UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH & LIFE SCIENCES

School of Nursing and Midwifery

Stakeholders' and Users' Views of a Leisure Centre Based Continence Clinic

by

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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STAKEHOLDERS' AND USERS' VIEWS OF A LEISURE CENTRE BASED CONTINENCE CLINIC

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This thesis describes a study of stakeholders' and women's views of a nurse-led continence clinic held in a leisure centre. Its purpose was to explore their perceptions of the clinic to provide a response to the following research questions: 'What prompted the development of a nurse-led continence clinic within a leisure centre and in what way is this unique or different?'; 'In what way do the philosophies differ between the stakeholders involved in developing the 'Quay to Health' and the views of the women who use the clinic?', 'How does incontinence impact on women's lives and what are the coping strategies employed by them?' and 'How might a leisure based continence clinic meet women's needs?'

This qualitative study used a single case study design (Stake 1995) with elements of a grounded theory approach for the data analysis (Glaser & Strauss 1967, Strauss & Corbin 1998). The analysis was based on interviews with seven stakeholders and 12 women who attended the continence clinic at the 'Quay to Health'. The women were interviewed twice, once soon after their initial appointment at the clinic and again six months later. Two incontinence impact questionnaires (IIQ-7, Uebersax *et al* 1995 and ICIQ-SF, Donovan *et al* 2001) were completed, together with a frequency/volume chart prior to both interviews.

Findings indicated that partnership working was a key issue for stakeholders underpinning the development of the 'Quay to Health'. Both stakeholders and users also identified several cross benefits by co-locating health and leisure services including opportunities for increased levels of physical activity and a more relaxed and informal environment. The impact of incontinence on women's lives can involve limitations on their social activities, relationships and compromises their self-esteem. A range of coping strategies were employed by women to manage these difficulties. The women preferred to attend a clinic in a non-clinical setting and suggested that as they did not see incontinence as an illness, a leisure centre was a more acceptable environment within which to seek help. The implications of these views are explored.

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DECLARATION OF AUTHORSHIP

I, Elizabeth Mary Donnelly, declare that the thesis entitled 'Stakeholders and User's Views of a Leisure Centre Based Continence Clinic' and the work presented in it are my own. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission

Signed: [redacted]

Date: 27.8.04

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INTRODUCTION

This is a study about stakeholders and women's views of a nurse-led continence clinic held in a leisure centre. The continence clinic at the "Quay to Health" has been open since July 1999 when a partnership was formed between the city council and the local primary care trust. Partnership working between agencies had been encouraged by government initiatives (Department of Health 1997,1998a, 1999) and with additional funding from the national lottery a health suite, the "Quay to Health" had been included in the new leisure centre. Additional clinics operating at the "Quay to Health" include: contraceptive and sexual health, stoma and psychosexual counselling.

The continence clinic at the "Quay to Health" is unique in that although other continence clinics are usually held in traditional settings such as health centres or hospitals, this particular clinic, co-located with leisure facilities, appears to be an unusual setting for a continence clinic. The opportunity to explore both stakeholders and women's views of this continence clinic could provide data that will influence the future development of continence clinics in non-clinical settings.

The development of health clinics in leisure settings was initiated in the 1930s with the "Peckham Experiment". This was an innovative project providing subsidised membership of a purpose built swimming pool and gymnasium in exchange for an annual medical examination by members. Although successful with over 1,000 members, with the introduction of the National Health Service in 1948 and a lack of funding the centre closed in the 1950s (Ashton, 1976). When the "Quay to Health" opened in 1999 the underlying philosophy behind the development of services appeared to be similar to that of the "Peckham Experiment" believing that people would be more likely to access certain health services in a non-clinical environment.

This study set out to explore what is different about the setting of the continence clinic in a leisure centre. The continence clinic at the "Quay to Health" warranted study because several assumptions had been made about why this would be a good setting for a clinic, and yet the people who used the service had not had the opportunity to discuss how they felt about the service or their incontinence. Chapter One focuses on the literature review looking at what incontinence means to women, how incontinence is managed in primary care, users views of nurse-led clinics and partnership working between different services. Chapter Two discusses the research methodology chosen which was a single case study with data analysis utilising elements of a grounded theory approach. Chapters Three and Four discuss the findings from interviews with the seven stakeholders and twelve women, including the results from the incontinence impact questionnaires and frequency/volume charts. Chapter Five presents a discussion of the findings with implications for practice. Chapter Six discusses the methodological issues and limitations of the study with recommendations for future research and the conclusion.

CHAPTER ONE

Introduction to the Literature Review

The purpose of this review is to critique the literature available on women with urinary incontinence who attend a nurse-led clinic and the literature available on partnership working between health and leisure services. It will focus on the following:

- The prevalence of urinary incontinence.
- Quality of life and urinary incontinence: and the incontinence-specific tools that can be used to measure it.
- What urinary incontinence means to women.
- The development of specialist nurses to promote continence and manage incontinence.
- The management of incontinence in Primary Care.
- Care Pathways.
- The development and evaluation of nurse-led clinics in Primary Care.
- Users' views of nurse-led clinics.
- Partnership working between health and leisure services.

Search Strategy

A search of the literature was undertaken using the on-line databases, Medline, Ovid, PsychInfo and Embase, between 1980-June 2004. The keywords incontinence, continence, women and incontinence, urinary incontinence, quality of life and incontinence, nurse-led clinics and continence, open-access clinics and incontinence, continence advisors, incontinence impact, help-seeking and incontinence, continence clinics, conservative management of incontinence, coping with incontinence, prevalence of incontinence were used. In addition, supplementary searching of reference lists of articles was undertaken. MESH headings used were urinary incontinence + quality of life as well as searches on text words Urin* and Quality of Life* (asterisks represent wild cards). The Cochrane database of randomized trials for all RCTs including the word "incontinence" from 1998-2003 identified 48 trials measuring the outcome of incontinence treatments. Hand searches of the Community Practitioner Journal and the Journal of Community Nursing from 1995-2003 were also undertaken. These journals focus on nursing issues in Primary Care, but did not contain papers examining nurse-led continence clinics in Primary Care. The Department of Health website was searched using the keywords continence, incontinence, patient views, consumer views, user views and nurse-led clinics.

The search was limited to papers in the English language and those including findings involving women over 18 years of age. From this initial broad search of the literature 953 papers were identified. To refine this initial broad search papers that looked at treatment strategies for incontinence were rejected together with those looking at urinary retention, catheter use, male incontinence, paediatric incontinence and faecal incontinence. The search strategy enabled the identification of 56 papers that have been included in this review. Three of these were specifically on the management of incontinence in primary care and these are noted on p18. Five were on the development and evaluation of nurse-led clinics in primary care and these are noted on pages 29-30. In order to identify papers exploring the meaning of incontinence to women the search terms were refined to focus on women with urinary incontinence and the impact incontinence had on their lives. There are only a few papers that explore the meaning of incontinence to women; those that looked at measurement of urinary symptoms or that focused on specialist investigation or surgery for incontinence were rejected. This process enabled the identification of five articles, mainly using qualitative methodologies to explore the construct. These five papers are noted on p12. The remaining 43 articles are included in the body of the review.

A search of the literature relating to partnership working was undertaken using the same on-line databases as the search for women and incontinence, between 1980-June 2004. The keywords partnership working, joint working, partnership working in health and leisure, healthy living centres and collaborative working identified 28 papers. In order to refine the focus articles that did not relate to partnership working or healthy living centres were rejected. This process enabled the identification of twelve publications, mainly government reports, that explored this construct. These twelve publications are noted on pages 35-36.

The Prevalence of Urinary Incontinence

During the 1980s continence advisory services were developed following recognition by government that the needs of incontinence sufferers within the community were largely unmet. Thomas *et al* (1980) looked at the prevalence of urinary incontinence within General Practices and identified incontinence as a "hidden" problem within communities. Findings from a large postal survey suggested that urinary incontinence occurred in 16% (age 15-64) and 22% (age 65 years and over) of 17,694 patients randomly selected from the practice registers of surgeries throughout the U.K. The use of a postal questionnaire may have encouraged people to reveal their problem, which due to embarrassment may have previously been undisclosed. Several prevalence studies followed e.g. (Smith 1982, O`Brien *et al* 1991, Royal College of Physicians 1995) and more recently the Department of Health published its guidance on "Good practice in continence services" (Department of Health 2000a), containing prevalence rates for urinary incontinence which represent a synthesis from the best available evidence.

For people living at home:

- "Between 1 in 14 and 1 in 20 women aged 15-44.
- Between 1 in 7 and 1 in 13 women aged 45-64.
- Between 1 in 5 and 1 in 10 women aged 65 and over;
- Over 1 in 33 men aged 15-64;
- Between 1 in 10 and 1 in 14 men aged 65 and over."

(Department of Health 2000a, p7).

A study by Perry *et al* (2000) in a large postal survey of 15, 904 adults aged 40 years or more indicated that prevalence rates for urinary incontinence varied depending on the definitions used. A recent study by Mc Grother *et al* (2004) used a postal questionnaire to assess prevalence of incontinence involving 92, 491 respondents over 40 years of age. Findings indicated that in the UK over a one year period over a third of people aged 40 years or more (nine million) are estimated to have urinary storage symptoms, with five million needing health care. This clearly represents a major public health problem.

The prevalence of urinary incontinence has many implications for the planning and provision of services. With an ageing population the number of individuals suffering from incontinence will place an additional strain on existing services and has cost implications. A report by Euromonitor (1999) estimated that the retail market for incontinence pads in 1998 was £11.3 million, having grown from £7.7 million in 1996. These figures do not include the NHS Supplies share that accounts for £69 million in England alone. The Continence Foundation (2000b) have estimated the minimum total cost of incontinence in England (including drugs, containment products, appliances and staff costs) to be £353,595,000 (in 1998).

The Continence Foundation (2000b) have also calculated that the cost of providing a patient with incontinence pads is between £100 and £600 per year (with no cost calculation for reassessments, administration or treatment of complications). By comparison conservative treatment offered by a continence advisor or physiotherapist with ten hours of input would cost under £150. On a cost basis alone it is clearly important to examine the evidence for conservative treatment aimed at improving symptoms.

Quality of Life and Urinary Incontinence

Quality of life is clearly an important issue for most people but although there is a general awareness and understanding of what is meant by the phrase it is actually quite difficult to define and is commonly used in different ways by different people. Bowling & Brazier (1995) note that traditionally philosophers, theologians and social scientists focused on "satisfaction with life" and the "good life". Although there remains no precise consensus on what is quality of life, Anderson & Burckhardt (1999) found that when patients were asked about the meaning of quality of life by health care researchers, similar responses were elicited as those from general populations. It appeared that quality of life had the same basic constituents for everyone, although the relative importance of individual dimensions may change throughout life or during episodes of illness. Women with continence problems can experience a significant impact on their quality of life, leading to embarrassment and social isolation. The impact urinary incontinence has on life quality is a highly individual response dependent in part on how successfully a woman is able to manage and control her continence problem (Ashworth & Hagan 1993).

The assessment of incontinence and its impact on quality of life can be undertaken in many different ways. Historically, the initial assessment with a patient either in a clinic setting or at home focused on a clinical history and a general discussion about specific problems they may be experiencing in managing and coping with their incontinence. The impact of the symptoms they were experiencing was recognized, but tended to form a small part of the overall assessment. However, more recently greater attention has been paid to women's own perceptions of their problem through the use of self-completion questionnaires and data from frequency/volume charts (Seim *et al* 1996, Lewey, Billington, O'Hara 1997, Williams, Perry, Brittain 2001).

The measurement of quality of life remains a difficult issue, with generic measures of health status only appropriate to describe health status in the general population. They tend to be generally insensitive to specific medical conditions such as incontinence. However, generic measures of health status have been applied to people with incontinence with some success. Roe *et al* (2000) used the SF36 (Ware 1993, Jenkinson *et al* 1993) to determine health status among 12,529 adults, randomly selected from two health authorities in England. Findings indicated that people who were incontinent had a significantly lower health status than those who were not incontinent ($p<0.0001$). They recommended that the SF36 should be used in conjunction with disease or condition-specific health measures to provide additional information on outcomes.

Several incontinence-specific measures of quality of life have been developed, with the International Continence Society recently publishing recommendations for standardized questionnaires (Abrams 2002). Two of these measures are discussed below. These have been selected because they provide a quick, reliable tool for looking at the impact of incontinence on quality of life.

Condition-Specific Quality of Life Measures

The Incontinence Impact Questionnaire-Short Form (IIQ-7) was developed and validated by Uebersax *et al* (1995) comprising 7 domains predicting the severity of incontinence for each individual. A Likert scale with assigned values of 0 for incontinence impact "not at all" to 3 for "greatly" enables scoring to provide a single index of life impact associated with incontinence. Validation of the IIQ-7 followed the development of the long form version (Shumaker *et al* 1994), which used the data from the 162 women in its construction. A high percentage of the women (96%) were white, 62% were married and 78% had received education beyond high school. The nature of the sample may mean that caution needs to be exercised when considering using the tool with different client groups, but the tool has also been translated into French and used in a study of women with stress and mixed incontinence (Blanc *et al* 1999). The advantages associated with the use of the IIQ-7 include the quick completion time required and the ease of use in clinical practice.

