National Continence Management Strategy:
Innovative Grants (Round One)
Department of Health and Ageing

THE
waterworx
CENTRE
Gold Coast Community Continence Service

Making Links:
Evaluation of an Integrated Multi-Disciplinary Community-Focussed Model of Service Delivery for Inter-Sectoral Transition and Community Support for People Suffering Urinary Incontinence in the Gold Coast Region

Final Report to the Department of Health and Ageing
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Executive Summary

Overview
The Waterworx Centre: Gold Coast Community Continence Service was established as a demonstration project funded through the National Continence Management Strategy – Innovative Grants by the Department of Health and Ageing. The purpose of this project was to establish and evaluate the effectiveness of an integrated community-focused multi-disciplinary model of service delivery for people suffering urinary incontinence. This project was a collaborative initiative of Griffith University, School of Nursing with the Gold Coast Health Service District (GCHSD).

The Model of Service Delivery
This model of service delivery provided services to community-dwelling clients with urinary incontinence. The model includes the following key components:
- Services provided by multi-disciplinary staff with specialist continence skills;
- Tailoring services for community-dwelling sufferers, not currently in institutional care;
- Service delivery located in the community;
- Comprehensive client services including assessment, conservative management, education and support;
- Multi-disciplinary tools for client assessment and conservative management;
- Collaborative approaches to service provision, client care and management of the service;
- Time limited service to clients (that is, for up to six months);
- Development and monitoring of linkages with generalist health services;
- Provision of staff development for generalist health practitioners and continence specialists
- Evidence-based practice and comprehensive evaluation of services;

Clients were provided with comprehensive assessment, conservative management, liaison with existing hospital and community health practitioners and resources, education and support for up to six months. Under the auspices of the project, services were provided by a multi-disciplinary staff of continence nurse specialists and physiotherapists from 24 February, 2001 until February 24th, 2002. The GCHSD has undertaken to fund staffing of the Centre from March 2002 until June 2003, at which time the service will be reviewed.

Services were offered via a clinic service, limited home visiting and group work at the Centre and in the community. A range of continence services were provided to clients including advice on fluids / diet, hygiene / skin care, sexuality, mobility, bladder training, pelvic floor re-training / re-education, toileting technique, bowel management, continence aids, education about their condition, social management and referral. The services of the Centre were promoted widely in the community and to generalist health practitioners. Clients were self-referred, referred from hospitals, medical specialists, general medical practitioners and nurses. Concurrent with services provided by the Centre, each clients' own general practitioner was sent a linkage letter outlining care provided. Other referrals were made as appropriate.

Evaluation Results
Symptoms of incontinence improved overall by at least 20%. The reduction in the severity of symptoms was equal for men and women and for those in the over 65 years and the 65 or less age groups. Pelvic floor strength and endurance improved, but the number of incontinent episodes remained the same for the small number who completed follow-up appointments for six months. There was a reduction in the bothersomeness of the symptoms experienced by women over the three time periods of the study.

Generally, Health-Related Quality of Life - Short Form (SF-36) scores before attending the centre were similar to the general population, except for the ways in which UI limited their physical, emotional and social roles. The physical functioning of the over 65 year age group improved significantly over the six month follow-up period.
The clients’ knowledge regarding their condition and strategies they could employ to minimise symptoms improved following the intervention and the amount of money they spent on managing their UI decreased. Clients were very satisfied with services provided, across all four evaluation domains examined: access, clinical management, interpersonal management and continuity of care. Continuity of care was considered to be very important to clients.

**Achievements of the Project**

The project has provided benefits for clients, the service and the staff of the service as well as generating knowledge that may inform continence service delivery in an Australian setting. This project resulted in a range of significant outcomes for continence health services as follows:

- Provided seed funding for the establishment of more effective secondary and tertiary preventative services to a previously underserved community-based population;
- Clients have benefited from improved continence, incontinence self-management, a support network and/or access to suitable community and health resources;
- Raised the profile of continence-specific services within the region;
- Improved linkages between existing continence-specific services and generalist services within the region;
- Demonstrated an approach to providing quality care in a cost effective manner;
- Made more effective use of current community health resources for continence care;
- Provided an opportunity for up-skilling in continence care of generalist and specialist staff;
- Generated knowledge about the outcomes and effectiveness of conservative management of urinary continence;
- Enabled development of a set of continence assessment and management clinical tools;
- Provided information about approaches to promotion of a community-based service;
- Provided a case study of effective multi-disciplinary teamwork;
- Enabled development of a client evaluation tool;
- Provided a model of multi-disciplinary, community-based continence care that has been replicated in other services within the state;
- Developed links between clinicians and researchers.

Generalist health practitioners now have more effective communication channels, access to specialist continence practitioners and client educational materials. Specialist continence practitioners have more effective referral pathways, support for community-based clients and a focal point for developing professional links in the region. Health practitioners have access to knowledge about best practice in continence care.

**Recommendations**

Recommendations arising from this report are:

1. Multi-disciplinary, community-based continence services should continue to be offered to community-based incontinence sufferers.
2. Work needs to continue to establish links between the hospital and community sectors in relation to continence care provision. In particular, attention should be given to developing better structures for patients being discharged from hospital.
3. Within the constraints of staffing and service management, continuity of care should be maintained for clients, allowing clients to consult with the same clinical staff (nurse and physiotherapist) at each visit where possible.
4. Services should continue to be provided by clinicians with specialist preparation in providing continence care. The provision of expert clinical staff has provided a high level of patient satisfaction and should be maintained.
5. The availability of continence services should continue to be promoted to generalist health practitioners and the general public.
6. Because many suffering UI do not access other health professionals for their incontinence, facility for self-referral should be maintained.
7. The multi-disciplinary nature of the service should be maintained.
8. The reasons for the high number of appointments made and not attended should be investigated.
9. Staff should be supported to develop specialist expertise in continence care provision.
10. There should be continued collaboration between the clinicians and researchers.
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### Abbreviations

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<th>Description</th>
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<tbody>
<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<tr>
<td>CFA</td>
<td>Continence Foundation of Australia</td>
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<tr>
<td>CNS</td>
<td>Continence nurse specialist</td>
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<tr>
<td>CVA</td>
<td>Cerebrovascular accident</td>
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<tr>
<td>DVA</td>
<td>Department of Veterans’ Affairs</td>
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<tr>
<td>GCHSD</td>
<td>Gold Coast Health Service District</td>
</tr>
<tr>
<td>GP</td>
<td>General medical practitioner</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
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<tr>
<td>HR-QoL</td>
<td>Health-related quality of life</td>
</tr>
<tr>
<td>ICS</td>
<td>International Continence Society</td>
</tr>
<tr>
<td>MASS</td>
<td>Medical Aids Subsidy Scheme (Queensland)</td>
</tr>
<tr>
<td>MS</td>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>SF-36</td>
<td>Health-Related Quality of Life – Short Form (36 questions) questionnaire</td>
</tr>
<tr>
<td>TUR</td>
<td>Transurethral resection</td>
</tr>
<tr>
<td>UI</td>
<td>Urinary incontinence</td>
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SECTION ONE

Overview of the Project

1.1 Introduction

This project was funded under the National Continence Management Strategy – Innovative Grants (Round One). The purpose of this project was to establish and evaluate the effectiveness of an integrated community-focused multi-disciplinary model of service delivery, based on Australian and international best practice, for people living in the Gold Coast region. The model was implemented with the establishment of The Waterworx Centre: Gold Coast Continence Service at Palm Beach Community Health Centre. This report describes the model, its implementation and evaluation.

Effectiveness of the structures, processes and outcomes of the Centre’s services were comprehensively evaluated to determine:

- Appropriateness of demand and service utilisation;
- Appropriate client access by those living in the community suffering urinary incontinence (UI);
- Appropriateness and sources of incoming and outgoing referrals;
- Ability to provide links with other health services and resources;
- Satisfaction with services provided;
- Improvement in clients’ severity of UI, health-related quality of life (HR-QoL) and knowledge about UI.

1.2 Objectives of the Project and Service

The purpose of this project was to establish and evaluate the effectiveness of an integrated community-focused multi-disciplinary model of service delivery for people suffering UI. There were two components to this project. They were to:

1.1.1 to set up a demonstration project, being an integrated, multi-disciplinary, community-focused model of service delivery; and
1.1.2 to evaluate structures, processes and outcomes of the service.

In order to achieve these aims The Waterworx Centre: Gold Coast Continence Services was established as a collaborative venture between the School of Nursing, Griffith University and the Gold Coast Health Service District (GCHSD), Community Health. The aims of The Waterworx Centre were to:

- Promote independence in the community, functional and social continence and prevent continence-related disease processes;
- Use health resources more efficiently by reducing continence-related disease processes;
- Foster links by providing a focal point for referral, service, education and research;
- Provide a hub for the development of specialised professional expertise and collaboration in the provision of continence services;
- Improve communication between continence specialists and other health service providers accessed by sufferers.

1.3 Background to the Project

There have been few Australian prevalence studies, however, it is estimated that about 900,000 adult Australians suffer from UI (National Health and Medical Research Council, 1994). Although estimates vary, studies have consistently revealed that the prevalence of UI increases with age, and is more common in women (Chiarelli, Brown, & McElduff, 1999; Millard, 1998). Compared with the rest of Australia (26.5%) the Gold Coast region of Queensland has a higher proportion of people over the age of fifty (29.5%) (Australian Bureau of Statistics, 1999). As a consequence, it may be assumed that the Gold Coast region has a high proportion of people living with UI.
In 1998/99 the research team conducted a comprehensive review of continence interdisciplinary health services for community-dwelling people in the Gold Coast region, funded by Home and Community Care (HACC) and in collaboration with St Vincents’ Community Services (St John, McKenzie, & James, 1999; St John, James, & McKenzie, 2001). The review identified the need for integrated, multi-disciplinary services addressing inter-sectoral care and support for people suffering UI, living in the community. The review found that, consistent with national and international findings, current services in the region were fragmented for community-dwelling sufferers. Furthermore, the report found that many generalist health practitioners had poor knowledge of advances in continence treatment and care and of the nature of services available from continence specialists. St John, McKenzie, & James (2002) found that sufferers in the Gold Coast region were generally dissatisfied with information, resources and referral. There was a need to improve links between existing multidisciplinary services and sectors, from hospital to community and within the community. The report recommended that there was a need for improvements to community support for UI sufferers including both clinic-based and home visiting services.

This project built on the links already established by completion of the 1999 review of services undertaken by the project team. It established an innovative model of service in a cost effective manner for a previously underserved group of people suffering UI. Funding under the National Continence Management Strategy enabled this project to be implemented. As part of this project the following was achieved:

- Development of a new model of continence care provision
- Establishment of The Waterworx Centre: Gold Coast Continence Service, located at the Palm Beach Community Health Centre, staffed by specialist continence nurse specialists (CNSs), specialist physiotherapists and a research assistant
- Provision of multi-disciplinary comprehensive assessment and conservative management for UI sufferers
- Development of a set of multi-disciplinary tools for specialist comprehensive assessment and conservative management of UI
- A limited home visiting service to house-bound clients in the Gold Coast Health Services District
- A raised profile of specialist continence services in the general community and the generalist health professional community
- Development of a hub for specialist continence practitioners and continence services in the Gold Coast region
- Linkage with existing community-based health services, particularly home nursing services and general practitioners (GP) and existing continence services
- A comprehensive evaluation of the structures, processes and outcomes of the model
- Provision of a venue for multi-disciplinary education and research related to UI
- Presentation of the work of this project and the model at professional seminars and conferences.

1.4 Structure, Process and Outcome Evaluation of the Model: The Waterworx Centre

The discipline of evaluation is devoted to the systematic determination of merit, worth, or significance. It is divided into fields according to the type of entity evaluated – for example, program evaluation, or personnel evaluation – and there are more than twenty of these recognized fields of evaluation. Increasingly, agencies not only want to know what is happening when an intervention is supported and exactly what causes the results, but also:

1. whether the intervention is worth what it cost;
2. whether there are unintended bad results as well as planned good ones;
3. whether the methods used in the intervention were proper by current professional and ethical standards; and
4. whether there are better ways to do the same thing.

The father of modern evaluation research is Avedis Donabedian. Donabedian (1988) suggested that the quality of healthcare could be evaluated within the three distinct domains of structure, process and outcome. As this project was concerned with evaluating an integrated, multi-disciplinary, community-focussed centre, it was decided that structure, process and outcomes evaluations of the service would be undertaken.
Structure evaluation examines the availability and appropriateness of resources available to provide health services. For the purposes of this study, structure evaluation consisted of a discussion of the structures of the model and a description of how the model was implemented. It should be noted that descriptive analyses are presented for all clients who attended The Waterworx Centre, whether or not they participated in the process and outcome evaluation study.

Process evaluation is concerned with the extent to which health professionals provide the services required and outcome evaluation investigates changes in clients’ condition following the intervention. In this project a sample of people who accessed the services of The Waterworx Centre participated in the process and outcome evaluation study.

Further aspects were identified by Donabedian, who broadened the definition of quality to include not just technical management, but also management of interpersonal relationships, access and continuity of care. Where appropriate aspects relating to relationships are presented and discussed. In addition, access and continuity of care were included in the Client Evaluation Survey.

1.5 Overview of the Report

This section of the report has provided an overview of the project. Section two presents a literature review that provides a background for the approaches taken in developing the model of continence care implemented in this project and designing the evaluation process. The model itself is then presented in section three. Implementation of the model is outlined in section four, providing a picture of the structures used for the model developed in this project.

The methods used for the evaluation study are presented in section five. The characteristics of the participant sample are presented in section six, providing a profile of the types of clients who access a community-focused service. Results of the process and outcome evaluation are presented in sections seven and eight. The lessons learned from implementation of this project and results of the evaluation study are discussed in section nine. Based on the experiences of this project and results of the evaluation project, conclusions are drawn and recommendation made for the future in relation to the provision of community-based continence services.
SECTION TWO

Literature Review

2.1 Introduction

In this section, current knowledge and practice from the Australian and international literature are reviewed as a basis for the perspectives taken in establishing and evaluating this integrated community-focused multi-disciplinary model of service delivery for people suffering UI. The prevalence of UI in community dwelling populations is examined in order to profile the population targeted by this project and to demonstrate need in this area. As this project aimed to develop a service that targeted a population that has previously been underserved, current knowledge about treatment-seeking behaviour and access to services is discussed. Approaches to evaluating the outcomes of continence services are then reviewed.

2.2 Prevalence and Impact of Urinary Incontinence in Community-Dwelling Populations

Although findings vary, studies in many Western countries have indicated a disturbingly high prevalence of UI in community-dwelling populations at approximately 34% in older women, 25% in younger women, 7% in older men and 5% in younger men, varying according to sample type and definition of UI (Burgio, Matthews, & Engel, 1991; Chiarelli et al., 1999; Millard, 1998; Roberts et al., 1998; Thom, 1998; Roe & Doll, 2000).

The consequences of UI include embarrassment, odour, avoidance by others, social isolation, personal cost, psychological stress and may lead to institutionalisation and depression (National Health and Medical Research Council, 1994; Dugan et al., 2000; Fultz & Hersog, 2001; Engberg et al., 2001; Meade-D'Alisera, Merriweather, Wentland, Fatal, & Ghafar, 2001). Many studies have demonstrated that UI has a major impact on sufferers' health status, quality of life in the areas of travel, leisure, sexuality, social, physical and emotional activities (Roe & Doll, 2000; Hunskaar & Vinsnes, 1991; Kelleher, Cardozo, & D'Toozs-Hobson, 1995; Lee, Reid, Saltmarsche, & Linton, 1995; Valerius, 1997; Johnson et al., 1998). The impact of UI is highly individual and complex, with many researchers finding that the "bother" of UI does not necessarily correlate with objective measures of severity (Bird & Fonda, 1998; Wyman, Harkins, & Fantl, 1990; Wong, 1995; Lagro-Janssen, Smits, & Van Weel, 1990). While experts tend to focus on the functional impact of UI, patients focus on emotional well-being and interruption to daily activities, experiencing UI as a "tremendous psychological burden" (DuBeau, Levy, Mangione, & Resnick, 1998).

It is clear that UI has a major impact on physical, emotional and social health and well-being, and that the impact on quality of life should be considered within the individual’s context and frame of reference. Many of these studies identified that UI is often considered by generalist health professionals to be secondary to other health problems, a view not necessarily shared by sufferers (St John, McKenzie & James, 2002).

2.3 Conservative Management for Urinary Incontinence

Treatments can provide assistance for UI. In up to 80% of clients, conservative treatment of UI is effective, with objective and subjective improvements demonstrated in many studies, sustained over periods of up to a year (Burgio, Locher et al., 1998; Fonda, Woodward, D'Astoli, & Chin, 1995; Lewey, Billington, & O'Hara, 1997; McGhee, O'Neill, Major, & Twaddle, 1997; Publicover & Bear, 1997; Walling, 1998; Paterson & Marshall, 1997). Borrie, Bawden, Speechley, & Kloseck (2002) conducted a randomised controlled trial of lifestyle and behavioural approaches and found that behavioural and lifestyle counselling provided by specialist nurses reduced incontinence events and incontinence pad use.

These studies indicate that conservative management of UI are an important component of health service that should be provided to those suffering incontinence.
2.4 Treatment Seeking and Assistance Received from Health Professionals

Despite a high prevalence of UI, its profound impact, and that it is often treatable, there is mounting evidence that many do not seek care, or do not believe that help is available or effective (Millsard, 1998; Muscatello, Rissel, & Szonyi, 2001; Roberts et al., 1998; Branch, Walker, Wetle, DuBeau, & Renick, 1994; Henry, 1996). Burton (1996), in a focus group study of 80 Australian elderly migrant women found that many did not share their problems, even with their families. These studies indicate that there are many people living in the community who do not seek and/or receive professional help for a health problem that has a significant impact.

A major concern is that although there may be many client factors for not seeking treatment (Goldstein, Hawthorne, Engeberg, McDowell, & Burgio, 1992; Bush, Castellucci, & Phillips, 2001), many people who seek assistance for UI do not receive meaningful help. Health professionals may lack knowledge and/or treat UI as a nuisance, or secondary to other conditions (St John, McKenzie et al., in press). UI is often not identified by practitioners (Welligs, 1989; McDowell, Silverman, Martin, Musa, & Keane, 1994; Chiarelli & Campbell, 1996; Goepel, Hoffmann, Piro, Rubben, & Michel, 2002) or raised as an issue with clients. Generalist practitioners often lack a knowledge base about the causes, investigation and management of UI (Cheater, 1992; Moore & Bennett, 1996), with most of their education being focussed on palliative rather than therapeutic or rehabilitative strategies. Jeter & Wagner (1990) in a North American study of 12,097 people who used an incontinence helpline, found that, although over half had sought help, 56% reported that their consultations had been “no help at all”. Only 9% indicated that they had been helped “very much”. Participants described medical practitioners or nurses as being not helpful, too busy, unknowledgeable, embarrassed or unsympathetic. Results did not differ between people suffering major, medium or minor UI. A small Australian study carried out by the researchers found similar results (St John, McKenzie et al., in press). Thus, there is a need to ensure that health services are appropriate to the needs of sufferers.

2.5 Service Delivery for Urinary Incontinence

There is a range of issues that should be considered when developing an appropriate model of service delivery. In a report providing best practice guidelines for continence services in the United Kingdom (UK), the Department of Health (2000) stated that continence services should be multi-disciplinary and integrated. They identified that service components should raise awareness among the public and health professionals; identify incontinent individuals; provide individual assessment, manage planning and instigation of initial treatment; review treatment; supply continence aids when indicated; advise and assist carers; and provide specialist services in community and hospital settings. Furthermore, they suggested that continence services should include designated medical and surgical specialists, access to diagnostic and treatment facilities and robust care pathways. They recommended that generalists and continence specialists require appropriate education and that there is a need for public education and awareness.

2.5.1 Models of Service Delivery

Specialist continence services have been described nationally and internationally, however, Clayton, Smith, Qureshi, & Ferguson (1998) pointed out that there are many ‘models’ of service provision, and that continence agencies offer a range of different services and may not all deal with incontinent people in the same way. Some specifically focus on client or diagnostic groups, such as children or the elderly, while others provide comprehensive continence services to the general population. The size of agencies vary from single independent practitioners to large full-time services operating out of major hospitals or home visiting nursing services. Many agencies report a high demand due to the limited availability of services in their regions (Sullivan, 1996; Chesher, 1995; Shields, Thomas, Benson, Major, & Tree, 1998).

Four types of services are described in the literature, primarily influenced by where they are located. The first service type is hospital/clinic-based with little or limited home-visiting (Chase & McCathy, 1996; Brown, 1994; Mooney, Newman, Smith, & Grey, 1993, Chesher, 1995; O’Brien, Gibb, & Bradford, 1994). The second is provided via community/home-visiting agencies, which may or may not include some in-reach to hospitals (Winnick, 1988; Rogers, 1997). The third service type offers both clinic-based (in either hospitals or community agencies) and home visiting services. This is accomplished through either a single agency or collaboratively by hospital and community-based
agencies working together (Bryant & Jarvis, 1999; Hall, Castleden, & Grove, 1988; Pomfret, 1996; Hughes, 1992; McGhee et al., 1997). The final service type is very different from the other three, in that it serves as an information centre and/or clearinghouse, usually with a view to linking with other agencies providing continence services and raising the profile of continence services in the community (Bower, 1994; Wilson, 1995). As an example, the Australian National Continence Helpline’s 1800 number was launched in September 1998, providing a focal point and an important vehicle for providing information, and linking inquirers to services providing continence care.

A further issue is that many continence services have been developed to provide services for particular client or diagnostic groups. The location of continence services in such an array of specialty areas illustrates the complex causal factors associated with UI. Because UI may be chronic and the causes multi-factorial, there is a need to situate continence services within a generalist framework without regard to presenting diagnosis or gender, rather than confining them within a diagnostic specialty area that may exclude sufferers not meeting a particular set of criteria.

2.5.2 Expertise and Multi-Disciplinarity
An important aspect of providing high quality services to those suffering UI is the need for appropriately qualified health practitioners. As UI is a symptom rather than a disease, it has many causes. This, together with its profound impact on sufferers’ daily lives, means that client needs will be individual and that they will require multi-disciplinary services. Practitioners from different disciplines who provide services for an incontinent sufferer need to work together in order to provide optimum services. The UK Department of Health guidelines (2000) suggest that agencies providing continence-specific services should, as a minimum, be staffed with nursing and also, preferably, physiotherapy staff who are specialists in continence. They argue that qualified specialist staff are able to focus exclusively on continence, develop a higher profile for services, and develop clear pathways and links between hospital and community sectors, client services (such as for continence aids) and with generalist health practitioners. Thus the key health practitioners for continence service provision are CNSs and physiotherapists, who need to work with medical specialists and GPs.

