ensure appropriate consumption of products, avoiding the need for rationing.

- The use of technology should be integral to the delivery of continence care. Technology should enable self-care and connect patients, caregivers and enable providers to monitor progress and troubleshoot problems

Telehealth has been highlighted as an area of underused potential while there are a number of online tools, applications, networks and online support that could be used to benefit patients. Advances in the sophistication of electronic medical records could potentially enhance case detection and evidence-based management and treatment.

- For payers: in order to provide the highest quality continence care, ensure care standards are incentivised. This can be achieved through stipulating the achievement of targets on clinical outcomes rather than operational measures alone, careful use of quality-related financial incentives, and an emphasis on clinical governance

Use of outcome and performance measures can be a powerful motivator for healthcare providers looking to ensure that they are providing the best possible care for patients. We recommend sharing outcomes and performance data in the public domain and reporting of results to internal and external stakeholders including patients, staff, payers, associated services and health system administrators in a timely manner. This should be done in connection with efforts to develop mutually-agreed indicators and improvement measures, on the basis of partnership working. Linking outcome indicators and performance measures to financial incentives could be a powerful lever to improve performance.

- Establish accredited programmes of training for 1) nurses wanting to become continence nurse specialists, and 2) other health or social care professionals such as social workers wishing to improve their competence in delivering continence care

For nurse specialists to play an enhanced role in continence care will require a substantial programme of training of existing nurses even in systems where there are relatively high numbers of continence nurse specialists.

In the short term, in almost all healthcare systems there will need to be a focus on the training of existing healthcare professionals including generalist and specialist physicians, specialist physiotherapists, generalist nurses and existing continence care specialists. There may also be a role for other care professionals with more basic healthcare training such as rural health workers or even related professionals with no healthcare training such as social workers.

## Introduction

Incontinence, whether urinary or faecal, is an under-treated problem that imposes a considerable burden on the quality of life of patients and their caregivers. Whilst incontinence is often a treatable, manageable condition for which national and international treatment guidelines exist, the quality of continence care both at a global level and within national and local boundaries is variable.

There are currently no service specifications for continence services that have been designed for use internationally. This is a serious limitation as most healthcare systems are under severe financial pressure and may not be able to afford the time or resources necessary to design a care service specification, even though such an activity may improve patient outcomes and be, at the very least, cost-neutral. This expert panel has undertaken the ambitious task of detailing an evidence-based service specification for global use that can be developed further to take into account specific local circumstances.

The objective was to create a modular service specification that can be used by any organisation that commissions or pays for the provision of continence care to pick out those service components that they can reasonably expect to procure for their population. The document directs payers and commissioners of healthcare towards the essential components which make up such a service and explains how these service components could vary according to local needs and circumstances.

In order to help payers and commissioners in their decision on whether or not to adopt this service specification we commissioned the Institute for Medical Technology Assessment at the Erasmus University, Rotterdam, to create a model to assess the clinical, quality of life and economic impact of the service specification on a broad range of stakeholders.

We also provide a framework for implementation and monitoring: the aim was not only to provide a blueprint for a high-quality continence service but also to create actionable recommendations for payers and commissioners to deliver such a service 'on the ground'.

## Scope

The expert panel adhered to the following principles when designing the approach to the service specification:

1. Optimum use of resources
2. Equity of access and treatment
3. Patient-centred care
4. Upholding professional standards
5. Strong clinical governance

This specification has also been designed to be sensitive to variables between different healthcare localities including:

- Population demographics and patient characteristics;
- Cultural differences e.g. in healthcare seeking and disease recognition;
- Levels of geographical and financial healthcare access;
- Maturity and development of existing continence care provision;
- Extent to which services are integrated;
- Economic and regulatory levers available to influence health care provision;
- Application of technology in the delivery of care.

It is intended that an organisation commissioning or paying for a continence service in any part of the world will be able to pick out those service components that they can reasonably expect to procure for their population.

Areas of continence care that are not covered in this document include:

- Paediatric care
- Care for people in institutional, long-term or continuing care settings e.g. residential/nursing homes
- Primary prevention

## Impact of incontinence

### Health and quality of life

Urinary incontinence can affect men and women of all ages – including between 30-60% of middle-aged and older women and a significant proportion of men – while up to 10% of adults are affected by faecal incontinence. Both urinary and faecal incontinence can have a major impact on the quality of life of a sufferer and possibly their caregiver. Indeed the development of urinary or faecal incontinence is one of the major triggers for elderly or other dependent patients to move to long-term institutional care.

There are also a number of associated conditions resulting from incontinence including urinary tract infections, depression, falls and skin damage. All of these conditions add to the demand on healthcare services. By dealing with this condition via our recommended integrated approach, resources can be freed up for healthcare services, while the burden of disease and care can be alleviated for patient and caregiver respectively.

### Economic impact

Incontinence presents a significant health and economic burden comparable with major global diseases such as arthritis and pneumonia. There are:

- Direct costs related to health and social care - these may be taken on by the patient or the public payer/health insurer

In 2008-2009, the estimated direct costs of incontinence care in Australia totalled (US) \$1.1bn or approximately \$51 per person and (US) \$3.3.bn in Canada or \$97 per person. In 2000, the total direct health care costs for urinary incontinence alone in the United States were estimated to be \$13.7bn for community-dwelling adults (\$18.6bn in 2013 dollars) or approximately \$51 per person.

- Indirect costs e.g. due to loss of productivity of incontinence sufferers and their caregivers

An Australian study in 2011 calculated productivity costs of sufferers of incontinence of (US) \$30.5bn and those of their unpaid caregivers of \$2.4bn. The indirect costs of incontinence are more than 19 times greater than the direct healthcare costs in this example, and this is before intangible costs are taken into account.

- Intangible costs i.e. the economic value of suffering of both patients and caregivers

The same Australian study mentioned above has estimated the intangible costs or - "burden of disease" to be equivalent to (US)\$ 21.6.4bn annually for community-dwelling individuals in Australia.

The total cost for Australia based on direct, indirect and intangible costs per year was estimated to be (US) \$59.6 billion. The impact of incontinence is large and well worth further investment in providing additional or extended services.



## Why it makes sense to invest in continence services

Although incontinence is rarely life-threatening, the chronic nature of the problem combined with the considerable effect on health and quality of life mean there is a large overall cost to the patient, to caregivers and to society as a whole.

While some studies have concentrated on the cost-effectiveness of services in isolation, there is evidence to show that routinely trying conservative treatments before surgical interventions is likely to be the most cost-effective treatment strategy.

It is important to recognise the indirect and intangible costs of incontinence. Successful delivery of services at a community-based primary care level will likely pay for themselves through the beneficial impact on the independence of sufferers, and the improved well-being and productivity of both patients and their caregivers.



