
Report for the New Zealand Continence Association (known as Continence NZ)

Report on Good Practice of Continence Services in New Zealand

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About Sapere Research Group Limited

Sapere Research Group is one of the largest expert consulting firms in Australasia and a leader in provision of independent economic, forensic accounting and public policy services. Sapere provides independent expert testimony, strategic advisory services, data analytics and other advice to Australasia's private sector corporate clients, major law firms, government agencies, and regulatory bodies.

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Executive summary

Purpose and methodology

Continence NZ contracted Sapere Research Group (Sapere) to undertake an independent analysis of the current state of continence services in District Health Boards (DHBs) in New Zealand. The purpose is to profile what is currently happening for service delivery against known good practice and then to make comment on that for the future for New Zealand.

The methodology included:

- a rapid literature scan;
- interviews with key Continence NZ staff;
- independent analysis (via SurveyMonkey) of surveys of DHB services, that were undertaken previously by Continence NZ; and
- a cost-benefit analysis.

Prevalence is under-reported and increasing

The prevalence of incontinence is difficult to estimate as it is widely understood to be highly under-reported. Studies have found that only around one third of people experiencing incontinence seek professional help due to embarrassment and shame, or for other reasons, such as thinking this is ‘normal’ after child birth or with ageing. However it is estimated that in New Zealand 590,000 people have urinary incontinence and 340,000 people have faecal incontinence. The prevalence of incontinence for Māori is understood to be higher (47%). The key risk factors are pregnancy and childbirth, obesity and prostate cancer; followed by diabetes, menopause, urinary infections and chronic illness.

Costs are a considerable burden for the New Zealand health system and individual, families and employers yet many can be avoided over time.

Costs of incontinence are a significant burden to individuals and the health system, as well as society as a whole

In 2011, it was estimated that incontinence costs New Zealand \$8.05 billion per year (7). This figure includes the costs to the health system, the productivity impacts, and the cost of products and formal care. This equates to around \$7,000 per person per year.¹ This does not include the burden of disease, which was estimated at a further \$4.68 billion, or additional financial costs such as the lost taxation revenue and cost of welfare payments for those unable to work.

These costs are projected to increase significantly given the ageing population (7).

¹ Per person aged 15 and over with incontinence.

Key issues include significant variation in access to services and equity of outcome for New Zealanders

Key issues are that, with the current level of investment in continence services in New Zealand, there is a significant burden to:

- people with continence issues; such as embarrassment and loss of dignity, health issues such as impaired skin integrity and urinary tract infections, as well as loss of earnings, cost of product², cleaning / laundry; and
- DHBs who fund the services; such as additional cost of products over and above what would be more cost effective if investment in specialist continence staff was made for a prevention and bladder retraining process and unnecessary hospital admissions and admissions to aged residential care.

The significant variation in how DHBs are providing continence services is causing inequity in access and outcome across the country, and for different parts of the population, e.g., different ages.

Best practice principles are not being met by many

The literature shows that continence issues are prevalent but overall appropriate assessment and treatment is neglected due to a lack of nurse and therapist continence specialists and them not having adequate time or resource to meet patients' needs. There is plenty of information about treatment and management of continence issues, but generally international and local experience indicates fragmented services and gaps in good practice implementation.

Best practice principles include:

- access for all and to specialist continence nurses and specialists;
- an integrated service;
- organisational and clinical leadership;
- focus on prevention;
- encouraging self-management where possible;
- use of evidence based treatments;
- ongoing workforce training and education;
- use of technology e.g., adopting new products and treatments; and
- monitoring and evaluation from service users as to their experience and feedback.

Findings are that overall there are opportunities for significant service improvement, health outcomes and cost savings

Taken together the triangulation of this review inputs suggests that conservative management techniques are not being used as the first port of call, as intended by the service

² E.g., reports of some people not affording products and so using cut up towels and black rubbish bags to try and ensure dryness. There are other reports of people trying to dry and reuse their pads due to non-affordability of purchasing, over and above what is allocated.

specification and recommended by best practice from the literature. Moreover, the gaps in reassessments in some services and lack of change in product range may mean that clients on supply are not being provided with the product or treatment best suited to their needs, as their condition may have changed and new treatments and products may have become available.

'The service for patients is deteriorating with the reduction in continence nurse FTE and increase in patient numbers and acuity. The cost to the health service is huge due to the side effects. e.g., recurrent urinary tract infections (UTIs) and overactive bladders requiring long term medications, admission to hospital due to urosepsis³, fractures from falls rushing to the toilet or chronic faecal impaction. Admission to rest homes as patients/carers cannot cope with incontinence at home.'

Cost benefit analysis shows potential for significant savings

Sapere estimates that an investment of \$4.6 million in an additional 33 staff across DHBs will result in a \$7.3 million saving on incontinence products alone. This could lead to significantly improved quality of life outcomes for people (including reduction in adverse health events), and productivity of people who could participate in employment. These estimates do not include these wider benefits, or the potential savings in terms of reduced hospital or aged residential care admissions.

Conclusions

Based on analysis and findings from the survey analysis, literature scan, interviews and cost benefit analysis, Sapere concludes that:

- there is high variability and inequity in how continence services are delivered across New Zealand; and
- services are in the main not working towards good practice.

This costs:

- the dignity and relationships of people with continence issues, their families and carers, and their financial position (having to pay for additional product as not enough is supplied);
- as well as the health system (product, hospital admissions and aged residential care); and
- there is a further ongoing economic impact from loss of employment or presence at work.

The main barrier appears to be the lack of investment by many DHBs in continence specialist services in terms of:

- resourcing of the right specialist staff (i.e., staff trained in continence issues, prevention, treatment and reversal) and volumes of staff (especially per head of population ratios);

³ Urosepsis is the acute condition of a systemic infection in the blood that develops secondary to a urinary tract infection (UTI), and then circulates throughout the entire body. A lay term for this critical condition is blood poisoning because it is an infection in the bloodstream.

- early investment approaches to prevent deterioration and reverse continence issues (that is variable and in many areas there are long wait times);
- when required, use of the most appropriate product (as opposed to the cheapest product), i.e., it seems mainly funding is based on product cost not patients' clinical need; and
- the volume of product (that is, in some areas people can only access one pad per day when up to four or more might be required).

We note that the NHS guidance recommends one FTE specialist continence practitioner per 100,000 population. From the information available to us for this review, it appears that New Zealand may be some way from meeting this standard, at least in some DHBs. This reflects the evidence in the literature that continence services are frequently a 'neglected' (i.e., poorly resourced) area of health services resourcing.

In summary, we found that there is significant opportunity to improve continence services in New Zealand and in turn save health care dollars, while improving health and wellbeing outcomes and health equity for people and their families and carers.

1. Purpose and methodology

1.1 Purpose is to inform service improvement

Continence NZ contracted Sapere Research Group (Sapere) to undertake an independent analysis of the current provision of continence services in District Health Boards (DHBs) in New Zealand. The purpose is to profile what is happening against good practice and make comment on that for the future.