The CNS is able to provide comprehensive assessment, education, management and support. The CNS role has developed internationally (Rhodes & Parker, 1995) and in Australia over the last decade (National Health and Medical Research Council, 1994). These specialist nurses provide comprehensive assessment, treatment, management and education in the hospital and community sectors. There are some specialist continence courses that prepare nurses for this role (St John, James, & Griffiths, 2001). CNSs have been found to provide effective management (Anderson et al., 1998; O’Brien, Austin, Parminder, & O’Boyle, 1991) and Simons, Moore et al. (1998) found that CNSs were more effective that uro-gynaecologist specialists for mild cases of UI and equally as effective in moderate cases. They also calculated that treatment costs for CNSs were 30% less than for uro-gynaecologists. They recommended that the CNS should be employed more widely, leaving specialists to treat more severe cases.

Physiotherapists provide specialist services using a range of exercise modalities where indicated (Chiarelli, 1998). Nuemann, (1999) showed that a physiotherapist continence adviser was effective in management of UI, concluding that there could be a substantial cost benefit if women were routinely seen before surgery. Physiotherapists have argued that it is important to take a multi-disciplinary and collaborative approach (Haslam, 1996; Laycock, 1998).

There are instances where UI may be improved by addressing an underlying medical problem, use of pharmacological approaches and surgery. Specialist medical referrals should occur where specific gynaecological, urological and neurological disorders are identified. It may also be relevant to refer clients to a geriatrician or paediatrician. Ongoing research is required to develop better medical and surgical treatments and examine the long-term effectiveness of non-conservative methods of intervention.

2.5.3 Linkages
Some services described in the literature emphasised specific features in the way they delivered services. Due to the multi-factorial, multi-disciplinary nature of continence services, many agencies have acted to ensure better communication and linkages between different professional groups and sectors. McCammon, Dodd, & Waddell (1999) described an integrated continence service that used
an information technology (IT) system to link members of the multi-disciplinary team such as CNSs, GPs, and community nurses. Shields et al. (1998) described a link scheme, where designated 'link' nurses from wards liaised between clinical nurse specialists and hospital wards. Other activities carried out by agencies providing continence services included providing information and promoting continence (Haugen & Moore, 1995; Conlon, 1996; Smith & Nichols, 1995; Snyder, 1997), developing support groups (Rigby, 1996; Schade, 1996; Wells & White, 1991), using standardised care plans (Chadburn, Hagggar, & Gooch, 1998) and acting as a pad delivery service (Pyne & Stott, 1996). St John & McKenzie (2002) reviewed the services of 14 continence services in Australia, finding that there was a need for ready access, either within an agency or by links with other agencies, to appropriate diagnostic services, specialist medical care (such as urology, gynaecology and neurology) and home visiting nursing services. Based on the prevalence data and this review of service delivery models, it can be concluded that community-based services need better linkages with hospitals, home visiting nursing agencies, community-based primary care services and specialist continence services in order to provide a full complement of services, investigations, treatments and follow-up. This requires different parts of the health care system to work together in order to deliver optimal services.

A further linkage that requires consideration relates to access and referral. Due to the chronic and multi-factorial nature of UI, clients may be referred from hospital and community agencies, medical specialists, GPs, allied health practitioners and home nursing services. However, the literature reviewed above also suggests that many sufferers may not be accessing any health services. Given the lack of knowledge, poor links between general and specialist services and that UI is an embarrassing and personal health problem, the facility for clients to self refer appears to be important. The multi-factorial nature of UI suggests a need for multiple pathways for access and referral to continence services, including the facility for self-referral.

In summary, this review of current thinking suggests that continence services should be community-focussed, multi-disciplinary, generalist in nature and provide conservative management in the first instance.

2.6 Health-Related Quality of Life and Incontinence

Many studies have demonstrated that UI has a major impact on sufferers’ HR-QoL in the areas of travel, leisure, sexuality, social, physical and emotional activities (Hunskaar & Vinsnes, 1991; Kelleher et al., 1995; Lee et al., 1995; Norton, 1996; Roberts et al., 1998; Szonyi; Szonyi et al.; Szonyi et al., 1996, 1997a, 1997b; Valerius, 1997). There has also been found to be a relationship between UI and poor self-rated health (Johnson et al., 1998) with Breakwell & Walker (1988) finding a significant impact on social interaction, particularly with family members. UI is an important predictive factor in the need for nursing home admission (Harris, 1996; National Health and Medical Research Council, 1994, p. 18) and is associated with perceived limitations in usual role activities because of physical health problems (Kutner et al., 1994).

Many researchers have explored HR-QoL factors, focussing on development of effective tools for assessing HR-QoL (Bird & Fonda, 1998; Wagner, Patrick, Bavendam, Martin, & Buesching, 1996; Resnick, Beckett, Branch, Scherr, & Wette, 1994; Simons, Dowell, & Bryant, 1998; Valerius, 1997). These measures are important for identifying the impact of UI on clients and evaluating the effectiveness of interventions. However, they should be used with care as the impact of UI is highly individual and complex, with many researchers finding that the “bother” of UI may not necessarily correlate with objective measures of severity (Bird & Fonda, 1998; Wyman, Wyman et al., 1990, 1998; Wong, 1995; Lagro-Janssen et al., 1990; Hunskaar & Vinsnes, 1991). However, other studies have suggested that the severity of UI does have an impact on HR-QoL, with more severe UI negatively correlating with HR-QoL (Hayden & Plant, 1996). Robinson et al. (1998) found a correlation between “bothersomeness” and more frequent episodes of UI, greater amounts of urine loss and more frequent voids.

Fonda et al. (1995), in one of the few Australian studies into HR-QoL related to UI, described a continence service set up at the Heidelberg Repatriation Hospital in Melbourne in 1985. They examined improvement in both subjective HR-QoL and objective measures of severity of UI in 73 older community-dwelling people after non-pharmacological, non-surgical management provided by a CNS and a physiotherapist in a randomised comparative study. They found that conservative management of UI is effective in improving both UI and also patient well-being and that significant improvements could be sustained over a 12-month period. These studies have shown that the impact of UI on HR-
QoL may be affected by cultural values, beliefs, self-concept, relationships, normal routines and usual activities. This body of research suggests that while the effectiveness of continence services should be evaluated using objective measures, subjective outcomes from the client’s perspective should also be evaluated.

Although there have been many quantitative studies examining HR-QoL, few qualitative studies have sought to understand the experience of incontinence from the perspective of the sufferer. The studies that have been carried out have demonstrated a profound impact on well-being. Pinnock, O’Brien, & Marshall (1997) who undertook 20 focus groups with 154 men and 14 women found that the issues that most concerned men were voiding symptoms, particularly nocturia, frequency, urgency and post-micturition dribble. Their participants felt that poor access to toilets had a particular impact on their HR-QoL. Jolleys, Donovan, Nanchahal, Peters, & Abrams (1994) in a study of community-dwelling men with benign prostatic hyperplasia found that the most bothersome symptoms were frequency, nocturia and incontinence episodes causing social embarrassment.

DuBeau et al. (1998) found that the most frequent issues cited by the female participants were the treatment burden and stress from anticipation of UI. Men cited ‘taboo’ issues and fear of aging. They also found an association between a negative explanatory style and specific UI-related HR-QoL factors: inevitability, UI as psychological and not physical problem, self concept, shame, association with women’s biology, and fear of aging. DuBeau, Levy, et al. (1998) also added UI-related HR-QoL factors previously identified in the literature. HR-QoL factors they identified in order of frequency were: a need for pre-emptive strategies to avert UI, a lack of self control, adaptation of daily routine, shame, fear of public embarrassment, lack of predictability, loss of sleep, resignation, an effect on self concept, UI as a psychological rather than a physical problem, the burden of treatment, concern about cause, constant preoccupation, thinking of it as inevitable, vigilance, a fear of aging, being a constant burden, dealing with burdensome compensatory activities, body odour and cleanliness, stress from anticipation of UI, competing morbidities taking precedence, interruption of activities, financial expenses, feeling alone with UI problem, loss of dignity, loss of self esteem, fear of dependency, an effect on intimate relationships, UI lacking the status of a legitimate problem, UI being a taboo or forbidden topic, an association with women’s biology and an alteration in social or gender role.

It is clear that UI has a major impact on physical, emotional and social health and well-being, and that the impact on HR-QoL should be considered within the individual’s context and frame of reference. These studies suggest that even less severe UI can have a major impact on sufferers. While one person may cope with objectively severe UI symptoms, another may find less objectively severe UI symptoms devastating. An issue that is raised by many of these studies was that UI is often considered by health professionals as a ‘nuisance’ that is secondary to other health problems, a view not necessarily shared by sufferers.

2.7 Knowledge

Appropriate, integrated, acceptable, accessible and empowering health services for common health problems are fundamental principles in the provision of primary health care (World Health Organization & United Nations Children’s Fund, 1978). Ensuring that clients have appropriate information is foundational to providing clients with the quality care. In order to take control of their problem, sufferers need information about their condition. St John, McKenzie & James (2002) found that participants overwhelmingly expressed a wish for greater information. Where sufferers received useful and detailed information from health practitioners, they were very grateful.

2.8 The Cost of Incontinence

It is difficult to estimate the costs of UI. Statistics are often not collected regarding this problem, so costs are often hidden, absorbed by clients. Financial costs borne by sufferers include incontinence aids, extra clothing, laundering, extra health care costs, treatment, medications, rehabilitation, earlier nursing home admission, and skin care products. There are also many costs to the health care system. Hu (1990) identified the American direct health-care costs of incontinence as including diagnosis and medical evaluation, treatment, routine care, incontinence consequences (skin irritation, urinary tract infections, falls) and added admissions due to incontinence in the community at seven billion dollars, using 1987 prices. He argued that given this cost impact, the potential economic benefits from research and intervention into UI would improve not only physical and psychological well-being, but also provide a substantial economic benefit. Findings of a study by Bryant, Dowell,
Moore (1997) in Sydney supported Hu’s finding that UI had a cost impact and the argument that treatment of UI could substantially reduce costs. However, they cast doubt on the extent to which Hu’s estimations were portable into an Australian setting, finding that incontinence in the community had a median personal and treatment cost for individuals of $293.80 annually with a median cost to the health system of $105.00. In a more recent study, Doran, Chiarelli, & Cockburn (1998) estimated the costs of incontinence for women at $710.44 million, or $387 per incontinent woman, comprising $338.47 million in treatment costs and $371.97 million in personal costs. This included all resources used or lost by ill individuals, treatment providers or others as a result of the illness. Direct costs they included were resources used for diagnosis, treatment and care of UI, while indirect costs included the value of lost earnings and time spent by carers. They concluded that UI imposes a considerable drain on individuals and Australian healthcare resources.

Apart from direct costs, effective treatment and care of UI will result in other cost savings. Taylor (1990) indicated that, in Australia, each 1% reduction in nursing home admissions equated 13 million per annum in residential care expenditure, and that studies have consistently concluded that the cost of providing home care services is always much less than the cost of nursing home care, except for people requiring extremely intensive levels of home care services. He estimated the personal cost of supplying pads was between $1.50 - $3.00 per day or between $500-$1000 per annum. Other continence-specific service providers have calculated the health-care cost savings of their services, concluding that providing continence-related care results in significant savings (McGhee et al., 1997).

While there is a cost in providing services to people suffering UI, calculations consistently show that the health care cost impacts of failing to address UI are greater. While ignoring UI and leaving sufferers to shoulder the financial burden may appear to provide short-term savings, the financial impact on health system costs demand that services be provided to address UI.

2.9 Satisfaction With Continence Services

According to Goldstein, Elliott, & Guccione (2000), patients’ perspectives on the quality of health care and their satisfaction with services is increasingly recognised as an important indicator of the effectiveness of health care provision and can usefully inform organizational change by opening up alternatives for future services. Patient satisfaction questionnaires are a phenomena of the last 25 years and their rise in popularity parallels the recognition of the role patients play in health care processes and the increasing focus on evaluation of health care programs (Draper & Hill, 1996). The increasing demand for patient involvement in health care and hospital accreditation has driven health service managers to evaluate patient satisfaction with health care provision (Sincock, Dunn, & Pretty., 1998). Patient satisfaction is always relative to the patient’s expectations of care and perhaps most importantly, is indicative of patient compliance with treatment and attendance at outpatient clinics (Thomas, Glynne-Jones, & Chait, 1997). This factor was particularly important with The Waterworx Centre, as there was a requirement to attend a clinic in addition to adhering to a substantial regimen of therapy.

Research regarding patient satisfaction and outcomes has been performed extensively in the United States, Canada and the United Kingdom (Sincock et al., 1998). However for the purpose of this research study, no validated patient satisfaction tools specifically related to an Australian community continence services were found. While the benefits of patient satisfaction questionnaires have been well documented, the determination of which variables to include in an instrument that measures patient satisfaction is a much more difficult task. Patient satisfaction is recognised as a fundamental quality assurance process, however, a common criticism of patient satisfaction surveys is the subjective nature of the data generated (Sincock et al., 1998). Patient satisfaction is a multidimensional concept (Goldstein, Elliott et al., 2000) and it is difficult to determine which information is most important to consumers when making decisions regarding health care provision. Levels of patient satisfaction alter when a patient’s expectations or standards of comparison change, even though the object of comparison may stay constant. Different types of consumers are likely to have different needs. Therefore, the use of general patient satisfaction tools may be problematic when evaluating different patient groups in specific health care settings (Shaw, Williams, & Phil, 2000), as is the case in this study where evaluation of continence services is required.

Although there is no “Gold Standard” for the measurement of patient satisfaction, research by Nelson (1990), is helpful in determining the areas that comprise patient satisfaction. Nelson performed a content analysis on surveys from 18 selected health care institutions and attempted to match...
questions to indicators of quality. From this study, Nelson developed domains of care that defined patient satisfaction: access; administrative technical management; clinical technical management; interpersonal management and continuity of care. These were described as:

- **Access:** Physical location of facility, hours of operation, telephone access, appointment waiting time, waiting time in waiting room.
- **Administrative Technical Management:** Ambience of facility, parking, payments/claims processing, quality-assurance programs.
- **Clinical Technical Management:** Qualifications of staff, including clinical and technical skills of staff, explanation of care provided.
- **Interpersonal Management:** Responses to complaints or suggestions, warmth/friendliness of staff, appropriate amount of time spent with each patient, respect for patient's privacy.
- **Continuity of Care:** Intent to continue to have condition managed by provider, knowledge of patient's history by the attending health practitioner, patient's recommendation of the health practitioner to others, general satisfaction with interventions received. It is clear in the service industry, that quality of customer delivery is inseparable from the staff who deliver the services, so that staff issues are a crucial key to good service delivery (Draper & Hill, 1995).

### 2.10 Conclusions from the Literature

This body of research strongly suggests that, despite the high prevalence and a significant impact on HR-QoL, many people needlessly suffer the impact of UI. Sufferers may fail to seek help, have limited knowledge of, or misconceptions about UI and/or believe that there is no help available. However, it also appears that many available health services in the community are not providing continence services that are appropriate to clients’ needs.
SECTION THREE

The Model of Service Delivery

3.1 Description of the Continence Service Delivery Model

This section describes the model of service delivery developed in this project, being an integrated multidisciplinary community-based approach, designed to deliver a service aimed at conservative management of UI for independent adults, based on Australian and international research and best practice. Community-dwelling clients were provided with comprehensive assessment, conservative management, liaison with existing hospital and community health practitioners and resources, education and support for up to six months. Please see Appendix 1 for client pathways through the service. The model includes the following key components:

- Services provided by multi-disciplinary staff with specialist continence skills
- Tailoring services for community-dwelling sufferers, not currently in institutional care
- Service delivery located in the community
- Comprehensive client services including assessment, conservative management, education and support
- Multi-disciplinary tools for client assessment and conservative management
- Collaborative approaches to service provision, client care and management of the service
- Time limited service to clients (that is, for up to six months)
- Development and monitoring of incoming and outgoing linkages with generalist health services
- Provision of staff development for generalist health practitioners and continence specialists
- Evidence-based practice and comprehensive evaluation of services

Under the auspices of this project, The Waterworx Centre: Gold Coast Community Continence Service, a service for community-dwelling incontinence sufferers, was established at the Palm Beach Community Health Service, in the Gold Coast region. It opened in March 2001, operating two days per week. Establishment and management of this centre was coordinated by a Clinical Management Team (see p. iv) and informed by an Advisory Group of health practitioners (Appendix 2). The evaluative component of the project was overseen by the Research Team (see p. iv).

The aims of The Waterworx Centre were to:

- Promote independence in the community, and functional and social continence
- Prevent continence-related disease processes
- Provide specialist high quality care in a cost effective manner
- Create interdisciplinary linkages for continence care, in particular, improve communication between generalist practitioners, such as GPs, nurses and physiotherapists, and continence specialists.
- Provide a focal point for referral, service, education and research
- Provide a hub for the development of specialised professional expertise in the provision of continence services.

3.2 Community-Focussed Care

An important aspect of the model was that it focussed on care provision for those suffering UI, living in the community. Due to the visibility of UI in an institutional setting, there is often a disproportionate focus in the literature on care for sufferers in aged care facilities and sometimes hospitals. However, it is clear from prevalence data that there is a silent group of sufferers who are not currently residing in these facilities, or necessarily at risk of being admitted to them. While sufferers can be admitted to an acute care facility for unrelated medical problems, or discharged from hospital experiencing UI as sequelae of another medical condition, they are living in the community and, apart from their UI, may be leading ‘normal’ lives. This is a significant group of people living in the community experiencing UI who require appropriate continence care.
This model of care focussed on this underserved community-based group, providing secondary and tertiary preventative services. In order to target this particular group it was considered appropriate to locate The Waterworx Centre in a community health centre, rather than a hospital or institutional setting. The following groups were targeted:

- People living independently in the community suffering UI
- People suffering UI on discharge from hospital into the community, particularly those suffering ongoing UI for the first time
- People being referred by their GP, medical specialist or other health practitioner
- Self-referred clients

Criteria for admission to the centre were that they had UI, were living independently in the community and that they did not suffer dementia.

### 3.3 Services Offered by The Waterworx Centre

All clients were provided with information about The Waterworx Centre (Appendix 3) on admission to the Centre. Clients had access to services provided by The Waterworx Centre until their continence was resolved or for six months, which ever occurred sooner. Services were offered via a clinic service, limited home visiting and group work at The Waterworx Centre and in the community.

At the heart of the model was comprehensive clinical assessment and development of an individualised management program. Clients were comprehensively assessed on admission to The Waterworx Centre (Appendix 4.1 & 4.2). Formal follow-up assessments were undertaken at 3 months and 6 months (Appendix 4.3). Most clients also had appointments between these points, as clinicians deemed appropriate. Prior to attending their first appointment, clients were asked to complete an International Continence Society (ICS) Urinary Symptom Index questionnaire (Appendices 8 & 9) and a bladder diary (Appendix 4.6). The information from the ICS Urinary Symptom Index and bladder diary was used by clinicians to inform initial assessment. Clients undertook a pad test (Appendix 4.7) at home prior to their second appointment at The Waterworx Centre and this was repeated at 3 and 6 months, where the clinician deemed it appropriate.

Following comprehensive assessment, an individualised case management plan was devised for each client (Appendix 4.4). Most clients were followed up individually, but also invited to participate in group work. A range of continence services were provided to clients by the multi-disciplinary team as follows:

- Advice on:
  - Fluids / Diet
  - Hygiene / Skin Care
  - Sexuality
  - Mobility
  - Bladder training
  - Pelvic Floor re-training / re-education
  - Toileting technique
  - Bowel Management
  - Continence Aids
- Education about their condition and UI
- Social management of UI
- Referral to linkage partner

A range of multi-disciplinary tools (Appendix 4) were specifically developed by the project team for use by clinicians at The Waterworx Centre as follows:

- Multi-disciplinary assessment forms:
  - Initial Assessment- Male (Appendix 4.1),
  - Initial Assessment- Female (Appendix 4.2),
  - 3/6 months Assessment (Appendix 4.3)
- Case Management (Appendix 4.4)
- Linkage form (used for referral/communication with other health professionals) (Appendix 4.5)
- Client bladder diary (Appendix 4.6)
- 24 hour pad measure (Appendix 4.7)
These documents, developed consultatively by the clinical and research teams, were used by both CNSs and physiotherapists. A particular feature of these clinical tools were that the same tools were to be used by all members of the multi-disciplinary team. The aim of developing a shared tool was to promote collaboration and communication between members of the multi-disciplinary team.

3.4 Education and Support

A feature of the model was ongoing client education and support. Clients were provided with information about their condition individually, via written information and also in a group context.

Specific individualised information, tailored to their individual condition, was provided to clients when they came for appointments. Clients were also provided with written information about UI as appropriate. The clinical team developed materials for client education. Materials took the form of hints sheets, and focussed on common areas often addressed with clients. In addition to these materials, a range of other materials were used. In particular, the Continence Foundation of Australia (CFA) material used for client education.

All clients were invited to appropriate group sessions. Group sessions included those specifically focussing on pelvic floor exercises, a ‘refresher’ group providing revision of information given at individual consultations, and fun group sessions where belly dancing was used to promote understanding of the need to strengthen the pelvic floor musculature.

3.5 Linkages

Linkages were an integral part of the service model. The aim was to provide specialist continence services, but also to link clients back to their normal health care providers and existing health services. A major focus of the project was to generate referral networks, interest, and awareness among generalist health professionals that incontinent patients/clients can be helped with appropriate care. There were two components to linkages – incoming linkages and outgoing linkages.

Outgoing linkages or referrals were built into the activities of The Waterworx Centre. Because services were only being provided on a short-term basis, there was a focus on communication and linking clients back to their existing health service providers, including GPs and other generalist and specialist health service providers. The rationale was twofold. The aim was to inform generalist health practitioners about the services provided to their clients, but also to educate them about current approaches to conservative treatment and management of UI. As general medical practitioners (GP) are integral to primary care, the major focus was on the GP. A linkage letter was sent to every clients’ GP (Appendix 4.5). For clients with more complex needs, Centre staff were available to conduct case conferences with GPs, using the Enhanced Primary Care MBS item numbers. Clients requiring further investigation and/or non-conservative treatment were referred appropriately. Clients requiring ongoing care for their UI after the six month period were referred to local home visiting agencies.

Incoming linkages required different approaches, as they were not under the control of the clinical team. An effort was made to develop linkages that would generate appropriate incoming referrals, information flows and understanding of the services provided by The Waterworx Centre. This required promotion about the availability of the services provided by The Waterworx Centre to generalist health practitioners in general practice, home visiting nursing agencies and hospitals (see section 4.3). A brochure was developed specifically to inform health practitioners about the services provided by The Waterworx Centre. All hospitals in the region were personally visited by a member of the project team targeting discharge liaison officers and appropriate wards, such as maternity, urology and general medical. Although it was identified in the literature that information links and strategies, such as link persons, could promote better links, these strategies were outside the scope of this project.