## Current Problems with Service Delivery

### Continence promotion

Continence is a low priority for health system administrators and the resources available are decreasing. Basic levels of continence care are often not delivered well by generalist healthcare professionals either in the identification of cases or in the adherence to the clinical evidence base. In addition, there are low levels of healthcare-seeking in affected people.

In order for a continence service to reach and treat those affected people successfully, a concurrent public health effort will be needed. This requires the problem to be highlighted in the public domain and for its profile to be raised amongst policymakers and health care administrators.

### Over-emphasis on specialised care

Provision is often dictated by imbalances in the level of reimbursement versus the true cost of providing treatment. For example, in the United States, fee-for-service reimbursement has incentivised specialist provision of activities across many common medical conditions: in the case of continence care provision, this results in a bias towards surgical intervention over more conservative treatment strategies, as well as overuse of expensive and often unnecessary investigations such as urodynamic testing.

Offering conservative treatments before surgical interventions is likely to be the most cost-effective treatment strategy. This requires trained healthcare professionals to provide more effective treatment in community-based care.

### No integration between services

The interaction of health and social care needs in continence patients is often overlooked, with significant negative implications for the overall well-being of patient and caregiver. In addition, the use of containment products is both insensitive to the needs of patients and caregivers and inconsistent across individual services. There is a lack of emphasis on self-management, which could be used to empower patients and reduce costs in the longer term. In particular, advancements in technology have not been used optimally to enhance standard care.

Appropriately trained nurses should deal with both patient and caregiver, interacting with all aspects of the patient's care including advising on use of containment products, self-management techniques and dealing with everyday issues from both caregiver and patient. The continence nurse specialist will also liaise with specialists dealing with existing conditions, for example the diabetic nurse or multiple sclerosis nurse as well as specialists involved with the specialist management of lower urinary tract symptoms.



## The components of a high-quality integrated continence service

Taking into account the varying ability of different countries to provide a comprehensive service, the elements of the comprehensive service is broken down into modular components in the service specification, allowing selective use of component parts which may be more practical or feasible to adopt.

### 1. Robust referral pathways from case detection to initial assessment and treatment

Case detection refers to the first point of contact at which a patient reveals their incontinence-related problems to a health care provider. This can be through self-referral to a primary care physician or specialised continence nurse, general history-taking by primary care professional or specialist, incidental discovery by community / hospital nursing staff or through a systematic screening programme. Each route to detection represents a possible entry point into care. Depending on skills and experience, those healthcare professionals who detect cases then either perform the assessment themselves, or refer on for initial assessment and treatment.

Robust referral pathways linking all possible routes of case detection to appropriate assessment and treatment are important to ensure patients receive timely and effective care. A poor initial experience of healthcare-seeking may discourage patients, while reinforcing personal and cultural beliefs that denigrate the status of incontinence as a genuine medical problem. Appropriate referral will depend on adherence to structured referral guidelines/instruments to ensure that the required information is captured and to prompt the referring clinician to try the correct evidence-based approach before referral, or to order necessary tests to support the referral.

### 2. Initial assessment and treatment

This refers to the initial visit, clinical assessment, and treatment for a patient with incontinence. We recommend initial assessment and treatment need not be performed by the case detector. Initial assessment and treatment is optimally delivered by a dedicated local nurse-led continence service, situated in the community or (in some cases) adjacent to a specialist clinic.

Nurses with the requisite training are capable of managing and treating incontinence more effectively than primary care physicians. Many primary care physicians are unaware of clinical guidelines or find them difficult to adhere to for a variety of reasons. Nurses are also able to independently triage and manage a significant proportion of patients referred for specialist care. There is evidence that patients appreciate the good communication skills provided by nurses, hence the recommendation that a continence nurse specialist should deliver basic continence care.

It is worth noting that the majority of evidence for the effectiveness of nurse specialists in continence care originates from the United Kingdom, the United States, the Netherlands, Canada, Australia and Sweden (urotherapist model). We can only recommend this model in countries where nurses have the funding, support and training programmes required to substitute in for physicians. In other countries, it will be necessary to focus on re-educating existing healthcare professionals such as primary care physicians or training other groups, - such as primary care-based nurse practitioners, community nurses, physician's assistants and community healthcare workers- in new roles.

### 3. Case co-ordination

Case co-ordination is important for providing 'patient-centred' care and ensuring patients do not 'fall through the gaps' between providers. The case co-ordinator can accompany the user along the care pathway and across organisational boundaries. A single point of contact can co-ordinate the multiple agencies involved in providing continence care to ensure that all the following are delivered smoothly and in a timely fashion, improving the quality of care and reducing costs by minimising overlaps in provision:

- initial management and investigations;
- specialist care;
- information and advice for patients and caregiver on managing their disease;
- information and advice on appropriate use of containment products; and
- related social care interventions e.g. increased frequency of formal caregiver visits (where available).

#### **4. Self-care and caregiver support**

Patients and their caregivers wish to be at least well-informed and may prefer to have an active role in treatment decision-making. The presence of a case co-ordinator allows discussion of their options with an available and knowledgeable health practitioner. The specification also recommends training for formal caregivers and advice and access to appropriate containment products.

#### **5. Community-based support**

It is vital that providers of community-based support can step in to fill the gaps where the patient is restricted in their ability to look after him/her but there are no informal caregivers to help. The provision of formal caregivers is an important element of sustaining the quality of life and independence of disabled or dependent patients, and will help avoid or delay admissions to institutionalised long-term care.

#### **6. Specialist assessment and treatment**

This refers to the treatment of incontinence by medical specialists - such as urologists, gynaecologists, colorectal surgeons, care of the elderly physicians - and other health care professionals with specialist training such as physiotherapists. Such provision should ideally be separate from those providing the initial assessment and treatment to avoid too much reliance on specialists for more straightforward cases. However it is important that there is integration with other components of the service via the case co-ordinator and collaboration in developing services – specialists should play a key role in clinical governance, training and dissemination of best practice.

#### **7. Use of containment products**

In many countries, patients are underserved by containment product provision that is neither sensitive to clinical need nor wider care needs. The international standard for the evaluation of containment products (ISO 15621:2011) recommends consideration of a number of factors separated into three categories:

- user-related factors: quality of life, independence or assistance, nature of incontinence, end-user characteristics, activities, individual needs, handling products;
- product-related factors: freedom from leakage, freedom from odour leakage, skin health, comfort and fit, discretion;
- usage-related factors: ergonomics, needs of caregivers, information supplied, disposal facilities, laundry facilities, sustainability and environment, product safety, cost.

Where the continence care service also funds the provision of products, a standardised assessment tool should be used to reduce variation in provision. The needs of each patient can then be reassessed periodically to ensure effective, efficient and satisfactory use of products.

In order for patients, formal and informal caregivers to make informed decisions regarding containment products, patients should be provided with information on the ranges of products available and factors to consider when making the choice. This should be supplemented with samples to test the best possible product to suit patient and caregiver needs.