This report will be used to inform future discussions on how to improve continence services in New Zealand and reduce unnecessary health costs.

1.2 Mixed methods approach

Our methodology included a:

- rapid literature scan;
- independent analysis (via SurveyMonkey) of web-based surveys of DHB services that were previously undertaken by Continence NZ;
- interviews with key Continence NZ staff; and
- cost-benefit analysis.

1.3 Survey data

The survey data covered three separate surveys run over 2014-2016:

- two surveys on nationwide continence services
 - one of these covered all continence services (n=19 respondents);
 - for the other there were three different versions aimed at different providers (nurses, physiotherapists and providers of children's services) (n=46 respondents);
- a survey on the care of women with urinary incontinence (n=18 respondents).

Sapere encountered some issues with the survey methodology and data: there was often only one respondent per DHB, meaning the responses may not be representative of the overall workforce or an accurate portrayal of each service; and some of the responses did not tally with evidence from other sources, including the interviews. We therefore triangulated the survey data with the other qualitative evidence and considered these findings against what we know from the international literature.

We note that the surveys were undertaken up to three years ago and were conducted by Continence NZ. However, with the best intentions, that may not have been seen by respondents as independent enough to give open responses.

We would usually recommend that surveys such as this, where there are sensitive issues (both topic and service level) that it be undertaken by independent evaluators, to encourage participation and full and frank responses.

2. Context

2.1 Prevalence and costs

2.1.1 Incontinence affects around a quarter of all New Zealanders...

It is difficult to accurately estimate the prevalence of incontinence due to the high rates of under-reporting (e.g., from embarrassment, belief that it is 'normal' due to child birth and ageing etc.). The stigma and embarrassment associated with incontinence means as many as two-thirds of people do not report problems with their own or their child's incontinence to a health professional (7).

A 2011 study (7) estimated that urinary and/or faecal incontinence affects around 1.1 million or a quarter of New Zealanders aged 15 years or over.

Urinary incontinence is more prevalent than faecal incontinence (2). Women are far more likely to experience incontinence than men, with common risk factors for urinary incontinence including pregnancy, childbirth and menopause. Other risk factors include diabetes, obesity, prostate cancer, urinary infections and chronic illness (2). Māori are also more likely to experience incontinence (47%).

In addition the prevalence of incontinence increases markedly with age, meaning that with an ageing population, overall prevalence is expected to increase.

2.1.2 ...with significant and wide-reaching impacts

Incontinence has significant impacts, both for those who have it and those in their family, those may who care for them, social networks and employers. The immediate physical impacts include discomfort and odour, cleaning/laundry and using continence products. Incontinence can also lead to secondary problems such as skin infections and integrity issues, pressure injuries and urinary tract infections, which themselves impose impacts on both suffers and costs to the health system (5, 7).

Incontinence can have ramifications for children's schooling, and for adults' productivity and ability to participate in the workplace. It also affects their ability to interact socially – including ability to travel, play sports, and participate in family and community and Church activities – as well as inter-personal relationships, including their sex life. As a result, people with incontinence are more likely to experience social isolation, loss of self-esteem and depression (7), which in turn can add more costs to the health system across a range of areas.

‘There are significant and often devastating impacts on the physical and emotional health of people with incontinence issues. It can be humiliating, restrict activity including schooling, intimate relations and employment options.... Reported rates of child punishment [associated with continence problems] are 20 to 30 per cent with an increased risk of physical abuse’ (5).

In 2011, it was estimated that incontinence costs New Zealand \$8.05 billion per year (7). This figure includes the costs to the health system, the productivity impacts, and the cost of products and formal care. This equates to around \$7,000 per person per year.⁴ This does not include the burden of disease, which was estimated at a further \$4.68 billion, or additional financial costs such as the lost taxation revenue and cost of welfare payments for those unable to work.

These costs are projected to increase significantly given the ageing population (7).

2.2 Good evidence about what works

There is good evidence about how to effectively treat and manage incontinence.

2.2.1 Continence nurse and other practitioners are cost effective

Discussion of the benefit of treatment provided by a continence nurse practitioner (CNP⁵) in continence-related literature includes the following findings and conclusions.

- Conservative treatment by a CNP was the most cost-effective treatment of patients, with fewer incontinence events, lower clinician costs and lower pad usage costs (20).
- Combined lifestyle and behavioural interventions led by CNPs resulted in reduced incontinence events and pad use (17)
- A new service led by CNPs resulted in 59% of individuals with improved symptoms compared with 48% in the standard care group. Patients reporting no symptoms or being 'cured' made up 25% in the CNP-led group, compared with 15% in the standard care group. The improvements were maintained at three and six months, and patient satisfaction was high (18).
- A strategy in the Netherlands, co-locating a CNP in a GP practice, achieved a quality adjusted life years (QALY) gain of 0.005 per patient, while saving €402 per patient over a three year period from a societal perspective. The occurrence of incontinence was reduced, quality of life improved, and costs were reduced (19).
- Treatment by a CNP has a positive effect on the quality of life for women with urinary incontinence (15).
- Providing structured treatment by a CNP resulted in a significant reduction in the mean Female Urinary Symptom Score assessment tool score (16).

⁴ Per person aged 15 and over with incontinence.

⁵ Generally known in New Zealand as Continence Specialist.

2.2.2 Bladder re-training (pelvic floor) least invasive and most cost effective option overall

Conservative treatments such as nurse led, physiotherapy and behavioural treatments are often the most effective and least invasive of all incontinence treatment solutions (8). For example, a 2005 Australian study found that physiotherapy in the form of pelvic floor muscle training can have up to an 80% cure rate of stress incontinence (9).⁶

Other studies show that:

- supervised pelvic floor muscle training should be offered as a first line conservative therapy for women of all ages (Grade of Recommendation: A)⁷
- nurse-led telephone follow-up has a high satisfaction and advantages of consistent follow-up by the same clinician, convenience to the patient, and cost-savings (12);
- nurse-led continence clinics offer improved quality as more patients receive comprehensive assessment, and can cover an increase in referrals without the need for secondary referrals (14); and
- vaginal pessaries have been reported to relieve urge incontinence in over 60% of patients, and are substantially cheaper than surgery, easier on patients, and pose fewer risks (13).

2.3 A neglected area, typified by fragmented services

Despite this evidence, and the availability of best practice guidance, reviews in other jurisdictions have found fragmented services and gaps in implementation (1, 5). For instance, a review of continence services in the UK identified a number of issues, including geographic variability in access and eligibility, and in the delivery of services, and inflexible application of arbitrary rules around the provision of continence products (23).

2.4 Strategic context

The *New Zealand Health Strategy* envisages a society where:

*All New Zealanders live well, stay well, get well, in a system that is people-powered, provides services closer to home, is designed for value and high performance, and works as one team in a smart system.*⁸

This vision provides the basis for the *Healthy Ageing Strategy*.⁹ This strategy describes a context where New Zealand's population is ageing and becoming more ethnically diverse. As older

⁶ From other inputs it is understood this includes lifestyle advice and bladder re-training.