3.6 Multi-Disciplinary Specialist Staffing

A foundational principle of the project was that The Waterworx Centre be staffed by continence specialists. Furthermore, there was a requirement for multi-disciplinary skills to provide a generalist multi-faceted service. It was considered that, as a minimum, The Waterworx Centre needed to be staffed by CNSs and specialist physiotherapists. Inclusion of a GP on the team would have enhanced the service, although this was not realised for this project.
SECTION FOUR

Implementation and Structure Evaluation: The Waterworx Centre

Section four describes implementation and structure evaluation of the model. Descriptive analyses are reported for the resources provided to implement services provided by The Waterworx Centre, including staffing, management, sources of referrals, client attendances and linkages made. These data are provided for all clients who attended The Waterworx Centre in a twelve month period.

4.1 Staffing

All staff employed in The Waterworx Centre were qualified and/or experienced in continence care. The Waterworx Centre was staffed by CNSs 0.4-0.6 Equivalent Full Time (EFT) and a physiotherapists (0.2 EFT), who were employed by the GCHSD to work solely on this project. They were supported by a research assistant (0.4 EFT), employed by the University. The research assistant provided administrative support for management of The Waterworx Centre, as well as research-related activities. Throughout the whole project, Ms Shona McKenzie (CNS) managed the clinical team, working 0.4 EFT. Although there were some changes in the clinical personnel throughout the life of The Waterworx Centre (for example, due to maternity leave), vacancies were filled by high quality staff with specialist qualifications and skills in continence care provision.

Staff commenced work on the project on 24 February, 2001. Services were offered to clients from March 3rd, 2001 to 22nd February, 2002. During this period The Waterworx Centre operated two days a week as follows:

- Staffed by CNSs and physiotherapists:
  - CNS (0.4-0.6 EFT)
    - 0.6 EFT 24 February, 2001 – 23 November, 2001;
    - 0.4 EFT 23 November – 22 February, 2002
  - Physiotherapists (0.2 EFT)
    - 0.2 EFT 24 February, 2001 – 22 February, 2002
- All staff worked on Fridays, and one CNS worked on Tuesdays.
- The Waterworx Centre closed between December 21, 2001 and January 8, 2002.

An important outcome of implementing this project related to health practitioners’ skill development. The project brought together a multi-disciplinary specialist clinicians who had previously been pursuing their interest in continence care, essentially as lone practitioners. Coming together at The Waterworx Centre provided synergy and a high morale, with clinicians sharing knowledge and skills. The Centre staff were able to engage in activities that developed their own skills including interdisciplinary peer learning, and attending the Gold Coast Hospital to up-skill in the area of undertaking urodynamics. Nurses were up-skilled in the areas of pelvic floor assessment and pelvic floor exercises, while physiotherapists gained skills in relation to taking an holistic approach, working with clients’ aims, integrating regimens within clients social context and activities of daily living. This was facilitated by collaborative development of assessment tools that were used by all members of the clinical team.

The other issue highlighted in the course of managing this project was that there were a very limited number of clinicians with expertise in continence care within the region. During the course of this project, due to maternity leave, there was a requirement to replace clinicians. It was very difficult to find appropriately prepared nurses and physiotherapists to take their places.

4.2 Management of the Service

This project was a result of collaboration between the School of Nursing, Griffith University and the GCHSD, Community Health. An agreement was made between the University and the District for this project to proceed. The Waterworx Centre was established so that the research component and the service component could be separated at the end of the project, enabling The Waterworx Centre to continue to operate and provide clinical services without major disruption. Clinical staff working on this project were employees of the District, which was particularly important in ensuring that clients
attending The Waterworx Centre were clients of the District. All services of The Waterworx Centre were provided free of charge to clients.

The Waterworx Centre operated under the auspices of this project for a one year period. At the conclusion of the project, in February 2002, the management of The Waterworx Centre was transferred to the GCHSD. The GCHSD has provided funding to enable The Waterworx Centre to remain open from March, 2002 until the end of June, 2003, at which time its future will be reviewed. The District has recognised that there is the potential to expand the service to operate from a community centre in the north of the Gold Coast region.

The Waterworx Centre was managed by a Management Committee made up of the research team, the clinical team, the research assistant, the Director of Nursing, Community (GCHSD) and the Clinical Nurse Consultant – Community. The Committee met monthly to discuss management, clinical and research issues related to The Waterworx Centre. Management meetings enabled input, discussion of clinical, research and management issues, feedback on research processes and problem solving. These meetings contributed to a high morale within the clinical team, and enabled a harmonious multi-disciplinary approach to occur. In addition to these informal methods of process evaluation, more formal process evaluation was conducted using the Client Evaluation Survey (see below).

The Waterworx Centre was advised by a multi-disciplinary Advisory Group of health practitioners from the community with an interest in continence care, including physiotherapists and continence nurses (Appendix 2). Although interest in attending advisory group meetings was expressed by GPs and medical specialists, they were unable to attend and submitted their apologies. Dr Malcolm Fraser (consultant obstetrician and editor of The Australian Continence Journal) provided advice and support, but was unable to attend meetings. The Advisory Group provided advice to the project, particularly in the area of developing linkages and promotion of the service. The group met three times.

4.3 Promotion of the Service

Because continence services often have a poor profile within the community, an effort was made to promote the service and raise its visibility with incontinence sufferers, the general community and generalist health professionals. Factors considered in approaches used to promote the service included: developing a corporate and professional identity; using eye-catching, clean, professional, non age-specific, non threatening images; targeting un-serviced groups of sufferers; and the need to create referral networks. Informal methods and word of mouth proved to be most important in promoting the service. Activities aimed to promote the service included:

- Development of quality promotional materials including a pamphlet aimed at sufferers and a poster. These were distributed to general practices, gymnasiums, libraries, bowls clubs, community health centres, childcare centres and pharmacies in the region;
- Development of a quality promotional pamphlet aimed at generalist health professionals. These were distributed to all local general practices, physiotherapists, the community health service and local public and private hospitals;
- Posters promoting group sessions;
- Press releases and special interest stories, resulting in coverage on television and in several local newspapers;
- Presentations to local self help and community groups;
- Information to general practices via faxstream from the local Division of General Practice;
- Presentations at local seminars, conferences, and Continence Foundation Australia functions.

Staff visited many agencies to promote The Waterworx Centre and distribute pamphlets specifically targeting appropriate wards, including:

- Local GP Surgeries;
- Pharmacies;
- Child Health centres;
- Bundall Community Health Centre;
- Gold Coast Hospital: particularly maternity and medical wards. Material was distributed at a senior nurses’ meeting;
- Allamanda Hospital – Stomal Therapist/ Continence Advisor, material given to the nurse educator for distribution;
- Robina Hospital – Discharge Planning Nurse;
• John Flynn Hospital – Nurse Manager and a medical ward;
• Pindarra – Visits to maternity, critical care, medical and surgical wards.

4.4 Sources of Referrals

The ability of the service to address unmet need was reviewed by monitoring the numbers and sources of incoming referrals and client numbers.

Referrals were received from a range of sources, including nursing and allied health and medical practitioners (both GPs and specialists). However, many attending The Waterworx Centre were self referred and were not seeing any health practitioner about their UI at that time (Table 1). The trends in referral sources (Figure 1) show that there were several spikes in sources. These spikes were concurrent with promotional efforts in hospitals, and the media.

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Media</th>
<th>Nursing &amp; Allied Health</th>
<th>Medical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Referral</td>
<td>50</td>
<td>40</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>90</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>193</td>
<td>90</td>
<td>53</td>
</tr>
</tbody>
</table>

NB. ‘Other’ includes: general promotion (posters, pamphlets etc), talks by clinicians at different venues and word of mouth.

Sources of referral are only included for those clients who attended an appointment at The Waterworx Centre, and exclude group attendances.

Table 1: Sources of referral from 19 March 2001 to 28 February 2002

4.5 Client Type and Client Attendances

The Waterworx Centre provided services to men and women suffering UI. Criteria for admission to the centre were that they had UI, were living independently in the community and that they did not suffer dementia.

Unless stipulated, all client attendances are reported for the period of March 3rd, 2001 to 22nd February, 2002, including those who participated in the research study and those who did not (see below). The client waiting period prior to attending The Waterworx Centre was approximately 2-3 weeks. Client attendances are summarised in Table 2.
Attendance Number and Type (as at February 22nd, 2002)

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of attendances at appointments, classes and community groups</td>
<td>731</td>
</tr>
<tr>
<td>Clients attending appointments at least once</td>
<td>203</td>
</tr>
<tr>
<td>Appointments attended (total)</td>
<td>613</td>
</tr>
<tr>
<td>NB. 245 appointments were missed in the period 31 March 2001 to 31 March 2002 – either cancelled or DNA</td>
<td></td>
</tr>
<tr>
<td>Home visits</td>
<td>5</td>
</tr>
<tr>
<td>Group classes (May, 2001 – May, 2002)</td>
<td>113</td>
</tr>
<tr>
<td>Pelvic floor group classes</td>
<td>56</td>
</tr>
<tr>
<td>Refresher class</td>
<td>9</td>
</tr>
<tr>
<td>International Women’s Day Promotion (Belly Dancing)</td>
<td>11</td>
</tr>
<tr>
<td>Pelvic power and tummy tightening Class</td>
<td>37</td>
</tr>
<tr>
<td>Clients participating in the evaluation research</td>
<td>140</td>
</tr>
</tbody>
</table>

Table 2: Client attendances

Analysis of monthly attendance figures at clinical appointments (Figure 2) and a combination of clinical appointments and group sessions (Figure 3) show that demand was steady, with a fall over the 2001 Christmas period, when The Waterworx Centre closed. When figures for new clients (Figure 4) are examined, it can be seen that there was a fall in admission of new clients from the time that staffing time allocation was reduced in late November, 2001. An area of concern is the high number of appointments made that were not attended. This issue was noted and communicated to the GCHSD to be addressed in subsequent management of The Waterworx Centre.
4.6 Linkages

In the short period that the project operated, The Waterworx Centre was very successful in creating a profile and establishing linkages within the region.

4.6.1 Linkages for Client Care

The focus on linkages with GPs was a particular focus. As described above all clients’ GPs received a linkage letter. As time progressed and The Waterworx Centre became better known, more referrals were received from GPs. The focus on linkages resulted in successfully building effective relationships with GPs who were interested in continence care for their clients. Subsequently, these linkages contributed to a greater number of appropriate referrals from these general practices. Clinicians attended case conferences with the following GPs: Dr Hudson, Dr Yu, Dr Coates, Dr Hawney.

Although linkages were made with hospitals, it can be seen that referrals from this source were not as high as was hoped. It had been envisaged that the strategies implemented in this project would lead
to a greater number of referrals from hospitals, particularly on patient discharge. In particular, it was hoped that the strong informal links of staff who worked at the Gold Coast Hospital and other private hospitals would be effective in creating effective informal linkages.

Links were also made to services providing support for clients, such as assisting clients to apply for the financial support schemes for incontinence pads for which they were eligible.

4.6.2 Providing a Hub for Specialists and Generalists in the Region

An aim of the project was to provide a hub for specialist continence services and to develop linkages between existing services. The Waterworx Centre was successful in creating a hub for specialist professional expertise in provision of continence services. Links were made with continence specialists in the Gold Coast region including:

- Dr Malcolm Fraser (obstetrics and gynaecology, Gold Coast Hospital, Editor of the Australian Continence Journal)
- Ms Jenny Nucifora, Focus on Women Physiotherapy
- Ms Melissa Wilson, Urology Nurse Specialist, Gold Coast Hospital
- Dr John Hudson, GP
- Ms Noelene Williams, Bluecare
- Ms Elaine Lambi, Stomal Therapy Clinical Nurse, Allamanda Private Hospital
- Ms Kim Fraser, Research Nurse, Community Health, GCHSD
- Ms Sally Cadden, Project Officer, HACC
- Ms Leanne Bedwell, Stomal Therapist, John Flynn Hospital
- Ms Marie Ku, School of Nursing, Australian Catholic University
- Dr Brian Kirkup, Director, Community Health, GCHSD
- Company representatives – Kimberley Clark, and Sani Care
- Ms Lyn Waddington, CNS, St Vincent’s Community Services
- Ms Trudy Wilson, Registered Nurse, St Vincent’s Community Services
- Ms Sue Bedford, Stomal Therapist / Continence Nurse Advisor, Tweed Community Health

The Waterworx Centre and the supporting Advisory Group provided a means of bringing together health professionals within the region with an interest in UI.

4.6.3 Providing a Venue for Staff Development in Continence Care

The Waterworx Centre provided an important focal point for professional development in the region. In particular, it provided a venue for staff wishing to up-skill in the area of continence care. The following health professionals/students visited The Waterworx Centre for a period to observe the clinic and update their clinical knowledge and skills:

- Ms Michelle Ferris, GCHSD, Community Health
- Ms Judy Grant, GCHSD, Community Health
- Ms Sue Coffee, GCHSD, Community Health
- Ms Monique King, GCHSD, Community Health
- Ms Noelene Williams, Bluecare
- Ms Sue Walker MASS
- 3rd Year Griffith University School of Nursing students
  - 2 for assessment of a community service
  - 5 for a clinical placement
- Leanne Bedwell – Stomal Therapist, John Flynn Hospital
- Physiotherapy student – clinical placement
- Physio students on placement at GC Hospital with Sheridan Guyatt
- Ms Astrid Raines - CNS Rural Community Health, Laidley
- Ms Valerie MacKenzie, CNS Rural Community Health, Laidley
- Lydie Guerin – Physiotherapist (Prince Charles Hospital District)
- Mary McKernan – Project Officer from Redcliffe Caboolture

4.7 Other Staff Activities

Staff of The Waterworx Centre participated in other activities related to continence care including:

- Promotion of The Waterworx Centre at a Continence Awareness Week function
- Information sessions about UI at Continence Awareness Week function
- Information sessions about UI for community groups
- Participation in a State funded HACC review focus group for the Gold Coast region. The project officer also interviewed the principal researcher and the clinical coordinator about the Waterworx project, and considered it a clinical practice model that could be duplicated in other regions.
- Providing information and support to other health regions that were planning continence services.
SECTION FIVE

Methods for Process and Outcome Evaluation

5.1 Introduction

Donabedian (1970) suggested that the quality of healthcare could be evaluated within the three distinct domains of structure, process and outcome. Structure evaluation examines the resources available to provide healthcare. Process evaluation is concerned with the extent to which health professionals provide the services required and outcome evaluation investigates the change in the client's condition following the intervention (Donabedian, 1992).

Following Donabedian's early work Bloch (1975) advocated the combining of process and outcome in the evaluation of programs. As the Making the Links project was concerned with evaluating the multi-disciplinary Waterworx Continence Centre it was decided that structure, process and outcomes evaluations of the service would be undertaken.

Structure evaluation refers to the evaluation techniques undertaken to explore the resources available to provide the services of the Waterworx Continence Centre and to assess the appropriateness of these resources. For the purposes of this study structure evaluation consisted of exploring both the level of service provided and the resources required to provide this level of service. Thus in Section Four descriptive analyses were reported for the source of referrals to the Waterworx Centre, the numbers of clients who attended the Waterworx Centre, and the number and types of linkages made for the clients. A financial report of the costs of providing these are provided under separate cover.

The following sections are concerned with the process and outcome evaluation of the project. The process evaluation incorporated health professional informal evaluation and the Client Evaluation Survey. The outcome evaluation was multifaceted and addressed outcomes in terms of symptoms, costs, health-related quality of life and client knowledge regarding conservative management principles.

5.2 Study Design

Process and outcome evaluation of the model was undertaken using a multi-method, longitudinal approach focusing on a range of parameters. The study incorporated pretest - posttest design with data being collected before initial consultation at the Waterworx Centre and then at three months and six months following the initial consultation.

5.3 Recruitment and Data Collection Process

All participants who sought the services of The Waterworx Centre between March 2001 and February 2002 were invited to participate in the research project. When potential clients of the Waterworx Centre telephoned for an appointment they were booked for an appointment and sent information about The Waterworx Centre (Appendix 3), a bladder diary and instructions regarding how to complete the bladder diary (Appendix 4.6) and a ICS Urinary Symptom Index questionnaire (Appendix 8 & 9). The clinicians used these measures as part of their comprehensive initial assessment. If the client consented to participate in the research study this material was also used for the outcome evaluation.

When clients attended their first appointment at The Waterworx Centre, the research study was explained to them and they were given an information sheet to read (Appendix 5). If the clients were willing to participate they were asked to sign the consent form (Appendix 6) and to complete the initial client questionnaire (Appendix 10). This initial survey contained questions related to the client's demographic profile, their health-related quality of life (HR-QoL) and knowledge of the causes of incontinence and the principles of conservative management. It was also explained that if they consented to be involved in the study, information from the bladder diary, the ICS Urinary Symptom Index, the 24-hour pad test and the clinical assessment data recorded by the health professionals would also become part of the study data.
At the end of the first appointment clients were given the Cost Index and asked to complete this at home within the next 24 hours and return it to the research assistant in the stamped addressed envelope that was attached. Those participants for whom a pad test was considered appropriate by the clinicians were given the materials to complete the test and instructions and returned the pads the following week. Participants were also informed that, whether they were still attending the Waterworx Centre or not, in three and six months they would be asked to complete a number of follow-up questionnaires.

At the three and six month data collection point, clients were either given the data collection instruments to complete during a Waterworx Centre visit (if they were still attending) or sent the instruments in the post and asked to return them in the envelope provided. At the three-month point clients were asked to complete the ICS Symptom Index, the HR-QoL measure, the knowledge test and the Client Evaluation Survey (Appendix 7). At the six month follow-up the clients were asked to complete the ICF Symptoms Index, the HR-QoL measure and the Cost Index.

5.4 Data Collection Instruments

The data collection instruments were chosen or designed to collect accurate information about the demographic profile of the research participants as well as the process and outcome evaluation measures. The main client outcome instruments and measures used to evaluate the services provided by The Waterworx Centre were:

- Chart audit
- Physical measures of UI and pelvic floor strength and endurance
- International Continence Society Symptom Index (ICF Symptom Index) – male and female
- Health related HR-QoL as measured by the Medical Outcomes Studies SF-36 (SF-36)
- Knowledge test – related to important continence promoting self-care strategies
- Cost index – measuring the cost of UI to the client

5.4.1 Chart Audit

The research tools were specifically designed to complement the clinical charts, so that clients were not asked for any piece of information twice. The research team designed chart audit tools that were used to extract data relating to client demographics, medical history and clinical assessment. The clinicians collected the information and the research assistant transcribed this information onto the chart audit forms. Information garnered from chart audits included:

- Demographic information: age, sex, place of birth, employment status
- How long continence has been experienced in years
- Previous care for UI
- Medical and surgical information
- Mobility and dexterity impairment
- Number of incontinence episodes in 24 hours from the bladder diary
- Results of 24 hour pad test in mg.
- Residual urine in mls: conducted by clinicians following voiding using a bladder scanner
- Current medication regime
- Pelvic floor strength and endurance: assessed by clinicians as per scale in assessment chart
- Incontinence type: based on clinical assessment
- Number of visits to The Waterworx Centre

The first chart audit was carried out at the initial appointment. If the client was still attending the Waterworx Centre at the three and six-month follow-up points the charts were audited again. If the client was not attending the service then these data were not collected.

5.4.2 Physical Measures of Incontinence

Two physical measures were used to measure UI severity and change over time: the 24 hour pad test and pelvic floor endurance and strength.

5.4.2.1 24-hour pad test

A 24-hour pad test was conducted with those participants for whom clinicians considered a pad test was appropriate. They were given a plastic bag and pads, all of which had been weighed.
Participants placed all the pads they used over a 24 hour period into the plastic bag. At the completion of the 24-hour period they returned the bag to the Waterworx Centre, where it was weighed. The weight of the returned pads was subtracted from the original weight and the amount of urine leakage in 24 hours was then expressed in milligrams.

5.4.2.2 Pelvic floor endurance and strength
Pelvic floor endurance and strength was assessed by clinicians as per the scale in the clinical assessment chart. At the beginning of the project, the CNSs engaged in staff development in order to develop their skills in making these assessments. The measurements were based on clinician assessment.

5.4.3 Health-Related Quality of Life Questionnaire
The instrument used to measure health related quality of life in this study was the Medical Outcomes Study – Short Form 36 (SF-36). The SF-36 is a well-validated tool designed to measure generic manifestations of health-related quality of life. It does not provide information related concepts specific to any age, disease, or treatment group (Ware & Sherbourne, 1992; Ware, Kosinski, Bayliss et al., 1995).

The SF-36 has three levels: 1) 36 individual items, 2) eight scales that aggregate 2-10 items each, and 3) two summary measures that aggregate scales. All but one of the 36 items (self-reported health transition) are used to score the eight SF-36 scales. Each item is used in scoring only one scale. The eight scales are: Physical Functioning (PF), Role-Physical (R-P), Bodily Pain (BP), Mental Health (MH), Role-Emotional (R-E), Social Functioning (SF), Vitality (V) and General Health (GH).

The eight scales are hypothesised to form two distinct higher-ordered clusters called the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Factor analysis has confirmed physical and mental health factors that account for 80-85% of the reliable variance in the eight scales in the US general population (Ware, Kosinski, & Keller, 1994), among patients included in the original research (McHorney, Ware Jnr, & Raczek, 1993; Ware et al., 1994), and in general populations in Sweden (Sullivan, Karlsson, Bengtsson, & Steen, 1994) and the UK (Ware et al., 1994). Three scales (Physical Functioning, Role-Physical, Bodily Pain) correlate most highly with the physical component and contribute most to the scoring of the PCS measure (Ware et al., 1994). The mental component correlates most highly with the Mental Health, Role-Emotional, and Social Functioning scales, which also contribute most to the scoring of the MCS measure. Three of the scales (Vitality, General Health, and Social Functioning) have correlations with both components.

The SF-36 has been designed so that items shown in the same scale can be aggregated without score standardisation or item weighing (Ware et al., 1994). Standardisation of items within a scale was avoided by selecting or constructing items with roughly equivalent means and standard deviations. Weighing was avoided by using equally representative items (that is, items with roughly equivalent relationships to the underlying scale dimension). All items have been shown to correlate substantially (greater than 0.40, corrected for overlap) with their hypothesised scales with rare exceptions (McHorney et al., 1994; Ware et al., 1994). These results support analysis as interval-level measurement scales.