## 8. Enabling technologies as an enhancement to other modes of continence care

Telehealth has been highlighted as an area of underused potential. There are a number of benefits including:

- filling the gaps where resources and manpower are lacking by enhancing self-management and surveillance;
- connecting health care professionals with those that live in a rural area for example via the internet, mobile telephony, video consultation and remote monitoring;
- overcoming the embarrassment and stigma that stops patients visiting the doctor, via email support and facilitated patient networks;
- providing a method by which professionals communicate about their experiences of providing care;

Advances in the sophistication of electronic medical records could potentially enhance case detection and evidence-based management and treatment.

This modular specification caters for variations in both geographical and socio-economic conditions as well patients' own circumstances.



## Key considerations for delivering an integrated continence service

One of the major recommendations presented in this service specification is the introduction of a continence case co-ordinator, ideally a continence nurse specialist. Where available and possible, this healthcare professional should be trained to a high standard to deal with all aspects of continence care. Case co-ordination is important for providing 'patient-centred' care and ensuring patients do not 'fall through the gaps' between different providers or healthcare professionals.

Integrated care models have demonstrated positive outcomes in other chronic diseases. For example, a simple disease management programme for chronic obstructive pulmonary disease (COPD) that involved the use of a COPD case manager has been shown to significantly reduce emergency department visits and hospital admissions.

The absence of a central individual who is purely focused on continence care may result in un-coordinated care with potential for either a lack of communication between different providers, duplication of provision or the responsibility of co-ordinating care remaining with the primary care contact, who may not place a priority on continence care.

Healthcare professionals responsible for initial assessment and management will usually be best placed to perform the role of case co-ordination in patients with incontinence. Nurses with specific training in incontinence are particularly suitable for this role: patients with lower urinary tract symptoms have been shown to express greater satisfaction with nurse-led telephone follow-up consultations rather than clinic visits with the advantages of consistent follow-up with the same healthcare professional, greater convenience, and cost savings.

When the patient is suffering from a complex primary illness, it is important to avoid duplication of care. For example, in the case of a patient with multiple sclerosis, continence care may be one of a number of clinical problems. Similarly, elderly patients will often have a complex array of conditions with associated health and social care needs that require a wider lens than that provided by a continence case co-ordinator. In these circumstances, the case co-ordinator will have to adapt to take a more facilitative and advisory role, filling in the gaps in care and care co-ordination where they exist.

In order to incentivise integrated continence care for the population covered by a payer, we recommend tying payments to a patient experience outcome indicator relating to patient-centred or 'joined-up' care, together with outcome indicators relating to clinical and (for patients and caregivers) quality of life improvements. In the UK, the Quality Outcomes Framework (QOF) uses payments linked to the achievement of certain outcomes. However, since there are many other competing healthcare priorities, continence is not currently included in this framework. Acute hospitals are also incentivised to achieve certain quality outcomes in the UK but these payments, called CQUINs, usually form a relatively small proportion of the overall contract.

In developing regions with an absence of a primary care contact and dedicated nurse-led continence services, there may be inadequate healthcare infrastructure and social care provision to justify a case co-ordinator role in the strictest sense. In these countries, it will be important for providers of initial assessment and treatment to be aware of the wider health and social care needs of the patient and caregiver, and advise on how to make best use of available health and social care services.

## Patient profiles

The expert panel identified four different profiles of patients requiring care for incontinence:

- stress and urgency;
- faecal incontinence;
- neurological;
- elderly/cognitively impaired.

Each profile of patients has its own specific health and social care considerations, including specific clinical guidelines. The patient profiles also vary in their typical requirements for containment products. Below we set out which aspects of the service specification will apply to each profile of patients and show how the service would ensure completeness of care.

### Stress and urgency

This profile of patients consists of two subgroups, stress and urgency. The stress group includes especially those younger and middle-aged women affected by stress incontinence, often during pregnancy and after childbirth. The urgency group refers to patients with urgency incontinence and mixed urinary incontinence. This includes especially those middle-aged women affected by bladder and/or pelvic floor problems and middle-aged and older men with urgency incontinence. These patients tend to suffer from higher volume leakage episodes.

Stress and urgency cases should be detected by the main primary care contact: usually the primary care physician, where they should be referred on to a dedicated nurse-led continence service if available for initial assessment and treatment and case co-ordination. It should also be possible for this profile of patients to self-refer to a dedicated nurse-led continence service.

According to established guidelines, a subgroup of patients will require immediate referral to specialist services. More straightforward cases will undergo initial assessment and treatments including lifestyle/behavioural interventions e.g. dietary modifications, bladder training, pelvic floor muscle exercises. The case co-ordinator will ensure treatment and care is timely and appropriate for the patient's specific needs, and be available throughout to answer any queries regarding their care.

If, following a course of treatment, symptoms do not improve to the satisfaction of the patient, he/she will be referred on to the relevant specialist in alignment with established guidelines.

### Faecal incontinence

This profile of patients includes men and women with faecal incontinence and covers all ages.

Faecally incontinent patients, like those with urinary incontinence will usually be detected by the main primary care contact e.g. primary care physician who will refer on to a dedicated nurse-led continence service for initial assessment and treatment and case co-ordination. Also like stress and urgency patients, faecally-incontinent patients should also have the option of self-referral to a dedicated nurse-led continence service. As per accepted clinical guidelines, patients with 'red flag' symptoms must be referred on to a specialist doctor for immediate investigation.

Initial assessment and treatment can be carried out by the dedicated nurse-led continence service - in the same way as stress and urgency patients while more straightforward cases will undergo initial treatments. The case-co-ordinator's role will also be similar to that in the *stress and urgency* profile.

If, following a course of treatment, symptoms do not improve to the satisfaction of the patient, he/she will be referred on to the relevant specialist. Likewise, patients with a clear indication for surgical evaluation will be transferred into the care of an appropriate specialist.

## Neurological

The neurological group includes patients with a variety of neurological conditions such as multiple sclerosis, motor neurone disease and different forms of paralysis. They can have urgency or sphincter dysfunction with/without faecal incontinence.

In most cases, referral to continence care will be activated by their neurology specialists or specialist neurology nurses e.g. multiple sclerosis nurse specialist. These patients will usually need joint management by the continence specialist physician and nurse specialist. Patients often need evaluation to differentiate neurogenic urinary incontinence from non-neurological pathologies. Most patients with neurogenic urinary incontinence require specialist assessment with urodynamic studies and/or renal tract imaging. Treatment is usually conservative for both urinary and faecal incontinence but may involve surgery for some patients.