⁷ International Guidelines, 5th International Consultation on Incontinence, Paris, February 2012

⁸ Ministry of Health (2016) *New Zealand Health Strategy: future direction* (New Zealand Government: Wellington, New Zealand), p.13.

⁹ Ministry of Health (2016) *Positive Ageing Strategy* (New Zealand Government: Wellington, New Zealand).

people have higher rates of chronic health conditions and disabilities, this will place increasing pressure on our health system, including continence services. This trend will be exacerbated by the increasing ethnic diversity, due to the inequities in health outcomes experienced by groups including Māori and Pacific people.

The strategy sets out a framework for healthy ageing that focuses on enhancing participation and social connection and ensuring the dignity of older people, including those with long-term illness or disability. Elements include:

- removing barriers to participation;
- supporting capacity-enhancing behaviours and ensuring a dignified late life; and
- preventing chronic conditions/ensuring early detection and control.

A number of principles and objectives of the *Healthy Ageing Strategy* are relevant for this report, including:

- achieving equity for Māori and other population groups with poorer health outcomes;
- staying healthy and active, and independent in old age – including keeping people well-connected, respected and able to participate fully in society;
- reducing unnecessary hospital admissions – including through prevention; and
- detecting long-term conditions at the early stages and treating, rehabilitating and managing them well.

2.5 Service specification

The Ministry of Health has published a mandatory, nationwide description of services for continence education and consumables services, for District Health Boards, which was last updated in 2012.

2.5.1 Service objective

The objective of the service is:

To maximise the Service User's self-management, independence and quality of life to minimise the health complications which could arise from incontinence.

The service specification is clear in its emphasis on prevention and conservative management. According to the service specification, providers will undertake a thorough assessment of each user that covers:

- the physical and psychological effects of incontinence;
- the cause of their incontinence;
- any emerging complications and the need for medical intervention;
- their ability to self-manage; and
- any social circumstances which may impact on their continence or ability to self-manage.

Continence advisors are to utilise a conservative management approach, and to explore the ‘range of treatment options’. If there is no improvement after 3-4 months, they are to provide onward referral where appropriate. The description states that ‘the provision of Continence Consumables, in most cases, is not first line treatment’. Moreover, reassessment of the need for continence products is to be conducted annually.

2.5.2 Access and eligibility

Access to the service is via referral (from a health professional, or medical or surgical specialist) or by self-referral. Eligibility for the service is determined by the degree of incontinence, which in summary includes:

- for children aged between 4 and 10 years old, urinary incontinence of >50ml per day and more than four times per day, and/or a problem with bowel control;
- for people aged over 10, urinary incontinence of at least 400ml over 24 hours and/or a problem with bowel control.

Response times are based on the level of risk, which is to be assessed from the information provided with the referral. The risk assessment framework is provided in Appendix 1 to the service specification. Table 1 details this framework.

Table 1 Referral management process: response times

Urgency for initiation of service provision	Receipt/acknowledgement of referral to the service	Service response
Low risk	Within 10 working days of receipt of referral	Within 8 weeks of receipt of referral according to assessed need
Medium risk	Within 10 working days of receipt of referral	Within 2 weeks of receipt of referral
High risk	Within 8-24 hours of receipt of referral	Within 24 hours of receipt of referral

Source: Ministry of Health, Community Health, Transitional and Support Services - Continence Services Tier Three service specification, November 2012, p.5.

2.5.3 Supply of continence products

The service specification states that continence products are to be supplied as clinically appropriate. Guidelines are provided, and for pads the range is 2-4 per day. However, the specification explains that products are to be supplied at the discretion of the Specialist Continence Nurse and notes that:

There may be occasions when it is appropriate to prescribe more product than is indicated in the guidelines, or when it may be justifiable to prescribe products not included in these guidelines that are listed in the relevant National Product Supply Agreement (Source: Service Specification p.13).

3. Summary of best practice principles

We undertook a rapid literature scan of best practice guidance and models of care for continence services in selected other comparable jurisdictions (focussing on the UK, Canada and Australia). We found some common themes in the literature we located, which is summarised below.

3.1 Principles of care

Some general principles of continence services were evident in the literature, particularly in the NHS guidance. These include:

- **access for all** – a service that is available for people of all ages and needs (including those with disabilities, and both for those residing in their own homes and elsewhere), and includes the ability to self-refer;
- an **integrated** service – with clear referral pathways, and linkages across primary, secondary and tertiary health services, education, social services and the voluntary sector;
- **organisational and clinical leadership** of continence services;
- a focus on **prevention**;
- the use of **self-management** where possible;
- **access to specialist** continence nurses and therapists;
- use of effective, **evidence-based** treatments;
- ongoing workforce **training and education**;
- use of **technology** (e.g., adopting innovative new products and treatments); and
- **monitoring** of service users' experiences and active **evaluation** that incorporates feedback from service users and their carers.

3.2 Practice guidelines

The following broad elements of care are consistent in the international guidance we reviewed:

1. **identification** of continence problem e.g., by way of referral or (for those in e.g., aged residential care facilities) screening.
2. **specialist assessment** of continence problem.
3. **planning** – developing a management and treatment plan.
4. **implementation** of the care plan.
5. **periodic review** of needs and the effectiveness of the care plan (at least annually).

For continence products, the National Health Service (NHS, UK) good practice guidance recommends that:

- pads are only issued after an initial assessment;
- the **full range of products** is available;
- the supply of products should only be **governed by clinical need (arbitrary ceilings on supply are inappropriate)**; and
- needs are **regularly reviewed** (23).

This guidance states that:

It is important to consider cost-effectiveness and quality rather than just products costs. A focus on costs alone is likely to be unsatisfactory, is not conducive to treatment and will discourage companies from being creative and innovative in developing better products (23).

4. Overall findings show significant variation in services

4.1 Summary of findings

The following table compares elements of best practice to what we have heard and learnt about current practice in New Zealand, from this review.

Table 2 Comparison of services against best practice

Element of best practice (international)	NZ findings from this review
Principles	
Access for all	Widespread variation, appear to be gaps in some services
Integrated service	Inconsistent, and often difficult to find, referral pathways and practices
Organisational and clinical leadership	Workforce feel under-resourced and lacking support – service lacks profile
Focus on prevention and self-management	Over-emphasis on ‘low cost’ products instead of conservative management or best patient focus products – reportedly due to stretched clinical resources and DHB financial constraints
Effective, evidence-based treatments	Significant scope to increase use of conservative management techniques and improve quality of life as well as saving health costs over time
Ongoing workforce training and education	Workforce lack paid time to attend training
Use of technology	Product ranges in most services have not changed over time, suggesting potential lack of uptake of new technology and good practice for patient care
Monitoring and evaluation	Insufficient focus – lack of evidence this is occurring

Element of best practice (international)	NZ findings from this review
Practice	
Specialist assessments	Yes but may be time-constrained and significant wait times to get an assessment
Management and treatment plan	Some, but overly focused on least cost products, not patient need-based
Periodic reassessment of client needs – at least annually	Some, though not in all services due to clinical resource constraints
<i>Product supply</i>	
Issued only after initial assessment	Yes
Full range of products available	No – shortages/waiting lists for some products, not best practice products
Supply governed by clinical need	Mostly no, constrained by DHB budgets, e.g., insufficient clinical specialist resource and supply of pads

4.2 Survey shows high degree of variation across DHBs

Overall, we found a high degree of variation across DHBs, much of which does not meet the good practice needs for patients.