The reliability of the eight scales and two summary measures has been estimated using both internal consistency and test-retest methods. With rare exceptions, published reliability statistics have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons; most have exceeded 0.80 (McHorney et al., 1994; Ware et al., 1994). Reliability estimates for physical and mental summary scores usually exceed 0.90 (Ware et al., 1994).

The content validity of the SF-36 has been compared to that of other widely used generic health surveys (Ware et al., 1994; Ware et al., 1995). Systematic comparisons indicate that the SF-36 includes eight of the most frequently represented health concepts. Among the content areas included in widely-used surveys, but not included in the SF-36, are: sleep adequacy, cognitive functioning, sexual functioning, health distress, family functioning, self-esteem, eating, recreation/hobbies, communication, and symptoms/problems that are specific to one condition.
5.4.4 Urinary Symptom Index Questionnaire

As the SF-36 does not measure disease specific health-related issues, symptom severity or the impact of illness on issues such as sexuality research, participants were also asked to complete a specific urinary symptom scale. There are a number of symptom scales reported in the literature such as the American Urological Association Symptom Index (Barry, Fowler, & O'Leary, 1992), the EORTC genitourinary group questionnaire (Fossa, Aaronson, Newling, & et al., 1990) and the MUSIQ (Robinson et al., 2002). In this study the International Continence Society (ICS) scales for men and women was used. These scales were chosen because they have been developed and tested over a long period, they have high levels of psychometric validity and reliability (Donovan et al., 1996) and they were developed with the expressed intention of characterising symptom severity, impact on quality of life and to evaluate treatment outcome (Jackson et al., 1996).

The ICSmale was initially designed to assess urinary incontinence in men enrolled in the “Benign Prostatic Hyperplasia” study conducted by the ICS. This instrument includes 32 items with multiple-choice answers, 25 of which have associated questions that ask how much the symptom is a problem for the respondent. There are also two open-ended questions that ask about the bothersomeness and worrisomeness of different symptoms. The multiple choice questions relate to frequency of urination and incontinence, severity of incontinence, severity of symptoms related to voiding problems and storage problems, sexual problems and one question on the effect of incontinence on lifestyle. In 2000 a short form of the ICSmale was developed. The ICSmale – Short Form (ICSmale-SF) has 11 items related to two distinct factors of voiding and incontinence symptoms. In this study the long form of the questionnaire was used.

The reliability of both the long and short forms of the ICSmale is reported as being high. The Cronbach’s alpha for the symptoms in the long form was 0.86 and for the bothersomness scale was 0.91 (Donovan et al., 1996). For the short form the voiding scale recorded a Cronbach’s alpha of 0.76 and the incontinence scale a Cronbach’s alpha of 0.78 (Donovan et al., 2000).

The ICSfemale was specifically developed to assess lower urinary tract symptoms in women. It was based on the ICSmale questionnaire and was specifically adapted for use in women (Jackson et al., 1996). It has 33 items, one of which is an open-ended item requiring a qualitative response. This instrument is divided into four sections: incontinence frequency, type and severity, effect of incontinence on sexual matters, effect of incontinence on lifestyle and overall effect on quality of life. In addition, there are 22 items in which the respondent is asked about the bothersomeness of the symptom. The Cronbach’s alpha scores of the symptom questions and the bothersomeness questions were 0.78 and 0.85 respectively (Jackson et al., 1996).

5.4.5 Knowledge Test

Changes in knowledge were evaluated using a research-developed knowledge test. The clinicians involved in the study devised a simple nine item multiple-choice test, based on current knowledge about UI. Educators experienced in the design of multiple-choice test questions reviewed the test and refined the questions and layout of the questionnaire.

5.4.6 Cost Index Questionnaire

A modified Dowell/Bryant tool (Simons, Prashar, & Moore, 1998; Dowell, Bryant, Moore, & Simons, 1999) was used to estimate the cost of UI to community-dwelling women. Dowell, et al. (1999) found that the tool had test-retest reliability. Construct validity of the tool was confirmed by significant correlation with other measures of incontinence (p=0.001). The personal incontinence expenditure section of the Dowell/Bryant tool was used in the tool for this study, which asked participants to identify the cost of laundry, disposable and reusable incontinence products and ‘other’. In addition to these items, participants were asked to estimate the extra costs of cleaning products, hygiene products, extra clothing using the same question layout (Appendix 11).

5.4.7 Client Evaluation Questionnaire

A search of available patient satisfaction literature in both CINAHL and Medline databases, failed to identify a “gold standard” patient satisfaction survey tool to measure service delivery in a community continence clinic. With no validated tool available, the research team developed a Client Evaluation Survey questionnaire (Appendix 7) using the five domains of care described by Nelson (1990).
Specific questions were adapted from the patient satisfaction survey questionnaire used by Thomas et al. (1997), that was originally developed to assess patient satisfaction with a community oncology clinic in Britain, with a test-retest reliability calculated using Pearson’s Product Moment Correlation Coefficient of $r = 0.684$.

The researcher-developed tool used twenty-six questions to determine clients’ level of satisfaction with The Waterworx Centre’s service using four domains of care, including:
- Access
- Clinical technical management
- Interpersonal management
- Continuity of care

The domain relating to administrative technical management was not included because this was a free service, the other aspects within this domain were included in other domains.

Two expert clinical CNSs and the research team members examined the final survey questionnaire. It was determined that the tool reflected the specific clinical services provided at the Waterworx Community Continence Clinic. The questionnaire was not tested for reliability or validity, because of a limited sample size. These limitations should be considered when interpreting the findings of this evaluation.

In addition to the four domains of care, further questions focused on participants’ knowledge of other continence services and links with other service providers. Further to these questions, respondents were given an opportunity to provide written comment and feedback.

In addition to the questionnaire, informal feedback from clients was noted throughout the project. This informal feedback was used as formative evaluation throughout the project.

5.5 Ethical Considerations

Prior to any data collection, this study was approved by the Griffith University Human Ethics Committee and the GCHSD Ethics Committee. All participants were provided with an information sheet, had any questions answered and signed a consent form. Data was collected by the research assistant, and only the research team had access to the raw data. Results were only provided to the clinical team in aggregated form. Those who did not attend The Waterworx Centre, or elected to complete questionnaires at home returned them using a reply paid envelope.

Data were stored in a locked filing cabinet in an office at the health facility for the duration of the project. On completion of the project, the research materials were transferred to the University, where they are kept in a locked filing cabinet in the researcher’s office. They will be kept for a period of 5 years.

It was made clear to participants throughout the study that participation in the study would not affect treatment, and that they were free to withdraw at any time without explanation. The benefits of this project to participants were that they were having their UI problems addressed.

5.6 Limitations of Study Design

There are limitations to this study. Care should be taken with interpretation of results because process and outcome evaluation was based on a convenience sample. Participants consenting to participate in the study did not all complete all tools. Further, there was variation in the number of attendances at The Waterworx Centre. However, it should be noted that perusal of the literature demonstrates that there is often difficulty in obtaining large or random sample sizes for studies related to UI in community-dwelling populations. These all contribute to a lack of a control and missing data due to attrition. Thus, caution should be taken with any generalisation of results. However, this study does provide some information about outcomes, particularly in relation to women who would otherwise not access services.

The main issue arising from the conduct of the project was that of attrition. All participants attended the first appointment. However, many participants did not return for further appointments. Reasons
for this could have been because one appointment was all that they required, or because they did not feel that the services were appropriate for their needs.

This study incorporated only a pretest-posttest design rather than a randomised controlled trial because the benefits of conservative management over no treatment, for incontinence is well established and it was not deemed ethical to leave one group untreated. The study design is weak as the participants’ responses to treatment cannot be compared with untreated controls. However, the two follow-up data collection points do allow for the estimation of long-term effect of treatment.

The use of the SF-36 as the generic health-related quality of life measure was appropriate because of the widespread use of this instrument in assessing the outcome of health related interventions. However, it is known that often a pre-test conducted on a patient population prior to intervention may result in higher than expected scores (Goedhart & Hoogstraten, 1992; Kreulen, Stommel, Gutek, Burns, & Braden, 2000; Pratt, McGuigan, & Katzev, 2000). In many psychological studies in which the SF-36 or equivalent measures are used researchers are now incorporating retrospective pre-tests. It is thought that once client groups have been sensitised to their problems and how much they impact on their quality of life, having been exposed to an intervention, that they then score their quality of life lower in the post-test. Often, if asked to complete a retrospective pre-test, clients will score themselves much lower in hindsight than they actually scored themselves at pre-test itself. This study did not include a retrospective pre-test and this is a limitation of the study.
SECTION SIX

Description of Study Participants

6.1 Demographic Data

Of nearly 200 clients who accessed the services of the Waterworx centre during the project period, 140 agreed to participate in the process and outcome research study. The process and outcome evaluation was conducted on these participants. The following section describes the study participants and provides some comparative data between the group that completed follow-up to three months and those who dropped out of the study before the three months data collection was completed. There was wide variability in the research participants. Table 3 gives a summary of the demographic data related to all the research participants. The average age of the clients was 65.2 years (n=140; sd=12.25), however, the age range was 33 years to 88 years and there were 46.4% of the clients who were under 65 years of age. The clients were generally well educated and most were retired, Australian born, women, who either lived with a partner or lived alone.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Grouping</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Female</td>
<td>123</td>
<td>87.9</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>17</td>
<td>12.1</td>
</tr>
<tr>
<td>Australian born</td>
<td>Yes</td>
<td>109</td>
<td>78.4</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>30</td>
<td>21.6</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>81</td>
<td>59.6</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>25</td>
<td>18.4</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>20</td>
<td>14.7</td>
</tr>
<tr>
<td></td>
<td>Never married</td>
<td>5</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>De Facto</td>
<td>3</td>
<td>2.2</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Highest level of formal education</td>
<td>Primary school</td>
<td>10</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>Secondary school</td>
<td>70</td>
<td>51.9</td>
</tr>
<tr>
<td></td>
<td>Apprenticeship</td>
<td>7</td>
<td>5.2</td>
</tr>
<tr>
<td></td>
<td>Trade school TAFE</td>
<td>18</td>
<td>13.3</td>
</tr>
<tr>
<td></td>
<td>College</td>
<td>18</td>
<td>13.3</td>
</tr>
<tr>
<td></td>
<td>University</td>
<td>12</td>
<td>8.9</td>
</tr>
<tr>
<td>Employment</td>
<td>Pensioner/benefit recipient</td>
<td>54</td>
<td>38.8</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>45</td>
<td>32.4</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>22</td>
<td>15.8</td>
</tr>
<tr>
<td></td>
<td>Home duties</td>
<td>16</td>
<td>11.5</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2</td>
<td>1.4</td>
</tr>
<tr>
<td>Location of abode</td>
<td>South of Surfer’s Paradise</td>
<td>115</td>
<td>82.1</td>
</tr>
<tr>
<td></td>
<td>North of Surfer’s Paradise</td>
<td>25</td>
<td>17.9</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>Spouse/partner only</td>
<td>61</td>
<td>45.2</td>
</tr>
<tr>
<td></td>
<td>Alone</td>
<td>42</td>
<td>31.1</td>
</tr>
<tr>
<td></td>
<td>Spouse/partner + children</td>
<td>21</td>
<td>15.6</td>
</tr>
<tr>
<td></td>
<td>Friends/other family</td>
<td>8</td>
<td>5.9</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Table 3: Summary of demographic data for client group

6.2 Medical History

Over half of the research participants of The Waterworx Centre reported co-morbidities (See Table 4). Nearly 46% of the female clients had undergone a hysterectomy (n=140) and over 20% had had a pelvic floor or bladder repair previously.
Variable | Group | n | Percentage of sample
---|---|---|---
Medical History - General (n=140) | Back pain | 40 | 28.8
 | Respiratory problems | 32 | 23.0
 | Neurological problems | 14 | 10.1
 | Spinal injury | 8 | 5.8
 | CVA | 6 | 4.3
 | MS | 1 | 0.7

- Females (n=121) | Abdominal hysterectomy | 44 | 36.1
 | Vaginal hysterectomy | 12 | 9.8
 | Pelvic floor repair | 7 | 5.7
 | Bladder repair | 20 | 16.4

- Males (n=17) | Medical / surgical other | 7 | 41.2
 | Enlarged prostate | 6 | 40.0
 | TUR | 5 | 29.4

NB. None of the males had had a urethral dilatation, bladder neck surgery or sphincterotomy

**Table 4: Medical history of sample**

### 6.3 History of Incontinence

The mean length of time this group had suffered with UI was 9.1 years (n=134; s.d.=12.6; range 1 month to 70 years). The most common types of UI were urge incontinence (72.1%; 101/138) and stress incontinence (68.6%; 96/138), with many having both urge and stress incontinence. Other types of incontinence included overflow incontinence (7%; 10/138), reflex incontinence (0.7%; 1/138) and ‘other’ (22%; 32/138). A few clients were taking prescribed drugs to treat their incontinence, including Pro-Banthine (n=1), Oxybutynin (n=1), Tofranil (n=1) and Oestrogens (n=16).

Most of the clients had sought help from health professionals before (see Table 5 below), although only 1.4% (2/139) had sought help from a CNS and 7.9% (11/139) from a physiotherapist.

| Variable | Group | n | %
---|---|---|---
Previous care (n=138) | Yes | 50 | 36.3
 | No | 88 | 63.7

Previous Caregiver (n=139) | GP | 62 | 44.5
 | Medical Specialist | 53 | 38.1
 | Hospital | 11 | 7.9
 | CNS | 2 | 1.4
 | Home nursing service | 1 | 0.7
 | Physiotherapist | 11 | 7.9
 | Other | 6 | 4.3

**Table 5: Health professionals accessed for incontinence by clients prior to attending The Waterworx Centre**

None of the sample group were chair bound or had difficulty with distance to the toilet. However, 11.4% (16/138) had some mobility impairment, 10% (14/138) used a walking aid, and 5.7% (8/138) had limited manual dexterity.

### 6.4 Comparison Between Completers and Non-completers at Three Month Follow-Up

The group that completed the three month follow-up were similar to those who did not complete follow-up with regards to mean age (64.6 years v 65.6 years t=0.46; p=0.65); sex (chi square = 1.19; p=0.27) and scores in the urinary symptoms indices and SF-36 scales and summary measures. However, the group that did not complete data collection had fewer scheduled appointments, on average (2.73 v 4.28 t=-5.43; p<0.0001) and made fewer visits, on average, to the Waterworx Centre (appointments and classes) (3.07 v 4.84 t=-4.66; p<0.0001).
SECTION SEVEN

Process Evaluation Results

7.1 Overview

Of the 140 research participants, there were 61 responses to the Client Evaluation Survey, indicating a response rate of 43.5%. Results are outlined in Table 6. The survey used Likert-type scales, asking participants to indicate “strongly agree”, “agree”, “unsure”, “disagree”, or “strongly disagree” to statements. Respondents also had the opportunity to provide written comment. Questions focused on overall satisfaction, access, technical management, interpersonal communication and continuity of care. In addition to these domains of care, question 13 addressed clients’ perceptions of change in their knowledge about their condition. This question is discussed below in section eight. Question 14 asked about the usefulness of educational packages provided to clients “The information/education packages did not provide me with any useful information”. Only 5.2% Strongly Agreed with this statement, while 5.2% remained unsure. The remaining 89.6% (Disagree - 37.9% and Strongly disagree - 51.7%) indicated that the packages and information provided useful information.
Table 6: Client evaluation survey

<table>
<thead>
<tr>
<th>N=61</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The clinic is conveniently located for me</td>
<td>49.2%</td>
<td>42.6%</td>
<td>1.6%</td>
<td>3.3%</td>
</tr>
<tr>
<td>2</td>
<td>Transport to the clinic is a problem for me because of my incontinence</td>
<td>1.7%</td>
<td>1.7%</td>
<td>1.7%</td>
<td>38.3%</td>
</tr>
<tr>
<td>3</td>
<td>I believe the waiting time at the clinic is too long</td>
<td>4.9%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>36.1%</td>
</tr>
<tr>
<td>4</td>
<td>I always see the same nurse or physiotherapist every visit</td>
<td>51.7%</td>
<td>37.9%</td>
<td>3.4%</td>
<td>5.2%</td>
</tr>
<tr>
<td>5</td>
<td>It is important for me to see the same nurse or physiotherapist each time I visit the clinic</td>
<td>42.6%</td>
<td>41.0%</td>
<td>6.6%</td>
<td>8.2%</td>
</tr>
<tr>
<td>6</td>
<td>I was aware of other continence services before being referred by the clinic staff</td>
<td>8.2%</td>
<td>11.5%</td>
<td>13.1%</td>
<td>34.4%</td>
</tr>
<tr>
<td>7</td>
<td>I used other health services for my continence problem before being referred by the clinic staff</td>
<td>8.5%</td>
<td>11.9%</td>
<td>6.8%</td>
<td>37.3%</td>
</tr>
<tr>
<td>8</td>
<td>The clinical (nurse &amp; physiotherapist) understood my personal continence problem</td>
<td>73.8%</td>
<td>24.6%</td>
<td>0.0%</td>
<td>1.6%</td>
</tr>
<tr>
<td>9</td>
<td>I was satisfied with the explanations the clinical staff provided about my continence problem</td>
<td>73.8%</td>
<td>26.2%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>10</td>
<td>I always felt the clinical staff spent the right amount of time with me during my visits</td>
<td>77.0%</td>
<td>23.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>11</td>
<td>I always felt confident with the clinical skills of the nurse/physiotherapist during my visit</td>
<td>80.3%</td>
<td>19.7%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>12</td>
<td>I wish to know as much as possible about my continence problem</td>
<td>71.7%</td>
<td>28.3%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>13</td>
<td>Since visiting the clinic - my knowledge about my continence problem has improved</td>
<td>72.1%</td>
<td>27.9%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>14</td>
<td>The information/education packages did not provide me with any useful information</td>
<td>5.2%</td>
<td>0.0%</td>
<td>5.2%</td>
<td>37.9%</td>
</tr>
<tr>
<td>15</td>
<td>I prefer to leave the decisions about my continence care/management to the health professionals</td>
<td>36.2%</td>
<td>25.9%</td>
<td>12.1%</td>
<td>15.5%</td>
</tr>
<tr>
<td>16</td>
<td>I found it easy to ask the clinical staff questions about my continence problem</td>
<td>72.9%</td>
<td>27.1%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>17</td>
<td>I feel very anxious/nervous when I come to the clinic</td>
<td>0.0%</td>
<td>0.0%</td>
<td>7.0%</td>
<td>45.6%</td>
</tr>
<tr>
<td>18</td>
<td>My level of anxiety is related to feelings of embarrassment about coming to the clinic for my continence problem</td>
<td>1.7%</td>
<td>8.6%</td>
<td>1.7%</td>
<td>46.6%</td>
</tr>
<tr>
<td>19</td>
<td>Overall I think the standard of care at the Waterworx Centre is very good</td>
<td>83.1%</td>
<td>13.6%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>20</td>
<td>Overall I think there are many improvements that could be made to the Centre</td>
<td>1.8%</td>
<td>1.8%</td>
<td>14.0%</td>
<td>45.6%</td>
</tr>
</tbody>
</table>

7.2 Overall Satisfaction with the Services of the The Waterworx Centre

Clients were asked to rate their overall satisfaction with the standard of care provided at The Waterworx Centre by responding to the question: “Overall I think the standard of care at the Waterworx Centre is very good”. Analysis indicated an extremely high level of satisfaction with the standard of care at the Centre. The responses were polarised between the two highest categories and the lowest category. Of the 61 responses, 96.7% ranked their satisfaction in the two highest categories (Strongly Agree 83.1% and Agree, 13.6%), with 3.4% ranking at the lowest scale (Strongly Disagree). Qualitative responses supported these results, for example:

Accessibility; professional service; great service for the community. (Participant No. 53).

Staff – well trained and very helpful and dedicated, making it easy to relate about a difficult problem. Health program – well worth attending for all people. Staff to be congratulated. (Participant No. 46).

I was informed of this service by a social worker when she came to see me re: home care. It’s a very worthwhile clinic. Although I am handicapped in various ways, it has helped. It was a great relief to speak to someone about my problem. I enjoyed the exercise classes with other women in the same predicament. (Participant No. 62)
Has given me back my confidence again. I can help myself to control the leaking and feel very happy to know I don’t need another operation. (Participant No. 14)

Responses to the question 26 asking “What is the worst aspect of the clinic for you personally?” was included to identify any negative aspects of the clinic. However, the majority of the responses did not indicate any aspects of the clinic that were negative.

Have not found any worst aspect for myself, all staff are very caring, and couldn’t be more helpful. (Participant No. 14)

Don’t have one[worst aspect]. (Participant No. 113)

None that I can think of. (Participant No. 68)

Negative comments that were made related to access, the needs of the research assistant and the embarrassment of having urinary incontinence.

Two respondents identified issues with parking and travelling to The Waterworx Centre:

Parking problems. (Participant No. 55)
The travelling from my home to the clinic. Holiday time and INDY [Indycar car street race carnival] it takes nearly two hours from home to clinic. Quite a problem when you are incontinent. THERE ARE NO TOILETS ON THE BUS. (Participant No. 90)

One respondent noted that she was younger than others at the clinic:

If I had a worst [thing], it would have to be my age, as most other ladies are much older than I. (Participant No. 5)

Two respondents commented on the lack of space and facilities for the research assistant:

Lack of office space for the researcher. (Participant No. 6)
The staff provide a professional service and should be supplied with appropriate facilities, especially appropriate reception desk and storage facilities. The make-shift arrangements at Palm Beach Community Health seem to indicate a lack of commitment to staff conditions, in contrast to the commitment shown by staff for their clients.

The only other negative issue was embarrassment at having a continence problem:

No worst aspect outside of having the embarrassment of continence. (Participant No. 25)

Embarrassment talking about it. (Participant No. 52)

Having a continence problem in the first place. (Participant No. 88)

7.3 Domain of Care One: Access

Issues considered in the Access domain of care were the location of the clinic, transport to the clinic and waiting time. Four questions were summed to determine a score for the Access domain: questions 1, 2, 3 and 22. The total scores for the Access domain indicated a very high level of satisfaction. A total of 99.9% of responses scored between 15 and 20 (20 being the highest possible score and 4 being the lowest possible score).

Location was considered in question 1, which asked respondents to respond to the statement “The clinic is conveniently located for me”. Responses indicated that the Palm Beach Currumbin location provided a high level of satisfaction for the target client group. A total of 91.8% of responses indicated a high level of satisfaction to this question (49.2% Strongly Agreed and 42.6% Agreed). Only 6.6% answered strongly disagreed (3.3%) or Disagreed (3.3%).