The International Consultation on Incontinence Questionnaire Short Form (ICIQ-SF) has been developed and validated with the full support of the International Continence Society (ICS). A need for a comprehensive, incontinence-specific, validated questionnaire that could be used by clinicians and researchers to gain a subjective assessment of the impact of incontinence on people's lives was recognised. The ICIQ-SF has been validated for use in Europe and America, and a Japanese version has recently been developed (Gotoh *et al* 2001).

Validation of the ICIQ-SF involved a robust process of patient interviews, observation and postal requests to complete the questionnaires (Donovan *et al* 1999). In-depth interviews were completed with 63 UK urology clinic attendees (46 females, 17 males) who were observed self-completing the questionnaires. Questionnaires were then modified to include symptoms of "bothersomeness", use of protection, amount of urine leakage, overall quality of life and interference with social life and sex life. A further 374 urology clinic attendees (305 females, 69 males) were invited to complete the questionnaires by post with a 60% (n=223) response rate. A further 230 participants from two UK general practices were invited to self-complete the questionnaire, with 96% (n=221) and 83% (n=25) responding.

The levels of incontinence were compared between the urology clinic attendees and the community sample to assess the construct validity of the tool, and results indicated that the ICIQ-SF could detect a difference in the prevalence of incontinence between the two genders, and different types of incontinence. The frequency, severity and impact on quality of life of incontinence among men and women of all ages is measured by a three item scale including frequency of urine leakage, the amount of urine people think they leak and a Likert scale from 0 (not at all) to 10 (a great deal) measuring the impact urine leakage has on their everyday lives. An unscored self-diagnostic fourth item enables the person completing the form to record when urine leakage occurs (Donovan *et al* 1999). The questionnaire can be completed very quickly by patients and provides a useful discussion tool within consultations when looking at the impact of incontinence on quality of life.

What Urinary Incontinence Means To Women

This section of the literature review explores what urinary incontinence means to women, the impact it has on their lives and the coping mechanisms adopted by sufferers. Urinary incontinence is a difficult condition for people to define, and to acknowledge a problem exists. Incontinence itself is not given an "illness label" or an "illness identity" by individuals themselves or by the general public and is therefore not legitimised as a medical condition worthy of discussion with a General Practitioner (Shaw 2001). Women may be too embarrassed to raise the topic and may need "prompts" from health professionals to feel able to explain the symptoms they are experiencing. Factors that prompt women to seek help for their incontinence have been explored by Brittain, Perry and Williams (2001) in a study forming part of the Leicestershire Medical Research Council Incontinence Study.

Findings indicated that raised awareness of incontinence was the most frequently cited reason for seeking help. A deterioration in symptoms, or the presence of the symptoms themselves prompted help seeking in over 40% (n=112). Personal triggers, including embarrassment, depression, frustration, inconvenience and annoyance, together with feeling dirty or smelling were also given in 40% of cases (n=112). It was interesting to note that women reported more personal triggers than men and also cited embarrassment or depression as their main reason for seeking help.

A few studies have looked at the percentage of women seeking help for their incontinence, with most women consulting a General Practitioner (GP). The definitions of incontinence used by each of the studies differ so it can be problematic trying to make any comparisons. However, the percentage of women seeking help appears to increase with the severity of the incontinence and the degree to which the problem has an adverse impact on their lives (Yarnell *et al* 1981, Harrison & Memel 1994 and Dolan *et al* 1999).

The picture of women suffering with their incontinence problems, trying to make sense of what is happening to their bodies and contemplating whether to seek help or not prompted an earlier enquiry into parous women's feelings about their incontinence and the impact it had on their lives by the author (Donnelly 1997). The study used a grounded theory approach that informed a) the collection of the data, which consisted of five tape recorded semi-structured interviews and b) the process of analysis. The act of discussing their continence problem posed a threat to self-esteem for some with one participant describing how she would only discuss her incontinence with a health professional or certain friend. Women needed to feel comfortable about disclosing incontinence and few of the women involved in the study had been referred to the clinic by their GP, but had needed to actively seek out details of the clinic from posters displayed at the hospital or surgery.

The advice given by the GPs was often interpreted as inappropriate by the women, with no clear indication of expected outcomes or review. Women were easily dissuaded from disclosing their continence problems to their GPs by a sense of guilt and self-blame coupled with the belief that nothing could be done to offer them any help. They believed that the GPs were extremely busy, an idea reinforced by full waiting rooms at the surgery, and were reluctant to waste their time discussing a problem that may not have been amenable to treatment. The sufferers exhibited a general feeling of hostility towards health professionals, particularly doctors, a finding also noted by Ashworth and Hagan (1993).

Women often see incontinence as an inevitable outcome of childbirth, believing that it is something to be tolerated or endured, a view that may be perpetuated by myth or reinforced by family or friends. Lack of information in the antenatal period about normal and abnormal bladder function can result in women being confused about whether some leakage of urine may be usual or not, and embarrassed to seek help. Some women may think that it is their fault that they have incontinence, as having a child means that the body is bound to be damaged, and so a reluctant acceptance of the situation may be the outcome (Ashworth & Hagan 1993, Mason *et al* 1999, 2001).

The meaning of incontinence to women's lives has been described by a limited number of studies with small sample sizes that tend to be convenience samples. Although there are limitations with the generalisability of these studies they provide a valuable insight into women's experiences in their own words, and describe the emotional nature of their problems in a powerful and moving way. When discussing the impact incontinence has on people, the use of sufferers' own words can give information in a clear and understandable format, facilitating improved understanding of their problems (Dowd 1991, Skoner & Haylor 1993, Chiverton & Wells 1996), (Table 1, p12).

Findings from studies undertaken in the United States of America (USA) (Dowd 1991, Skoner & Haylor 1993, Chiverton & Wells 1996), Norway (Sandvik, Kveine & Hunskaar 1993) and the United Kingdom (UK) (Ashworth & Hagan 1993, Shaw 2001) indicate that many women feel devastated by incontinence with psychological, social and relationship problems manifesting themselves as a result. Women plan their lives around managing the symptoms and coping with everyday life in as normal a way as possible. This "normalising" of incontinence can involve complex routines, with the restriction of fluids, use of protective pads worn inside pants and frequent toileting commonly used to manage and cope with their situation (Dowd 1991, Skoner & Haylor 1993, Ashworth & Hagan 1993).

Sandvik, Kveine & Hunskaar (1993) have explored the impact of different types of incontinence on women. They recruited their sample from newspaper advertisements offering incontinence pads and information to those who responded. When a request was made for information an inquiry was included to see if they would also consent to an interview. Over 1,000 enquiries were made, with 187 agreeing to be interviewed.

One of the key findings of this research was that women with urge incontinence reported more "mental distress" than those with stress incontinence (28% v 21% n=187) This was defined as fear of smelling, fear of discovery, despair, feeling dirty, inferior, lacking in self-confidence and feeling alone with the problem. The diagnoses of stress incontinence and urge incontinence were made by the Detrusor Instability Score (Kauppila *et al* 1982) with 117 suffering from stress incontinence and 70 with urge incontinence. Young women with stress incontinence were more distressed than older women (24% v 17% n=187), and severe incontinence was more closely associated with mental distress than slight incontinence (30% v 19% n=187).

Table 1: What Urinary Incontinence Means to Women

Author and Year	Title	Country of Study	What Studied and Research Design	Sample Size and Characteristics	Findings	Conclusions
Ashworth & Hagan (1993)	The Meaning of Incontinence: a Qualitative Study of non-geriatric urinary incontinence sufferers	U.K.	Meaning of incontinence to individuals. In-depth interviews using phenomenology.	28 women aged 25-55 years with 1-4 children. 14 0f 28 had not sought help for incontinence.	Incontinence is a difficult and vague condition with impact on women's lives affecting self-esteem causing isolation and distress.	Incontinence is taboo. Health professionals need to help sufferers discuss their problem. Clear information about each individual's problem needs to be given with feedback on progress.
Skoner & Haylor (1993)	Managing Incontinence: Women's Normalizing Strategies	U.S.A.	How women perceived being incontinent and how they self-managed their problem. In-depth interviews using a grounded theory approach.	8 women aged 31-50 years with at least 1 child. All had some college education.	Women needed to be able to deal with incontinence in a manner they perceived as normal. Normalizing incontinence achieved by self-management.	Women saw invasive treatment options offered by doctors as unacceptable. Their understanding of incontinence differed from health professionals who gave the condition a "medical label".
Dowd (1991)	Discovering Older Women's Experience of Urinary Incontinence.	U.S.A.	Women's experiences of living with and managing urinary incontinence. In-depth interviews using a grounded theory approach.	Convenience sample of 7 women aged 58-79.	The main threat to women's self-esteem was fear of accidental urine leakage in public.	If women were able to manage and control their incontinence then it was possible to "normalize" the problem.
Sandvik ; Kveine & Hunskaar. (1993)	Female Urinary Incontinence Psychosocial Impact, Self-Care and Consultations.	Norway	The impact of different types of incontinence on women was explored using a 38-item questionnaire and interviews.	187 women aged between 19-91 who responded to a newspaper advertisement.	Women with urge incontinence reported more "mental distress" than those with stress incontinence.	Young women were affected more by stress incontinence than older women. Only a third of the women who had consulted a doctor about this problem were satisfied with the outcome.
Chiverton & Wells (1996)	Psychological Factors Associated with Urinary Incontinence.	U.S.A.	Questionnaire exploring mastery, self-esteem, depression and quality of life.	Convenience sample of 125 well educated women aged 27-90. 58 responded to the questionnaire.	Women with urinary incontinence had a higher incidence of depression than women of the same age in the general population.	Women with a poor sense of mastery and self-esteem may have an increased risk of developing depression.

Findings by Chiverton & Wells (1996) are similar to Sandvik, Kveine and Hunskaar (1993). Chiverton & Wells (1996) examined the link between mastery, depression and self-esteem, in relation to the quality of life of women with urinary incontinence. They recruited a convenience sample of 125 women with incontinence who were all well educated. The bias in this sample means that the results may only be transferable to white, middle-class, well educated women in the U.S.A.; it may not be possible to generalise the findings to this country.

One significant finding related to whether or not women with urinary incontinence had a higher incidence of depression than women of the same age in the general population. Results showed that 22% who completed the questionnaire were rated clinically depressed, compared with 6% of the general population. The limitations to this study design include the omission of criteria used to diagnose depression.

Another study that has linked incontinence with depression and anxiety is by Macauley, Stern and Stanton (1991), reviewing women attending a urodynamic clinic. They noted that women with urodynamic disorders were more depressed than a normal population of a similar age, but it is worth considering that people attending a specialist, diagnostic clinic, such as this are subjected to embarrassing and humiliating procedures that may influence the outcome of the research. However, Chiverton & Wells (1996), when looking at factors influencing quality of life found that depression did not emerge as a mediating factor in quality of life for women with urinary incontinence. The "mastery" or control they had over their incontinence and their self-esteem as independent variables, and depression as the dependent variable revealed significant relationships. They suggested that women who had a low self-esteem and little sense of "mastery" were at risk of depression. When they examined all three variables together ("mastery", self-esteem and depression), the only variable with an effect on quality of life was the degree of control women felt they had over their own lives.

Ashworth and Hagan (1993) explored the meaning of urinary incontinence to women in the first qualitative study to look at young women (Table 1 p12). They used a phenomenological approach, with free-format interviews to ascertain how women perceived incontinence and the impact it had on their lives. To manage and cope with their incontinence several different strategies were employed. The "constant avoidance of danger" involved restricting outings away from home, long walks, travelling on buses or aeroplanes and avoiding sexual intercourse. Additional precautions were taken to enable the problem to be concealed and these could involve elaborate plans with frequent bladder emptying, a map of the location of all local toilets, limiting fluid intake and wearing easily laundered dark clothes. The fear of smells involved constant checking of their own bodies for odours, and using vaginal deodorants that could exacerbate the problem by causing local skin irritation. Denial that a problem exists or minimising the problem enabled some of the women to carry on with their lives even though they were experiencing some leakage of urine.

Dowd (1991) who conducted a grounded theory study looking at older women's experiences of urinary incontinence has noted similar findings. The fear of an "accident" in public where uncontrolled urine leakage would be detected by others was found to be the main threat to women's self-esteem. These events had a profound impact on them as they were embarrassing and indicated a lack of self- control, with the frightening possibility that they could recur at any time without warning. To achieve a "normal" life women needed to feel they were "in charge" and were able to cope with managing their urinary output. The strategies used were similar to those noted by Ashworth and Hagan (1993) and involved frequent toileting, wearing pads and planning activities. The minimising of the problem enabled women to carry on with their lives and to focus on other interests, to accept their incontinence. If the continence care routines they had developed were effective then, even if they resented the incontinence, the problem was manageable. If they were unsure about the effectiveness of their routines then the problem was unacceptable and interfered with their lives.

A study by Skoner and Haylor (1993) also had similar findings to Dowd (1991) and Ashworth and Hagan (1993) about the management of incontinence. An interesting finding that does not appear to be in other currently reviewed papers, is that women view their incontinence as an integral part of their everyday existence, something that is unavoidable and reluctantly tolerated. Skoner and Haylor (1993) found medical practitioners tend to assess, diagnose and treat incontinence in a disease framework and expect women to agree to this process. They also found in addition to the above that women prefer to manage their incontinence with non-invasive techniques including pelvic floor exercises, modification of fluid intake, weight loss and bladder retraining, rather than submit to surgery to correct the problem.