Referral practices vary, both in to and from the service, as do follow-up procedures. Some services do not accept self-referrals, even though this is required in the service specification and is recommended best practice.

Criteria for accepting referrals varied – while several survey respondents to the 2014 survey cited the service specification, some stated that the client needed to have a three month history and two stated a six month history requirement. These pose delays in assessment and hence delayed opportunities for conservative treatment, such as bladder re-training.

Timeframes for responding to referrals also varied widely, often well outside the timeframes required by the service specification. Some survey respondents indicated that they do not acknowledge receipt of referral – and we were told that this is often due to a lack of administration staff. We did not manage to locate best practice guidance on response timeframes, but the survey responses are compared to the service specification in the table below.

Table 3 Response timeframes compared to service specification

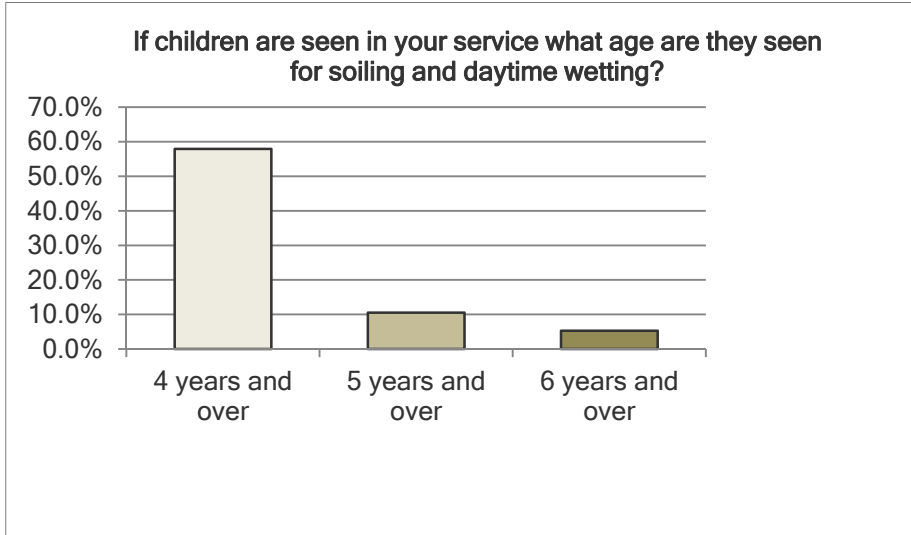
Urgency	Service specification	Survey responses
Low risk	Within 8 weeks of receipt of referral according to assessed need	<ul style="list-style-type: none"> • Nurses: 1– 32 weeks, usually within 6 weeks • Physiotherapists: 1 – 9 months, usually within 3 months • Children’s services: within 3 months • Women’s services: 1 day – 22 weeks
Medium risk	Within 2 weeks of receipt of referral	<ul style="list-style-type: none"> • Nurses: 1 day – 24 weeks, usually within 2 weeks • Physiotherapists: 2 weeks – 9 months, usually within 3 months • Children’s services: 1-3 months • Women’s services: 24 hours – 8 weeks
High risk	Within 24 hours of receipt of referral	<ul style="list-style-type: none"> • Nurses: 1 day – 4 weeks, usually 1-2 days • Physiotherapists: 1 day – 12 weeks, usually within 2 weeks • Children’s services: 1 day – 2 weeks • Women’s services: same day – 6 weeks

Source: Nationwide continence survey 2016

There appear to be some gaps in service provision. While children under the age of four are outside the scope of this specialist service, some survey respondents highlighted that this group were also unable to be seen elsewhere, suggesting a gap in the wider system.

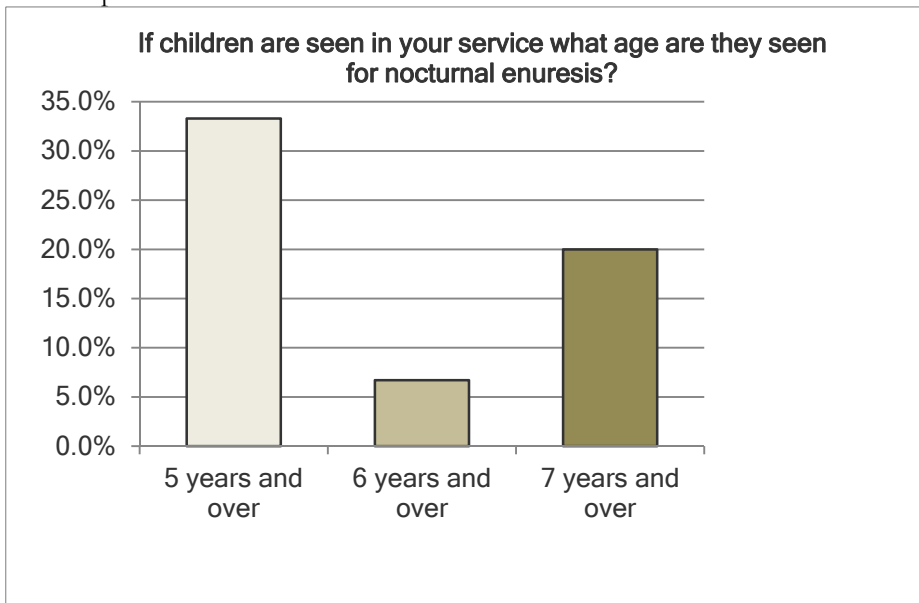
Within children’s services, there seems to be variation in what services are provided and for which age groups (see chart below).

Figure 1 Age at which children are seen for soiling and daytime wetting
n=14 respondents



Source: Nationwide continence survey 2014

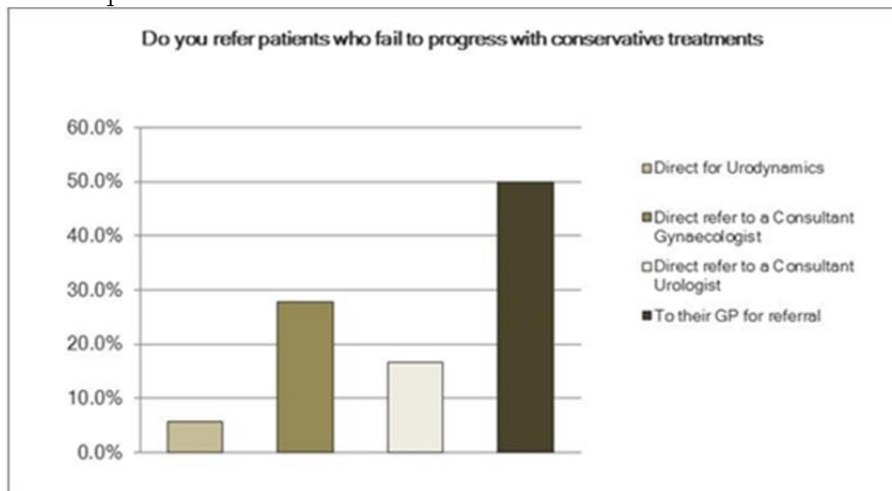
Figure 2 Age at which children are seen for nocturnal enuresis
n= 9 respondents



Source: Nationwide continence survey 2014

Onwards referrals also appear to vary across services. In the survey of women's incontinence services, respondents varied in how they would refer a patient who fails to progress with conservative management treatments (see chart below).