Responses to the statement 2 “Transport to the clinic is a problem for me because of my incontinence” indicated that access to The Waterworx Centre related to their UI was not a significant problem for the largest majority of clients, with 95% (Strongly Disagree – 56.7%; Disagree – 38.3%) with the statement.
Question 22 asked participants “How long do you usually have to wait in the clinic before being seen by the clinical staff?” Clients had minimal waiting times at the clinic, with 94.9% of responses indicating a waiting time of less than 15 minutes and only 5.1% waiting more than 15 minutes, but less than 30 minutes.

When asked how they travelled to the clinic, the responses were: car 76%, bus 11.9%, taxi 1.7%, other 1.7%, walk 6.8% and walk or bus 1.7%.

7.4 Domain of Care Two: Clinical Technical Management

Domain Two, which included questions 8, 9 and 11, assessed clients’ satisfaction with the clinical, technical and communication skills of clinical staff in the provision of care. Respondents were asked to respond the statements: “The clinical [nurse and physiotherapist] understood my personal continence problem”, “I was satisfied with the explanations the clinical staff provided about my continence problem” and “I always felt confident with the clinical skills of the nurse or physiotherapist during my visit”. The results from these questions were summed to achieve a score, with the highest possible score being 15 and the lowest being 3.

Questions, 8, 9, 11 were reverse scored and summed to determine a possible score out of 15, with 15 being the highest and 3 being the lowest score. A total of 100% of responses between 12 and 15.

Qualitative responses supported these results, for example:

- Staff well trained and very helpful and dedicated, making it easy to relate about a difficult problem. Health Program – well worth attending for all people. Staff to be congratulated. (Participant No.46)
- Confidence. I know more about what is occurring, feel positive about the condition, since the information from the ‘girls’ (sic). (Participant No. 52)
- The thoroughness and caring staff. (Participant No. 6)

7.5 Domain of Care Three: Interpersonal Management

The third domain of care, based on questions 10 and 16, surveyed the interpersonal skills of the Centre staff, including: the physical time spent during each consultation, and the ease of communicating with the clinical staff about their condition. The questions were “I always felt the clinical staff spent the right amount of time with me during my visits” (Question 10); and “I found it easy to ask the clinical staff questions about my continence problem” (Question 25). Analysis indicated a very high level of satisfaction in this domain, with a 100% positive response rate, either Strongly Agree or Agree (See Appendix 5).

Qualitative responses to question 25, which asked “What is the best aspect of the clinic for you personally?” supported these results:

- Sympathetic care and attention. (Participant No. 2)
- Help with incontinence and the wonderful staff reminding me to keep working on it. (Participant No. 6)
- The wonderful staff and the caring and interest shown to me personally and also the confidence gained by attending the clinic, to attend to my problem. (Participant No. 27)
- “The staff were courteous, punctual, pleasant and ‘interested’. (Participant No. 38)

7.6 Domain of Care Four: Continuity of Care

Satisfaction within the Continuity of Care domain was measured by two questions. Question 4 was used to determine if the participants saw the same nurse or physiotherapist at each consultation: “I always see the same nurse or physiotherapist every visit”. Question 5 identified whether respondents perceived this to be an important aspect of their care: “It is important for me to see the same nurse or physiotherapist each time I visit the clinic.”

Analysis indicated that 89.6% of participants did see the same clinician (Strongly Agree - 51.7% or Agree - 37.9%), while 6.9% responded negatively with Strongly Disagree (1.7%) and Disagree (5.2%).

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Responses to the second question (Q 5) in this domain indicated that, for most (strongly Agree - 42.6% and Agree 41.0%) it was important for them to have continuity of care, although some disagreed with this statement (9.8%) and 6.6% remained undecided.

Again, results were supported by qualitative responses:

I see the same nurse each time, she is very understanding and easy to talk to. I no longer feel that I am the only one with this problem and that I can improve things by following the nurse’s instructions. I am very grateful for the help I have received. (Participant No. 88)

7.7 Use of other Continence Services

The Client Evaluation Survey included questions that sought to identify participants’ knowledge of other continence services, and the services they used.

Question 6, 7 and 23 identified participants’ knowledge of other continence services and the continence services they accessed following referral from The Waterworx Centre. Question 6 asked for a response to the statement “I was aware of other continence services before being referred by the clinic staff”. Of the responses, 67.2% (strongly disagree 32.8% and 34.4% disagree), indicated that the majority of clients were not aware of other available continence services prior to attending The Waterworx Centre.

To identify what services were accessed prior to attending The Waterworx Centre, Question 7 asked participants to respond to the statement “I used other health services for my continence problem before being referred by the clinic.” Responses indicated that the majority 72.9% (35.6% Strongly Disagree and 37.3% Disagree) of clients had not accessed other health care services prior to attending the clinic. The remaining 20.4% (Strongly Agree 8.5% and agree – 11.9%) were using other services prior to coming to the clinic, while 6.7% were unsure.

Question 23 aimed to identify services used following referral from the clinic to other health services by asking “Can you name the services you used after being referred from the clinic?” Responses indicated that 37 participants had accessed at least one other continence service (GP, physiotherapist, specialist, nurse specialist, or other service provider) after being referred from The Waterworx Centre. Within this group, 11 clients used more than one service and 21 clients did not access any other services.

7.8 Limitations of the Client Evaluation Survey

The small response rate to the Client Evaluation Survey (43.5%) poses a limitation to the findings of this survey.

The survey was distributed only once to participants. The two different collection methods used may also pose a limitation to the findings of the survey. Some surveys were completed while the participant was still in attendance at The Waterworx Centre, while other surveys were completed after leaving the Centre and were posted back. The lapse in time between distribution and collection has not been identified and this may have implications to the responses noted on the survey.

The processes involved in the provision of multidisciplinary care through The Waterworx Centre were evaluated in both a formal and informal manner. Initially, it was hoped that there would be a formal survey and/or a focus group with the health professionals associated with the project, mostly GPs. This plan was abandoned because it was considered that it would be difficult, if not impossible, to organise such a focus group, particularly with GPs. Mail surveys of General Practitioners traditionally have a low response rate (St John, McKenzie et al., 1999) and informal discussions with the local Division of General Practice indicated that they thought that it was very unlikely that GPs would have time to attend. This was also consistent with the difficulty the team had experienced in finding a GP who was interested in participating in the Advisory Group. It was decided to conduct this evaluation in an informal manner and that communication and linkages with GPs would be reported instead. Consequently, at each management group and advisory group meeting the health professionals were asked about the processes employed within the project and asked to offer suggestions for improving these processes.
It had also been planned to conduct focus group interviews with participants. However, in the light of the volume and nature of data already collected from participants, it was decided that sufficient information had already been provided via existing data collection methods.
SECTION EIGHT

Outcome Evaluation Results

8.1 Introduction

This section of the report will address the changes in outcome measures before and after attending The Waterworx Centre. Thus the analysis reflects pre-test and post-test comparisons.

The main client outcome measures used to evaluate the services provided by The Waterworx Centre were:

- Severity of UI measured by symptom indices, physical measurements of incontinence and pelvic floor strength
- HR-QoL as measured by the Medical Outcomes Studies SF-36 (SF-36)
- Knowledge test – related to important continence promoting self-care strategies
- Cost index – measuring the cost of UI to the client

8.2 Severity of Incontinence

8.2.1 ICS Urinary Symptom Index

The data indicates that the severity of incontinence symptoms decreased for both men and women following the intervention and that this decrease was both sustained until six months and statistically significant. Repeated measures ANOVA indicated a significant main effect for time (ICSmale: $F_{2,20} = 3.49; p<0.05$ and ICSfemale: $F=21.01, p<.001$). Figure 5 below illustrates the improvement in scores over time.

The effect size calculations suggest that there was approximately a 20% reduction in the severity of symptoms for all participants overall.

![Figure 5: Severity of symptoms of urinary incontinence over time by sex](image)

For the data related to female clients of the service it was also possible to explore whether there was any difference in effectiveness of the service between those above and below 65 years of age. As Figure 6 indicates, while older women have more severe symptoms at all data measurement points, the intervention was equally effective for those above and below 65 years of age.
8.2.2 Physical Measurements of Incontinence and Pelvic Floor Parameters

The physical measures of UI that were collected for this study were: pelvic floor endurance, pelvic floor power, amount of residual urine following voiding and frequency of incontinent episodes in 24 hours.

Pelvic floor endurance ($\Lambda=.333$ $F_{2,10}=10.02$, $p<.004$) and power ($\Lambda = 0.537$ $F_{2,10}=4.31$, $p<.045$) both increased following the intervention and continued to increase up to six months after the intervention. The mean values for pelvic floor endurance are plotted in Figure 7 and the mean values for pelvic floor power are plotted in Figure 6 below.
8.2.3 Other Measures

The mean residual urine volume in clients on admission to The Waterworx Centre was 60mls. However, 27.9% of clients did not have a residual volume following voiding while 54.5% had between 1ml and 100mls and only 17.6% had over 100mls (with only 5% of clients having a residual volume of more than 200mls). The repeated measures ANOVA did not show a statistically significant reduction in residual volumes over time, but that was probably because the clients with large residuals were referred on immediately and were lost to follow-up.

On average, clients reported only two (n=129; s.d.=2.86; range=0-18) incontinent episodes in the 24 hour period prior to their first visit to The Waterworx Centre. There was no significant change in this over time, but again this was probably because only 23 clients completed the 6 months follow-up data and these were probably the clients who experienced more severe problems.

8.3 Health Related Quality of Life

The HR-QoL survey used in this study was the Medical Outcomes Study Short Form – 36 (SF-36). This is a well-developed tool that measures self-reported health status. The 36 items of the SF-36 have a five-choice response scale. There are eight scales that aggregate 2-10 items each. The eight scales are: Physical functioning, Role physical, Bodily pain, General health, Vitality, Social functioning, Role emotional and Mental health. There are also two summary measures (Physical component summary and Mental component summary). Norms for the Australian population are available calculated by age and sex.
Once again many clients were lost to follow-up and this means that a repeated measure ANOVA failed to demonstrate improvements in SF-36 scale scores over time. This may have been a function of the fact that those clients whose HR-QoL improved did not complete the follow-up surveys.

### 8.3.1 Scale Score Variations

Further analysis of the physical functioning scale scores was undertaken using the co-variates of number of visits to the clinic, age group (>65 years and ≤65 years) and length of time with UI. With both covariates included in the Age Group analysis (N=44), there was a significant main effect for time ($\lambda=.749$, $F_{2,26}=4.37$, $p<.023$), and significant interaction effects for time by number of attendances at clinic ($\lambda=.726$, $F_{2,26}=4.91$, $p<.016$), and for time by Age Group ($\lambda=.606$, $F_{2,26}=8.44$, $p<.002$). Figure 10 shows how in the older age group the PF scale scores improved over time, but they worsened for the very small group of under 65 year olds who completed the survey at all three time points.

![Figure 10: Estimated marginal mean scores for the physical functioning scale](image)

There were slight improvements in the social functioning and mental health scales for those with urge incontinence. While these results may have been statistically significant the small numbers of clients in the end analysis and the small degree of change would not suggest clinically significant change.

### 8.4 Bothersomeness of Urinary Incontinence

There was a reduction in the bothersomeness of the symptoms experienced by women over the three time periods of the study and the difference over time reached statistical significance ($F=13.09$, $p<0.0001$). Figure 11 shows the improvement in the bothersomeness of symptoms over time. The data relating to the male participants was not statistically significant but this was probably due to the small numbers of participants who completed follow-up. A t-test of the difference between the initial data collection period and three months later showed a change in the bothersomeness score from 34.5 to 23.7 ($t= 2.23; p=0.041$).
8.5 Knowledge of Continence Promoting Self-Care Strategies

There was an improvement in knowledge score between the pre-test and the 3 months post test and the difference in the mean scores reached statistical significance ($t = -3.643; \text{df} = 76; p<.0001$). This improvement in score was maintained at the six month period (See Figure 11). An overall oneway repeated measures ANOVA for the three knowledge scores was significant ($\Lambda=.731$, $F_{2,76}=7.72$, $p<.001$; multivariate test used as sphericity was violated, Mauchly's $W=.829$, $p=.019$).

8.6 Cost of Incontinence

The mean cost to the clients on admission to the centre of items such as incontinence pads and extra laundry was only $3.48 per week, however, the range was from no cost to $51.80 per week. By the six month follow-up the mean cost had reduced to $2.25 per week with the highest amount reported being $10.55. These differences did not reach statistical significance.

8.7 Summary of Outcomes

The lack of a control group in the research design and the loss of considerable numbers of clients to follow-up means that these results have to be interpreted with some caution. However, some results are quite clear. For this sample, symptoms improved overall by at least 20%. The reduction in the severity of symptoms was equal for men and women and for those in the over 65 years and the 65 or less age groups. Pelvic floor strength and endurance improved, but number of incontinent episodes remained the same for the small number who completed all follow-up.

Generally, this sample had SF-36 scores for HR-QoL before attending the centre that were similar to the general population, except for the ways in which their UI limited their physical, emotional and social roles. No great changes in SF-36 scale scores were evident before and after the intervention, but this may have been because many people whose symptoms improved declined to complete the SF-36 at...
the six-month data collection point. The physical functioning of the over 65 year age group did improve significantly over the six month follow-up period.

The clients’ knowledge regarding their condition and strategies they could employ to minimise symptoms improved following the intervention and the amount of money they spent on managing their UI decreased, although this latter difference did not reach statistical significance.
SECTION NINE

Discussion, Conclusions and Recommendations

9.1 Overview
The findings of this project support the need for community based multi-disciplinary specialist services. This practical, service-based project focused on evaluating secondary and tertiary preventive services to community-dwelling people suffering UI. Based on the best prevalence data available, demand for services at The Waterworx Centre, and the results of this study, it appears that this is an underserved group.

This project has confirmed the importance of community-based conservative continence services. It has also demonstrated the importance of providing specialist services that then link back to generalist primary care health service providers. The patterns of use, outcomes and satisfaction with services all indicate that there is an important place for specialist services that provide a comprehensive approach.

9.2 Structures and Processes
Clients received appropriate, effective, cost effective specialist continence care. In particular, secondary prevention services were offered to previously underserved clients. This project generated information on a range of process and structure issues that were of interest, including that:

- Waiting times were minimal, with the majority waiting less than 15 minutes
- The Waterworx Centre provided a valuable referral link to other generalist and continence service providers
- The Waterworx Centre has provided a hub for continence specialists in the Gold Coast region. Staff have been up-skilled in the area of continence care.
- Although comprehensive individual assessment and advice are very important to continence sufferers, group work can also be very successful and useful. Group work can make effective use of clinicians’ time, but also provide a support to sufferers.
- There was an unacceptably high number of appointments that were made, but not attended. Possible reasons for this could be the commitment required in attending and participating in treatment, as clients were asked to complete a symptom index and a bladder diary prior to attending their first appointment. Another reason could be related to embarrassment about their continence condition
- That there are hidden costs of UI, usually borne by the client.

9.2.1 Clients Accessing the Service
This service was successful in providing access to services for people who normally did not access continence services. The clients who attended the clinic were generally fully independent, community dwelling, older adults who were prepared to travel considerable distances to access the service. Many had previously had unsuccessful treatment for UI. It would appear that these clients are not at risk of institutionalisation, and that services being provided were secondary preventative services. It is of concern that a large proportion were not receiving health services for their UI, indicating that this population is currently not adequately served. The response to media promotions suggest that many in the general public do not know that help is available for UI.

9.2.2 Access to Services
Participants indicated that the service was suitably located at the Palm Beach Community Health Centre. However, most of the clients accessing The Waterworx Centre came from south of Surfers Paradise and were, thus, local. This indicates that it is probable that demand would sustain a similar service in the north of the District and that locality could be in important factor in relation to providing appropriate access. Another issue raised is that most clients travelled to The Waterworx Centre by private vehicle, despite the Centre being located on a major bus route. It is possible that those who do not have access to private transport could find it difficult to access a clinic setting via public transport.
Thus, in any future planning, location convenience would need to be considered. The facility for home visits should be maintained to provide for clients who cannot get to a central clinic because of the severity of the UI.

9.2.3 Linkages and Referrals

A large number of clients were self-referred, and not seeing a health practitioner about their UI. These findings are consistent with the national and international research data discussed above that suggest many people do not seek help or know that help is available for UI.

Although it was a focus of this project, a major disappointment was the difficulty in addressing the needs of clients in transition between hospitals and the community. It had been hoped that The Waterworx Centre would receive a greater number of referrals from hospitals, specifically for clients on discharge. Referrals from this source did not reach expectations, despite development of promotional pamphlets targeted at health professionals, and team members individually visiting liaison officers and wards in all hospitals in the local area, particularly targeting specific wards such as medical, maternity and urology. It appears that communication with staff at the ward level is difficult to establish, perhaps because UI is often not a major focus or primary consideration during hospitalisation. The findings of this project suggest that there is a need to promote the service within the general community, educate generalist health practitioners and maintain a facility for self-referral. Generalist health professionals also need education about the nature of continence services, and that conservative management can be pro-active, rather than simply palliative. This would contribute to more appropriate referrals on discharge from hospital.

This project has demonstrated that creating linkages using persuasive and informal methods alone will only have limited effectiveness. More formal structured strategies are required to improve linkages between hospital and community sectors, and subsequent transitional care. Further, until generalist ward staff at the ‘coal face’ understand the nature, importance and availability of continence services, it does not appear that referrals and discharge planning will improve.

9.2.4 Client Evaluation of Services

Respondents indicated a very high level of satisfaction with services provided by The Waterworx Centre in all four evaluation domains of care: access, clinical technical management, interpersonal management and continuity of care. Clients indicated a high level of satisfaction with staffs’ interpersonal skills. Clients valued being able to discuss this private and embarrassing problem with health professionals who had expertise in which they were confident. In relation to continuity of care, although most clients always saw the same practitioner, some did not (mainly due to staff factors such as maternity leave), which they would have preferred. The results of this study indicate that those suffering UI are extremely grateful to have access to a specialist continence service providing continuity of care.

9.2.5 Staff Issues

It should be noted that the staff of The Waterworx Centre were all specialists in continence care, in most cases having specific postgraduate qualifications in continence care. This was a principle that was maintained throughout the life of this project. This was, at times, difficult to maintain, due to the very small number of nurses and physiotherapists within the region with specialist skills in continence care. However, it is arguable that this expertise has been pivotal in the resulting outcomes of the project and the high satisfaction with services, in particular with confidence in clinicians’ skills. This outcome would confirm the importance the United Kingdom guidelines (Department of Health, 2000) place on qualified staff. The lack of qualified clinicians point to the need to support expert clinicians and to provide education and pathways for new specialist clinicians to gain expertise in continence care. In many instances those with expertise in continence care work alone. A centre such as this provides clinicians with learning opportunities and peer support. A pleasing outcome of this project is the synergy and high morale that has been provided by bringing together those with an interest in continence care. The Waterworx Centre also demonstrated the importance of providing critical mass to the extent that students can be placed for clinical experience.

Another defining characteristic of The Waterworx Centre was its multi-disciplinary nature. Continence care draws on knowledge from many of the health disciplines. The Waterworx Centre’s philosophy of drawing on the expertise of a range of professionals has been most successful, resulting in up-skilling
of staff and provision of a more comprehensive range of services. This project demonstrated that multi-disciplinarity can be a positive experience. In particular the communication and cross-disciplinary sharing resulting from developing and using shared assessment and management tools contributed to positive communication, knowledge, skills and client care.

Another positive aspect was the involvement of clinicians in research. Their contribution was pivotal to success of the project, and collaboration between clinicians with researchers has had positive outcomes in relation to the development clinical and research protocols, and a focus on evidenced-based practice.

9.3 Continence Outcomes

The range of outcomes in relation to continence from this project demonstrated that there was improvement client outcomes following intervention. These improvements reached statistical significance in the following:

- Severity of symptoms decreased for men and women and for those both above and below 65 years of age. This reduction in severity of symptoms was maintained for six months post admission to The Waterworx Centre;
- Pelvic floor endurance and power both increased following the intervention and continued to increase up to six months after the intervention;
- HR-QoL was not very different to that of the general healthy population before admission to The Waterworx Centre. The only major improvement in SF-36 scale scores before and after the intervention was in the Physical Functional scale for the over 65 year age group;
- There was an improvement in client knowledge of their condition and the strategies they could use to minimise symptoms. These improvements were maintained for six months post admission to the centre. Clients themselves perceived that they had gained knowledge and understanding of their condition;
- There was a reduction in the bothersomeness of the symptoms experienced by women over the three time periods of the study;
- Although it did not reach statistical significance, there was a reduction in the costs to clients of personal continence care.

9.4 Achievements of the Project

The project has provided benefits for clients, the service and the staff of the service as well as generating knowledge that may inform continence service delivery in an Australian setting. This project resulted in a range of significant outcomes for continence health services as follows:

- Provided seed funding for the establishment of more effective secondary and tertiary preventative services to a previously underserved community-based population;
- Clients have benefited from improved continence, incontinence self-management, a support network and/or access to suitable community and health resources;
- Raised the profile of continence-specific services within the region;
- Improved linkages between existing continence-specific services and generalist services within the region;
- Demonstrated an approach to providing quality care in a cost effective manner;
- Made more effective use of current community health resources for continence care;
- Provided an opportunity for up-skilling in continence care of generalist and specialist staff;
- Generated knowledge about the outcomes and effectiveness of conservative management of urinary continence;
- Enabled development of a set of continence assessment and management clinical tools;
- Provided information about approaches to promotion of a community-based service;
- Provided a case study of effective multi-disciplinary teamwork;
- Enabled development of a client evaluation tool;
- Provided a model of multi-disciplinary, community-based continence care that has been replicated in other services within the state;
- Developed links between clinicians and researchers.

Generalist health practitioners now have more effective communication channels, access to specialist continence practitioners and client educational materials. Specialist continence practitioners have more effective referral pathways, support for community-based clients and a focal point for developing
professional links in the region. Health practitioners have access to knowledge about best practice in continence care.

### 9.5 Recommendations

Based on the findings of this project the following recommendations are made:

1. Multi-disciplinary, community-based continence services should continue to be offered to community-based incontinence sufferers.
2. Work needs to continue to establish links between the hospital and community sectors in relation to continence care provision. In particular, attention should be given to developing better structures for patients being discharged from hospital.
3. Within the constraints of staffing and service management, continuity of care should be maintained for clients, allowing clients to consult with the same clinical staff (nurse and physiotherapist) at each visit where possible.
4. Services should continue to be provided by clinicians with specialist preparation in providing continence care. The provision of expert clinical staff has provided a high level of patient satisfaction and should be maintained.
5. The availability of continence services should continue to be promoted to generalist health practitioners and the general public.
6. Because many suffering UI do not access other health professionals for their incontinence, facility for self-referral should be maintained.
7. The multi-disciplinary nature of the service should be maintained.
8. The reasons for the high number of appointments made and not attended should be investigated.
9. Staff should be supported to develop specialist expertise in continence care provision.
10. There should be continued collaboration between the clinicians and researchers.