With studies using different definitions for depression or distress it can be difficult to compare whether the incidence of depression is, in fact, higher in women with urinary incontinence or not. However, from the studies reviewed it can be suggested that incontinence has a significant impact on women's lives of all ages and needs to be addressed in a sensitive and practical way.

The development of routines to manage and cope with incontinence has not been investigated, although the maintenance of these has been explored within research conducted by Ashworth and Hagan (1993). Most of the qualitative research conducted in this area has included women who were well educated, attending universities within the U.S.A. By recruiting small samples of a discrete group it is not possible to generalise these studies to other countries and cultures or different groups of women.

The Development of Specialist Nurses to Promote Continence and Manage Incontinence

The Chief Nursing Officer at the Department of Health and Social Security, Dame Phyllis Friend (1977) encouraged the development of local continence services by recommending that a senior nurse should take responsibility within each District Health Authority for ensuring that the needs of continence sufferers were met (Standards of Nursing Care: Promotion of Continence and Management of Incontinence- CNO (SNC) (77). This endorsement of continence services was very valuable, as it was the first time a senior nurse had highlighted the importance of providing appropriate services for incontinence sufferers.

An Action on Incontinence working group reviewed the content of nursing and medical education in relation to incontinence and recommended the foundation of incontinence clinics with urodynamics assessment and the appointment of a continence advisor to each district (King's Fund Project 1983). This Incontinence Action Group included members of social care, health professions and industry. Findings indicated that education in the promotion and management of incontinence was sadly lacking in both nursing and medical education, leading to a recommendation that this should be addressed together with the education of the general public in incontinence awareness.

Throughout the 1980s continence services rapidly expanded with the appointment of over 300 continence advisors to continence advisory services within District Health Authorities (Roe 1990, Mandelstam 1990, Rhodes & Parker 1993). The continence advisors were registered nurses, employed as clinical nurse specialists but without a clearly defined role. The lack of a formal definition for the role led to a wide variety of interpretations of the nature of the service provided. Rhodes and Parker (1993) recommended that continence advisors were most effective when employed in an educational and training role, with a small clinical caseload to maintain their clinical expertise. They conducted a survey of the views of continence advisors throughout England and Wales and identified three models where continence advisors felt that their skills could be fully utilised:

- "A continence manager with one or more continence advisors"
- "A continence adviser/manager with a network of link or resource nurses"
- "A continence manager with one or more continence advisers, with a network of link or resource nurses".

It is interesting to note that this model has been included within the latest Department of Health guidance on good practice in continence services (Department of Health 2000a) and expanded to include a director of Continence Services who leads a multidisciplinary team including continence advisors, link nurses, physiotherapists, occupational therapists and urodynamic services to provide integrated continence services.

Continence services tended to develop in a random fashion with little assessment of local population need or links to strategy, leading to inequity of service provision. In 1992 Jean Rooker the Shadow Minister for community care summed up the provision of services as "a continence lottery" dependant on location. Clearly this situation could not continue and following Sanderson's "Agenda for Action for Continence Services" report in 1991 the NHS Executive made the implementation of these guidelines a priority for purchasers in 1994-5. A key report by the Royal College of Physicians in 1995 reviewed the state of continence care in this country, and helped to shift the focus from provision of containment products for incontinence towards assessment and diagnosis of the problem.

The National Service Framework for Older People (Department of Health 2001) recommended that integrated continence services (ICS) should be in place by April 2004. However, Thomas (2003) found in a national survey of the extent of the implementation of the "Good practice in continence services" guidance (Department of Health 2000a) that of 204 sample Primary Care Organisations although 91% planned to develop an ICS only 31% had discussed their proposals at board level. The development of integrated continence services clearly requires Primary Care Organisations to promote the development of continence services as a priority.

The Management of Incontinence in Primary Care

The promotion of continence and management of incontinence within Primary Care, with sufferers initially seeking help from community nurses and GPs, is a model for both current and future provision of services. Members of the Primary Health Care Team (PHCT) are ideally placed as the first point of contact for patients, who may be attending the surgery for another reason. Sufferers often disclose their continence problem only after direct questioning about symptoms related to bladder dysfunction, as they may consider a normal consequence of ageing or childbirth (Lagro-Janssen, Smits & van Weel 1990; Roe, Doll & Wilson 1999).

Advice and treatment for urinary incontinence can successfully be provided in Primary Care. Studies by Lewey, Billington & O'Hara (1997) and Sander *et al* (2000) found that a majority of women were successfully managed with conservative treatment.

Shaw (1999, 2001) proposed that the way people managed and coped with their incontinence depended upon an individual's appraisal of the situation (Table 2 p18).

Table 2: The Management of Incontinence in Primary Care

Author and Year	Title	Country of Study	What Studied and Research design	Sample Size and Characteristics	Findings	Conclusions
Shaw (1999, 2001)	A Review of the Psychosocial predictors of Help-Seeking Behaviour and Impact on Quality of Life in People with Urinary Incontinence	U.K.	How a framework developed by Shaw (1999) could be applied to studies related to incontinence from 1980-2000.	Literature Search	Illness and coping appraisal are important moderators of behaviour and may influence the impact of incontinence.	An improved understanding of health and behaviour can be achieved by relating research findings to theoretical models.
Button *et al* (1998)	Consensus Guidelines for the Promotion and Management of Continence by Primary Health Care Teams: Development, Implementation and Evaluation	U.K.	The impact of implementation of clinical guidelines on clinical outcomes. Pre and post-implementation postal survey with 3 month interval.	Pre-test: Random sample of men and women over 18 years from one GP practice (n=1503) Post-test: Incontinence sufferers identified from pre-test (n=174)	The majority of incontinence sufferers had not sought help (61%, n=124) Severity found to be a key factor in help-seeking.	Deficits identified in pre-implementation survey regarding continence assessments were not all rectified following introduction of guidelines. The 3 month follow-up period may have been too short to allow time for full implementation of guidelines.
Bignell & Getliffe (2000)	The Promotion of Continence for Elderly People in Primary Care: The Role of Community Nurses (South Thames Evidence-Based Practice Project)	U.K.	Quasi-experimental design to compare knowledge, practice and perceptions of nurse's pre and post guideline implementation.	Whole population of community nurses within one Trust (n=246), Clinical service managers, one locality director & 3 GP's.	Increased knowledge related to assessment and treatment of incontinence reported by health professionals in the intervention group.	General acceptance that promotion of continence is part of a nurse's role, especially district nurses. Recommendations included the effective use of existing expertise, ongoing education and multidisciplinary team working.

In 2001 Shaw reviewed how the framework could be applied to findings from studies related to incontinence from 1980-2000. Two theoretical models were identified that could enable health promotion initiatives to focus on gaps in knowledge that have a negative impact on help-seeking behaviours (Leventhal & Nerenz 1985) and Lazarus's transactional stress model (Lazarus *et al* 1980), that focuses on behavioural and cognitive strategies based on problem solving.

Both models relate to how people decide whether or not their symptoms are a health threat. Shaw (2001) gives examples from the literature on urinary incontinence and demonstrates how this could fit with parts of each model. For example: Urinary incontinence may not be seen as a medical condition, but as a normal consequence of the ageing process (Simons, 1985, Holst & Wilson 1988, Branch *et al* 1994). Therefore, urinary incontinence is not given an illness "identity" and may not be discussed with a health professional. Health practitioners may not use these models in practice but as the purpose of the research is to inform, and support the development of services it may not be necessary for practitioners to have an in-depth knowledge of the theories.

One of the first studies to examine the management of incontinence using clinical guidelines within Primary Care was undertaken as part of the NHS Executive Strategy for Major Clinical Guidelines, and involved their implementation at one GP practice in an urban area (Button *et al* 1998). The evaluation of the effectiveness of the clinical guidelines involved the use of a pre-test and post-test design involving a pre-test and post- test implementation postal survey of a random sample of 17% people aged 18 years and over from the Practice (n=1503). The sample included both patients with and without incontinence. A response rate of 61% (n=909) for the pre-test survey was achieved with no significant difference between the number and ages of males and females who responded. Twenty-two per cent of women (n=101) and 7% of men (n=31) reported symptoms of urinary incontinence at least once a month with 35% (n=165) of women and 9.9% (n=41) of men suffering from incontinence in the previous two months. Results from the pre-test survey indicated that 61% (n = 124) had not discussed their incontinence with any health professional. People who had not sought help for their incontinence problem tended to be younger (under 46 years of age) and did not consider their urine loss to be a problem.

Implications following from these results for health professionals working in Primary Care involve the use of direct questions relating to urine loss together with the use of care pathways to enable the appropriate assessment and treatment of urinary incontinence to take place. The raised awareness that younger women may be less likely to seek help for their continence problems should prompt health professionals to raise the topic and take appropriate action.

Of the 225 people who were incontinent 77% (n=174) agreed to participate in the post-test survey, three months later. A response rate of 69% (n = 119) was achieved and included 22% (n = 26) males and 78% (n = 93) females. However, only 19 people (16%) (5 males and 14 females) had sought help for their problem since the initial survey. The mediating factor was the severity of the urinary incontinence, with those people experiencing the greatest limitations as a direct result of their incontinence being the most likely to seek help. This finding has also been noted in other studies that have examined the link between help-seeking behaviour and the severity of the incontinence (Lagro-Janssen *et al* 1990, Sandvik *et al* 1993, Sandvik, Kveine & Hunskaar 1993, Uebersax *et al* 1995, Roe, Doll & Wilson 1999, Shaw 2001).

The assessment and treatment of urinary incontinence by members of the PHCT prior to the implementation of the guidelines was based on an individual practitioner's own model, and was therefore unique to each individual. There was a wide variation in the assessment and treatment methods employed with urine specimens occasionally obtained and abdominal and vaginal examinations carried out on an ad hoc basis.

Following the implementation of the guidelines the deficits identified in the pre-implementation survey were not all addressed. All patients received an abdominal examination, but only six of 14 women had their urine tested. Vaginal examinations were not carried out in the 4 new referrals and there was no increase in the number of frequency/volume charts issued by GPs. There was no measurable impact of the implementation of the guidelines on identified clinical outcomes relating to incontinence although there were some mitigating factors. The length of time between the introduction and evaluation of the outcomes was very short, with only three months given to produce a single assessment tool, provide additional education and training for members and improve record keeping. As most of these elements were ongoing during the three-month period, evidence of some improvement in outcomes indicated that the guidelines were actually being used by the PHCT. Further evaluation of the effectiveness of these guidelines following a longer time period has not been reported in the literature.

Evidence that incontinence can be successfully managed within Primary Care by the introduction of clinical guidelines was supported by research conducted as part of the South Thames Evidence-based Practice project (STEP) (Bignell & Getliffe 2000). The study focussed on the development and implementation of evidence-based guidelines for the promotion of continence for elderly people and evaluated changes in service, professional and patient outcomes. A quasi-experimental design was used to compare base-line outcome measures in matched control and intervention groups of community nurses (which each comprised two localities within the Trust studied). Post-intervention measures followed development and implementation of clinical guidelines in the intervention group only. Results demonstrated increased knowledge relating to continence assessment and treatment held by health professionals in the intervention group but also identified practical limitations to a continence promotion role linked to competing demands on time and lack of role clarity.

As part of the Leicestershire Medical Research Council (MRC) Incontinence Study evidence-based intervention protocols were developed for use in a new nurse-led continence service (Williams *et al* 2002). The service was led by a continence nurse practitioner with evidence-based interventions implemented on the basis of a thorough clinical assessment. Documentation was developed by the nurses from existing published literature, practice protocols, patient information leaflets and standardised letters to GPs to inform them of patient progress. The importance of clearly documenting the assessment process, together with interventions provided, so that those interventions can be applied consistently by different nurses was highlighted. The ongoing involvement and regular updating of progress with the patient's GP enabled the work of the nurse-led clinic to be widely disseminated. Limitations to the service were acknowledged with the recognition that the evidence-based interventions developed were specifically for use for adults 40 years and over.

Care Pathways

There are several different treatment options for patients with continence problems within Primary Care. Some inconsistency between the responsibility for the assessment and treatment of incontinence exists between community nurses and GPs, with some GPs conducting assessments and then referring patients to community nurses. In other GP practices nurses are expected to conduct initial continence assessments and then manage the care pathway for that patient which may involve initial conservative treatment (fluid and dietary advice, urinalysis, frequency/volume charts and the teaching and monitoring of pelvic floor exercises) or referral to a Continence Advisor, Physiotherapist or Urologist (Bignell & Getliffe 2001).

When a patient first discloses a continence problem to a GP a number of different pathways may be followed depending upon the GPs preferred clinical judgement and the availability of resources to manage the condition (Diagram One, p154). Following an initial assessment the GP may decide to manage the problem himself or herself and may advocate dietary and fluid changes together with verbal instruction in pelvic floor exercises to alleviate stress incontinence. If following a vaginal examination a prolapse of the urethra, bladder, rectum or cervix is detected, pelvic floor exercises may be initiated or the patient may be referred to an Urogynaecologist, for further assessment and possible corrective surgery. Referral to a Community Nurse for initial assessment and management of the problem or referral to a Continence Advisor or Physiotherapist are other options that may be considered.

A study by Norton (1996) found that incontinence was seen as a nursing problem by many GPs with the focus on containment and coping with the problem, rather than the therapeutic approach of trying to resolve the problem. Studies that have examined help-seeking behaviour in women with incontinence have found that if an unhelpful response is received to requests for help with incontinence then people may wait several years before attempting to seek help for their problem (Brittain, Perry & Williams 2001).