Figure 3 Onwards referrals for women with urinary incontinence
n=17 respondents



Source: Survey of women’s urinary continence services 2016

The best practice literature is clear that services should be available to all ages, and that there should be consistency of services and access. The extent of variation suggested by the evidence we reviewed implies that there are currently equity issues with access to continence services in New Zealand.

4.3 Product supply may be too limited

Survey respondents were asked about the supply of continence products (such as pads or other items). Of those who responded to these questions, most indicated they supply up to four pads in a 24 hour period, depending on the patient and condition. No-one responded that they may provide more than four pads depending on need and clinical judgment, even though there is this flexibility in the service specification and it would be consistent with best practice.

One responded stated that:

‘The current supply of 2-4 pads is not adequate for some patients who have to buy extras - this is impossible on a benefit. I know patients who have gone without food to pay for extra pads. The disability allowance is not enough either as they often have to use this money for other medical essentials. District Nurses doing assessments will often not do a trial of pads so patients may be given the wrong product.’

The majority of respondents to both nationwide surveys indicated that there has been no change in the products allocated¹⁰, or the range of products available. A shortage of enuresis alarms was often highlighted by nurses as an issue. Some respondents noted there is a waiting list for the alarms, and also that funding for enuresis alarms was often provided by donations and charities.

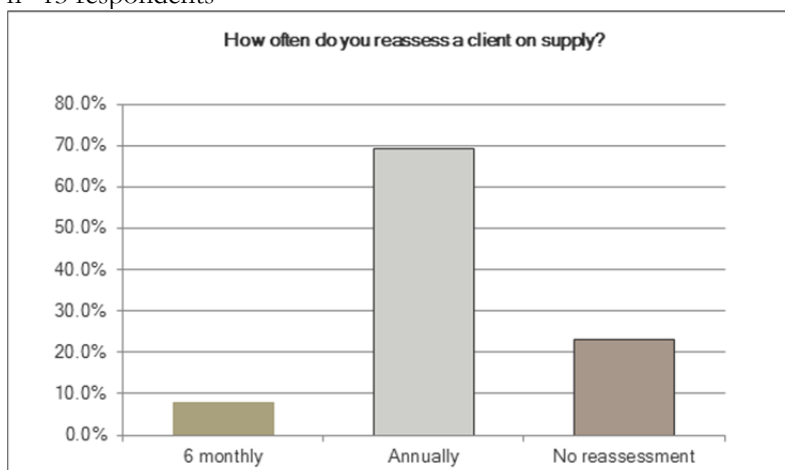
¹⁰ For example one interviewee said for some people there are better products than pads for volume, ease and non-leakage, e.g. pull ups.

4.4 Room for greater focus on proactive conservative management treatments

Information garnered through interviews suggests that there is an undue emphasis on products, due to lack of clinical resource, as opposed to conservative management such as bladder retraining. This is supported by the survey results which found that most clients are on supply. The majority of nurses reported that while they do provide bladder retraining and conservative management treatments, it is not always at the level required.

While some services do six-monthly reassessments for clients on supply, the required annual reassessments are not always occurring (see figure below). Some explained that this was due to time constraints.

Figure 4 Frequency of reassessment of clients on supply
n=13 respondents



Source: Nationwide continence survey 2014

Summary

Taken together, the evidence suggests that conservative management techniques are not being used as the first port of call, as intended by the service specification and recommended by best practice from the literature. Moreover, the gaps in reassessments in some services and lack of change in product range may mean that clients on supply are not being provided with the product or treatment best suited to their needs, as their condition may have changed and new products may have become available.

One survey respondent suggested that supplies are being wasted by this approach:

'Patients just get pads when they may be able to have retraining to cure them. We need more continence nurses to reduce the huge wastage on pads and to improve patient care and outcomes.'

This was reiterated in our interviews, where we were told that not only was there not enough clinical resource to undertake effective proactive conservative management but that due to lack of ability to follow up costs were escalating unnecessarily, including of wastage of product.

'I know of several circumstances where product is on an automated send out [from the DHB] and so patients keep receiving it. No one checks, as there is not time to do so, if that patient is even still alive or has gone in to a rest home. At times product keeps being sent to people.'

'There are examples of this type of surplus product [i.e. for people no longer in their previous circumstances] being on-sold at local markets as the family no longer need it.'

4.5 Lack of resourcing and support for workforce

4.5.1 Staffing levels putting pressure on the workforce

For nurses, staffing estimates vary extremely widely. For physiotherapists and children's services, survey respondents did not consistently report their population figures.

Total numbers of clients reported by survey respondents ranged from 48 to 2,200. But without complete data, we cannot draw conclusions on either the sufficiency or consistency of staffing ratios across DHBs. However we were told that most services feel their staffing levels are inadequate. For comparison, the NHS guidance recommends 1 FTE specialist continence practitioner per 100,000 population.

Notwithstanding, both survey respondents and interviewees reported that services felt unable to cope with growing demand. The majority of respondents reported no change in staffing levels over the past 12-24 months. A minority reported a decrease in staffing levels, while others reported an increase. One respondent noted that while the staff numbers have increased, the skill level has decreased in their service¹¹.

The majority of nurses and physiotherapists have stated that there have been no discussions to increase staff. Several respondents stated that a business case was put forward for an increase, but the majority of those were rejected. Budget constraints were often mentioned as the reason for no increases in staff.

This reflects the evidence in the literature that continence services are frequently a 'neglected' area of health services resourcing. To illustrate this, one nurse who responded to the 2016 survey and whose service did not have a continence resource nurse said:

'I have tried to set this up on the ward but due to the fact that continence is not seen as fashionable no one wants to take up the role'.

Another said:

'I have concerns that as continence nurses we work in nurse led situations, with little support available. Though I am part of a great team, isolation is an issue. Consults with other health professionals is not on hand, and I feel I often work outside of my scope of

¹¹ Anecdotally from the interviews it was reported that more latterly, since the surveys, this practice of reducing the specialised continence skill mix, is increasing.

practice. Though theoretically I am hospital based and thus not seen as doing a nurse led clinic, my role tends to be advising specialists and other staff rather than getting support from them. There is no title or financial recognition for what I see as a specialist nurse role, rather than specialty role.'

Some respondents stated that continence seemed to take a lower priority than other services:

'Continence is the downtrodden CNS job, people don't understand what is involved and only see it as a pad service, it would be nice to be given some praise for what I do. So often I see other CNS getting recognised for what they do, but continence is just termed as the pad service. I would like my manager or DNs to come out with me to see what I do.'