### 9.6 Dissemination of Information about Project

Information about this project has been promulgated in a range of forums within the professional community. It is intended that findings related to the development of this model, assessment approaches and results of the evaluation study will be presented at conferences and seminars and published in professional journals.

A pleasing outcome has been that the model has provided interest from other clinicians. The model is currently being replicated in other regions, with permission being granted for use of the model and the logo to set up a similar Centre in the Brisbane region. Ms Shona McKenzie has been invited to Townsville to present the work of The Waterworx Centre and to act as a consultant to a continence project they are implementing.

The work on this project has been presented as follows:


St John, W., Developing and evaluating a community-based continence service: The Waterworx Centre. Making the connections across the profession. *RCNA National Conference.* Launceston, Tasmania. 31.5.2002

St John, W., Developing and evaluating a community-based continence service: The Waterworx Centre. Centre for Practice Innovation in Nursing and Midwifery, Griffith University, Nathan Campus. 21.5.2002


Appendix One: The Model

The GC Continence Centre Model of Continence Promotion and Evaluation

Liaison/Referral Network

- Self-referring client (not currently accessing services)
- Specialist medical services including urodynamics
- Community based health professionals
- Generalist and domiciliary nursing services
- Community and hospital based allied health professionals
- Community resources

Client Process

- Client referred to Gold Coast Continence Centre
- Multidisciplinary Assessment
- Development of individualised plan of care with client, HCPs and carers

- HCP referral
- Support and Education
- HCP Treatment e.g. Bladder training
- Resource access and utilisation

Research Process

- Develop clinical pathways and set up Continence Centre
- Recruit patients into evaluative study
- Preliminary / baseline data collection for client outcome evaluation
- Data collection for structure and process evaluation
- Follow-up outcome data collection at 3 months
- Follow-up outcome data collection at 6 months

Evaluation of client progress
## Appendix 2: Advisory Group

<table>
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<td>Phone contact:</td>
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Appendix 3: Client Information Sheet - The Waterworx Centre

Welcome to The Waterworx Centre, a community support program for people suffering from urinary incontinence. This Centre is a demonstration project that provides care for people living in the community who suffer from urinary incontinence. It aims to provide transitional (between hospital and community) or initial care, and will link you with existing health services. You will attend The Waterworx Centre or (if necessary) be visited in your own home by staff of the Centre as part of your normal access to the Centre.

The Centre will provide you with services for six months or until you get better (which ever happens first) as follows:

- An individualised assessment and follow-up
- Information and educational materials about your health problem
- An opportunity to participate in group sessions
- Referral for further assessment (if necessary)
- Conservative management as a first approach
- Support, and advice about sources of support
- Links to appropriate health practitioner/s or to your own health practitioner/s

The Centre is staffed by continence nurse specialists and a physiotherapist with specialist knowledge and expertise in providing care for people with urinary incontinence. As a client of the Centre, you will be a client of the Gold Coast Health Service District. If you have any further questions about your care, please ask the staff of the Centre.

Your clinical management team are:

Ms Shona McKenzie RN, BSc, AssDipHealthEd, PostGradCert in Gerontological Nursing, Continence Nurse Adviser, Community Nurse
Ms Jennifer Rayner RN, Clinical Nurse Consultant, Stomal Therapy, Continence Nurse Adviser
Ms Sheridan Guyatt BPhysioth, Assistant Director of Physiotherapy, Continence and Women’s Health, Gold Coast Hospital

Contact details for the Centre are:
The Waterworx Centre: Gold Coast Community Continence Centre
Palm Beach Community Health Centre
9 Fifth Avenue
Palm Beach Queensland 4221
Telephone 07 5525 5600
Appendix 4: Clinical Forms
Appendix 4.1: Initial Assessment Form – Male

Surname:  
UR No.:  
First Name:  
DOB:  
Address:  

Phone: (h) (w)

Presenting problem and associated factors (as reported by the client)
DURATION of incontinence problem_______ Yrs/Mths
How long have these problems bothered you? _____

Tick where appropriate

PREVIOUS CARE FOR INCONTINENCE
[ ] None
[ ] GP (name) ______
[ ] Medical specialist (name) ______
[ ] Hospital (name) ______
[ ] CNS (name) ______
[ ] Home nursing service (name) ______
[ ] Physiotherapist (name) ______
[ ] Self referred ______
[ ] Other (specify) ______

FAMILY HISTORY – Enuresis / incontinence
[ ] Parents (specify) ______
[ ] Siblings (specify) ______
[ ] Self as a child (specify) ______

TRAUMA / ABNORMALITY OF THE URINARY TRACT
[ ] CA Urinary Tract (specify) ______
[ ] Congenital abnormality (specify) ______

MEDICAL HISTORY

NEUROLOGICAL
[ ] Multiple Sclerosis
[ ] CVA
[ ] Spinal Injury
[ ] Back Pain
[ ] Other (specify) ______

MEDICAL / SURGICAL HISTORY – MALE
[ ] Urethral Dilatation
[ ] Bladder Neck Surgery
[ ] TUR
[ ] Enlarged Prostate
[ ] Sphincterotomy
[ ] Other (Specify) ______

OTHER CONDITIONS
[ ] Trauma (specify) ______
[ ] Other (specify) ______

INVESTIGATIONS
[ ] Cystoscopy
[ ] Urodynamics
[ ] IVP
[ ] Other (specify) ______

URODYNAMICS (results if known)

CURRENT DRUG THERAPY

<table>
<thead>
<tr>
<th>Medication</th>
<th>Comment</th>
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</table>
MOBILITY
[ ] Mobile
[ ] Impaired
[ ] Walks with aid (specify) _______
[ ] Chair bound
[ ] Difficulty with distance to toilet

MANUAL DEXTERITY
[ ] Good  [ ] Limited  [ ] Poor

TOILETING POSITION
[ ] Posture / Footstool ___________
[ ] Sitting / Standing ____________

BOWEL HABITS
Frequency _______________________
Awareness _______________________
Control _________________________
Difficulty emptying [ ] Yes  [ ] No
Other (specify) __________________

STOOL
Soft, formed [ ] Yes  [ ] No
Constipated [ ] Yes  [ ] No
Loose [ ] Yes  [ ] No

SUMMARY OF BLADDER DIARY
Fluid intake ____________ ml/24 hours
Caffeine [ ] Yes  [ ] No [ ] Amt
Alcohol [ ] Yes  [ ] No [ ] Amt
Number of times/DAY continent ______
Number of times/NIGHT continent ______
Maximum volume ____________ ml

24 hour volume _________________ ml
Number of times/DAY incontinent _____
Number of times/NIGHT incontinent _____
*1. Frequency, during the day? __________
*2. Frequency, during the night? __________
*20. Do you leak urine when you are asleep __

Urge: Number/mean no. of times _____

SEVERITY
Wet pads [ ] Yes  [ ] No  [ ] NA
Wet pants [ ] Yes  [ ] No
Wet clothing [ ] Yes  [ ] No

What do you do to manage this?
________________________________
________________________________
________________________________
________________________________

Protection worn
________________________________
________________________________
________________________________
________________________________

URINALYSIS
SG _______ Ph __________
Protein _______ Glucose _______
Ketones _______ Blood _______
Nitrates _______ Leucocytes _______

24 hour Pad Test ________mg/24hours
Body Weight ____________kg

Bladder scan: residual: __________mls

______________________________________________________________________

TYPE OF INCONTINENCE
[ ] Urge  [ ] Functional  [ ] Reflex
[ ] Stress  [ ] Overflow  [ ] Other (specify) ________

SUMMARY OF FINDINGS
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

______________________________________________________________________
SOCIAL PARTICIPATION
HOBBIES

What things about your problem worry you the most socially?

34. Which of your urinary symptoms bother you most at the moment?

GOALS: What goals do you have for attending the Centre?

PREVIOUS INFORMATION RECEIVED ABOUT CONDITION

PHYSICAL ASSESSMENT  Procedure explained and verbal consent given. (please tick)

External Observation

Skin condition
Prolapse
Other
Perineal descent
External Anal Sphincter
Cough
PF activation
Transverse abdominis co-activation

Practitioner’s signature ________________________________ Date ____________
Designation _________________________________________
* (the following questions are based on the ICS urinary symptom index - male)

3. Do you have to rush to the toilet to urinate?
4. Does urine leak before you can get to the toilet?
5. Do you have pain in your bladder?
6. Does urine leak when you cough or sneeze?
7. Do you ever leak for no obvious reason and without feeling that you want to go?
8. Is there a delay before you can start to urinate?
9. Do you have to strain to start urinating?
10. Do you have to strain to continue urinating?
11. Do you usually urinate standing up or sitting down?
12/14. Would you say that the strength of your urinary stream is.
13. Do you think you have always had a weak stream?
15. Do you stop and start (>once) while you urinate?
16. Do you have a burning feeling when urinating?
17. How often do you feel that your bladder has not emptied properly after you have urinated?
18. Does your urine stream end with a dribble?
19. How often have you had a slight wetting of your pants after voiding?
21. If you leak urine during the day, do you have to change your clothes or wear pads?
22. Do you have to urinate again (within 15 minutes) after you thought you had finished urinating?
23. Have you ever been unable to urinate at all and had to have a catheter passed to drain the bladder?
24. To what extent do you feel that your sex life has been spoilt by your urinary symptoms?
24B. If you have no sex life, how long ago did this stop?
25. Do you get erections?
26. Do you have an ejaculation of semen?
27. Do you have pain or discomfort during ejaculation?
28. How often do you pass urine during the day?
29. Do you cut down on the amount you drink so that you can do the things you want to do?
30. Overall, how much do your urinary symptoms interfere with your life?
32. Do you have any worries about your urinary problems?
33. If you had to spend the rest of your life with your urinary symptoms as they are now, how would you feel?
Appendix 4.2: Initial Assessment Form – Female

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Phone: (h) (w)

Presenting problem and associated factors (as reported by the client)

**DURATION** of incontinence problem ____ Yrs/Mths *32. How long have these problems bothered you? _______

Tick where appropriate

**PREVIOUS CARE FOR INCONTINENCE**

- [ ] None
- [ ] GP (name)
- [ ] Medical specialist (name)
- [ ] Hospital (name)
- [ ] CNS (name)
- [ ] Home nursing service (name)
- [ ] Physiotherapist (name)
- [ ] Self referred
- [ ] Other (specify)

**FAMILY HISTORY – Enuresis / incontinence**

- [ ] Parents (specify)
- [ ] Siblings (specify)
- [ ] Self as a child (specify)

**TRAUMA / ABNORMALITY OF THE URINARY TRACT**

- [ ] CA Urinary Tract (specify)
- [ ] Congenital abnormality (specify)

**MEDICAL HISTORY**

**NEUROLOGICAL**

- [ ] Multiple Sclerosis
- [ ] CVA
- [ ] Spinal Injury
- [ ] Back Pain
- [ ] Other (specify)

**MEDICAL / SURGICAL HISTORY – FEMALE**

- [ ] Abd. Hysterectomy
- [ ] Vag. Hysterectomy
- [ ] Pelvic Floor Repair
- [ ] Bladder Repair
- [ ] Other (specify)

**CHILD BIRTH**

- [ ] Pregnancies (Number)
- [ ] Forceps / Vac
- [ ] Difficult deliveries
- [ ] Babies over 4 Kg
- [ ] Other (specify)

**INVESTIGATIONS**

- [ ] Cystoscopy
- [ ] Urodynamics
- [ ] IVP
- [ ] Other (specify)

**OTHER CONDITIONS**

- [ ] Previous UTIs
- [ ] Diabetes
- [ ] Dementia
- [ ] Obesity
- [ ] Respiratory
- [ ] Other

**URODYNAMICS** (results if known)

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<th>Medication</th>
<th>Comment</th>
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56 |
MOBILITY
[ ] Mobile
[ ] Impaired
[ ] Walks with aid (specify) ________
[ ] Chair bound
[ ] Difficulty with distance to toilet

MANUAL DEXTERITY
[ ] Good [ ] Limited [ ] Poor

TOILETING POSITION
[ ] Posture / Footstool ___________
[ ] Sitting / Hover _______________

BOWEL HABITS
Frequency _______________________
Awareness _______________________
Control _________________________
Difficulty emptying [ ] Yes [ ] No
Other (specify) __________________

STOOL
Soft, formed [ ] Yes [ ] No
Constipated [ ] Yes [ ] No
Loose [ ] Yes [ ] No

SUMMARY OF BLADDER DIARY
Fluid intake ____________ ml/24 hours
Caffeine [ ] Yes [ ] No [ ] Amt
Alcohol [ ] Yes [ ] No [ ] Amt
Number of times/DAY continent_______
Number of times/NIGHT continent_______
Maximum volume _______________ml

24 hour volume _______________ml
Number of times/DAY incontinent_____
Number of times/NIGHT incontinent_____
1. Frequency, during the day _________
2. Frequency, during the night ________

Urge: Number/mean no. of time _______

SEVERITY
Wet pads [ ] Yes [ ] No [ ] NA
Wet pants [ ] Yes [ ] No
Wet clothing [ ] Yes [ ] No

What do you do to manage this?

Protection worn

URINALYSIS
SG _______ Ph ___________
Protein _______ Glucose ___________
Ketones _______ Blood ___________
Nitrates _______ Leucocytes _______

24 hour Pad Test ___________ mg/24hours
Body Weight ___________________ kg
Bladder scan: residual: ___________ mls

TYPE OF INCONTINENCE
[ ] Urge [ ] Functional [ ] Reflex
[ ] Stress [ ] Overflow [ ] Other (specify) ________

SUMMARY OF FINDINGS
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

57
SOCIAL PARTICIPATION

HOBBIES

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

What things about your problem worry you the most socially?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

*34. Which of your urinary symptoms bother you most at the moment?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

GOALS: What goals do you have for attending the Centre?

_______________________________________________________________________
_______________________________________________________________________

PREVIOUS INFORMATION RECEIVED ABOUT CONDITION

_______________________________________________________________________
_______________________________________________________________________

PHYSICAL ASSESSMENT

Procedure explained and verbal consent given. #(please tick)

External Observation
Skin condition

Prolapse

Perineal descent

External Anal Sphincter

Cough

PF activation

Transverse abdominis co-activation

Internal / Vaginal Examination

Sensation / Discomfort

Vaginal wall tone

Endurance Puborectalis ____________ secs

Power 0-5 (please circle)

Puborectalis

0=Nil  1=Minimal  2=Weak  3=Moderate  4=Good  5=Strong

Puboccygeus (L)

0=Nil  1=Minimal  2=Weak  3=Moderate  4=Good  5=Strong

Puboccygeus (R)

0=Nil  1=Minimal  2=Weak  3=Moderate  4=Good  5=Strong

Scar Tissue

Cystocele / rectocele
(The following questions are based on the ICS urinary symptom index – female)

3. Do you have to rush to the toilet to urinate? __________________________________

4. Does urine leak before you can get to the toilet? _______________________________

5. Do you have pain in your bladder? _________________________________________

6. How often do you leak urine? _____________________________________________

7. Does urine leak when you are physically active, exert yourself, cough or sneeze? ______

8. Do you ever leak urine for no obvious reason and without feeling that you want to go? ___


10A. Do you have to change your underclothes or wear protection because of your leakage? __________

10B. How many times a day do you change the above items because of leakage? ______

11. Do you need to change your outer clothing during the day because of urine leakage?

12. Is there a delay before you can start to urinate? _____________________________

13. Do you have to strain to urinate? __________________________________________

14. Do you stop and start more than once while you urinate without meaning to? ______

15. Do you leak urine when you are asleep? ___________________________________

16. Would you say that the strength of your urinary stream is? ______________________

17. Have you ever been unable to urinate at all and had to have a catheter? _________

18. Do you have a burning feeling when you urinate? ____________________________

19. How often do you feel that your bladder has not emptied properly after you have urinated?

20. Can you stop the flow of urine if you try while you are urinating? _________________

21. Do you have pain or discomfort because of a dry vagina? _______________________

22a. Do you have a sex life at present? _______________________________________

22b. To what extent do you feel that your sex life has been spoilt by your urinary symptoms?

23. Do you have pain when you have sexual intercourse? _________________________

24. Do you leak urine when you have sexual intercourse? _________________________

25. How often do you pass urine during the day? _________________________________

26. Do you cut down on the amount of fluid you drink to help control your urinary symptoms?

27. To what extent have your urinary symptoms affected your ability to perform daily tasks?

28. Do you avoid places and situations where you know a toilet is not nearby? __________

29. Do your urinary symptoms interfere with physical activity? ______________________

30. How much do your urinary symptoms interfere with your social life? ______________

31. Overall, how much do your urinary symptoms interfere with your life? ______________

32. If you had to spend the rest of your life with your symptoms as they are now, how would you feel?

Practitioner’s signature __________________________ Date _____________________

Designation _________________________________________
Appendix 4.3: 3 & 6 Month Assessment Form

Surname:  
UR No.:  
First Name:  
DOB:  
Address:  

Phone: (h)  (w)

INVESTIGATIONS

[ ] Other (specify) ____________
____________________________________________________________________________

BOWEL HABITS

Frequency _____________________
Awareness _____________________
Control _______________________
Difficulty emptying [ ] Yes [ ] No
Other (specify) ____________________

STOOL

Soft, formed [ ] Yes [ ] No
Constipated [ ] Yes [ ] No
Loose [ ] Yes [ ] No

URINALYSIS

SG _______ Ph ________
Protein _______ Glucose ________
Ketones _______ Blood ______
Nitrates ___ Leucocytes ________

BLADDER DIARY

Fluid intake ________ ml/24 hours

Caffeine [ ] Yes [ ] No [ ]
Amt ____________________

Alcohol [ ] Yes [ ] No [ ]
Amt ____________________

Times/DAY passed urine (0700-2200) ____________
Times/NIGHT passed urine (2200-0700) ____________

Maximum volume ____________ ml
24 hour volume ____________ ml

Number of times wet a day (0700-2200) ____________
Number of times wet a night (0700-2200) ____________

SEVERITY

Wet pads [ ] Yes [ ] No [ ] NA
Wet pants [ ] Yes [ ] No [ ]
Wet clothing [ ] Yes [ ] No

Urges ________________

24 hour Pad Test __________ mg/24hours

Body Weight ____________ kg

Bladder scan: residual: __________ ml

NEW DRUG THERAPY

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Other Information (Goals achieved etc)
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

60
PHYSICAL ASSESSMENT

Procedure explained and verbal consent given. ☑ (please tick)

External Observation
Skin condition ___________________________________________________________
Prolapse _______________________________________________________________
Perineal descent _________________________________________________________
External Anal Sphincter_____________________________________________________
Cough _________________________________________________________________
PF activation ___________________________________________________________
Transverse abdominis co-activation _________________________________________

Internal / Vaginal Examination
Sensation / Discomfort _____________________________________________________
Vaginal wall tone _________________________________________________________
Endurance Puborectalis ____________ secs
Power 0-5 (please circle)
Puborectalis 0=Nil 1=Minimal 2=Weak 3=Moderate 4=Good 5=Strong
Pubococcygeus (L ) 0=Nil 1=Minimal 2=Weak 3=Moderate 4=Good 5=Strong
Pubococcygeus (R ) 0=Nil 1=Minimal 2=Weak 3=Moderate 4=Good 5=Strong
Scar Tissue _____________________________________________________________
Cystocele / rectocele _____________________________________________________

SUMMARY OF FINDINGS
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

GOALS: What goals do you currently have for attending the Centre?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Interactions with Linkage partner and outcomes
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Practitioner’s signature __________________________ Date _____________________
Designation ____________________________________________
## Appendix 4.4: Case Management Form

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<td>Address:</td>
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<tr>
<th>Phone: (h)</th>
<th>(w)</th>
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</thead>
</table>

### Further investigations
- MSU at ________
- Urodynamics at ________
- Other (Specify) __________

### Action (as appropriate)
- Fluids / Diet
- Hygiene / Skin Care
- Sexuality
- Mobility
- Bladder training
- Pelvic Floor re-training / re-education
- Toileting technique
- Bowel Management

### Continence Aids Recommended

### Other Advice / Education

### Group Recommended
- No
- Yes (specify) __________

### Literature Given
- Bladder Training
- Urinary Incontinence – What is it?
- Dementia and urinary incontinence
- Constipation and Urinary Incontinence
- Urge Control Techniques

### Referrals

<table>
<thead>
<tr>
<th>Group</th>
<th>Current</th>
<th>New Referral</th>
<th>Other</th>
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<tbody>
<tr>
<td>GP</td>
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<tr>
<td>St Lukes</td>
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<td>St Vincent’s</td>
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<tr>
<td>ACAT</td>
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<tr>
<td>Med. Specialist (specify)</td>
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<tr>
<td>St Vincent’s</td>
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<td>Dietician</td>
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<td>Physio</td>
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<td>CNS</td>
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<tr>
<td>Community Health</td>
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<tr>
<td>Blue Nurses</td>
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<tr>
<td>GCH (Continence)</td>
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<td></td>
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<tr>
<td>Other (specify)</td>
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</table>

### Contacted:
- Yes
- No

### Next follow up appointment: __________

### Services/Resources
- MASS
- CASS
- RAP
- Other (specify) __________

- Current
- New Referral
- NA

### Signature __________ Date __________

### Designation __________
<table>
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<tr>
<th>Date</th>
<th>Linkage partner (Name)</th>
<th>Partner type*</th>
<th>Address</th>
<th>Phone No.</th>
<th>Letter sent (date)</th>
<th>Contact date</th>
<th>Follow-up (date)</th>
<th>Feedback received (date)</th>
<th>Comments</th>
<th>Sign</th>
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Partner Type Legend: 1= Medical – GP  2= Medical – specialist  3= Physio  4= Nurse – home visiting  5= CNS  6= GCH Continence  7= ACAT  8= Dietician  9= Other
Appendix 4.5: Linkage Form

LINKAGE PARTNER REFERRAL:  Client Name:  
Referring Clinician:  

Linkage Partner:  
Medial - GP  
Medical - Specialist  
Physiotherapist  
Nurse - Domiciliary  
Community Health Nurse  
Other:  

Role of linkage partner in assisting client:  

History and Management Plan  
Admission date:  

Source of Referral:  
Self  
Specialist: Name:  
GP: Name:  

Client's description of problem  

Investigations:  
MSU  
Urinalysis  
Bladder scan: residual:  
24Hr pad test:  
bladder diary  
Pelvic Floor strength  

Other Results of investigations:  

Type of Incontinence:  
Stress  
Urge  
reflex  
Overflow  
Functional  

Contributing Factors:  

Treatments offered:  
Pelvic floor training  
Bowel management  
Bladder training  
Other:  

Proposed Treatment Plan  
Client Education;  
Toileting Technique  
Skin Care  
Fluids management  
Diet management  
Other:  

Continence Aids recommended for Client:  

Government Assistance programs client eligible for:  
MASS  
CASS  
RAP  
Not eligible, other advice given re purchase of continence aids:  

Appendix 4.6: Bladder Diary

What is a bladder diary?
A bladder diary can give important information about how your bladder works. It can give information about how often you go to the toilet, how often you wet yourself, and how much fluid you drink. Please bring your diary to each appointment.