## Elderly/cognitively impaired

Elderly/cognitively impaired patients are characterised by functional impairment and/or cognitive problems. Healthy elderly with full, active lives with few care needs should be managed in the same way as stress and urgency patients or faecal incontinence patients. UI and FI in frail older people are each normally a result of the interaction of multiple concurrent risk factors, including age-related physiological changes, multi-morbidity, and polypharmacy. Co-morbid illnesses in the elderly include dementia, Parkinson's disease, diabetes or the effects of complex medication regimens. Elderly/cognitively impaired patients may be affected by urinary or faecal incontinence and often both.

These patients will typically be picked up by a primary care physician or a specialist elderly care physician/ nurse. Case co-ordination in this group is usually best undertaken by a specialist elderly care nurse or other healthcare professional who is experienced in managing the frequently complex mix of health and social care needs of elderly patients. Dedicated nurse-led continence services would play a facilitatory role – providing advice and information for the case co-coordinator on usability of containment products in certain care situations – and will also provide the initial assessment and treatment.

Elderly/cognitively impaired require tailored management and treatment plans according to the effect on patient/caregiver quality of life, the presence of co-morbid illnesses, patient/caregiver expectations and goals, remaining life expectancy, the likelihood of concordance and ability to tolerate treatment. The basis of management may mostly be containment or management of 'contained incontinence': In this state, patients can remain dry with the judicious use of toilet assistance, containment products, behavioural interventions and/or medications. More complex cases or patients who fail initial treatment may require referral for specialist assessment from a surgical specialist, care of the elderly physician or physiotherapist.

### Non-clinical care needs may be mostly met by informal caregivers

These caregivers must be supported to ensure they are able to cope with the burden of caring through:

- distribution of information and advice on the nature of the disease;
- the usability of containment products;
- timely respite care.

Some patients with intractable incontinence superimposed on multiple health and social care needs will be given more intensive formal home care or they or their family/caregiver may decide on a move into a residential care facility. Adequate care planning and the involvement of all relevant stakeholders in related decisions and 'handovers', e.g. from home care to a nursing home, has to be ensured as changes of living environment may have a detrimental impact on this group.



## Application of the service specification in four distinct healthcare systems

### United States

Significant improvement in the state of continence care in the United States will likely require fundamental changes in the healthcare economy to encourage investment in continence services in such a way that reduces the risk of providing continence care. This would necessarily involve greater integration of health and social care, multi-disciplinary working and clearly defined pathways between primary, secondary and tertiary care providers. With the increasing prominence of the accountable care organisations (ACOs) advanced under the recent healthcare reforms, the structure of the healthcare system(s) could be more conducive to making the required improvements.

A concerted public health campaign is required to raise the profile of continence care in the United States. There are a number of patient advocacy groups such as the National Association for Continence, the Simon Foundation for Continence and the International Foundation for Functional Gastrointestinal Disorders seeking to improve patient awareness of services and provide education and advice. Working with such groups will help providers raise awareness of incontinence as a medical problem and encourage healthcare-seeking behaviour. Equally, continence promotion can help raise awareness in primary care providers who are perfectly placed to take on the role of case detection. However, considering the poor track record of primary care to pick up cases of incontinence, open-access services led by nurses with specific training in incontinence may improve the numbers successfully seeking help for incontinence.

The role of community-based support is important but also challenging to implement. Community health workers, who are currently based mainly in rural areas, may be part of the solution. Because of the lack of available healthcare infrastructure these non-medically trained individuals are beginning to be used in diabetes care. Unfortunately, community healthcare workers are not reimbursable for their role in the care of anyone other than those on public health programmes. There do exist rural health clinics and Native American health services that would be potential places to employ community health workers without necessarily requiring healthcare payer funding. These clinics, which are funded by the Federal Government, would employ these individuals and have the freedom to choose how to use them.

The increasing role of Accountable Care Organisations in the U.S. healthcare system should help aid a trend to more integrated care and greater emphasis on more conservative treatments. The Accountable Care Organisation would need to contract with providers in such a way that routes patients with symptoms to a low-cost model that can manage the majority of patients and ensure effective onward referral of more difficult cases. Nurse-led continence services would be well equipped to meet these requirements by:

- co-ordinating care with an informal caregiver, and any other relevant healthcare professional regarding their holistic care needs;
- acting in a facilitatory/advisory role when working with neurologic/care of the elderly/other nurse specialists who have a better understanding of the holistic care needs of the patient;
- providing evidence-based continence care based on a conservative step-wise approach unless there is clear indication for specialist referral;
- making best use of technology to enable self-care and to share information amongst healthcare professionals;
- achieving certain outcome and performance targets. The increasing role of accountable care organisations in the U.S. healthcare system should help aid a trend to more integrated care and greater emphasis on more conservative treatments. The accountable care organisation would need to contract with providers in such a way that routes patients with symptoms to a low-cost model that can manage the majority of patients and ensure effective onward referral of more difficult cases.

Accountable Care Organisations may also find themselves in the useful position of being able to specify requirements for providers to share their datasets and insights from their analyses. This can potentially be used as a platform to perform predictive analytics - to pick out those patients who are most at risk of developing incontinence, and therefore look at ways to redesign the service to detect more elusive cases, and to intervene early in these patients.

In terms of measuring the performance of insurers and providers the Centers for Medicare and Medicaid Services (CMS) has been rating the performance of plans according to 5 priority areas called 'Stars' – one of these Stars is 'improvement in bladder control'. Using these ratings, plans can have their premiums adjusted according to their performance. This is a potentially useful lever to improve the performance of insurers and, through them, providers of continence services or elderly / gynaecological / urological care.

## Netherlands

We recommend that the focus of continence care be shifted to the primary care setting, where we propose that increased numbers of continence care nurse practitioners be located. Because there are currently so few of these nurse practitioners we suggest that existing HBO-level continence nurses receive further training to allow them to practise in the primary care setting and to prescribe containment products and medicines. These nurses would take on the role of providing initial assessment and treatment, while other primary care professionals, community pharmacists and home care agency staff would primarily perform the case detection role.

The primary care-based continence care nurse practitioners would collaborate with primary care physicians to perform the case coordination function and address the wider needs of patient and caregiver. These nurse practitioners carry out physical examinations and are allowed to prescribe containment products and, in future, medicines. A trained continence nurse's expertise will be useful in advising on and prescribing containment products based not just on absorbency criteria but also taking account of user-, product- and usage-related factors. Their nursing training will help them when they liaise with home care agencies to address care needs arising from other morbidities as well as non-medical care needs. In more complex cases they can consult with continence nurse specialists based in secondary care. There are currently few continence care nurse practitioners, but with 350 continence nurses in the field it is likely that a significant proportion would be interested in extending their training to include continence related physical examination and prescribing.

Considering the payers' interest in procuring high quality care, these organisations should have the capability to specify certain aspects of providing a good continence service as in the case of the United States (see above). By ensuring efficient and effective early assessment and conservative approaches before referral to secondary care cost-effectiveness can be ensured over the whole care pathway, helping to lessen resources spent through the inadequate management of patients.