'Incontinence is not seen by management and funders/government as a major and expensive health issue.'

Static resourcing is also reflected within Continence NZ itself, which receives government funding of \$62,621 per annum – a level that, apart from a single two per cent increase, has remained unchanged for the last 20 years. This is despite a large increase in service demand and provision, resulting in resources needing to be used to try and raise funds from charitable sources. This makes planning difficult.

4.5.2 Workload is stressful

When asked whether they felt stressed or overwhelmed by the current workload, the majority of both nurses and physiotherapists who responded to the 2016 survey said 'yes' or 'sometimes'. A couple of respondents highlighted the difficulty of having multiple roles to juggle. One respondent said they were unable to get proper leave as there was no one else who could do their role. Respondents stated that it is the patients that *'pay the price'* as there are only so many patients they can see in a day.

This was similar to the 2014 survey, where several respondents stated that they feel their service is stretched to the limit, due to a combination of staffing shortages and an increase in demand and/or complexity. This creates an environment where staff are stressed and overworked and reviews are not done in a timely manner, if at all.

'DHBs should be putting better resources into education and prevention with the general population and ensuring they have adequate staff numbers and purpose built facilities to carry out the care.'

4.5.3 Administrative resources would free up nursing staff

Nurses were asked how much of their work could be done by an administrator. The vast majority said at least some of their work could be. For those respondents who already have administrative support, they often said that the support provided was great – *'it helps immensely'*.

4.6 Quality of care could be better

When asked whether their service was adequate, the majority of nurses and physiotherapists who responded to the 2016 survey said 'no' or 'it could be better'. Comments from nurses who thought the service was inadequate tended to focus on the time constraints, and a

couple commented that having to deal with pad and product supply takes up too much time that could be spent on actually treating the issue:

'Have to deal with pad and product supply, far too much time and could be done by another RN or speciality clinical nurse but it is extremely unlikely this will happen'.

Respondents stated that the service is under resourced, and if they had more staff, the quality of care could be greatly improved.

'The service for patients is deteriorating with the reduction in continence nurse FTE and increase in patient numbers and acuity. The cost to the health service is huge due to the side effects. e.g., recurrent UTI's and overactive bladders requiring long term medications, admission to hospital due to urosepsis, fractures from falls rushing to the toilet or chronic faecal impaction. Admission to rest homes as patients/carers cannot cope with incontinence at home.'

Physiotherapists had similar responses, with negative comments focussed on the lack of staff and time.

'No inadequate has delayed time frames to see people, inadequate resources, inadequate slots for timely follow-ups'.

For those who provide children's services, half thought they provided a successful service. Comments regarding under-resourcing were still made.

'Since rheumatic fever prevention programme has started, we as public health nurses do struggle at times to cope with the referrals we do get'.

The literature shows that inadequate continence care can lead to secondary problems such as urinary tract infections and pressure injuries, and resulting ED presentations and hospital admissions.

4.7 Scope for greater emphasis on review

Around half of respondents to the 2016 survey stated that research or audits are undertaken in their service, with 20 per cent stating that annual reviews are not undertaken. The best practice guidance emphasises the importance of systematic monitoring and review, including seeking feedback from clients and their carers.

5. Cost benefit analysis shows it is worth investing more

5.1 Contenance cost-benefit analysis – investing in extra nurses and physiotherapists

We estimate that an investment of \$4.6 million per year for an additional 33 nurses/physiotherapists would result in \$7.3 million saved on incontinence products; i.e., cost savings to DHBs of \$2.7 million. There may also be wider benefits such as improved productivity. There will also be other benefits we have not quantified such as the quality of life improvements of the extra patients who have their incontinence reversed.

It is important to note that our estimates are uncertain due to the lack of information regarding the current resourcing and expenditure across each of the DHBs in New Zealand. The assumptions underpinning our estimates of current staffing rates and the potential to reduced product expenditure from raising staffing levels are based on anecdotal evidence gathered through this review. This has not been able to be validated via DHBs.

Summary of costs and benefits from investing in extra nurses and physiotherapists

- Investment: \$4.6 million per annum to DHBs via 33 extra specialist staff and overheads.
- Direct benefit: \$7.3 million per annum for savings to DHBs via e.g., savings in products (note this review's scope did not include savings via preventable hospital admissions or aged care residential admissions).

Key assumptions

The following assumptions underpin our base case analysis.

- Three quarters of DHBs are currently staffed at rates below best practice. An additional 33 nurses or physiotherapists would be required to take them up to best practice rates of staffing per head of population.
- Total nationwide current expenditure on incontinence products is estimated to be \$8.3 million.
- DHBs with increased staffing will have a 90 per cent reduction in incontinence product expenditure.
- The total financial cost of incontinence in New Zealand is estimated to be \$8 billion per year. Between 2 and 20 per cent of this cost may be avoided with the extra provision of nurses/physiotherapists.

Issue

- There is a significant burden to people who have incontinence issues. Many people are able to resolve their incontinence with education and training from a specialist, such as a continence nurse or physiotherapist specialist.
- In the absence of this education and training, patients continue to be incontinent and use products such as pads, pull ups and catheters to manage their incontinence. Incontinence adversely impacts on patient's life by (e.g., ability to work, ability to form/maintain relationships). The cost of products such as pads is covered by either the DHB or directly by the patient if they need to self-fund, or a mix of both.
- DHBs vary greatly in how they deliver continence services – both in the level of staffing resource (therefore the amount of actual education and retraining e.g., of the bladder and pelvic floor muscles, that can occur) and the amount of product delivered. For example some DHBs allow one pad per day and others up to four per day. There is anecdotal evidence of retirees spending nearly all their pension on products to keep their continence under control and to provide themselves with dignity. This can be at the expense of buying food. Other examples included some people cutting up towels and using plastic rubbish bags to try and fashion their own pads.

5.2 Proposed/possible solution

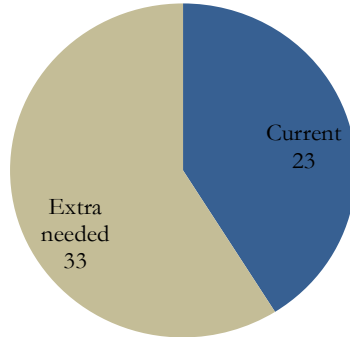
There are many elements to the treatment and management of incontinence, including retraining of the bladder, surgery, pessaries, pharmaceuticals and community based management. We have focused on community-based management delivered by nurses and physiotherapists, as requested in our brief.

We estimate that the amount of nurses/physiotherapists required to deliver best practice is 1.25 per 100,000 population (total population, those with and without incontinence). That is equivalent to 56 nurses/physiotherapists across New Zealand. This estimate is based on an example of an average-sized DHB having three for a population just over 200,000 and where it is reported that there is the ability to effectively work with patients.