How do I keep a bladder diary?
We would like you to try to keep to your normal schedule of activity and eating and drinking.
We would like you to use the diary for a 24 or 48 hour period (1 or 2 days) before your appointment. (We can get better information if you are able to use the diary for 2 days)
Use one sheet for each day.

We would like you to record a number of things:
- The time of day or night each time that you empty your bladder.
- The amount of urine passed. Use a measuring cup to measure in mls.
- The time of day or night each time you experience leaking urine. Also we would like you to describe how the leak happened eg. Cough, sneeze, with urge, a flood, on the way to the toilet, or you’re not sure how.
- Whether the leakage is a few drops or a large amount
- The type of pad you are using (this helps us calculate approximate volumes)
- What you drink and how much is in each drink.
## 24 Hour Bladder Diary

<table>
<thead>
<tr>
<th>Time</th>
<th>Intake</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Amount of fluids (mls)</td>
<td>Amount of urine passed in toilet (mls)</td>
</tr>
<tr>
<td></td>
<td>Use a measure</td>
<td>Measure</td>
</tr>
<tr>
<td></td>
<td>Type of fluid</td>
<td>Amount of urine passed in toilet (mls)</td>
</tr>
<tr>
<td></td>
<td>Type of pad- Brand and weighting</td>
<td>Measure</td>
</tr>
<tr>
<td></td>
<td>Amount on pad:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 = Slightly damp (a few drops)</td>
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<tr>
<td></td>
<td>2 = Damp</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = Wet</td>
<td></td>
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<tr>
<td></td>
<td>4 = Soaked</td>
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<tr>
<td></td>
<td>5 = Soaked through to clothes</td>
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</tbody>
</table>

### Sample Entry

- **7 am**: 400 mls | Yes | _ | _ | Waking Up
- **7.30**: 200 mls | Juice | _ | _ | _
- **9 am**: 300 mls | Yes | Tena lady long | No | Slightly Damp | Coughing then strong urge
- **9.30**: _ | Yes | _ | _ | _ | Running water for washing up
- **9.45**: 150 mls | Coffee | _ | _ | _ | _
- **11 am**: 150 mls | No | _ | _ | About to go out

**TOTAL**

What things seem to contribute to or are associated with your leaking? *Coughing, Lifting things*
# 24 Hour Bladder Diary

<table>
<thead>
<tr>
<th>Intake</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>Amount of fluids (mls)</td>
</tr>
<tr>
<td></td>
<td>Use a measure</td>
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<tr>
<td>TOTAL</td>
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</table>

What things seem to contribute to or are associated with your leaking? _____________________________________________
Appendix 4.7: 24 Hour Pad Test Instructions

It is important for us to have a clear measure of your bladder problem – over a 24 hour period. This measure will allow us (and you) to identify the extent of your problem and get feedback about any improvements. Please don’t feel that you “pass” or “fail” this measure – it is actually better that we get a clear picture of your problem. The results will help us plan a better treatment and management plan.

You might find that it is easier to do the measure on a weekend, when you are at home. The aim is to provide an accurate measure of your leakage over a 24 hour period.

In order to do this test you should:
- Start and finish the test at a the same time of the day – eg. 9.00am.
- At the start time, begin using the pads that are provided.
- Use only the pads we have provided you for the full 24 hour period – including day and night.
- Place all the pads used over the 24 hour period in the bag provided.
- At the end of the 24 hour period, dispose of the provided pad into the bag and go back to your usual methods
- Bring the bag containing the used pads and the unused pads back to us. The bag should contain all of the pads you have used for a 24 hour period.

If you accidentally dispose of a pad, don’t worry - you will just need to start the test over again. If you need extra pads, please ask for some more.
Appendix 5: Information Sheet : Evaluation of a Community Support Program for People Suffering From Urinary Incontinence

Unfortunately urinary incontinence affects many people living in the community. This is a problem that we would like to learn more about from you. We would like to know more about the impact that it has on daily life and evaluate the effectiveness of services provided to clients of The WaterworX Centre. This research will provide knowledge that will help health practitioners to provide better services to people suffering urinary incontinence in the future.

Participation in the research study is voluntary. Prior to each appointment, there will be an opportunity for you to ask questions about your continued participation in this study. You are free to not participate or to withdraw at any time, without providing a reason. Your withdrawal will not affect your care. The treatment you receive from the Centre is not dependent on your participation in this research.

If you decide to participate, information for this study research study will be collected from you in questionnaires and an audit of your health record.

1. Questionnaires: We will ask you to fill out a questionnaire at your first appointment and again at appointments three months and six months later. You will be asked a little about yourself, the impact urinary incontinence has on your quality of life and functioning, what you know about your condition, the products you use, the costs you incur, the services you use and your satisfaction with services. If you are completing this questionnaire at home, can you please post it back to us using the reply paid envelope provided.

2. We would like to access information from your client record to gain a background to your condition, your progress and test results (if any have been ordered).

We may also approach you to participate in a focus group interview. At this stage, consent will again be requested. If we do ask you to participate in a focus group, you are free to decline. This group interview will seek feedback about health services that been provided to you.

All of the physical examination data collected for this research study is part of normal assessment and examination for continence problems. Undertaking some of the physical tests can be tiring and if blood tests or urodynamic studies required these may be mildly uncomfortable. These tests are part of your normal treatment and care and it is only the results of these tests that will be recorded as part of this research.

The questionnaires will ask you about your experiences and how you feel. Should any of the questionnaire items require you to remember distressing events, you may decide to stop giving information and withdraw consent without prejudice. If you withdraw consent it will not affect your care or your access to The WaterworX Centre or its resources. If you are distressed by any of the data collection you can be referred for further assistance.

All the information collected for the purposes of this research will be kept confidential. The only people having access to research data will be the research team and a research assistant. The clinicians working with you in the Centre will obviously have access to your health record, however, they will not have access to any research information that would identify you personally, only aggregated data. The reason for this is that we do not want your participation or non-participation in the research to affect your care or the results of the research project in any way.

A code number will be used to identify data from each research participant. The records linking your identity to the research data will be kept separately in a secure environment. All computer records of the data will be kept in files that will be password protected. When we publish or report the data, no individual will be identifiable. In the event that you do withdraw from this study, the information you
have already provided will be kept in the same confidential manner. If you wish, we can remove previous data relating to you and destroy it.

While we hope that the services provided by The WaterworX Centre will be of benefit, there may be no benefit to you personally of the data collection required for this research project. However, we hope that we will be able to determine the best way to provide continence services, benefiting future clients.

The results of the study will be reported to the Department of Health and Aged Care and may be prepared for publication in relevant health care journals. On request, a summary of the results can be provided to you as a participant of the study, once the study is complete. If you would like a summary, please let the staff at the Centre know.

For more information concerning this research you are free to contact the Chief Investigator Dr Winsome St John on (07) 5594 8935. The University requires that all participants be informed that if they have any complaints concerning the manner in which a research project is conducted it may be given to the researcher, or, if an independent person is preferred, either the University's Research Ethics Officer, Office for Research, Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 6618; or the Pro Vice-Chancellor (Administration), Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 7343

Thankyou for participating in this research. It is appreciated.

Chief Investigator:
Dr Winsome St John
School of Nursing
Griffith University
Gold Coast Campus,
Parkwood QLD 4214
Phone: (07) 5594 8935
Email: w.stjohn@mailbox.gu.edu.au

Co-Investigators:
A/Professor Marianne Wallis
Nursing, Education & Research
Unit
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108 Nerang St., Southport QLD 4215
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Email: Marianne.Wallis@health.qld.gov.au

Ms Heather James
School of Nursing,
Griffith University
Gold Coast Campus
Parkwood QLD 4214
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Email: h.james@mailbox.gu.edu.au
Appendix 6: Consent Form

Evaluation of a Community Support Program for People Suffering From Urinary Incontinence

This research project will evaluate the services provided to clients of The Waterworx Centre.

I will access Centre’s services as normal and data will be collected during the first appointment and again at appointments three months and six months later. The data collected will include a questionnaire and access of my health record for an audit of medical, nursing and physiotherapy records.

I understand that I am not required to participate in this research project if I do not wish to do so and that I can withdraw from the study at any time without needing to explain my reasons for withdrawing. I realise that whether or not I decide to participate is my decision and will not affect my treatment. No loss of benefit or treatment will occur as a result of my withdrawal, nor penalty incurred.

I understand that, on request, I can get a summary of the findings once the research is complete.

For more information concerning this research I am free to contact the Chief Investigator Dr Winsome St John on (07) 5594 8935.

I have read the information sheet and have retained a copy. I agree to participate in the “Evaluation of a Community Support Program for People Suffering From Urinary Incontinence” research study and give my consent freely. I have had all questions answered to my satisfaction.

Signatures:

.......................................................... ................................
Participant                                    Date

..........................................................
Investigator(s)                                    Date

..........................................................

Appendix 7: Waterworx Client Evaluation Survey

The Waterworx Centre would like to invite you to complete this anonymous survey. This survey should take about 5-10 minutes to complete. If you do not know the answer to any question please either leave it blank or write an explanation next to the question.

If you have any questions about this survey or the project please feel free to talk to Ms Susan Griffiths when visiting the Centre or by telephone on (07) 5525 5645 (Tuesdays or Fridays). Or please contact Dr Winsome St John at Griffith University on (07) 5552 8935 or Associate Professor Marianne Wallis in the Nursing Education and Research Unit at the Gold Coast Hospital on (07) 5571 8728.

In the event that you have any further queries in relation to any aspect of this study or any other matter related to the study or should you wish to speak to someone during the conduct of the study, the person to contact is Dr. Brian Bell, Chair, GCDHS, District Ethics Committee, C/O Gold Coast Hospital, Southport QLD 4215. Or by telephone (07) 5571 8276.

Please keep this front page and return the rest of the survey as soon as possible.

Thank you for taking the time to help us improve patient care.
## Waterworx Patient Survey

*Please tick the one box which best represents your experience related to each statement.*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The clinic is conveniently located for me</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>2. Transport to the clinic is a problem for me because of my incontinence</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>3. I believe the waiting time at the clinic is too long</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>4. I always see the same nurse or physiotherapist every visit</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>5. It is important for me to see the same nurse or physiotherapist each time I visit the clinic</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>6. I was aware of other continence services before being referred by the clinic staff</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>7. I used other health services for my continence problem before being referred by the clinic</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>8. The clinical (nurse &amp; physiotherapist) understood my personal continence problem</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>9. I was satisfied with the explanations the clinical staff provided about my continence problem</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>10. I always felt the clinical staff spent the right amount of time with me during my visits</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>11. I always felt confident with the clinical skills of the nurse/physiotherapist during my visit</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>12. I wish to know as much as possible about my continence problem</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>13. Since visiting the clinic - my knowledge about my continence problem has improved.</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>14. The information/education packages did not provide me with any useful information.</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>15. I prefer to leave the decisions about my continence care/management to the health professionals</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>16. I found it easy to ask the clinical staff questions about my continence problem.</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>17. I feel very anxious/nervous when I come to the clinic</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>18. My level of anxiety is related to feelings of embarrassment about coming to the clinic for my continence problem</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>19. Overall I think the standard of care at the Waterworx Centre is very good</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
<tr>
<td>20. Overall I think there are many improvements that could be made to the Centre</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
</tbody>
</table>
21. I travel to the clinic by:
    # car
    # bus
    # taxi
    # Transcord
    # Other (specify) ______________________________

_Please tick the box that represents your experience related to each statement_

22. How long do you usually have to wait in the clinic before being seen by the clinical staff?

<table>
<thead>
<tr>
<th>Less than 15 min.</th>
<th>Less than 30 min</th>
<th>More than 30 min</th>
<th>Less than 1 hour</th>
<th>1 - 2 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
</tbody>
</table>

23. Can you name the services you used after being referred from the clinic? Please tick all the services you used _**(tick multiple answers if needed)**_

<table>
<thead>
<tr>
<th>My local doctor</th>
<th>Physiotherapist</th>
<th>Specialist Doctor</th>
<th>Community nursing Services</th>
<th>Other</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
<td>#</td>
</tr>
</tbody>
</table>

24. If you circled "Other" in the above question, please specify what service you did use

__________________________________________________________
__________________________________________________________

25. What is the best aspect of the clinic for you personally?

__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________

26. What is the worst aspect of the clinic for you personally?

__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________

_Thank you very much for taking the time to complete this survey._
Appendix 8: ICS Urinary Symptom Index – Male

Name............................................ Patient No …………………………….
Date ……………………………. Date of Birth …………………………..

URINARY SYMPTOMS (Men)

We need to find out about your urinary symptoms and also how much of a problem they are. We are very grateful that you can help us by filling in this questionnaire.

Please answer both parts of each question, thinking about the symptoms you have experienced in the last month.

You will see that some questions ask if you have a symptom occasionally, sometimes or most of the time.

Occasionally = less than one third of the time
Sometimes = between one and two thirds of the time
Most of the time = more than two thirds of the time

Please put a tick in one box for each question ✓
If you have any difficulty answering any of the questions, please ask.

<table>
<thead>
<tr>
<th>Question</th>
<th>1 to 6 times</th>
<th>7 to 8 times</th>
<th>9 to 10 times</th>
<th>11 to 12 times</th>
<th>13 or more times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 During the day, how many times do you urinate, on average?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem</td>
<td>[ ]</td>
<td>a bit of a problem</td>
<td>[ ]</td>
<td>quite a problem</td>
</tr>
</tbody>
</table>

© ICS-‘BPH’ study, ICSmale, ICSSoL and ICSsex questionnaires held by ICS-‘BPH’ study group tel 44 117 928 7214
2. During the night, how many times do you have to get up to urinate, on average?

- none [ ] 0
- one [ ] 1
- two [ ] 2
- three [ ] 3
- four or more [ ] 4

How much of a problem is this for you?
- not a problem [ ] 1
- a bit of a problem [ ] 2
- quite a problem [ ] 3
- a serious problem [ ] 4

3. Do you have to rush to the toilet to urinate?

- never [ ] 1
- occasionally (less than one third of the time) [ ] 2
- sometimes (between one and two thirds of the time) [ ] 3
- most of the time (more than two thirds of the time) [ ] 4
- all of the time [ ] 5

How much of a problem is this for you?
- not a problem [ ] 1
- a bit of a problem [ ] 2
- quite a problem [ ] 3
- a serious problem [ ] 4

4. Does urine leak before you can get to the toilet?

- never [ ] 1
- occasionally [ ] 2
- sometimes [ ] 3
- most of the time [ ] 4
- all of the time [ ] 5

How much of a problem is this for you?
- not a problem [ ] 1
- a bit of a problem [ ] 2
- quite a problem [ ] 3
- a serious problem [ ] 4
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
</table>
| 5  Do you have pain in your bladder?                                   | never  
occasionally  
sometimes  
most of the time  
all of the time | not a problem  
a bit of a problem  
quite a problem  
a serious problem |
| 6  Does urine leak when you cough or sneeze?                          | never  
occasionally  
sometimes  
most of the time  
all of the time | not a problem  
a bit of a problem  
quite a problem  
a serious problem |
| 7  Do you ever leak for no obvious reason and without feeling that you want to go? | never  
occasionally (less than one third of the time)  
sometimes (between one and two thirds of the time)  
most of the time (more than two thirds of the time)  
all of the time | not a problem  
a bit of a problem  
quite a problem  
a serious problem |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Is there a delay before you can start to urinate?</td>
<td>never, occasionally, sometimes, most of the time, all of the time</td>
<td>1, 2, 3, 4, 5</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
<td>1, 2, 3, 4</td>
</tr>
<tr>
<td>9 Do you have to strain to <strong>start</strong> urinating?</td>
<td>never, occasionally, sometimes, most of the time, all of the time</td>
<td>1, 2, 3, 4, 5</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
<td>1, 2, 3, 4</td>
</tr>
<tr>
<td>10 Do you have to strain to <strong>continue</strong> urinating?</td>
<td>never, occasionally (less than one third of the time), sometimes (between one and two thirds of the time), most of the time (more than two thirds of the time), all of the time</td>
<td>1, 2, 3, 4, 5</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
<td>1, 2, 3, 4</td>
</tr>
</tbody>
</table>
11 Do you usually urinate standing up or sitting down?

- Standing up: 
- Sitting down: 

**How much of a problem is this for you?**

- Not a problem: 
- A bit of a problem: 
- Quite a problem: 
- A serious problem: 

12 Would you say that the strength of your urinary stream is...

- Normal: 
- Occasionally reduced: 
- Sometimes reduced: 
- Reduced most of the time: 
- Reduced all of the time: 

**How much of a problem is this for you?**

- Not a problem: 
- A bit of a problem: 
- Quite a problem: 
- A serious problem: 

13 Do you think you have *always* had a weak stream?

- No: 
- Yes: 

Office use only
14 Would you say that the strength of your urinary stream is... (please ring one number)

(from Peeling, 1989)

1 2 3 4

15 Do you stop and start more than once while you urinate?

never occasionally sometimes most of the time all of the time

1 2 3 4 5

How much of a problem is this for you?

not a problem a bit of a problem quite a problem a serious problem

1 2 3 4
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Do you have a burning feeling when you urinate?</td>
<td>never, occasionally, sometimes, most of the time, all of the time</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
</tr>
<tr>
<td>17. How often do you feel that your bladder has not emptied properly after you have urinated?</td>
<td>never, occasionally (less than one third of the time), sometimes (between one and two thirds of the time), most of the time (more than two thirds of the time), all of the time</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
</tr>
<tr>
<td>18. Does your urine stream end with a dribble?</td>
<td>never, occasionally, sometimes, most of the time, all of the time</td>
<td>not a problem, a bit of a problem, quite a problem, a serious problem</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
<td>Rating Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td>19 How often have you had a slight wetting of your pants a few minutes</td>
<td>never</td>
<td>1</td>
</tr>
<tr>
<td>after you had finished urinating and had dressed yourself?</td>
<td>occasionally</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>sometimes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>most of the time</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>all of the time</td>
<td>5</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>a bit of a problem</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>quite a problem</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>a serious problem</td>
<td>4</td>
</tr>
<tr>
<td>20 Do you leak urine when you are asleep?</td>
<td>never</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>occasionally (less than</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>one third of the time)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>sometimes (between one</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>and two thirds of the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>time)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>most of the time (more</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>than two thirds of the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>time)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>all of the time</td>
<td>5</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>a bit of a problem</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>quite a problem</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>a serious problem</td>
<td>4</td>
</tr>
<tr>
<td>21 If you leak urine during the day, do you have to change your clothes</td>
<td>no, urine does not leak</td>
<td>1</td>
</tr>
<tr>
<td>or wear pads?</td>
<td>yes, change underpants</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>yes, change clothes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>I wear pads</td>
<td>4</td>
</tr>
<tr>
<td>How much of a problem is this for you?</td>
<td>not a problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>a bit of a problem</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>quite a problem</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>a serious problem</td>
<td>4</td>
</tr>
</tbody>
</table>
22. Do you have to urinate again (within 15 minutes) after you thought you had finished urinating?

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23. Have you ever blocked up completely so that you could not urinate at all and had to have a catheter passed to drain the bladder?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, once</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, twice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, more than twice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

24. To what extent do you feel that your sex life has been spoilt by your urinary symptoms?

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a little</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If you have no sex life, how long ago did this stop?</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 25 Do you get erections?

- yes, with normal rigidity
- yes, with reduced rigidity
- yes, with severely reduced rigidity
- no, erection not possible

**How much of a problem is this for you?**

- not a problem
- a bit of a problem
- quite a problem
- a serious problem

### 26 Do you have an ejaculation of semen?

- yes, normal quantity
- yes, reduced quantity
- yes, significantly reduced quantity
- no ejaculation

**How much of a problem is this for you?**

- not a problem
- a bit of a problem
- quite a problem
- a serious problem

### 27 Do you have pain or discomfort during ejaculation?

- no
- yes, slight pain/discomfort
- yes, moderate pain/discomfort
- yes, severe pain/discomfort

**How much of a problem is this for you?**

- not a problem
- a bit of a problem
- quite a problem
- a serious problem
28 How often do you pass urine during the day?  
- hourly (1)
- every 2 hours (2)
- every 3 hours (3)
- every 4 hours or more (4)  

**How much of a problem is this for you?**  
- not a problem (1)
- a bit of a problem (2)
- quite a problem (3)
- a serious problem (4)  

29 Do you cut down on the amount you drink so that your urinary symptoms improve, and you can do the things you want to do??  
- never (1)
- occasionally (2)
- sometimes (3)
- most of the time (4)
- all of the time (5)  

30 Overall, how much do your urinary symptoms interfere with your life?  
- not at all (1)
- a little (2)
- somewhat (3)
- a lot (4)  

31 How long have you had urinary symptoms that bother you?  
- less than one year - give months
- between one and two years
- between two and three years
- more than three years
32 Do you have any worries about your urinary problems?

Please list any worries below:

33 If you had to spend the rest of your life with your urinary symptoms as they are now, how would you feel?

- perfectly happy
- pleased
- mostly satisfied
- mixed feelings
- mostly dissatisfied
- very unhappy
- desperate

34 Which of your urinary symptoms bother you most at the moment?

Please list the symptoms that bother you most below. Please describe the symptoms in your own words, or write the number of the question that comes closest to describing them:

1.

2.

3.

Thank you very much for your help.

If there are any comments you would like to make about the questionnaire or your urinary symptoms, please use the space below (or over the page)
Appendix 9: ICS Urinary Symptom Index – Female

URINARY SYMPTOMS (Women)

We are trying to find out how much of a problem your urinary symptoms are to you. We would be grateful if you could help us by filling out this questionnaire when answering the questions think about the symptoms you have experienced in the past month.

You will see that some questions ask if you have a problem occasionally, sometimes or most of the time.