With regards to the use of technology, continence care services in the Netherlands can learn from the success of ParkinsonNet: an innovative IT-enabled network for sharing of best practice amongst healthcare professionals. Other potential uses of technology are recommended and set out in the section entitled "The components of a high-quality integrated continence service".

## United Kingdom

In the UK, there is a need for patients to be seen at the right time by the right professional. There also needs to be better multi-disciplinary working to ensure patient-centred care that maintains patient (and caregiver) quality of life and places a priority on enabling self-care.

There should be less emphasis on care by medical practitioners and more involvement of nurse specialists delivering conservative treatment strategies as part of the initial assessment and treatment component. This is especially important in order to reduce the number of referrals to specialists. As part of the Leicestershire MRC Incontinence Study, nurses were trained to lead a continence service and provide conservative treatments: the outcomes have been shown to be good in the short and medium term, with patients more appreciative of some aspects of care. In view of these all-round skills UK continence nurse specialists would seem particularly well suited to performing the role of case co-ordinator.

Nurse specialism is a well-established concept now in the UK, not least in specialties such as elderly care and neurology (e.g. multiple sclerosis nurse specialist). It will be important to avoid duplication of care, and continence care nurses will need to reinforce the primacy of the role of their counterparts who may have a wider perspective on a patient's care needs, and who therefore should be the key interface between the patient, caregiver, social care and medical specialist (e.g. neurologist).

In those areas where there is no dedicated nurse-led continence service, primary care physicians need in the meantime to be better trained to deal with continence problems including initial assessment and treatment, patient education and appropriate referrals to specialist doctors and/or physiotherapists for specialist assessment and treatment.

There also needs to be greater awareness of local services. The saturation of local services may help to drive the case for further investment in continence care, which will in turn increase availability of services and reduce the level of unmet need. This can potentially be achieved through more co-ordinated working with patient advocacy organisations and 'third sector' organisations dedicated to incontinence, women's health issues or care for the elderly.

CQUINs (Commissioning for Quality and Innovation incentive payments) could be agreed locally between commissioner and provider to set targets for the quality of care according to specified outcomes including reduction in admissions related to incontinence and the reduction in the prevalence of in-dwelling catheters. While it is unlikely that continence care will be included in the Quality and Outcomes Framework in the near future, clearly linking the achievement of continence-related quality outcomes to payment could provide a huge boost to the profile of continence care amongst primary care physicians in the UK. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are likely to become increasingly important in the measurement of service quality in the UK: performance incentives could be usefully linked to these measures.

The clinical audit tool published with the most recent UK National Institute for Health and Care Excellence (NICE) guidelines for urinary incontinence for women [98] could be usefully deployed to monitor clinical practice against the guidelines.

## India

Owing to the current limited provision of continence care in India and 'bare bones' healthcare infrastructure across large swathes of the country, the combination of challenges is significantly different compared with the other country examples.

There is a need to train a new cadre of staff to improve access. Targeted training in continence care will be necessary for a variety of healthcare professionals. Owing to the lack of qualified nurses and the lack of precedent for nurses to provide care in substitution of doctors, the nurse specialist model is not viable. In India, nurses work under the supervision of the doctor and have limited scope for more autonomous roles. Training MBBS (degree-educated) doctors to provide basic treatment will improve adherence to evidence-based clinical guidelines and will also be helpful in bringing continence care to the forefront of the minds of physicians. However, even an increased emphasis on training existing healthcare professionals will be extremely challenging given the competing priorities on physicians' time in India's underdeveloped healthcare system.

An alternative will be to train willing community healthcare workers (i.e. healthcare workers with no formal qualifications) in the basic knowledge and practice of continence care. These trained community healthcare workers will be expected to provide the knowledge and insight required to help patients to self-care, without the benefit of scarcely available tests and investigations i.e. to some extent they will be providing the initial assessment and treatment component. These trained community healthcare workers will also be expected to identify those patients who would benefit from specialist assessment and treatment, which would usually require patients to travel to urban areas for the majority of the Indian population that lives in rural areas. It may be that the most effective way to train local community healthcare workers will be via the creation of satellite clinics run by teaching hospitals. Periodic exposure of these workers to specialists may help to disseminate basic continence care best practice amongst peers in neighbouring areas. While case co-ordination may not be a realistic component in India, it will be important that healthcare professionals providing

continence care communicate effectively with patients and caregivers alike to give the best chance of treatment concordance and best treatment solutions to address the holistic needs of the patient.

A further option is to use practitioners of alternative medicine. These practitioners constitute an existing infrastructure with good access to patients, and they could potentially be trained to perform case detection and a basic initial assessment and treatment.

Awareness amongst sufferers of the presence of continence care services is an important factor: there needs to be a push to raise societal awareness of incontinence as a medical problem and to remove the stigma associated with this condition in India. This potentially requires an aggressive promotion campaign over a significant period of time, in order to raise the issue with the public, patients, healthcare professionals and health system administrators. One of the biggest barriers to overcome will be to spread the message across to people in non-urban areas who are not easily reached.

Affordability must also be enhanced by providing national insurance cover. Public hospitals can help improve outcomes by increasing access in rural areas. However, most doctors prefer to be in urban localities. The provision of containment products is a key issue, as this represents a significant cost to patients when purchased. It is particularly important to provide effective containment products to those who use their own clothes for this purpose. These patients may be particularly socially restricted with profound effects on quality of life.

The use of technology is an untapped avenue of opportunity for augmenting continence care. While most Indians will not have access to the internet nor to smart mobile telephones, many will have access to simpler mobile technology. Technology to improve prevention, surveillance, self-management and compliance is well-established in developing countries, particularly in parts of Africa.



## Economic assessment of implementing the Optimum Continence Service Specification in the Netherlands

An economic evaluation was carried out to assess the cost-consequences and health effects of the implementation of the optimum continence service specification. This information is very relevant for decision makers such as governmental agencies, health care insurers and hospitals, but it is always context specific, as the assessment depends on the type of healthcare system in a country, what care is provided and how it is delivered.

A number of factors lay behind the choice of the Netherlands for an assessment of the economic impact of implementing the service specification. Its social health insurance model is similar to a number of other health systems in Europe, including those of Germany and France. But in contrast to those countries economic evaluation plays a significant part in Dutch health care decision making, for example with new medical technologies routinely being assessed for cost effectiveness before adoption. A significant body of health economic expertise therefore exists in Dutch universities which could be drawn on to conduct this economic evaluation. Furthermore, the Dutch health care system is currently undergoing significant transition and it was considered timely to provide health insurers and providers with an assessment of the economic implications of the service specification at a time when they are looking at ways to improve service delivery while reducing costs.