A study by Sandvik, Hunskaar and Eriksen (1990) in Norway examined the management of urinary incontinence in women by GPs. Questionnaires, consisting of six case histories were sent to 191 GPs and 139 (73%) responded. They were asked to respond to the cases in accordance with their normal consultation practice and not to provide an "ideal", but false answer. Results indicated that a gynaecological examination was performed less frequently in elderly patients than in the young (numbers were given for each case). The measurement of residual urine and the use of frequency/volume charts were reported as "rare" with the prospect of suitable treatment decreased with increasing age. As this study examined responses at an initial consultation only, without the benefit of a longitudinal view it may present a limited picture of the full nature of the treatment offered by the GPs.

A study conducted in Norway by Seim *et al* (1996) examined whether urinary incontinence could be successfully managed in general practice, and focussed solely on the GP's management of the problem. It was an observational study with interviews and clinical examination before, during and after treatment of 105 women aged 20 years and over with urinary incontinence. Interventions included: treatment with pelvic floor exercises, oestrogen, anti-cholinergic drugs, electrical stimulation, bladder training and provision of incontinence pads. The main outcome measures included both subjective and objective measures of incontinence together with the number of referrals to a specialist.

After 12 months the results were encouraging with 70% (69/99) of the women cured or much improved (subjective and objective improvement), with 16% (17/105) referred to a specialist. Recommendations included the initial treatment within general practice for six to twelve months before referral to a specialist and the observation that urinary incontinence can be successfully managed in general practice. Although this study was conducted in Norway the findings endorse the conservative management of incontinence before secondary referral to a specialist and could be generalised to the UK. Changes to the management of incontinence in women may well have occurred over the time elapsed between the two studies, accounting for the improved patient outcomes in the later study.

Other pathways explored by women with continence problems include contact with Community Nurses, Practice Nurses or Health Visitors (Diagram Two, p155). Information about bladder problems may be obtained from newspapers, magazines, television, radio or the Internet. The quality of this information may be variable with few controls available for articles posted on computer websites. It is therefore possible that some women have obtained factually incorrect information that may exacerbate their condition by suggesting inappropriate treatments, or dissuading them to seek professional help. However increasing sources of information do help to increase public awareness of continence issues.

Some continence sufferers seek help from complementary therapists (homeopaths, medical herbalists, and naturopaths) and will try anything to resolve their problem. Anecdotal evidence from practice has suggested that some people feel their problem has improved, but most appear to value the one to one attention and friendly manner of the therapist. Literature on the impact of complementary therapies on urinary incontinence appears to be scarce, with the author unable to locate any information within the published medical literature.

Contact with incontinence support groups and patient-focussed organisations (i.e. The Continence Foundation or "Incontact") provide sufferers with accurate, relevant information about their condition. However, accessing these groups can be problematic, with occasional advertisements in Sunday supplements, but few posters in GP surgeries or public areas.

The Development and Evaluation of Nurse-Led Clinics in Primary Care

Referrals to PHCT staff other than GPs may occur following attendance at the surgery for another health-related problem, or a self-referral. Problems exist for women trying to access appropriate services for continence care as the services offered can still vary across the country, and from one GP practice to another. However, things are changing with the development of the link nurse role, where nurses within Primary Care manage initial assessments for incontinence, working closely with Continence Advisors and GPs. Link nurses may be District Nurses, Practice Nurses, Health Visitors or Community Nurses who have either completed a "Promotion of Continence and Management of Incontinence" module, or have attended study days focusing on the assessment and management of incontinence. These are usually organised on a Trust-wide basis by the continence advisory service in the area. Nationally the link nurse role has still to be implemented, with District Nurses managing continence care as a significant proportion of their workload. In 1999 the Audit Commission report indicated that 20% of a District Nurse's workload involved continence care, with inadequate patient assessments and the management of incontinence predominantly involving the use of containment methods (pads).

Conservative treatments can be offered in Primary Care (pelvic floor exercises, bladder training, weighted vaginal cones, oestrogen replacement therapy, advice on fluid intake and diet and anticholinergic medication). Additional forms of conservative treatment that can be offered include biofeedback and electrical stimulation, although these tend to be managed by Continence Advisors with additional training or Physiotherapists specialising in obstetrics and gynaecology. Several studies have indicated the effectiveness of biofeedback in continence training (Burgio 1990, Smith & Newman 1994, Glavind *et al* 1998) and recommend that it is most effective when used in combination with other treatment options (i.e. bladder retraining). Conservative management of incontinence is defined as "…. Any therapy that does not involve medical or surgical intervention. It includes principally, lifestyle interventions, physical therapies, bladder retraining and anti-incontinence devices" (Bo *et al* 1999). It is appropriate where immediate referral to a specialist is not indicated and is the preferred initial approach to the management of urinary incontinence.

The further expansion of the link nurse role with nurses placed firmly at the cutting edge of continence management has been advocated by the Department of Health guidance "Good practice in continence services" (2000a). Primary Care is seen as the first place for people with incontinence to seek help and advice, with targets within the guidance suggesting that PHCTs should plan to:

- Identify all people with incontinence.
- Offer them an appropriate assessment.
- Help carers understand the condition and treatment.
- Deliver first line services.
- Facilitate access to specialist services.

This guidance means that nurses in Primary Care should be working towards:

- Identifying patients within the practice who have a continence problem.

- Completing a comprehensive assessment of their continence problem, together with an assessment of other physical or psychological problems that may exacerbate any identified problems.
- Starting treatment (usually conservative treatment), reviewing progress and referring (where appropriate) to a continence advisor, and/or urodynamic investigation.

The importance of integrated working with nurses seeking advice and guidance from other health professionals is essential in providing an efficient cost-effective and improved service, more locally to patients at their local practice.

The development of nurse-led continence clinics in Primary Care has often been instigated by practitioners who have identified a need for a more systematic approach to the management of incontinence, together with some associated frustration at the observation of the inappropriate management of some continence problems.

District Nurses in Birmingham working within a community nursing development unit sought to identify some of the problems associated with factors affecting positive health behaviour in relation to promoting continence and some of the problems experienced in maintaining the changed behaviour (Nolan 1997). Following an audit that revealed 45% of patients within one District Nurse caseload had continence problems, the current management of those patients was examined with their health outcomes and the resources they were using. It would have been interesting to see the general content of the audit, but unfortunately this was not covered in the article. However, this prompted the development of a joint nursing and GP continence clinic, where following a joint assessment patients were given a provisional diagnosis and a care plan was designed for that person to follow. Initial, conservative treatment for incontinence was offered together with referral to other specialists as appropriate. After six months an audit of the continence clinic was undertaken. Although the figures referred to the clinic appear to be small (12 referrals), six had improved or had achieved continence, with only one requiring continence pads (Table 3 p29).

An interesting finding was that patients who had been referred to the clinic following a Practice Nurse/GP consultation, or self-referral were making different progress to those who had previously been seen at home by the District Nurse. Of the seven patients who had never been seen or assessed before, five were either cured or showed signs of improvement at the time of the audit. This encouraged the team to look at assessing motivation and the patient's desire to change. Different theories were examined including the impact of the locus of control as related to health (Wallston & Wallston 1981), self-efficacy (Bandura 1986) and the cycle of change (Prochaska & Clementie 1983). The recognition of where patients were in each of these processes was cited as helpful in facilitating the effective management of incontinence. The clinic appears to have been successful in identifying those patients with incontinence and offering them appropriate treatment for their continence problems (Nolan 1997).

The literature relating to the development of nurse-led clinics within Primary Care focuses on the use of specially trained nurses to conduct the clinics, with little literature available on nurses currently working in Primary Care as District Nurses, Practice Nurses or Health Visitors who have expanded their roles to include continence promotion and management. Studies have examined the development of these clinics using specially trained nurses, with some success. A study in 1991 by O'Brien *et al* indicated that specially trained nurses with three-month training in assessment and management of incontinence could facilitate cure or improvement in patients in Primary Care. A randomised controlled trial recruited 292 women suffering from urinary incontinence (with two or more urine leaks a month), who were randomly assigned to immediate assessment and treatment by a nurse or were left for 12 weeks after which they followed the same intervention plan. The intervention comprised of four sessions of pelvic floor exercises or bladder retraining, and depended on the symptoms experienced. Encouragement was given to continue the plan at home and no further intervention was offered. Twelve weeks later 276 women reported their continence status to be either cured, improved, the same or worse. There was a 68% cure or improvement in the intervention group compared with 5% in the controls.

To see if these outcomes could be maintained in the longer term a four- year follow-up study was undertaken. Results from the questionnaire were available from 229 women and showed that 69% (158) had either maintained their original improvement or cure or had made further improvement. Sixteen per cent (38) had deteriorated and 15% (33) had neither benefited from the original interventions nor changed. By providing a training programme for nurses in assessment and management of incontinence a sustained improvement in the clinical outcomes of patients with incontinence appears to be demonstrated. A success rate of 69% (n=158) indicated the effectiveness of the programme and prompted further research into this area by the Leicestershire Incontinence Study (Williams *et al* 2002).

Table 3: The Development and Evaluation of Nurse-Led Clinics in Primary Care

Author and Year	Title	Country of Study	What Studied and Research Design	Sample Size and Characteristics	Findings	Conclusions
Nolan (1997)	Continence Clinic: Positive Outcomes Difficulties Encountered	U.K.	Audit of clinic, review of diagnosis and management plan.	Patients who had attended a joint nurse/GP continence clinic in a six-month period (n=12)	Of the 12 patients referred to the clinic six had improved or achieved continence and one referred for pad management.	Patients referred to the clinic following a practice nurse/GP consultation or self-referral made different progress to those who had been seen before at home by the district nurse. The team examined theories linked to assessing motivation and desire to change. The recognition of where people were in cycle of change enabled more effective assessment of treatment plan.
O'Brien *et al* (1991)	Urinary Incontinence: Prevalence, need for Treatment and the Effectiveness of Intervention by Nurse	U.K.	Randomized controlled trial of management of incontinence in Primary Care by nurse trained in assessment and management of incontinence.	292 women with validated urinary incontinence randomly assigned to immediate assessment and treatment by nurse or were left for 12 weeks and then followed same intervention plan.	12 weeks later 276 reported incontinence to be cured or improved There was a 68% cure or improvement in the intervention group compared with 5% in the controls.	A three-week training course for a nurse in the assessment and management of incontinence, can offer an accessible and acceptable service for women with incontinence.

Author and Year	Title	Country of Study	What Studied and Research Design	Sample Size and Characteristics	Findings	Conclusions
Williams *et al* (2000)	Development, Implementation and Evaluation of a New Nurse-Led Continence Service; A Pilot Study	U.K.	Care delivered by 5 specially trained nurses. All patients seen over an 8 week period, comprehensive assessment undertaken and treatment plan initiated.	8437 postal questionnaires mailed to a community population 40 years and over. 711 eligible for service provision, 274 agreed to enter service, 245 started service and 194 completed treatment.	Evaluation at 8 weeks, objective and subjective methods used. Patient's reports of impact of symptoms on life, feelings and relationships showed significant improvement. There was a small reduction in urinary symptoms.	The most appropriate provider of care for people with incontinence appears to be a specialist nurse, with additional training and an interest in the subject.
McGhee *et al* (1997)	Evaluation of a Nurse-Led Continence Service in the South-West of Glasgow, Scotland	U.K.	The effectiveness of a continence nurse in different settings.	62 community dwelling patients and 57 nursing home residents with urinary incontinence referred to the study by health professionals.	The nature of the interventions offered by the continence nurse varied between settings. A 69% improvement in the severity of incontinence was found in the community group with a 30% improvement in the nursing home.	Using a continence nurse to manage urinary incontinence in a community setting appeared to be an acceptable and cost-effective way to manage the problem.
Shields *et al* (1998)	Development of a Community Nurse-Led Continence Service	U.K.	5 full-time continence nurses and 1 part-time physiotherapist have been funded for 3 years to extend the community continence service.	Evaluation of the benefits of a nurse-led continence team to the community. Sample has yet to be determined.	The service is currently undergoing evaluation.	Evaluation will cover clinical, psychosocial and economic outcome measures.

The development of a community nurse-led continence service in south-west Glasgow, Scotland was prompted by a multidisciplinary health gain commissioning team set up to look at urinary incontinence (McGhee *et al* 1997). They found that urinary incontinence was a significant problem in Glasgow with 56,000 adults experiencing incontinence, with a third having been incontinent in the previous week, and concluded that continence services had developed without a strategic approach.

A research nurse was employed for two years to manage urinary incontinence in a community setting. Referrals were taken from GPs and family members, covering eight Primary Care Teams and including nursing homes. The aims of the study were comprehensive with assessment and implementation of a management plan for incontinence, the monitoring and evaluation of that plan and the examination of the economic implications for the service and the city of Glasgow. The Continence Nurse accepted referrals from all members of the PHCT and patients were assessed in their own homes. A comprehensive assessment was completed and included abdominal and vaginal examinations, urinalysis, food and drink diaries, toilet frequency and number of incontinence pads used. A questionnaire was also completed to elicit patients' perception of the severity of their incontinence and the impact this had on their lifestyle. It was not stated in the article, which questionnaire was used, and no data relating to the responses to the questionnaire were included, so it is difficult to assess the quality of the data gained and their generalisability.