Occasionally = less than one third of the time
Sometimes = between one third and two thirds of the time
Most of the time = more than two thirds of the time

Please tick one box for each question

1. During the day, how many times do you urinate on average?
   - 1 to 6 times
   - 7 to 8 times
   - 9 to 10 times
   - 11 to 12 times
   - 13 or more times

   How much of a problem is this for you?
   - not a problem
   - a bit of a problem
   - quite a problem
   - a serious problem

2. During the night, how many times do you have to get up to urinate, on average?
   - none
   - 1
   - 2
   - 3
   - 4 or more

   How much of a problem is this for you?
   - not a problem
   - a bit of a problem
   - quite a problem
   - a serious problem
3. **Do you have to rush to the toilet to urinate?**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Severity</th>
<th>Not a problem</th>
<th>A bit of a problem</th>
<th>Quite a problem</th>
<th>A serious problem</th>
</tr>
</thead>
</table>

4. **Does urine leak before you can get to the toilet?**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Severity</th>
<th>Not a problem</th>
<th>A bit of a problem</th>
<th>Quite a problem</th>
<th>A serious problem</th>
</tr>
</thead>
</table>

5. **Do you have pain in your bladder?**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Severity</th>
<th>Not a problem</th>
<th>A bit of a problem</th>
<th>Quite a problem</th>
<th>A serious problem</th>
</tr>
</thead>
</table>
6. **How often do you leak urine?**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>once or less per week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-3 times per week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>once per day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>several times per day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Problem Severity</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. **Does urine leak when you are physically active, exert yourself, cough or sneeze?**

<table>
<thead>
<tr>
<th>Activity Frequency</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally (less than one third of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes (between one and two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time (more than two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Problem Severity</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. **Do you ever leak urine for no obvious reason and without feeling that you want to go?**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How much of a problem is this for you?**

<table>
<thead>
<tr>
<th>Problem Severity</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. How much urinary leakage occurs?

<table>
<thead>
<tr>
<th>Leakage Type</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No leakage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drops/pants damp</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dribble/pants wet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floods, soaking through to outer clothing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floods, running down legs or onto floor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10A. Do you have to change your underclothes or wear protection because of your leakage?

<table>
<thead>
<tr>
<th>Protection Type</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change underclothes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panty liners/mini pads</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maxi/super sanitary towels</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nappies/Incontinence products</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other; please specify..........................</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10B How many times a day do you change the above items because of leakage

<table>
<thead>
<tr>
<th>Change Frequency</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No change required</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 5 times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Do you need to change your outer clothing during the day because of urine leakage?

<table>
<thead>
<tr>
<th>Change Frequency</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

12. Is there a delay before you can start to urinate?

<table>
<thead>
<tr>
<th>Delay Type</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally (less than one third of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes (between one and two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time (more than two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th>Problem Severity</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
13. **Do you have to strain to urinate?**

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>never □</td>
</tr>
<tr>
<td>occasionally □</td>
</tr>
<tr>
<td>sometimes □</td>
</tr>
<tr>
<td>most of the time □</td>
</tr>
<tr>
<td>all of the time □</td>
</tr>
<tr>
<td>not a problem □</td>
</tr>
<tr>
<td>a bit of a problem □</td>
</tr>
<tr>
<td>quite a problem □</td>
</tr>
<tr>
<td>a serious problem □</td>
</tr>
</tbody>
</table>

14. **Do you stop and start more than once while you urinate without meaning to?**

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>never □</td>
</tr>
<tr>
<td>occasionally □</td>
</tr>
<tr>
<td>sometimes □</td>
</tr>
<tr>
<td>most of the time □</td>
</tr>
<tr>
<td>all of the time □</td>
</tr>
<tr>
<td>not a problem □</td>
</tr>
<tr>
<td>a bit of a problem □</td>
</tr>
<tr>
<td>quite a problem □</td>
</tr>
<tr>
<td>a serious problem □</td>
</tr>
</tbody>
</table>

15. **Do you leak urine when you are asleep?**

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>never □</td>
</tr>
<tr>
<td>occasionally □</td>
</tr>
<tr>
<td>sometimes □</td>
</tr>
<tr>
<td>most of the time □</td>
</tr>
<tr>
<td>all of the time □</td>
</tr>
<tr>
<td>not a problem □</td>
</tr>
<tr>
<td>a bit of a problem □</td>
</tr>
<tr>
<td>quite a problem □</td>
</tr>
<tr>
<td>a serious problem □</td>
</tr>
</tbody>
</table>
16. Would you say that the strength of your urinary stream is...

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>not reduced</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>reduced a little</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite reduced</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>reduced a great deal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no stream</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17. Have you ever blocked up completely so that you could not urinate at all and had to have a catheter to drain the bladder?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, once</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, twice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes, more than twice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18. Do you have a burning feeling when you urinate?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally (less than one third of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes (between one and two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time (more than two thirds of the time)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19. How often do you feel that your bladder has not emptied properly after you have urinated?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>occasionally</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>sometimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>most of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>all of the time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Can you stop the flow of urine if you try while you are urinating?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, easily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, with difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No, cannot stop it flowing</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sexual Matters

Please think about the past month

21. Do you have pain or discomfort because of a dry vagina?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a little</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you have a sex life at present?

YES/NO

If YES please go to question 22
If NO please go to question 25

22. To what extent do you feel that your sex life has been spoilt by your urinary symptoms

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a little</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem is this for you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a bit of a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quite a problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
23. Do you have pain when you have sexual intercourse?

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all □ 1</td>
</tr>
<tr>
<td>somewhat □ 3</td>
</tr>
</tbody>
</table>

24. Do you leak urine when you have sexual intercourse?

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all □ 1</td>
</tr>
<tr>
<td>somewhat □ 3</td>
</tr>
</tbody>
</table>

Lifestyle

Please think about the past month

25. How often do you pass urine during the day?

<table>
<thead>
<tr>
<th>How much of a problem is this for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem □ 1</td>
</tr>
<tr>
<td>quite a problem □ 3</td>
</tr>
</tbody>
</table>
26. Do you cut down on the amount of fluid you drink so that your urinary symptoms improve, and you can do the things that you want to do?

- never ☐
- occasionally ☐
- sometimes ☐
- most of the time ☐
- all of the time ☐

How much of a problem is this for you?

- not a problem ☐
- a bit of a problem ☐
- quite a problem ☐
- a serious problem ☐

27. To what extent have your urinary symptoms affected your ability to perform daily tasks (e.g. cleaning, DIY, lifting objects)?

- not at all ☐
- a little ☐
- somewhat ☐
- a lot ☐

How much of a problem is this for you?

- not a problem ☐
- a bit of a problem ☐
- quite a problem ☐
- a serious problem ☐

28. Do you avoid places and situations where you know a toilet is not nearby (e.g. shopping, travelling, theatre, church)?

- never ☐
- occasionally ☐
- sometimes ☐
- most of the time ☐
- all of the time ☐

How much of a problem is this to you?

- not a problem ☐
- a bit of a problem ☐
- quite a problem ☐
- a serious problem ☐
29. **Do your urinary symptoms interfere with physical activity (e.g. walking, dancing, swimming)?**

<table>
<thead>
<tr>
<th>How much of a problem is this to you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
</tr>
<tr>
<td>a bit of a problem</td>
</tr>
<tr>
<td>quite a problem</td>
</tr>
<tr>
<td>a serious problem</td>
</tr>
</tbody>
</table>

30. **How much do your urinary symptoms interfere with your social life (going out, meeting friends and so on)?**

<table>
<thead>
<tr>
<th>How much of a problem is this to you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not a problem</td>
</tr>
<tr>
<td>a bit of a problem</td>
</tr>
<tr>
<td>quite a problem</td>
</tr>
<tr>
<td>a serious problem</td>
</tr>
</tbody>
</table>

31. **Overall, how much do your urinary symptoms interfere with your life?**

<table>
<thead>
<tr>
<th>How much of a problem is this to you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
</tr>
<tr>
<td>a little</td>
</tr>
<tr>
<td>somewhat</td>
</tr>
<tr>
<td>a lot</td>
</tr>
</tbody>
</table>

32. **How long have you had urinary symptoms that bother you?**

<table>
<thead>
<tr>
<th>How long have you had urinary symptoms that bother you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 1 year</td>
</tr>
<tr>
<td>1-2 years</td>
</tr>
<tr>
<td>2-3 years</td>
</tr>
<tr>
<td>more than 3 years</td>
</tr>
</tbody>
</table>
33. If you had to spend the rest of your life with your urinary symptoms as they are now, how would you feel?

- Perfectly happy □
- Pleased □
- Mostly satisfied □
- Mixed feelings □
- Mostly dissatisfied □
- Very unhappy □
- Desperate □

34. Which of your urinary symptoms bother you most at the moment? (please list the symptoms that bother you most below. Please describe the symptoms in your own words, or write the number of the question that comes closest to describing them):

1.
2.
3.
Evaluation of a Community Support Program for People Suffering From Urinary Incontinence

CLIENT QUESTIONNAIRE

This research project aims to evaluate the service provided to clients of the Gold Coast Continence Centre. Information for the research study will be collected from clients of the service, from general and specialist medical practitioners in the Gold Coast area and from nursing and allied health staff.

This questionnaire is one aspect of the data collection from the Gold Coast Continence centre clients. We would like to invite you to complete this questionnaire and return it before your first consultation. This questionnaire should take about 15 minutes to complete. If you do not know the answer to any question please either leave it blank or write an explanation next to the question.

For more information concerning this research you are free to contact the Chief Investigator Dr Winsome St John on (07) 5552 8935. The University requires that all participants be informed that if they have any complaints concerning the manner in which a research project is conducted it may be given to the researcher, or, if an independent person is preferred, either

the University's Research Ethics Officer, Office for Research, Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 6618;

or

the Pro Vice-Chancellor (Administration), Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 7343

Thank you for taking the time to complete this questionnaire.
Evaluation of a Community Support Program for People Suffering From Urinary Incontinence

Part One: A Health Related Quality of Life Scale (MOS SF-36)

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure of an answer, please give the best answer you can.

Q1 In general would you say your health is…

(circle one)

Excellent .................................................. 1
Very good .................................................. 2
Good ......................................................... 3
Fair .......................................................... 4
Poor .......................................................... 5

Q2 Compared to one year ago, how would you rate your health in general now? Would you say it is…

(circle one)

Much better now than one year ago ............ 1
Somewhat better now than one year ago ....... 2
About the same as one year ago ............... 3
Somewhat worse now than one year ago ...... 4
Much worse now than one year ago .......... 5

Q3. The following items are about activities that you might do during a typical day. Does your health now limit you in these activities? If so how much?

(c)ircle one number on each line)

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>Yes, Limited A Lot</th>
<th>Yes, Limited A Little</th>
<th>No, Not Limited At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c. Lifting or carrying groceries</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d. Climbing several flights of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Climbing one flight of stairs</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Bending, kneeling, or stooping</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Walking more than a mile</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>h. Walking several blocks</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Walking one block</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>j. Bathing or dressing yourself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Q4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as result of your physical health?

<table>
<thead>
<tr>
<th>(circle one number on each line)</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. Accomplished less than you would have liked</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. Were limited in the kind of work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>d. Had difficulty performing the work or other activities (for example, it took extra effort)</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th>(circle one number on each line)</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. Accomplished less than you would have liked</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. Didn’t do work or other activities as carefully as usual</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Q6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

<table>
<thead>
<tr>
<th>(circle one)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>1</td>
</tr>
<tr>
<td>A little bit</td>
<td>2</td>
</tr>
<tr>
<td>Moderately</td>
<td>3</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>4</td>
</tr>
<tr>
<td>Extremely</td>
<td>5</td>
</tr>
</tbody>
</table>

Q7. How much bodily pain have you had during the past 4 weeks?

<table>
<thead>
<tr>
<th>(circle one)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Very mild</td>
<td>2</td>
</tr>
<tr>
<td>Mild</td>
<td>3</td>
</tr>
<tr>
<td>Moderate</td>
<td>4</td>
</tr>
<tr>
<td>Severe</td>
<td>5</td>
</tr>
<tr>
<td>Very severe</td>
<td>6</td>
</tr>
</tbody>
</table>

Q8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th>(circle one)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>1</td>
</tr>
<tr>
<td>A little bit</td>
<td>2</td>
</tr>
<tr>
<td>Moderately</td>
<td>3</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>4</td>
</tr>
<tr>
<td>Extremely</td>
<td>5</td>
</tr>
</tbody>
</table>
Q9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question please give the one answer that comes closest to the way you have been feeling. How much time during the past four weeks -

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the Time</th>
<th>A Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel full of pep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>b. Have you been a very nervous person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>c. Have you felt so down in the dumps that nothing could cheer you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>d. Have you felt calm and peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>e. Did you have a lot of energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>f. Have you felt downhearted and blue?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>g. Did you feel worn out?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>h. Have you been a happy person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>i. Did you feel tired?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Q10. During the past 4 weeks, how much of the time has your physical or emotional problems interfered with your social activities (like visiting friends and relatives etc.)?

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Q11. How TRUE or FALSE is each of the following statements for you?

<table>
<thead>
<tr>
<th></th>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don't Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I seem to get sick a little easier than other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b. I am as healthy as anybody I know</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c. I expect my health to get worse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d. My health is excellent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Part Two: A few details about you

1. The highest level of education I have completed is:
   - Primary School
   - Secondary School
   - Apprenticeship
   - Trade school/ TAFE
   - College
   - University

2. I live with:
   - My spouse/partner only
   - My spouse /partner and children
   - Friends/other family
   - Alone
   - Other
   Please specify …………………

3. My marital status is:
   - Married
   - De Facto
   - Divorced
   - Widowed
   - Never married
   - Other
   #Please Specify ………………………

Part Three: We would like to ask you about other continence information you have received in the past

1. Have you received information about:
   - The cause of my condition
   - Where I could get help
   - Strategies for coping in my daily living
   - Pelvic floor exercises
   - Access to continence aids
   - Other (Please explain)

   YES  NO
   #    #
   #    #
   #    #
   #    #
   #    #
   #    #

If you answered yes to one or more options in Q.1, please identify where you received this information (You may tick more than one.)
If not, please turn to the next page.

Nurse – Generalist
Nurse – Specialist
(Continence Nurse Adviser)
GP
Medical – Specialist
Other
(please specify)________________

Physiotherapist – Generalist
Physio – Specialist
Self help group
Media and magazines
Books
Part Four: What do you know about incontinence?

We need to ask you a few questions about incontinence to see whether or not the Centre helps you access the correct information. Please circle one answer only per question. Do not worry if you do not know the answer to the question, simply circle the answer you believe to be most correct.

1. A person with urinary incontinence should:
   i. drink 4 (four) glasses of fluid a day.
   ii. have a drink when thirsty.
   iii. drink 6-8 glasses of water a day.
   iv. drink nothing after 4pm.

2. When a person has a urinary tract infection (a chill on the bladder) he/she:
   i. has pain and burning on passing urine.
   ii. passes urine very frequently.
   iii. i and ii
   iv. has green coloured urine.

3. When women go to the toilet it is better that they:
   i. hover over the seat.
   ii. stand on the seat and squat.
   iii. sit on the seat.
   iv. stand over the bowl.

4. It is best to go to the toilet to empty your bladder:
   i. when you think of it.
   ii. every two hours.
   iii. before going anywhere.
   iv. when you feel your bladder is full.

5. If prone to urinary incontinence it is best to:
   i. have soft regular bowel motions.
   ii. be constipated rather than having diarrhoea.
   iii. avoid constipation at all costs.
   iv. not worry about constipation.

6. If prone to incontinence the best fluid to drink is:
   i. cranberry juice
   ii. water
   iii. lemon barley water
   iv. orange juice

7. Please indicate which of the following drinks affect bladder function?
   i. Tea
   ii. Coffee
   iii. Lemonade
   iv. Coke/Pepsi
   v. Cordial
   vi. Orange Juice
   vii. Alcohol
   viii. Milo
   ix. Milk

   #Yes #No #Don’t Know

8. Does constipation affect bladder function?
   i. Yes
   ii. No
   iii. Don’t know

9. Is it normal to have some loss of bladder function after having a baby?
   i. Yes
   ii. No
   iii. Don’t know
Appendix 11: Cost Index

Evaluation of a Community Support Program for People Suffering From Urinary Incontinence

Cost Index Survey

This research project aims to evaluate the service provided to clients of the Gold Coast Continence Centre. Information for the research study will be collected from clients of the service, from general and specialist medical practitioners in the Gold Coast area and from nursing and allied health staff.

This survey is one aspect of the data collection from the Gold Coast Continence centre clients. We would like to invite you to complete this survey and return it upon your next appointment. This survey should take about 10 minutes to complete. If you do not know the answer to any question please either leave it blank or write an explanation next to the question.

For more information concerning this research you are free to contact the Chief Investigator Dr Winsome St John at Griffith University on (07) 5552 8935. The University requires that all participants be informed that if they have any complaints concerning the manner in which a research project is conducted it may be given to the researcher, or, if an independent person is preferred, either

- the University's Research Ethics Officer, Office for Research, Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 6618;
- or
- the Pro Vice-Chancellor (Administration), Bray Centre, Griffith University, Kessels Road, Nathan, Qld 4111, telephone (07) 3875 7343

Thank you for taking the time to complete this questionnaire.
Cost Index Survey

This section is to help us find out how much your incontinence problem is costing you personally (apart from medical and treatment costs). Knowing this will help policy makers make better decisions.

1. Which disposable incontinence products have you used in the past month?

<table>
<thead>
<tr>
<th>Brand Name</th>
<th>Product Name</th>
<th>Cost per Packet</th>
<th>Number per Packet</th>
<th>Min / Max / Day</th>
<th>Average per Week</th>
<th>Where Purchased</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>2</td>
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<td>4</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Total expenditure on disposable products Per Week $_________________
Per Annum $_________________

# Not applicable (please tick box if this question is not relevant to you)

2. Have you used re-usable incontinence products in the last year? Please specify:

a. Plastic sheeting – homemade – purchased
   Approx expenditure per annum $ __________

b. Net pants
   Approx expenditure per annum $ __________

c. Homemade pads
   Approx expenditure per annum $ __________

d. Chair pads
   Approx expenditure per annum $ __________

e. Bed pads
   Approx expenditure per annum $ __________

f. Washable i/c pants
   Approx expenditure per annum $ __________

g. Other (please specify)
   Approx expenditure per annum $ __________

Total expenditure on re-usable products Per Week $_________________
Per Annum $_________________

# Not applicable (please tick box if this question is not relevant to you)

3. How many times in the past seven days, due to your incontinence problem, did you need to change and wash your:

a) underwear _______ b) clothing _______ c) bed linen _______

   d) chair protection_______ e) bed pads _______ f) i/c pants _______

   g) towels __________ h) towelling pads _______

   i) other (please specify) _______

   __________

Total expenditure on laundry Per Week $_________________
Per Annum $_________________

# Not applicable (please tick box if this question is not relevant to you)
4. Have you used any cleaning agents in your home in the last year because of your incontinence problem? (Beyond what would normally be used.) Please specify:
   a. Cleaning agents (please specify) _________ □ Approx expenditure per annum $ _______
   b. Cleaning agents (please specify) _________ □ Approx expenditure per annum $ _______
   c. Cleaning agents (please specify) _________ □ Approx expenditure per annum $ _______
   Total expenditure on cleaning agents Per Week $____________________
   Per Annum $____________________
   # Not applicable (please tick box if this question is not relevant to you)

5. Have you used any hygiene products because of your incontinence problem in the last year? (Beyond what would normally be used.) Please specify:
   a. Hygiene product (please specify) _________ □ Approx expenditure per annum $ _______
   b. Hygiene product (please specify) _________ □ Approx expenditure per annum $ _______
   c. Hygiene product (please specify) _________ □ Approx expenditure per annum $ _______
   Total expenditure on hygiene products Per Week $____________________
   Per Annum $____________________
   # Not applicable (please tick box if this question is not relevant to you)

6. Do you buy particular clothing / more clothing because of your incontinence problem? (Beyond what would normally be used.) Please specify:
   a. Clothing item (please specify) _________ □ Approx expenditure per annum $ _______
   b. Clothing item (please specify) _________ □ Approx expenditure per annum $ _______
   c. Clothing item (please specify) _________ □ Approx expenditure per annum $ _______
   Total expenditure on clothing items Per Week $____________________
   Per Annum $____________________
   # Not applicable (please tick box if this question is not relevant to you)

7. Any other expenditures association with your incontinence problem over the past twelve months? (please specify)
   ___________________________ $_______
   ___________________________ $_______
   ___________________________ $_______
   ___________________________ $_______
   ___________________________ $_______
   Total other expenditure Per Week $____________________
   Per Annum $____________________
   # Not applicable (please tick box if this question is not relevant to you)

8. Please identify any financial support you receive specifically to help with incontinence
   # MASS (amount per week) $ _______
   # CASS (amount per week) $ _______
   # RAP (amount per week) $ _______
   # Other scheme / support (amount per week) $ _______
   (Please specify) ___________________________
   # None

Thankyou for filling out this survey.
Appendix 12: Glossary of Terms


Bladder scanner: Enables calculation of residual volume in the bladder.

**Incontinence – functional**: An involuntary, unpredictable passage of urine. The critical defining characteristics are the urge to void or bladder contractions sufficiently strong to result in loss of urine before reaching an appropriate receptacle. Related factors include altered environment; and sensory, cognitive, or mobility deficits.

**Incontinence – overflow**: An overflow of urine from a distended or paralysed bladder.

**Incontinence – reflex**: an involuntary loss of urine occurring at somewhat predictable intervals once a specific bladder volume is reached. Defining characteristics include no awareness of bladder filling; no urge to void or feelings of bladder fullness; or uninhibited bladder contractions/spasms at regular intervals. Related factors include neurologic impairment, as a spinal cord lesion that interferes with conduction of cerebral messages above the level of the reflex arc.

**Incontinence – stress**: a loss of urine of less than 50ml occurring with increased abdominal pressure. The major defining characteristic is reported or observed dribbling with increased abdominal pressure. Minor characteristics include urinary urgency or urinary frequency (more often than every 2 hours). Related factors are degenerative changes associated with increased age; high intra-abdominal pressure, such as obesity or gravid uterus; incompetent bladder outlet; over-distension between voidings; and weak pelvic muscles and structural supports.

**Incontinence – urge**: Involuntary passage of urine occurring soon after a strong sense of urgency to void. Critical defining characteristics are urinary urgency, frequency (voiding more than every 2 hours), and bladder contractions or spasms. Minor characteristics include nocturia (urination more than 2 times per night); voiding in small amounts (less than 100 ml), or in large amounts (500 ml), and an inability to reach a toilet on time. Related factors include pelvic inflammatory disease, abdominal surgery, or an indwelling urinary catheter, irritation of bladder stretch receptors causing spasm, increased urine concentration and over distension of the bladder.

**Residual urine**: Volume of urine that remains in the bladder after urination.

**Urinary incontinence**: An inability to control urination.

**Urodynamics**: A study of the hydrology and mechanics of urinary bladder filling and emptying.
Appendix 13: References


St John, W., McKenzie, S., & James, H. (1999). Urinary continence services for community-dwelling people in the South East Coast region of Queensland. Southport: Griffith University and St Vincent's Community Services. Southport: Faculty of Nursing and Health, Griffith University.