Given the large heterogeneity between the four profiles of patients requiring care for incontinence, one profile was selected for the purposes of testing the service specification, i.e. *elderly/cognitively impaired*. This population was deemed to have a greater unmet need than patients in the *stress and urgency* urinary incontinence profile. In addition, this population is expected to increase further in the next decade. However, various definitions of elderly/cognitive impaired exist, all of them multi-dimensional in that they include physical, social and mental dimensions. Thus, it would not be possible to find these patients in the sources from which data needed to be obtained for the economic evaluation, for example GP databases and national statistics. Instead the current evaluation has been based on a group of patients which can be specified precisely for the purposes of data extraction and which correspond to the profile of interest, namely patients who are 65 years or older, and have been diagnosed with four or more co-morbidities.

Healthy elderly with full, active lives with few care needs should be managed in the same way as younger patients with *stress and urgency* urinary incontinence or *faecal incontinence* patients. UI and FI in *elderly/cognitive impaired* are normally a result of the interaction of multiple concurrent risk factors, including age-related physiological changes, multi-morbidity, and polypharmacy (Wagg et al, 2013). Co-morbid illnesses in the elderly include dementia, Parkinson's disease, diabetes, COPD, cardio-vascular disease and the effects of complex medication regimens.

To calculate the cost-effectiveness of the implementation of the service specification, a decision analytic model was developed. The aim of the model was to calculate from a societal perspective the total costs and health benefits of the current standard of care (current care) for incontinence compared with an alternative standard of care approach which incorporates the optimum continence service specification (new care). The calculations for costs and health benefits were limited to a time frame of 3 years. The model was also used to perform a 3-year budget impact analysis.

The structure of the model was developed to reflect the entire care pathway for incontinence care in the Netherlands. All possible care pathways were identified by means of a series of interviews conducted with clinical experts. The care pathway begins with the detection phase, where patients can be detected by a primary general practitioner or never be detected and remain incontinent. Patients that are never detected remain in this category for the entire duration of the model. All patients that are detected for incontinence continue on to the assessment/diagnosis phase where the type and severity of incontinence is assessed. They then move to the treatment phase where they are followed for 3 years, moving between three possible health states: 1) incontinent, where patients experience less than 50% fewer incontinence episodes; 2) improvement, where patients experience at least 50% fewer incontinence episodes; and 3) success, where patients experience 100% fewer incontinence episodes.

The probability of moving between health states in the treatment phase is dependent on the type of care a patient receives: 1) active treatment for cure alongside treatment for containment; 2) treatment for containment; and 3) self-care where the patient is neither actively treated for cure nor treated for containment.

In the active treatment pathway, all patients are initially treated by the general practitioner who may subsequently refer patients for physiotherapy or specialist care for treatment.

Patients that enter the care pathways for treatment by containment only and self-care are assumed to remain incontinent. The only difference between these two care pathways is that the costs of pad use for patients treated by containment are reimbursed by the health insurer, thus representing costs borne by the health care system. The costs of pad use in the self-care pathway, however, are assumed to be borne by the patient and are included as out-of-pocket costs.

Besides costs of medical treatment and containment, the model also includes costs of incontinence-related adverse events, formal home care, informal care and travel costs.

Effects are expressed in quality-adjusted life years (QALYs), where a quality of life weight is given to each of the 3 health states defined.

Data for estimating the patient flow, probability of improvement or success, costs and quality of life were taken from published literature where possible, otherwise expert opinion was sought.

The model structure and patient flow is essentially the same for the usual care and new care. However, in the new care strategy, the nurse practitioner (NP) is assumed to be active in finding patients who are incontinent, thus increasing the detection rate. Also, instead of having an initial consultation with a GP patients now start with a consultation with the NP, who will either decide that patients will only receive containment or that they may start treatment for cure. In the latter case, the NP will have 3 follow-up consultations that are used for training and life-style advice. After that, the NP may refer patients to the physiotherapist and the specialist. We have assumed that from then on, the pathway is the same as in the current care strategy. The new care strategy includes an additional cost item pertaining to implementation, defined as the costs to train 500 nurse practitioners calculated on the basis of 4000 GP locations in the Netherlands with 1 NP visiting 8 locations per week.

The results of the analysis show that the new care strategy is cost-saving compared with usual care over the three year model time frame, with average savings of €313 per patient from a societal perspective. When the perspective is limited to the payer perspective, an average cost saving of €38 per patient is achieved. At the same time, a small gain in quality of life is achieved.

Mean costs and health benefits per patient	New care	Usual care	Incremental
Total QALYs:	2.481	2.477	0.004
<b>Total costs:</b>			
Societal perspective	€ 33,414	€ 33,727	- € 313
Health care payer perspective	€ 22,073	€ 22,111	- € 38

Improved outcomes result from the NP care increasing the percentage of successfully treated and improved patients, thus reducing the costs of formal home care, informal care and containment products. For new (incident) patients the NP care reduces the rate of referral to physiotherapy and specialist care and thus a reduction of these costs. This is partially offset by a small increase in the health care costs of higher rates of treatment resulting from improved detection of existing (prevalent) incontinent patients.

In addition to the per patient analysis, we looked at the impact of the optimum continence service specification on a national level, by estimating the budget impact. Over a 3 year period, the total savings would amount to € 14 million from a payer perspective and to € 106 million from a societal perspective.

	New care	Usual care	Incremental
Societal perspective	€ 11,179 M	€ 11,285 M	- € 106 M
Health care payer perspective	€ 7,384 M	€ 7,398 M	- € 14 M

Since many of the model input parameters are uncertain, we have assessed how the outcomes change when other input values are used. The most influential parameter was the percentage of patients that remain undetected in the current care pathway but is detected by the NP. However, even if no new patients are detected, the new care strategy is still cost saving from a societal perspective. Also of great importance is the success rate of treatment by the NP, and to a lesser extent the reduction in formal home care that may be achieved once a patient becomes continent. But again, even if these estimates are at their lowest value, we still find small cost savings.

Input parameter	Base value	Range applied (± 100%)	Lower value range		Upper value range	
			Incremental costs (societal)	Incremental QALYs	Incremental costs (societal)	Incremental QALYs
% additionally detected by NP	14%	0% - 28%	-60	0.001	-566	0.007
% improvement with NP	21%	0% - 42%	-285	0.003	-341	0.004
% success with NP	31%	0% - 62%	-71	0.002	-555	0.006
% improvement with PFMT in new care	37%	0% - 74%	-295	0.004	-327	0.004
Cost of implementing new care per year <sup>†</sup>	€ 172,032	€0 - €1,792,000	-315	0.004	-298	0.004
Cost of NP per hour	€ 41.39	€0 - € 82.78	-336	0.004	-290	0.004
% reduction home care when success	25%	0%-50%	-155	0.004	-471	0.004
% reduction informal care when success	25%	0%-50%	-234	0.004	-393	0.004

<sup>†</sup> Since the population assessed here (elderly with 4 or more comorbidities and urinary incontinence), is 9.6% of all urinary and faecal patients in the Netherlands, we used this fraction of the implementation costs in our base case analysis. The upper limit is based on a conservative assumption that all implementation costs are assigned to the current population.