Findings indicated that although the nature of the interventions varied widely between community dwelling and nursing home residents a 69% improvement in the severity of incontinence among the community group was noted. In the nursing home a 30% improvement in the severity of incontinence was noted, the level of improvement reflected by the physical and mental health of the patients. By employing a Research Nurse to manage incontinence in a community setting there was a notable improvement in management of incontinence (McGhee *et al* 1997).

The service in Glasgow expanded with the further development of the nurse-led service to enhance the link role between staff in Primary Care and Continence Advisors. Five full-time Continence Nurses (link nurses) and a part-time Physiotherapist were funded for three years, and unlike nurses in Primary Care who tend to have a number of different roles they were solely employed to promote continence and carry out comprehensive assessment and management programmes with continence sufferers. The assessments carried out by the Continence Nurses were broadly similar to those in the previous study, with referral to the Physiotherapist for people with stress or urge incontinence, especially those with poor pelvic muscle contraction. The Physiotherapist provides training in pelvic floor exercises, biofeedback and interferential treatment as appropriate. The team actively promotes the promotion of continence and literature and videos relating to incontinence are available in clinic waiting areas.

The evaluation of the service appears to be ongoing with the monitoring (including the development of audit tools, preparation of progress reports and review of baseline assessments) carried out by an evaluation officer. The formal evaluation of the service has yet to be published but the nurse-led community based continence service appears to provide a model of good practice in individualised patient care (Shields *et al* 1998).

Users' Views of Nurse-Led Clinics

Patients' views of a new nurse-led continence clinic in Leicestershire were elicited by in-depth qualitative interviews with 23 participants, seven males and sixteen females (Shaw, Williams, Assassa 2000). Five nurses who had received a three-month training programme in the assessment of incontinence and the use of evidence-based practice protocols provided the service. All patients participating in the study had received an eight-week course of treatment with a continence nurse practitioner in the preceding year and were recruited to the study if they had been offered further treatment and a urodynamic assessment.

Findings indicated that the interpersonal skills of the nurse were critical in patient satisfaction. A friendly, informal approach by the nurse enabled patients to feel relaxed, and to be able to talk freely about their concerns. The friendly nature of the relationship enabled them to feel empowered in the relationship and to feel that they were talking as equals both working towards a common goal. Other aspects of the relationship seen as important were trust and sensitivity. The alleviation of embarrassment helped to reduce the patient's anxiety and the feelings of trust and confidence were supported by the good communication skills demonstrated by the nurse.

The technical skills of the Continence Nurses were recognised by the patients, who valued the opportunity to see a nurse who specialised in continence care. They also felt that the Continence Nurses were more thorough in their approach to continence management than GPs or Practice Nurses, and especially valued the use of equipment (bladder scans).

Participants felt that it was important to have information about all aspects of their care including feedback on the results of tests and reassurance that nothing was seriously wrong with them. Information about anatomy and physiology, with diagrams showing the location of the bladder and its relationship to other organs enabled them to gain a better understanding of the nature of their problem (Shaw, Williams & Assassa 2000). These findings are similar to those in another part of the Leicester study that looked at patient satisfaction with urodynamic investigation, with the importance of good interpersonal skills and a friendly approach by the nurses serving to alleviate patient's concerns about this embarrassing procedure (Shaw *et al* 2000).

An evaluation of the effectiveness of conservative management of urinary incontinence was undertaken by Continence Advisors in North Herts, who provide advice and treatment for continence sufferers in their community clinics. A urinary symptoms and quality of life questionnaire was sent to 161 women aged 18-92 who had been discharged from the clinic between Oct 1992 and July 1996. Eighty nine (55%) responded. All the respondents had found the clinic to be useful and informative with 53% symptom free for up to three years following discharge. Only 1% felt that their urinary symptoms had become more severe and 77% were content with their current quality of life. It was interesting to note that although 100% of the respondents had found the clinic useful only 88% would make contact with the clinic again if their symptoms returned. The low response rate at 55% may have suggested that some of the women had continued to be symptom free, as they had not returned to the clinic. However, it is also possible that some of the women who failed to respond to the questionnaire may have had concerns about their treatment at the clinic and felt unable to address those concerns directly (Lewey, Billington & O'Hara 1997).

A multidisciplinary approach to the initial management of incontinence has also been explored in Denmark and the United States of America (USA). In Denmark a prospective observational study of 408 women attending an open-access, interdisciplinary continence clinic found that although the women tended to be over 68 years of age, with a prevalence of concomitant diseases, most were successfully managed with conservative treatment (Sander *et al* 2000). The multidisciplinary team described by Fiers & Siebert (1993) in the USA did not include a Urologist, but approval for attendance at the clinic had to be given by the patient's own GP. The inclusion within the team of a medical social worker, to "assist the patient in identifying the psychosocial effects and work with the patient to understand its impact" appears to be a role that many Continence Advisors in the UK would see as part of their skills as a practitioner. However, both clinic models were recommended as effective, acceptable treatment options for patients.

Patients' views of continence services have been explored by a number of qualitative studies that have used questionnaires and in-depth interviews, either during, or following a treatment programme. All the studies have certain similarities with health professionals tending to focus on clinical outcomes, non-compliance and attendance rates when evaluating services. Priorities for patients are different with impact of incontinence on quality of life, interpersonal aspects of continence care and the convenience and accessibility of services being valued more highly (Roe & May 1997; Clayton *et al* 1998; Roe, Wilson & Doll 2000).

The involvement of patients in planning and actively contributing to their care has been encouraged by the present UK Labour government with recommendations that the NHS should foster co-operation between NHS staff, patients, their carers and families to provide a patient-focused service (Department of Health 2000b, 2003). Within the NHS Plan (Department of Health 2000c) chapter 10 supports user involvement in health care at all levels.

Within the literature related to continence services and user involvement the guidance; "Good practice in continence services" (2000a) highlighted the lack of involvement in service planning and provision by users. One of the key recommendations made was that users should be involved in all aspects of the service, with the responsibility for implementation resting firmly with each Director of Continence Services in their area. Another document that strongly advocates patient participation in their care is "The Essence of Care" (Department of Health 2001a) this covered a number of health care issues, including continence care. The theme of user involvement included the following:

- Health Education.
- Setting up a user group for continence services.
- User group views to be involved in training programmes.
- The promotion of continence services to user groups and raising awareness by use of links with user groups.
- Staff training with user focus.
- Users must be involved in planning and evaluating services.

The development of user groups within continence care is still in its infancy, with one group established in Croydon, south London in 2001 (Addison 2002). User groups still need to be developed in the Southampton area to enable service users to look at the wider issues affecting the continence service for all the people who are going to use the service.

Integrated continence services for older people have been made a statutory requirement of the National Service Framework for older people (Department of Health 2001b), with inclusion in Health Improvement Plans by April 2003 and in operation by April 2004. Clearly fully integrated continence services have yet to be implemented, with Primary Care Organisations working towards this target. A national two year survey to measure the extent to which the guidance "Good practice in continence services" is being implemented was conducted by Thomas (2003) who suggested that although Primary Care Organisations were aware of the document, (with 99% of respondents having read the document), only 31% of Primary Care Organisations had plans to develop an integrated continence service.

Partnership Working between Health and Leisure

Several government initiatives have encouraged partnership working between health and leisure services, voluntary organisations and communities (Department of Health 1997, 1998a, 1999). However, partnership working is far from straightforward with different organisations retaining their own management structures and different aims and objectives. Threats to partnership working have been identified in studies by Kanter (1994) and Huxham (1996) who found that differences in cultures, goals and agendas could lead to problems understanding one another, impacting on the relationship. Huxham and Vangen (2004) explored the nature of the practice of collaboration in organisations by reviewing their own research over a 15- year period looking at the theory of "collaborative advantage". They concluded that because collaboration is highly resource-consuming and often painful, if there is a choice then they recommend avoiding collaboration. However, this generalised conclusion needs to be examined carefully within specific contexts. Clearly within the health service partnership working needs to be facilitated and insights from management and organisational research need to be recognised and utilised positively. Charlesworth (2001) suggested that paradoxically although government policy is encouraging partnerships, the pace of change and the need to meet targets may be counterproductive to partnership working.

The literature relating to the evaluation of continence clinics in settings other than GP surgeries, health centres or hospitals has been difficult to identify. The continence clinic at "The Quays" leisure centre in Southampton opened in July 1999, following partnership between the City Council, local Primary Care Trust (PCT) and lottery funding. The continence clinic is just one of the clinics held in "The Quay to Health" with the following additional clinics occurring on a regular basis:

- Contraception & Sexual Health Clinics.
- Counselling and Therapy for Women.
- Stoma Care (Well Ostomist Clinic).
- Asthma & Allergy Resource Centre.
- Psychosexual Counselling.
- Exercise & Health Education Group for People with Learning Disabilities.
- "Quitters"- Smoking Cessation Service.

Evaluations of the services provided at the "Quay to Health" have been undertaken by a Development Worker on a six- monthly basis from July 1999-July 2001 (Partington 2001). During each evaluation all service users were given forms to complete, irrespective of the service attended. The combined data from all four evaluations (n=498) represented a total of eight weeks of service users. A qualitative evaluation involved 25 people who had expressed an interest in participating and these were interviewed by telephone.

Findings indicated that people were surprised to find a health centre in the same building as a leisure centre, and felt that the setting encouraged the "de-medicalisation of health services", which was viewed as a good thing. People found it easier to use the services provided as the nature of a leisure centre meant that you could be going anywhere in the centre and "improved access to health" was a recurring theme. Some of the participants (numbers not stated) felt that the location of the "Quay to Health" in a leisure centre had prompted them to effect a behaviour change and this resulted in an increase in their physical activity levels. Although people tended to generally be satisfied with the service provided, some felt the building itself was "imposing" and could be "elitist" in that the services provided did not necessarily cater for those people who were overweight.

The integration of health and leisure facilities has been widely supported by the current government with the promotion of healthy living centres (Department of Health 1998b), but at present there is a paucity of published evaluations, making the effectiveness of the centres difficult to ascertain.

Conclusions from the literature review

Incontinence remains an embarrassing and difficult problem for people to legitimise and accept. It can have a devastating impact on their lives, affecting their quality of life and limiting their social contacts, enjoyment of activities and personal relationships (Ashworth & Hagan 1993, Skoner & Haylor 1993, Chiverton & Wells 1996).

Incontinence can be successfully managed in Primary Care with Primary Health Care Teams (PHCTs) working in an integrated and collaborative way to provide the optimum services for their patients. The development of nurse-led clinics within Primary Care has been supported by both government policy and guidance (Department of Health 2000a, 2001a) and by practitioners themselves. However, it has been difficult for some practitioners to make the promotion and management of incontinence a priority with a constantly evolving Primary care agenda that focuses on initial care and management of incontinence, but has yet to provide the additional capital to support any additional cost implications.

The development of integrated continence teams led by a Director of Continence Services is a model of good practice that will raise the profile of continence care and facilitate closer working relationships between continence advisors, Primary Care Nurses, GPs, Physiotherapists and other health professionals (Department of Health 2000a). Continence Clinics in different settings appear to be acceptable to women, although the perceived quality of the care received, together with the friendly and approachable nature of the staff and the quality of the technical information given are critical in patient satisfaction (Shaw, Williams & Assassa 2000).

The general evaluation of the "Quay to Health" may provide some useful insights into the general perceptions held by all the service users. However, the experiences of the women who use the continence service in particular, may or may not reflect the general evaluation already completed. Women living with incontinence can experience many different problems associated with their incontinence, and the opportunity to attend a clinic in an alternative setting may encourage more women to seek help and to suggest ways in which the service could be improved to meet their needs. This is the subject of the following research study.

CHAPTER TWO

Research Design and Methods

Introduction

The purpose of this chapter is to describe the research study design and to discuss the selection of the research site and the qualitative approach adopted by the author. The qualitative study used a single case study design (Stake, 1995) with elements of a grounded theory approach for the data analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1998). Further exploration of the adoption of this approach will be outlined during the chapter.

The study set out to explore women's and stakeholder's views of a nurse-led continence clinic held in a leisure centre and the underpinning philosophy that prompted the leisure department of the City Council and the local health providers to develop this new service. The clinic provides advice and treatment for adults with bladder problems from a continence advisor, a nurse with additional training in the management of bladder problems. Access to the service is open, with direct referrals accepted from any adults, including on a drop-in basis with instant access to treatment and advice. However, most of the referrals made to the service are from health professionals, especially general practitioners who may not have the time, skills or knowledge available to implement assessment and treatment programmes for incontinence. The appointments are made by a receptionist based at the "Quay to Health" (the name of the health centre complex), with one hour allocated to initial assessments and thirty minutes allocated to follow-up appointments. Confirmation of any appointment is made by telephone the day before, with the reminder being welcomed by many of the women who attend the clinic.

The advice and management strategies offered at the clinic are often referred to in the literature as "conservative treatment options" that include advice on fluid intake, diet, avoidance of caffeine and pelvic floor exercises and bladder training. These non-surgical approaches are advocated prior to referral to secondary sources (if unsuccessful) as they are non-invasive, more acceptable to patients, and may solve the problem avoiding the additional time and expense involved in further treatment or consultant referral (Department of Health 2000a).

The clinic is held in an unusual setting, located within a leisure centre with four consulting rooms, a waiting area and office space for support staff connected with the nearby contraception and sexual health clinic. The health centre is found on the ground floor of the leisure centre next to the changing rooms and the entrance to the gym. To reach the centre involves navigating a path through the upper floor of the leisure centre, looking for signs to the "Quay to Health", descending into the depths of the building and locating the clinic. Two different sets of reception staff may be encountered before reaching the receptionists at the health centre, the swimming pool receptionists and the gym staff (who tend to be young and fit).The clinic is not well signposted and clinic users often have to ask where the incontinence clinic is located, which might be experienced as embarrassing in a non-medical setting.