Based on anecdotal evidence gleaned through our interviews, we estimate that approximately one quarter of DHBs currently employ enough nurses/physiotherapists to deliver best practice. For the remaining three quarters of DHBs, we estimate from the surveys and other inputs they currently employ at a rate of 0.25 per 100,000 population, i.e., one fifth of what we have been told can deliver best practice. This current combination results in an estimated 23 nurses/physiotherapists currently employed to deliver incontinence services.

In order for all DHBs to have the staffing required to deliver good practice, we estimate a further 33 specialist continence nurses/physiotherapists are required. These staffing estimates are summarised in the figure below.

Figure 5 Full time equivalent nurses and physiotherapists to deliver best practice across New Zealand



5.3 Cost of providing the service

Total cost across NZ – annual

We estimate the total cost of providing an extra 33 specialist nurses/physiotherapists is \$4.6 million per annum, with half of the cost from salaries and the other half from overheads. These costs are summarised in the table below.

Table 4 Cost of extra resourcing to deliver best practice across NZ each year

Cost type	Annual amount
Total salary	\$2.28m
Overheads	\$2.28m
Total cost	\$4.55m

The salary costs are based on an average salary of \$69,000. This is based on the assumption that two thirds of the staff will be nurses (either continence specialists or district nurses) and the other third will be physiotherapists. Each FTE may be made up of nurses/physiotherapists working part time in the incontinence space. A summary of these costs are shown in the table below, with further details below.

Table 5 Average salary based on teams with a mix of nurses and physiotherapists

Staff	Salary	Weight
Nurse specialist - Continence or District	\$70,871	66%
Physio – specialist	\$65,000	34%
Average	\$69,000	

We have assumed the average annual salary for nurses is \$70,871. This salary is based on the Multi-Employer Collective Agreement (MECA)¹², with salaries from 4th July 2017 and the step 6 pay scales. The pay scale for district nurses ranges from step 1 to step 8, with step 8 having the highest salary. We expect that continence nurse specialists will be more senior and experienced and therefore closer to the top of the pay scale.

We have estimated the average annual salary for continence physio specialists to be \$65,000. This is based on the range of salary bands for physiotherapists across New Zealand reported by ENZ¹³; this estimate is within the range of pay reported by careers NZ.¹⁴

We have included overheads to cover costs such as:

- management;
- office space and equipment;
- support staff, administration, accounts and human resources; and
- transport.

We have estimated that the overheads are equal to the salaries of the nurses and physiotherapists. The ratio of overheads to salary is uncertain, and we have included a range of 50 – 125 per cent of salary (i.e. \$0.76 - \$1.9 million per annum) in our sensitivity analysis.

¹² MECA ratification bulletin2015 - <http://www.nzno.org.nz/Portals/0/Files/Documents/Groups/Health%20Sectors/2015-DHB-MECA-ratification-document.pdf>

¹³ ENZ - New Zealand Physiotherapist Salaries - <http://www.enz.org/salary-physiotherapist.html>

¹⁴ Careers NZ – Physiotherapist - <https://www.careers.govt.nz/jobs-database/health-and-community/health/physiotherapist/about-the-job>

5.4 Benefits

The economic impact of incontinence in New Zealand is uncertain. Therefore, the benefits of better treatment are difficult to quantify. However, we have provided a broad range of possible benefits based on the information available.

We have estimated the benefits based on the experience of two DHBs in New Zealand and estimates from Australia. We have split the benefits in to:

- direct benefits to DHBs – reduced product use;
- indirect benefits – including productivity improvements for those with incontinence; and
- unquantified benefits such as improved quality of life from more patients whose incontinence is reversed (or prevented).

Direct benefits to the DHB - savings from better managed products

In our interviews we heard how a large DHB only had one 0.9 FTE nurse for the entire continence service. The nurse was not able to offer best practice, and one flow on effect was a poor management of products resulting in a spend of approximately \$1.2 million per year, and eventually her resignation. In contrast, one average size DHB with three nurses spends about a tenth per head of population of continence products, \$0.30 compared with \$2.40 per year. We were told that this staffing rate (which equates to 1.25 FTE per 100,000 population) enables the service to work effectively with patients – thus delivering a better service for lower product expenditure. This example is further illustrated in the table below.

We have therefore used the staffing rate from this average-sized DHB as best practice for the purposes of our base case. In our sensitivity analysis, we have used the rate recommended by the NHS (1 FTE per 100,000 population).

Table 6 Average DHB spending on incontinence products, per head of population, comparing low service provision with best practice

Nurse/physio staffing	Product spend	Spend per population
1 nurse per 500,000 total population	\$1,200,000	\$2.40
3 nurses plus support for 200,000	\$50,000	\$0.30

If extra resourcing was provided for half of New Zealand to have access to best practice continence community care, our best estimate is that \$7.3 million in DHB incontinence product spend could be saved. However, given the uncertainty in the benefits we estimate the plausible range to be \$4.1 to \$7.7 million. The lower end of the range is based on the assumption of a 50 per cent reduction in expenditure on continence products were there is an increase in nurse/physiotherapist staffing; the upper end of the range is based on the

assumption of a 95 per cent reduction. These estimates are based on our best estimates given the information available to us for this review.

While our estimates of the amount DHBs spend on products with low and high nurse/physiotherapist resourcing is uncertain, our estimate of current expenditure on product is similar to the estimate based on Australian spending. Our estimates resulted in a current spend of approximately \$8.3 million per year (assuming a quarter of the country is already operating at best practice). The Australian Continence Aids Payment Scheme (CAPS) reported spend of \$32.7 million (AUD) in 2010; this is equivalent to approximately \$7 million in New Zealand, when adjusting for population and exchange rate.

Cost-benefit ratio – limited to direct benefits from reduced product spend

If limiting the benefits to reduced spending on incontinence products, our best estimate is that DHBs save 1.6 times the amount invested, i.e., a return on investment of 1.6. We estimate the plausible range to be saving of 1 – 2 times the amount invested; i.e., we expect the DHBs to at least break even and possibly get savings double the size of the investment.

Possible wider benefits

The total financial impact from incontinence in New Zealand has been estimated at \$8.05 billion per year, with the majority of the impact caused by reduced productivity for those with incontinence (7). These estimates are based on costs in Australia. A breakdown of this impact is included in the table below. While this estimate provides a useful estimate of the impact of incontinence, it is uncertain how accurate it is given it is based on the Australian experience; however nurses working in the New Zealand setting have reinforced that the impact per person will be similar for both New Zealand and Australia.

Further, it is difficult to know how much of the adverse impacts from incontinence may be avoided by the investments in more nurses/physiotherapists. Our best estimate is a 10 per cent reduction, and we have assumed a plausible range of 2 – 20 per cent. These estimated reductions in the impact result in possible wider benefits of \$805 million p.a.; with a range of \$161 million to \$1.6 billion.