From the above it may be concluded that it is very likely that introduction of a nurse practitioner specialised in continence care in GP practices will lead to overall cost savings, both from a payer perspective and from a societal perspective. The total budget savings may even increase as the population ages. At the same time, the current study has also shown that there are various areas of the care process for incontinence that lack data, and it would be of great value if the incontinence nurse practitioners are introduced in a study setting. This would also allow the assessment of the benefits of the NP as coordinator of incontinence care, and the improvements that can be achieved by the NP in management of faecal incontinence, as these elements were not quantified in the current assessment due to lack of data.

It is important to realise that the current results are specific for the Netherlands, where GPs function as gate keepers to specialist care and thus play a key role in the treatment of incontinence. It is likely that in countries where specialists play a more important role in patient care, other treatment pathways will need to be defined and the proportion of patients treated by GPs, specialists and physiotherapists may differ, resulting in different costs, and potentially also different outcomes. This also means that the best person to take on the coordinating role may vary between countries, which would in turn affect both the additional costs and the effects of implementing the changes recommended by the optimum continence service specification.

## Implementation considerations

Providing a truly integrated service for continence care will likely require development of a range of areas across a healthcare system. There will be implications locally, regionally and nationally for:

**Training and education of current healthcare professionals:** for nurse specialists to play a more prominent role in continence care will require a substantial programme of training of existing nurses even in systems which have relatively high numbers of continence nurse specialists. In particular we recommend the establishment of a certificate in continence care nursing to provide assurance on quality of practice of new and existing continence nurse specialists. Such a training programme will require substantial investment on the part of those organisations responsible for professional training and will likely take several years to bring continence nurse specialist numbers to the required level. A significant part of training will necessarily involve “on-the-job” experience, and this will require education institutions working effectively together with provider organisations.

In the short term, in almost all healthcare systems, there will need to be a focus on the training of existing healthcare professionals including a variety of programmes aimed at generalist and specialist physicians, specialist physiotherapists, generalist nurses and existing continence care specialists. We also recommend empowering existing “nursing champions” to help diffuse best practice within existing generalist nurses.

**Workforce planning:** to train sufficient numbers of additional nurses or other appropriate healthcare providers to specialise in continence care in the medium to long term.

**Continence care promotion:** to ensure sufficient healthcare seeking behaviour to produce the health and economic benefits that come from providing a high quality continence care service. Continence care promotion requires a combination of a heightened profile of incontinence as a medical problem, reduction in the stigma of incontinence, and raised awareness of available services. Services need to work together with public health teams and continence advocacy groups to ensure potential benefits of integrated continence care are realised.

**Patient and caregiver involvement:** development of services should involve greater participation of patients and caregivers: to be more sensitive to patient/caregiver needs, capabilities and preferences.

**Payer involvement:** to fund and actively procure the highest quality services for their patients according to our suggested service specification. Payers should use the levers available to design contracts in a way that encourages providers to meet the continence care needs of the population. Depending on the healthcare system there will be many different means to achieve this – including financial risk transfer, pricing more aligned to the real cost of delivering services, use of quality/outcome-related payment incentives, operational performance targets, and regulatory levers.

**Working across health and social care boundaries:** case co-ordination in continence care requires collaboration between providers of health and social care, particularly in those with multiple care needs such as elderly and disabled patients. Such collaborative working will be easier in socialised systems where health and social care providers are funded from the same source, but can be extremely challenging in more fragmented systems. In such situations, health and social care payers may collaborate to contract with specialist “integrator” organisations which can usefully act as “middlemen”, co-ordinating multiple providers while taking on the risk and administrative burden from payers to secure optimal healthcare outcomes for the population.

**Provision of containment products:** to ensure availability of the correct products and to uphold the principle of patient choice we recommend segmenting patients as per our patient profile categories when making provision for containment products. For more unusual requests and personal preferences it may be necessary to use a system of ‘top-up possibility’ per patient to supplement the general package provided by the service. The solution provided should ensure the best possible solution in terms of effectiveness, efficiency and satisfaction for patient and caregiver.

**Case coordinator:** it is important to make an agreement between health care professionals within a country health care system as to who in the majority of cases should take the case coordinator role. It may be any one of a range of professionals in a country as long as it is clearly agreed who takes on the case coordination role according to the patient profile.



**Data collection:** to ensure outcomes data and performance measures are reliably recorded for the purposes of monitoring and evaluating continence services.

Provision of the highest quality integrated continence services at reasonable cost may require fundamental changes in the healthcare economy that go beyond the scope of this document. These will involve a combination of changes to resource allocation, payment systems, regulatory codes and professional practices.



## Checklist for payers

Below is a table of variables that will be useful to consider when configuring a continence service for any particular locality or geographical area. Your answers to these questions will have implications for the way your service can be structured and delivered – as described in the third column.

Variable	Question(s) to consider	Effect on continence service configuration
<b>Physical access</b>	How close and how easy is it for a patient to travel to access continence care services?	Geographical location Required mobility / flexibility of practitioners
<b>Financial access</b>	How many patients are able to afford continence care? How many patients are covered for continence care under their insurance plan or can access free (usually state-provided) care or can “top-up” with little or moderate expense?	Size and range of available services, and options for level of coverage.
<b>Volume and quality of available services</b>	How many qualified healthcare practitioners provide initial assessment and treatment? And specialist services?	Size and range of available services
	What is the level of training / competency of these healthcare practitioners?	Ability to provide comprehensive service from basic care to more specialist care
<b>Level of integration</b>	To what extent do the available health and social care services work together? To what extent is the available healthcare “patient-centred” and delivered by multi-disciplinary teams? How can emergency department attendances and hospital admissions be avoided by providing more adequate services in the community? How can patients/users and their informal caregivers be supported in the community to avoid transfers to residential care?	Integration of services Internal communication systems/processes Provision of containment products that promotes independence from informal or formal care delivered by others
<b>Cultural factors</b>	Is incontinence recognised as a medical issue? (By healthcare professionals as well as wider society)	Level of service and healthcare promotion required
	To what extent do patients / those suffering from incontinence have a preference for self-managing their incontinence?	Size of available services (provision of services providing conservative treatments usually relies on patient engagement)
<b>Use of technology</b>	What is the maturity of technological development and patient willingness to use available technologies?	Extent to which services / elements of services are delivered remotely (online, via mobile)

## Measuring quality and service performance

The expert panel places a priority on procuring best value for the patient and best value for the commissioner or payer of services. This will require procuring the optimal healthcare benefit for the cost that the country health and social care administration/commissioner/payer is willing to take on.

It is important to decide which healthcare benefits ought to be considered a 'required outcome' from the service provided as these can be used to judge the effectiveness of a service.