The open-access or drop-in nature of this particular clinic, together with its unusual location and lack of previous evaluation from a users' perspective prompted the selection of this site for further investigation.

The underlying philosophy behind the development of the services at the "Quay to Health" was quite similar to the sentiments expressed in the 1930s by the "Peckham Experiment" with partnership working between the local Primary Care Trust and Southampton City Council. They believed that the health services at the "Quays" would encourage people with sensitive or stigmatized conditions to attend clinics because they were not based within a recognised health care facility. The setting of the clinics, they felt, would encourage people to use either the gym or the swimming pool because they were entering a "healthy environment" and would feel prompted to take action about other aspects of their health.

The continence clinic at the "Quays" warranted study because several assumptions had been made about why this would be a good setting for a clinic, and yet the people who used the service had not had the opportunity to discuss how they felt about the service or their incontinence. Although the study explored one clinic within a unique setting the findings will have some generalisability for other continence clinics based in leisure centres by identifying the benefits of co-locating health and leisure services, and will also be of relevance to continence clinics more broadly.

Incontinence occurs more frequently in women than in men with 35% of women reporting some degree of urine leakage and 14% of men (Brocklehurst 1993; Holst and Wilson, 1998; Lagro-Janssen *et al* 1990; Rekers *et al* 1992; Roberts *et al* 1998; Yarnell *et al* 1991, Perry *et al* 2000, Mc Grother *et al* 2004). The number of men attending the nurse-led clinic at the leisure centre is small with only five men attending over a one- year period and 115 women. The men who attend the clinic were referred by the Consultant Urologist for a clearly defined, single appointment to discuss bladder management following planned surgery.

Aims

The first aim of this study was to explore stakeholders' views of the continence clinic at the "Quay to Health" to examine what prompted the development of the clinic. The second aim was to discover what had prompted women to seek help for their incontinence, the impact on their lives and to enable them to reflect on their experience of attending the continence clinic at the "Quay to Health". The study was designed to answer the following research questions.

Research Questions

1) How does the nurse-led clinic provide continence services for women?
2) What prompted the development of a nurse-led continence clinic within a leisure centre, and in what way is this unique or different?
3) In what way do the philosophies differ between the service providers involved in developing the "Quay to Health" and the views of women who use the clinic?
4) How does incontinence impact on women's lives and what are the coping strategies employed by them?
5) How might a leisure-centre based continence clinic meet women's needs?

The following section will discuss the principles of case study research and some of the differing definitions attached to what constitutes a case. The case in point was the clinic and interviews were conducted with women who attended the clinic, and stakeholders involved with the development of the clinic.

Case Study Research Design

The focus of this study was to explore a nurse-led continence clinic held in the unique setting of a leisure centre. An approach that is flexible and able to facilitate access to data from a number of sources was indicated, with a grounded theory approach to a single case study meeting those needs. Case studies can encompass both qualitative and quantitative approaches, and have been used in a variety of settings including healthcare, education and business (Hammersley 1992). A case study has been described as a detailed study of one case (or just a few cases), using a variety of methods and conducting an in-depth investigation of the complexities of the case (Punch 1998, Vallis and Tierney 2000).

Several different definitions exist within the literature with Yin (1994, p13) describing case study as "an empirical inquiry that investigates a contemporary phenomena within its real life context, especially when the boundaries between phenomena and context are not clearly evident" and "in which multiple sources of evidence are used". A similar definition is given by Robson (1993), although Stake (1994, p237) states that it "is both the process of learning about the case and the product of our learning". In addition Miles and Huberman (1994) have suggested that case study research can also represent a temporal event, such as the development of an innovative training programme over time or dialogue between two people.

Different types of case study associated with the perspectives of Yin (1993, 1994) and Stake (1995) offer a focus on either single or multiple cases. Yin (1993) further defines cases in three ways as descriptive, exploratory or explanatory. A descriptive case study design records a full description of the phenomenon of interest within its context (Yin 1993). An exploratory case study "is aimed at defining the questions and hypotheses of a subsequent …study or determining the feasibility" of a research project (Yin 1993, p5). The explanatory case study attempts to demonstrate causal relationships. Yin's approach to case study has its roots firmly grounded within positivism, with a rigid approach to case study and prescriptive guidance. Within Yin's work there appears to be little recognition of the importance of knowledge and intuition in the process of data collection and analysis. He also suggested that traditional quantitative criteria including construct validity, internal validity, external validity and reliability should be used to evaluate the quality of a case study (Yin 1993, 1994). These terms do not seem appropriate for a constructivist paradigm where Guba and Lincoln (1981) and Sandelowski (1996) recommend that researchers tackle issues of trustworthiness and rigour by "truth value", "applicability", "consistency" and "neutrality".

The approach adopted by Stake (1994, 1995) suggests that it may not be possible to place cases into pre-selected categories, but the methods used will be different depending upon the intrinsic and instrumental interests of the case (Stake 1995, p4). Stake's approach to case study is closely aligned to a constructivist epistemology, the belief that knowledge is constructed rather than discovered and the understanding that any research inquiry can never be value free. He notes that "no aspects of knowledge are purely of the external world, devoid of human construction" (Stake 1995, p100). A constructivist epistemology and ontology provide the theoretical basis of this study, with an intrinsic approach appropriate for this study.

Three types of case study design have been developed by Stake (1995); these include an intrinsic case study design, useful when clarification and understanding of a particular case is required. In this type of design it is the unique case that is of interest. The instrumental case study is where "a particular case is examined to provide insight into an issue or refinement of a theory"(Stake 1994, p237). Here the case is not the main focus but is used to explore and understand another issue. The collective case study is an instrumental case study that has been enlarged to include a greater number of cases to explore a particular phenomenon or event. The study presented here can be classed as an intrinsic case study design.

Case study investigation can generate large amounts of data and the importance of clearly defining the boundaries of the study has been recognised by several authors (Stake 1978, 1995, Bromley 1986, Ragin 1992). This study was bounded by the definition a single case, namely the continence clinic held at the leisure centre, and by time with data collection occurring from January 2001-August 2003.

The method of data collection and analysis used to explore the case in question includes the following elements of a grounded theory approach: theoretical sampling, constant comparison of the data, open coding, memos, theoretical sensitivity and category development (Glaser & Strauss 1967). Theory development was not a specific aim of the study.

The following section will cover the elements of a grounded theory approach utilised in this study.

Using a Grounded Theory Approach

Grounded theory is a process of discovering theory from data that have been systematically gathered and analysed:

> "Generating a theory from data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of research" (Glaser & Strauss 1967 p12).

Although this study was not designed to promote the development of new theories relating to the experience of incontinence and continence care, key aspects of a grounded theory approach were utilised in sample selection and data analysis. The following were used and are discussed in more detail under "data analysis": Theoretical sampling, constant comparison of the data, open coding, memos, theoretical sensitivity and category development. The possible impact of researcher bias was recognised and is discussed further under "reflexivity" (page 52).

Study Design

In order to address the aims of the study and the research questions identified, a series of interviews were conducted with both clinic users and stakeholders. The study was conducted in two phases. Ethics committee approval was gained from the local research ethics committee (Appendix Twenty One).

Selection of the Research Site and Negotiation of Access

The provision of a continence clinic within a leisure centre was an unusual setting for a clinic. The service was a new initiative having started in July 1999, offering the only continence clinic in this setting in the area. Previous evaluations of nurse-led clinic services have focused on more traditional settings with continence nurses working to clear protocols and exclusion criteria offering an efficient, acceptable service to continence sufferers (Lewey *et al.* 1997; McGhee, *et al.* 1997, Nolan 1997).

I contacted the Continence Advisors based at Hythe to informally discuss the proposed study and to seek their suggestions and support. The time spent meeting with the team and offering to explore the experiences of clinic users was well spent as they were keen to have the opportunity to demonstrate to others the quality of the service they provided. The involvement of the team from the outset of the research had enabled them to feel part of the project and to "own" their input. The Continence Advisors indicated they had no time to carry out a study of the clinic themselves and as I had previously worked as a Continence Advisor they acknowledged my experience and appreciation of the issues involved.

Having discussed the study with the team the Continence Services Manager was then approached to obtain her support for the study. Before applying for ethics approval the proposal was presented at a team meeting, to enable questions to be asked and to present the information leaflets for participants and health professionals. It was agreed that the researcher would be given an honorary contract with Southampton City Primary Care Trust to provide them with indemnity and to enable them to maintain clinical competence by covering the occasional clinic. The implications of this are discussed further on page 52 under the heading "reflexivity".

I visited the clinic as an observer to become familiar with the operation and to meet the receptionists and other staff involved in the health centre. Gaining access to the research involved discussing the project informally with the receptionists, so that I was accepted as a researcher. As the research progressed I provided the practitioners and leisure services staff at the "Quay to Health" with regular verbal updates of the progress of the project. This enabled the staff at the leisure centre to continue to feel involved with, and to engage in, the study.

The Continence Advisor responsible for the clinic continued to be very supportive throughout the life of the study, and prior to the commencement of the study time was invested explaining the outline of the research and the potential benefits to both users of the service and to her personally. The general impression received was that the Continence Advisors were working hard to provide an excellent service to patients, and although they felt they were achieving this, they did not have the time or the skills to conduct their own research to demonstrate these outcomes.

Phase One Interviews with Users

Two face to face interviews with women attending the clinic were used to elicit their experiences of their incontinence and of the clinic. One interview followed their initial appointment at the clinic, and the second was six months later. Two incontinence impact questionnaires and a frequency/volume chart were completed before the initial interview (Appendices Five, Six, Seven and Eight) and repeated six months later. These questionnaires were selected because it was anticipated that they would provide a subjective measure of incontinence impact and a guide to the progress of their incontinence.

Phase Two Interviews with Stakeholders

Face to face interviews were conducted with key stakeholders (seven in total) to determine the underpinning philosophy behind clinics in leisure centres. These stakeholders comprised: One Continence Advisor, one Continence Services Manager, one Manager of the "Quay to Health", one Development Worker, one Primary Care Trust Manager and two City Council Leisure Services Managers.

A summary of the study design is provided in the table below.

Table 4: Study Design

Phase 1 Clinic Users
Two interviews (6 months apart) with each of 12 women attending the clinic.
Interview 1 + completion of frequency/volume chart, IIQ-7 and ICIQ-SF.
Interview 2 – 6 months later + completion of frequency/volume chart, IIQ-7 and ICIQ-SF.
Phase 2 Stakeholders
One interview with each of 7 stakeholders.
1 Continence Advisor.
1 Continence services Manager.
1 "Quay to Health" Manager.
1 Development Worker.
1 Primary Care Trust Manager.
2 City Council Leisure Services Managers.

Sampling

The main purpose of case study research is to understand as fully as possible the case that has been selected. Stake (1995, p4) suggests that case study research is not "sampling" research and the study of a particular case is not undertaken to primarily understand other cases. However, the findings from this study could be transferable to other continence clinics in other settings, providing information about what users of these services think is important and how services can be modified to meet those needs. The focus of the selection of the sample needed to be on those people who were likely to "lead us to understandings, to assertions, perhaps even to modifying of generalisations" (Stake 1995, p4). This view is also supported by Patton (1990, p169) who suggested that qualitative enquiry tends to focus on small samples, or even single cases "selected purposefully". This method of sampling involves the selection of "information rich" cases, people from whom we can learn a lot about the issues of central importance to the purpose of the research. Interviewees were sampled on the basis of being able to provide rich, descriptive data to understand the case, using opportunistic sampling. The protocol used to recruit women to the study is detailed below.

Participant Selection Phase One

The Continence Advisor invited all women who attended the nurse-led clinic for the first time to participate in the study. To improve recruitment to the study I visited the clinic on a weekly basis and was available to discuss the study with interested parties following their clinic consultation. Any women who had expressed an interest in participating in the study were shown into a separate room and the Continence Advisor made a personal introduction. I continued to visit the clinic for eighteen months to maintain contact with the Continence Advisor, although the initial recruitment to the study was completed within eight months.

A thorough explanation of the study was given together with an invitation letter, patient information sheet, patient return slip, consent form and pre-paid envelope (Appendices Nine, Ten, Eleven and Twelve). This consultation was invaluable as it enabled the women who were interested in the study to meet the researcher and to ask questions about the study and to clarify their involvement. Although some were keen to sign the consent form at this point they were encouraged to take the information away and to consider whether or not they wanted to participate in the study. On receipt of the signed consent form, a copy was sent to the patient's GP together with a covering letter, health professional's information sheet and contact details of the researcher (Appendices Thirteen, and Fourteen). Women who were less than 18 years of age and those who had a gross cognitive impairment who may have been unable to give informed consent were excluded.

Pilot Study

A pilot interview was conducted to try out a draft interview schedule for the first interview. The questions were guided by the research questions and covered what prompts people to seek help for their incontinence, how they accessed the clinic, their expectations of the clinic and the impact of incontinence on their lives. As the face to face interviews were part of a reflexive process to inform and guide future interviews, the pilot was limited to one interview. The interview schedule was modified to focus the questions more specifically around the research questions, with the following areas covered:

- Women's experience of their incontinence and the impact on their lives.
- What prompted people to seek help for their continence problem?
- How did they feel about attending a clinic within a leisure centre?
- What did they think was the underpinning philosophy behind the development of a continence clinic within a leisure centre?
- What were their expectations as a result of attending the clinic?
- Did they feel that the clinic at the "Quays" differed in any way from other clinics they have attended?
- Did they have any suggestions for improving the service offered at the "Quays"? (Appendix Fifteen).