Table 7 Estimated possible wider benefits of more an investment in more nurses/physiotherapists

Area	Current annual amount*	Estimated benefit‡
Health costs excluding continence products	\$53m	\$5m (\$1m - \$11m)
Productivity costs: Lower than average employment	\$6.7b	\$670m (\$134m - \$1340m)
Productivity costs: Friends and family opportunity costs	\$530m	\$53m (\$11m - \$106m)
Costs of formal care and aids	\$385m	\$39m (\$8m - \$77m)
Aged care	\$314m	\$31m (\$6m - \$63m)
Other indirect costs	\$63m	\$6m (\$1m - \$13m)
Total Costs (estimated)	\$8.0b	\$805m (\$161m - \$1,609m)

* Current annual amount taken from the 2011 Continence NZ report *The financial costs of incontinence in New Zealand – June 2011*; these estimates are based on costs in Australia.

‡ The estimated benefit is based on a reduction of 10 per cent, with a range of 2 - 20 per cent

5.4.2 Cost-benefit ratio – including possible wider benefits

When including the possible wider benefits (e.g. employment and productivity changes), this results in a very favourable cost benefit ratio. Our best estimate is that DHBs could save over 150 times the amount invested, i.e. a return on investment greater than 150. We estimate the plausible range to be saving of 30 – 300 times the amount invested.

5.5 Sensitivity analysis

We undertook one way sensitivity analysis to gain an understanding of which variables and assumptions have the largest impact on the result, and to gain a better understanding of the possible range of results given the uncertainty regarding each of the key assumptions.

5.5.1 Decreasing the benefit from reduced product use

When the benefits are limited to the direct benefits of reduced expenditure on products, the analysis is most sensitive to the assumptions regarding the reduction in product use and the amount of nurses/physiotherapists required to achieve the reduction in product use and improvement in quality of life and health outcomes. As mentioned in the cost-benefit section, assuming a reduction of continence product expenditure between 50 and 95 per cent results in a net benefit of -\$0.5 – \$3.1 million. We tested the impact of assuming 50 per cent decrease or increase in the number of nurses/physiotherapists required to achieve the reduction in continence product expenditure; assuming a range of between 17 and 50 nurses/physiotherapists needed results in a net benefit of \$0.4 – \$5.0 million (holding the proportion of DHBs requiring extra staff constant).

5.5.2 Including wider benefits

When we include the possible wider benefits, the analysis is most sensitive in the reduction in the wider impacts of incontinence and the proportion of DHBs requiring extra specialist nurse / physiotherapist resources. Assuming that the additional nurse/physiotherapist resource results in between 2 – 20 per cent reduction translates to an estimated net benefit of \$164 million to \$1.6 billion. Assuming that between 50 and 85 per cent of DHBs require additional resources to meet best practice translates to an estimated net benefit of \$538 million – \$915 million. If more DHBs require more additional resources the cost will also increase, although the additional benefits are expected to outweigh the additional costs.

5.5.3 Applying NHS best practice staffing rates

In our base case we assumed that best practice is to employ 1.25 nurses/staff per 100,000 population. In this section we estimate the costs and benefits if we assume a rate of 1 per 100,000 i.e., the same rate as recommended by the NHS.

The cost is relatively easy to estimate, as we scale our estimate of the number of additional staff. Using a rate of 1 nurse/staff per 100,000, we estimate 25 extra nurses/physiotherapists are needed. This investment is estimated to cost \$3.5 million per year. (i.e., using this lower rate results in 8 fewer nurses/physiotherapists which will require \$1.1 million less in investment).

It is relatively difficult to estimate what the benefits of investing at a nursing/staff rate of 1 per 100,000. We have estimated that the ratio of benefit to cost will be the same as in our base case. Given we are assuming a 20 per cent reduction in the investment needed, we assume a 20 percent reduction in benefit. Therefore, under this scenario we assume a 72 per cent reduction in product use, resulting in an estimated direct benefit of \$5.8 million. The return on investment is the same as our base case, if limiting the benefits to reduced spending on incontinence products.

Applying a 20 percent reduction in our estimate in avoided wider costs of incontinence results in an 8 percent reduction in possible wider community benefits. Therefore, our estimate of the possible wider benefits under this scenario is \$640 million per year.

Table 8 One way sensitivity analysis

Variable	Base case	Changed to	Net benefit - limited to direct benefits	Net benefit - including possible wider benefits
Base case			\$2.7m	\$807m
Reduction in continence product expenditure	90%	50%	-\$0.5m	\$804m
		95%	\$3.1m	\$808m
Reduction in wider impacts of incontinence	10%	2%	\$2.7m	\$164m
		20%	\$2.7m	\$1.6b
Increase in Nurse/Physio	33	17	\$5.0m	\$810m
		50	\$0.4m	\$805m
Proportion of DHBs requiring extra nurses	75%	50%	\$1.8m	\$538m
		85%	\$3.0m	\$915m

5.5.4 Unquantified benefits are significant too

As already mentioned there are benefits that can't be quantified in financial terms but are no less important. These include improved quality of life of patients, particularly those extra patients whose incontinence is reversed or prevented. This includes enabling participation in social life and employment, family life, community and intimate relationships.

5.5.5 Comparison with published estimates

It is difficult to draw comparisons of other cost-benefits analyses with our analysis. Our analysis is based on a specific investment in nurses/physiotherapists and assumes that many DHBs are currently under resourced to deliver good practice, whereas existing cost benefit analyses we identified are based in other countries, comparing different interventions and based on the provision of a different set of existing treatment and services.

Nevertheless, other studies have found that nurse specialists result in improved health outcomes and savings on incontinence products.

For example, one analysis from the Netherlands found that adding a nurse specialist to an existing primary care team would generate cost-savings. (19). The savings arose from increased percentage of successfully treated and improved patients, leading to reduced costs for formal home care, informal care and incontinence products. The analysis reported that there would be a small additional cost if the perspective is limited to the health care payer perspective, however we consider the cost-effectiveness ratio under this scenario of €19,400 to be reasonably cost-effective.

Another study compared advice and training provided Nurse Continence Advisors with Urogynaecologists in Australia (20). This study found that both options led to significant improvements in patient outcomes and reduced expenditure on incontinence pads. After three months, patients trained by the Nurse Continence Advisors had a 66 per cent reduction in expenditure on incontinence pads.¹⁵

¹⁵ Reported as an initial expenditure of \$4.4 per week with a reduction of \$2.9; values in 1995 AUS.

Appendix 1 : Literature search methodology

Search terms

Literature search terms included, but were not limited to:

- Continence
- Incontinence
- Urinary
- Faecal
- Data and statistics
- Best practice
- Good practice
- Continence aids/pads/products (i.e., use of)
- Prevalence
- Expenditure
- Costs
- Treatment outcome
- Healthcare costs/expenditure
- Cost benefit analysis
- Burden of costs
- Commissioning of services

Selected items were reviewed and summarised, focusing on:

- Costs
- Prevalence
- Aids
- Effectiveness of bladder training

Sources

For peer reviewed literature, sources included:

- PubMed
- ABI Inform
- Proquest Research Library
- Business Source Premier
- MasterFILE Complete
- Google Scholar

Grey literature sources included government and non-governmental sources, and comparable international organisations.

Exclusions

Literature was limited to English-language articles with a publication date of 2000 or later. Preference was given to content published after-2005.

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