There are several areas of outcome indicators that we would recommend to focus on in order to measure the quality of care:

- symptom relief: e.g. episodes of leakage, nocturia, urgency;
- clinical safety e.g. reduction in rate of complications such as falls, UTIs, skin damage;
- reduction in effect on quality of life for patients and caregivers e.g. improvement in EQ-5D score, re-employment rates, recovery to performing same level of activities of daily living;
- patient experience of care e.g. patient rating of communications, treatment outcomes versus expectations/goals, positive emotions and relationships with staff;
- appropriate use of containment products: e.g. freedom of choice, provision based on holistic assessment of patient and caregiver needs, use of a standardised assessment tool, availability of individual patient-level product testing/sampling.

We recommend regular systematic clinical audits to ensure the adherence of clinical care to evidence-based guidelines.

## Measuring quality through use of outcome indicators

There are a number of ways to use outcome indicators to promote the highest quality care. One of the most important is to increase transparency so that patients and payers can see how each service is performing. This is usually a powerful motivator for healthcare professionals looking to ensure that they are providing the best possible care for patients. We recommend sharing outcomes data in the public domain and reporting of results to internal and external stakeholders including patients, staff, payers, associated services and health system administrators. All stakeholders should be enabled to use results to reflect upon interventions and measures for continual improvements. Another way to use outcome indicators is to link financial incentives to the achievement of certain targets e.g. the 85% of patients satisfied with care received, or less than 2% of local hospital admissions associated with incontinence. However, as long as evidence-based outcome indicators in incontinence are rare, it is important not to overburden providers with financial targets as this can distract the attention of healthcare professionals from the task of providing comprehensive evidence-based care on a patient-by-patient basis. It may be appropriate therefore to use financial incentives in a targeted way to encourage pathway compliance rather than using them as an on-going system of monitoring.

## Performance measures

Performance measures are useful to help understand whether a service is functioning well. Certain trends in these indicators may indicate a service that is under strain or uncontrolled. Data need to be discussed and analysed regularly by team members to develop, if appropriate, adequate steering activities to counteract negative trends. Examples of performance measures include:

- proportion of at-risk patients screened;
- ratio of patients per trained staff member;
- number of patients seen, treated and discharged by the appropriate professional at each stage of pathway;
- waiting times for access/treatment;
- total costs of care per patient per year;
- rates of appropriate referrals for specialist investigations e.g. urodynamics, flowmetry studies.

## Glossary

<b>accountable care organisation</b>	(US) healthcare organization characterized by a payment and care delivery model that seeks to tie provider reimbursements to quality metrics and reductions in the total cost of care for an assigned population of patients
<b>advocacy group</b>	organisation promoting patient/carer interests and providing useful education, advice and assistance to patients
<b>advanced nurse practitioner</b>	see 'nurse practitioner'
<b>caregiver</b>	individual (usually friend or family member) providing informal care to another person
<b>clinical guidelines</b>	recommendations on the appropriate treatment and care of people with specific diseases and conditions
<b>community healthcare worker</b>	(especially rural areas of developing countries) individuals with no professional qualifications delivering healthcare to their community
<b>co-morbid</b>	relating to or denoting a medical condition that co-occurs with another
<b>co-payment</b>	a supplementary payment from an individual with health insurance that is always required regardless of coverage in order to purchase certain elements of care
<b>Commissioning for Quality and Innovation (CQUIN)</b>	(England) payment framework enabling payers to reward good practice, by linking a proportion of healthcare providers' income to the achievement of local quality improvement goals
<b>community nurses</b>	individuals providing nursing care in locations outside of the hospital including the patient's home
<b>concordance</b>	extent to which patients complete the treatments prescribed / recommended
<b>conservative management</b>	use of non-invasive treatment strategies e.g. behavioural modifications and pharmaceutical interventions rather than surgery
<b>containment products</b>	products that contain urine or faecal matter e.g. absorbent pads, catheters and sheaths etc.
<b>continence</b>	ability to control bladder or bowel movements
<b>continence nurse specialist</b>	nurses with specialist training in the area of incontinence
<b>enabling technologies</b>	technologies that can enhance care delivery
<b>evidence-based</b>	consistent with the most up-to-date peer-reviewed research
<b>faecal incontinence (FI)</b>	the involuntary loss of liquid or solid stool that is a social or hygienic problem
<b>healthcare professional</b>	individual qualified provider of healthcare
<b>incontinence</b>	involuntary loss of urine or faecal material

<b>institutional care setting</b>	permanent care setting e.g. residential care home, nursing home
<b>multi-disciplinary</b>	describes collaboration of staff from different healthcare professional groups e.g. nursing staff with physiotherapists
<b>National Institute for Health and Care Excellence (NICE)</b>	UK public body that develops and publishes guidance on clinical practice
<b>nurse-led continence service</b>	continence service delivered predominantly by nursing staff rather than physicians
<b>nurse practitioner</b>	a nurse who is qualified to treat certain medical conditions without the direct supervision of a doctor. This may involve taking a medical history, conducting a physical examination, ordering diagnostic tests and prescribing medicines or medical devices. The extent of the role depends on local legislation. In some countries, e.g. the United Kingdom, this role may be referred to as 'Advanced Nurse Practitioner'
<b>outcome indicator</b>	a measure of the outcome of care: e.g. objective measure of health status from a test/investigation, patient-reported well-being, time to recovery
<b>patient</b>	person who has sought healthcare for their incontinence
<b>patient-centred care</b>	organisation of care driven by the health and social care needs of the patient rather than the structures and/or convenience of healthcare providers
<b>Praktijk Ondersteuner Huisartsenzorg (POH)</b>	(Dutch) General Practitioner's assistant, with the responsibility for certain routine tasks such as regular measurement of patients' diabetes markers
<b>primary prevention</b>	prevention of incontinence before the development of symptoms i.e. through identification of known risk factors
<b>provider</b>	organisational entity delivering healthcare
<b>Quality and Outcomes Framework (QOF)</b>	system of performance management and payment of primary care physicians in the National Health Service (NHS) in England, Scotland, Wales and Northern Ireland
<b>referral pathway</b>	established route of referral from one type of care to another e.g. from a provider of initial assessment and treatment to a specialist
<b>self-management</b>	care or treatment that is led by the patient
<b>short messaging service (SMS)</b>	text messaging service component of phone, web, or mobile communication systems
<b>sufferer</b>	person with illness e.g. incontinence
<b>triage</b>	streaming of patients on accessing a service according to level and immediacy of healthcare need
<b>urinary incontinence (UI)</b>	involuntary leakage of urine and the majority of causes can be divided into three types: urgency incontinence, stress incontinence and mixed urinary incontinence
<b>urotherapist</b>	specialised role providing continence care that requires a combination of nursing and physiotherapy training

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