The initial interview demonstrated how participants have their own agendas when consenting to participate in research. The woman was elderly and had been widowed a year before the interview. She lived alone and suffered from diabetes and painful feet. Although she suffered from urge incontinence her main concern was how uncomfortable her feet were and how she could improve her mobility. During the interview she appeared to be reluctant to discuss her continence problem as, for her, that was not the main issue. She needed to talk about her husband and to grieve for the life she had once enjoyed. The interview was poorly focused, with too much input from myself and little space allowed for the participant to consider her responses and respond in a manner within which she felt comfortable.

During subsequent interviews the approach was modified to allow more time for participants to respond. Questions focused on responses directly related to their continence problem, and to the research questions (Appendix Sixteen).

Determining the Size of the Sample

Within case study research there is no pre-determined, universally agreed method for selecting the appropriate sample size. Patton (1990, p184) suggests that there are no rules for sample size in qualitative research, but that other factors should guide the size of the sample. These factors include: "what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility and what can be done with available time and resources". The focus of the enquiry is on the quality rather than the quantity of the data available (Stake 1995, Sandelowski 1995). Therefore if the sample was too large it may have followed that the detail within the case was lost, conversely if too small the credibility of the study may have been affected.

The number of women recruited to the study was not decided in advance, but guided by the analysis of the interviews. Interviews were analysed on an ongoing basis in order to determine whether any new categories were emerging. Women were recruited to the study until no new categories emerged from the data. Thirteen women consented to participate in the research, one was interviewed once; twelve women were interviewed twice. Recruitment to the study took place over an eight-month period with no apparent changes made to the operation of the clinic. Seven stakeholders were interviewed and following completion of the interviews with the women and the stakeholders field notes were recorded in the study diary (see p51).

Data Collection Methods

The main data collection methods utilised in this study were interviews, and questionnaires. This section will discuss how these methods were used.

Interviews with Women

Semi-structured interviews were used to elicit women's experiences of their incontinence in their own words. Incontinence can cause embarrassment to sufferers and face-to-face interviewing was selected rather than telephone interviewing so the researcher could respond to any non-verbal cues in an appropriate manner.

Open-ended questions enabled participants to describe their incontinence in their own words using language that expressed for them the essence of their problem. When questioned as to whether they found it difficult to find the words to do this none of the women identified this as a problem. This may be because all the women had attended the clinic before the interview, and had already been exposed to some of the terminology related to incontinence by the Continence Advisor.

During the interviews the use of language was explored by asking participants to clarify what they meant when they described their problem as " a little problem...you know?" Both parties may not have shared meanings and women's unspoken language is often not that explicit. A question used to encourage a clearer picture of what was happening: "How would you describe your problem?" or " Could you give me some idea what happens when you leak urine?" Probing further, asking questions around the participants' taken for granted meanings of "little problems" has informed subsequent data collection and enabled the focus to remain on the emerging data.

Interviews were arranged by telephone at a time and place chosen by the participant. Of the 13 women interviewed only one chose to be interviewed at the university, the rest were interviewed at home. All the participants consented to the tape recording of the interview and the tapes were transcribed to enable the analysis of the data and the identification of emerging themes and concepts.

The Interview Process

Before starting the interview and switching on the tape recorder the women were reminded that they were able to withdraw from the study at any point without compromising their medical care. The interviews lasted approximately 30-40 minutes and they were told when the machine was switched on or off. By introducing the tape recorder soon after arrival the machine became more familiar and was quickly disregarded by both parties when the interview commenced. Some researchers advocate taking detailed legible notes during an interview rather than taping the interview (Glaser, 1998, Morse, 1996). However in this study I decided to tape the interviews to enable me to hear the women's voices and any nuances in tone that would have been lost if I had been unable to tape record the interviews. When planning the interviews I decided not to make comprehensive notes during the interview as I felt that it may have been a distraction, affecting my ability to respond appropriately to the interviewee. However it may have been helpful to have taken brief notes during the interview rather than writing notes in the car, having left the woman's house.

Following the interview field notes were made to provide a written picture of the interview itself, and the impressions gained about the non-verbal cues used by the participant and the impact I had on the interview itself. Any anecdotal impressions of the impact of incontinence on women's lives were noted together with any discussions held that had not been recorded (Appendix Seventeen).

As an experienced Continence Advisor questions related to the management of continence problems and symptom control could arise during the course of the interview. If this happened women were advised that the questions would be addressed on completion of the interview, and once the tape recorder was switched off, any queries were addressed. This approach worked well in practice, with the interviews remaining focused on the research questions.

Questionnaires

Two incontinence impact questionnaires and bladder diaries were used to provide data on symptom severity and quality of life. A secondary aim was to examine changes during the six month period before the second interview. Subjective measurements of incontinence severity were obtained using the "Incontinence Impact Questionnaire-Short Form" (IIQ-SF) developed and validated by Uebersax *et al.* (1995). A Likert scale with assigned values of 0 for "not at all" to 3 for "greatly" enabled scoring to provide a single index of life impact associated with urinary incontinence. An additional measure the "International Consultation on Incontinence Questionnaire-Short Form" (ICIQ-SF, Donovan *et al* 2001) consists of three items to evaluate the frequency and severity of incontinence and its impact on everyday life. Objective clinical outcomes were measured using frequency/volume charts (bladder diaries) sent to women with their initial clinic appointment and again six months later.

Interviews with Stakeholders

Stakeholders were invited by telephone to participate in this study. If they agreed then they were sent an invitation letter inviting them to participate in the study

(Appendix Eighteen), a Health Professionals Information leaflet (Appendix Fourteen) and a consent form (Appendix Twelve). On receipt of a signed consent form the researcher invited them by telephone to arrange an appointment for the interview. All the stakeholders chose to be interviewed in their place of work and consented to the tape recording of the interview.

The interviews lasted approximately 30-40 minutes and an interview guide was used (Appendix Nineteen) to facilitate exploring the philosophy behind the "Quay to Health". The researcher adopted the same method used for introducing the tape recorder and reminding the interviewee that their participation was entirely voluntary. Field notes were completed following the interview and enabled the researcher to record impressions about the interview itself in a similar way to the interview notes made following contact with the women.

The following section explores the selection of the research site and how the researcher negotiated access.

Reflexivity

Reflexivity has many different definitions and involved the researcher continually evaluating their decision-making processes and the research process itself. De Poy and Gitlin (1998, p311) define the term as "process of self-examination" with Finlay (2002, p532) providing a more comprehensive definition:

> "…thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accompanied through detached scrutiny of 'what I know and how I know it' to recognise how we actively construct our knowledge".

Working with women with continence problems, being a woman herself and continuing to be a practising nurse and Health Visitor had an impact on the nature of the researcher/participant relationship. The personality and presence influenced the way in which participants responded, with the opportunity taken for a one-to-one consultation about their incontinence problems in their own home. Some studies have suggested that nurse researchers who distance themselves from their pre-existing knowledge and relationships with study participants lose rich data because they never achieve commonality with participants (Bamberger & Schon, 1991). Findings by Gardner (1996) suggest that richer data was obtained from participants when she disclosed she was a nurse.

In this study I recognised that role conflict between that of a researcher seeking to increase the knowledge base of nursing by collecting and analysing uncontaminated data and that of a nurse with professional responsibility to care for patients could be an issue in this study. Throughout the period of data collection I covered occasional continence clinics at the "Quay to Health" to maintain clinical competence and to support the Continence Advisor who ran the clinic. Although the women attending the clinic who had agreed to participate in the research were aware that I was primarily a researcher and only working as a Continence Advisor when actually at the clinic, it was not always clear that the women themselves made this distinction. During the research interviews questions could arise about the management of incontinence and I decided that to maintain the integrity of the data these issues were addressed on completion of the interview. This strategy worked well with the focus of the data collection remaining on the women's experiences of the clinic. Other studies have suggested that although nurses feel they are able to make this distinction between when they are a nurse, and when a researcher, other health care practitioners and patients view nurse researchers as primarily nurses who also happen to be researchers (Davis, 1983, Fowler, 1988, Munhall, 1988).

The essential contribution of women to this study was recognised, and by answering any queries about their incontinence problems, I felt that I "gave something back" to them. However, I also recognised that if I did not have the skills to provide clinical advice any questions related to management of the condition would need to be referred to the Continence Advisor responsible for their treatment.

Holloway & Fulbrook (2001) describe the "halo" effect where participants want to be seen in a favourable light by the researcher who is viewed as an expert. There may be a tendency for them to understate negative feelings, avoid difficult issues or to say things in "the right way" or to say "the right thing". It can be difficult to ascertain whether this is happening and to try and minimise this effect it was explained at the outset of the interview process, the value of receiving accurate and honest feedback. However, although the women provided positive feedback about the quality of care they had received at the "Quays", negative feedback was also given about the lack of information about referrals to other services. This would appear to suggest that the women in this study were able to provide a realistic picture of their experiences both of the clinic and their incontinence.

Data Analysis

Line by Line Coding

The data was studied line by line to facilitate the emergence of codes from the data. These codes explained the events occurring within the data and enabled me to remain close to the data. Each interview was initially coded line by line; an example is given in Appendix One. The codes that emerged covered many different topics from the impact of incontinence on women's lives to how they accessed the clinic at the "Quay to Health". These initial codes assisted the process of beginning to develop categories that were further developed during open coding.

Open and Selective Coding

Open coding is a process whereby large sections of data were exposed to show the ideas, thoughts and content within. The data were broken down into sections and compared for similarities and differences. This process facilitated the emergence of categories where conceptually similar events, emotions or interactions were grouped together (Appendix Two). The data were constantly questioned to facilitate open coding. Bohm *et al.* (1992 p28) suggested the following questions assist in disclosing the text:

- *"What*? What is it about here? Which phenomenon is mentioned?
- *Who*? Which persons, actors are involved? Which roles do they play? How do they interact?
- *How*? Which aspects of the phenomenon are mentioned (or not mentioned?).
- *When*? *How long? Where?* Time, course and location.
- *How much*? *How strong?* Aspects of intensity.
- *Why?* Which reasons are given or can be reconstructed?
- *What for?* With what intention, to which purpose?

- *By which?* Means, tactics and strategies for reaching the goal".

Once open coding led to the identification of categories the next step was to refine and differentiate these looking for subcategories, and for data to show the extreme possibilities. The identification of the core category by this process enabled the focus on particular codes and to develop codes that related to the core category. This was a conceptual process where data were named either by the meaning or imagery they evoked or by using the language of the respondents themselves. These were labelled "in vivo codes" (Glaser & Strauss 1967).

The Constant Comparative Method of Data Analysis

Central to the grounded theory method is the use of constant comparison. The constant comparative method involves the search for main concepts of those involved in the topic under investigation. Hutchinson (1986) described these concepts as follows:

> "Recurs frequently in the data, links the various data together and explains much in the variation of the data".

This method involved comparing incidents in the data to allow the identification of similarities and differences. In this study many similarities were found between stakeholders and women's experiences of the clinic. An example of this included the formation of the sub-category "non-clinical setting". Stakeholders had indicated that people would be more likely to use a health care facility in a non-clinical setting as you could be visiting the leisure centre for a number of different leisure activities. Women attending the continence clinic at the "Quay to Health" had also indicated that they preferred to attend a clinic in a non-clinical setting both because of the anonymity afforded by the setting and the relaxed and informal environment.

Provisional categories were created as a result of this process. As data collection and analysis were inseparable this was a developmental process that required that incidents be repeatedly examined for their "fit" within categories. The developing categories and their relationship to each other are constantly compared. Glaser (1969) describes four stages: "1. Comparing incidents applicable to each category, 2. Integrating categories and their properties, 3. Delimiting the theory, 4. Writing the theory" (p220). The process is described as a systematic circularity process where each stage transforms itself into the next with previous stages used during the analysis until the analysis is completed. This study compared incidents applicable to each category and integrated categories and their properties. A theory was not developed with the data analysis remaining descriptive.

Memos

Memos were written from the beginning of the research process. They were essential to the development of main categories and sub-categories and formed an evolving part of the picture (Glaser 1998 p218). They were a place where developing ideas, theoretical notes and operational notes could be recorded and tended to grow in complexity as the research developed. Diagrams were also used to add detail to the research and comprehensive memos, both written and diagrammatic, enabled the final categories to have conceptual density and integration (Appendix Three).

Theoretical Sampling

At the beginning of this study opportunistic sampling of women who attended the continence clinic at the "Quay to Health" for the first time, and who consented to participate in the study, identified thirteen women. Once the initial interviews had been analysed and categories developed that were relevant to, and explained the data, more data were collected from stakeholders to clarify ideas and plan how to fit them together.

Schreiber (2001 p64) suggests that to provide a wider perspective on the phenomenon of study the researcher will use more than one data source. By interviewing seven stakeholders (one Continence Advisor, one Continence Services Manager, one Manager of the "Quay to Health", one Primary Care Trust Manager, one Development Worker and two City Council Leisure Services Managers) it was possible to explore the underlying philosophy behind the development of the "Quay to Health" and to further refine the developing categories.

Theoretical Saturation

Theoretical saturation of the categories is an important part of the grounded theory method. This is the point where no new data emerge to develop the properties of a category. Glaser & Strauss (1967) provide the following definition of theoretical saturation:

> "The criterion for judging when to stop sampling the different groups pertinent to a category is the category's theoretical saturation. Saturation means that no additional data are being found whereby the sociologist can develop properties of the category" (p61).

Although no new categories were identified following the twenty-four interviews with the women who attended the continence clinic at the "Quay to Health" I cannot be sure that if sampling had continued other categories may have developed.

Theoretical Sensitivity

This was a process of thinking theoretically in relation to the data used to generate a new theoretical formulation. To facilitate the identification and interrelation of conceptually dense codes this theoretical sensitivity had to be developed. Both Glaser (1978) and Schreiber (2001) comprehensively examined theoretical sensitivity in the grounded theory approach and acknowledged that time needed to be spent cultivating this skill.

In this study I was aware of potential biases that could be a threat to the rigour of the study acknowledging that data are filtered through the personal background of the researcher. To guard against these potential biases the data were constantly questioned to explore what was happening and a variety of explanations were compared with the data to expand the number of theoretical possibilities within each interview. An example of theoretical sensitivity is given in Appendix Four.

Rigour in Qualitative Research

An ongoing dialogue exists about the difficulty of establishing validity criteria in qualitative research. Rigour and subjectivity together with creativity need to be incorporated into the scientific process and this remains a challenging task. Different and disparate qualitative methods require different criteria for evaluation. The concept that there may be some all-encompassing guidelines of validity crossing methodological and philosophical differences may yet be possible.

Forbes *et al* (1999) proposed three qualities or warrants that they suggested assist the development of core values regarding the 'constituents of good science' which are:

> "a) Scrutiny and critique of methodological rigor and findings by the scientific community; b) corroboration and intersubjectivity; and c) scope of the evidence".

A "dialogue of difference" proposed by Greene (1994 p61) suggested "committing to a search for sameness and connections, toward a solidarity of purpose, claiming for science a societal role of continuing relevance and vital consequence". In qualitative enquiry validity is dependent on the skill, competency and rigour of the researcher. Guba & Lincoln (1981 p113) comment on "naturalistic inquiry" as follows:

> "The inquirer is himself the instrument, changes resulting from fatigue, shifts in knowledge, and co-optation, as well as variations resulting from differences in training, skill, and experience among different 'instruments', easily occur. But this loss in rigor is more than offset by the flexibility, insight, and ability to build on tacit knowledge that is the peculiar province of the human instrument".

The criteria developed by Glaser (1978, 1992) for judging the rigour of a grounded theory study include fit, work, relevance, modifiability, parsimony and scope. "Fit" refers to the relationship of the core category to the identified social problem and its ability to explain most of the variation in behaviour used to address the problem. "Relevance and work" are defined as the relevance of the core category to the data and the ability of the core category to work with other concepts and properties so that most of them are related to the core category. A core category that "fits", is relevant and works is not just subject to qualification and modification but also integrates a theory so that it is dense and saturated with relationships. Maximum variation in the data with as few concepts as possible increases parsimony and scope.

In this study the criteria used to improve the validity of the research is based on Mays & Pope (2000) and includes respondent validation, a clear explanation of the methods of data collection and analysis, reflexivity (see page 52) and attention to negative cases.

Respondent Validation

Respondent validation or "member checking" was used as a means of clarifying different accounts within this study. Mays & Pope (2000) acknowledge the limitations of this approach citing the different perspectives of the researcher and the participant. For example the researcher will produce an account that is targeted at a wider audience and a participant will have a different perspective on what is happening. Some of the emerging themes and concepts were discussed with participants by telephone to check out with them their interpretation of events. This led to additional descriptive data and helped to clarify the nature of the emerging concepts.

An example of how this was applied in this study was related to the development of the core category "Prompts to Help-Seeking". Two of the women were concerned that their incontinence would deteriorate as they became older and following their initial interviews, telephone contact was made to clarify whether this had been one of the factors that had prompted them to seek help for their incontinence at this stage. Although they were both concerned about the future their current incontinence problems had prompted them to seek help, not future concerns.

Transparency of the Research Process

Detailed records were kept in the form of diaries documenting the progress of the research. Lincoln & Guba (1985) recognised that auditability is required to develop an explicit, clear position enabling others to follow the interpretative effort of the researcher. A diary recording the progress of the research with the development of new ideas enabled reflection on the development of the research and the core categories, key events and incidents and negative cases that emerged and were pursued during the research process (Appendix Twenty).

Detailed descriptions of observations made during an interview were recorded together with the reflections on the content of the interview itself (Appendix Seventeen). Any mismatches between the spoken word and the body language were noted together with a verbal picture of the participant to aid the reflective process. The rigour of a grounded theory study is partly assessed on the explanatory value of conceptual density and scope, which relies on detailed description (Glaser 1978).

Negative Case Analysis

Elements within the study that appeared to contradict the emerging explanation of the phenomena being studied were explored. Ten of the twelve women interviewed preferred to attend a clinic in a non-clinical setting. The two women who expressed a preference for attending a clinic in a hospital setting described different aspects of the leisure centre that they found unsuitable for a health clinic. One of the women felt that a leisure centre was for able-bodied people and reminded her of all the things she was no longer able to enjoy. The other woman thought that leisure centres were for younger people and not somewhere where medical problems should be addressed. The two negative cases informed the development of the core category "Experience of Service" and provided a different perspective to the development of the study.

Ethical Considerations

Prior to commencement of the study ethical approval was obtained from the Southampton Local Research Ethics Committee (Appendix Twenty One). Further ethical considerations are discussed below.

Informed Consent

To inform research participants of the purpose and scope of this study the following information was given to them if they indicated they may be interested in participating: an invitation letter (Appendix Nine), patient information leaflet (Appendix Ten), patient return slip (Appendix Eleven) and consent form (Appendix Twelve). Women were encouraged to ask questions about the study and to take the information away with them, to allow them time to consider whether or not they wanted to participate in the study.

The ethical issues of conducting research have been influenced by the Belmont Report (1979) that reviewed examples of the abuse of humans in research conducted during the holocaust. Two principles emerged from the report as a direct consequence of reviewing these cases. The first ethical principle identified the importance of distinguishing the boundaries between research and clinical practice. In this study the women who participated received the same care as other continence clinic clients, and were not affected by their participation in this study. The second principle comprised of three parts 1. Respect for persons. This suggests that individuals should be treated as autonomous and capable of making their own decisions. In this study women were encouraged to question any aspects of the study and reminded that they could opt out at any point without compromising their medical care. 2. Beneficence. This specifies that the research will "do no harm" and "maximise" benefits and "minimise possible harm" to individuals. In this study the avoidance of harm or distress is covered on page 60. 3. Justice. This specifies that people should be treated equitably and that vulnerable populations should not be included in research. In this study to protect women who may have been unable to give informed consent due to a cognitive impairment they were not invited to participate by the Continence Advisor.

Right to Privacy of Information

All participants in the study were informed that any information provided would be treated in confidence. All data was only identifiable by me as the researcher, no identifying characteristics or names were used in the transcribing of data and any information that could lead to the identification of the participant was not used. Data were stored in a locked filing cabinet in a locked office and computer files were password protected in accordance with the Data Protection Act (1998).

Avoidance of Harm/Distress

It was not anticipated that any participant would risk harm by participating in the study. If a participant had become distressed at any point in the research then I would have dealt with the situation and responded in a manner that would have protected the participant from any further distress. They would also have been reminded that they could withdraw from the study at any point, and by working closely with the Continence Advisor, ensured that patient care was not compromised. None of the women who participated in this study appeared to experience any signs of distress during the interviews.

Dissemination of Research Findings

The findings from this study will be shared with the women who participated by sending them a short summary report. The Continence Advisor, Continence Services Manager and the team at Hythe will have the opportunity to attend a presentation of the findings to be arranged, together with the leisure services staff and other stakeholders who were involved in this study. It is anticipated that an article to disseminate the findings to a wider audience, will be submitted for publication.

The following chapters discuss the findings from this study and are divided into two chapters. The first chapter (Chapter Three) reflects the experiences of stakeholders involved in the planning, development and operation of the "Quay to Health". The second chapter (Chapter Four) focuses on the women's experiences of incontinence and of the clinic itself.

CHAPTER THREE

Stakeholders and Users Views of "The Quays"

Introduction to Findings Chapters

The findings from this study have been divided into two chapters that reflect the experiences of the stakeholders involved in the planning, development and operation of the "Quay to Health" and the different experiences of the women who attended the continence clinic. Names have been changed to preserve anonymity and the general terms Planner, Practitioner or Health Professional used for the same reason. This chapter focuses on the categories identified from the data collected from stakeholders and users in relation to the development, setting and location of the clinic. ***Partnership*** was the only category identified from the data by stakeholders alone. The other core categories identified were ***Improving Access to Care*** and ***Location***. The table below (Table 5) identifies both the core categories and the sub-categories that form them.

Table 5 Categories Identified by Stakeholders and Users (*N.B.Partnership the only category identified by Stakeholders alone)*

Core Categories	Partnership	Improving Access to Care	Location
Sub-Categories	Interface	Non-Clinical Setting	Geographical Location
	Referral	Health Promotion	Location of Clinic in Building
	Future Developments	Anonymity	
		Drop-In	

The chapter will discuss each core category and its sub-categories in turn. Chapter Four focuses on the pathways taken by women following their initial help seeking for their problem, together with their experiences of their incontinence and the impact of the clinic itself. The categories relevant to these specific topics will be discussed in the next chapter.

Partnership was the first core category to be identified and appeared to be an issue for the stakeholders alone. This category was made up of three sub-categories: Interface, referral and future developments. The interface between the health professionals and leisure centre workers was viewed positively with an appreciation that different organisational structures can be a barrier to team working. Referral between health professionals and leisure centre staff tended to be one-way with leisure staff experiencing problems when trying to refer back to a health system that could accept referrals for some services only via a GP referral (physiotherapy and dietetics). Having identified some of the potential barriers to working together stakeholders had reflected on how to overcome these in future partnership working across the city. The proposed development of a healthy living centre within central Southampton has been supported by partnerships that have been cultivated between the City Council, the local Primary Care Trust (PCT) and central government. These partnerships formed throughout the development of the "Quay to Health" and may have facilitated future partnership working that is currently undergoing development.

Improving Access to Care emerged as a core category for both stakeholders and users. This category was made up of four sub-categories: Non-Clinical Setting, health promotion, anonymity and drop-in. The provision of care within a non-clinical setting appeared to be seen as something new and innovative, encouraging younger people to access services in a user-friendly environment. Stakeholders focussed on the improved access to care and this appeared to be one of the main thrusts behind the development of the "Quay to Health". The promotion of good health rather than the management of ill health were identified by stakeholders as one of the strengths of the "Quay to Health". The cross benefits of locating health and leisure together were also identified by stakeholders and users who suggested that people may be more likely to use health services within the building if they were visiting for a leisure activity. Some clinic users felt that they would not be more likely to use the leisure facilities provided at the centre simply because they had attended a clinic in the building.

The anonymity provided by locating the "Quay to Health" within a leisure centre appeared to be seen by both stakeholders and users as something very positive.

Access to health services was enhanced by "drop-in" availability whereby help and advice could be provided to continence sufferers and their families within half an hour of making a request.

Location emerged as the third core category from the stakeholders and users. This category was made up of two sub-categories: Geographical location and Location of clinic in building. The location of the leisure centre within the city centre appeared to be ideal for users who had access to private transport but some problems were identified with the public transport. Stakeholders acknowledged that the location of the clinic within the basement of the building was convenient, but not necessarily ideal. This was clearly an issue for the users of the continence clinic who either found the leisure centre environment a relaxed pleasant atmosphere in which to attend a clinic, or a strange, dark place for a clinic held in the basement of the building.

Background to the Clinic

The impetus behind the development of the "Quay to Health" was seen by many of the stakeholders involved as opportunistic, with the City Council having closed the swimming pool on the site of the proposed new development.

P1 (2) 30-34: ...I don't know where the idea eventually came from, I don't know who approached who, but probably the council because they'd got rid of their swimming pool so they probably wanted to replace that and they perhaps wanted some money and attract lottery funding and needed an innovative scheme, which it is (Sarah, Health Professional).

The opportunity was seized by other potential partners with the City Council who were able to envisage a small health facility within a leisure centre environment and recognised that some partnership working may be possible.

P5 (1) 11-14: There wasn't a wonderful planning build up to it. It was sort of opportunistic, just a chance conversation and so we then took up with the City Council and said "what are the chances?" and they talked to us about the space that was available (Arthur, Planner).

P6 (1) 17-19: There became an opportunity potentially of working with other providers or other organisations. I instinctively thought that leisure would, health would be the first opportunity to try and pursue (Verity, Planner).

P7 (1) 10-12 ... it all kind of came together as an opportunity to sort of extend the kind of range of services that we were able to offer at the Quays (James, Planner).

Core Category Partnership

The category ***Partnership*** involved partnership working at different levels and between different groups of people. This was the only category identified by stakeholders alone. The partnerships identified were between:

- Stakeholders managing the services.
- Leisure Services Managers (within the City Council).
- Health Service Managers (both at PCT level and direct service level).
- Practitioners within the "Quay to Health" and leisure services staff.

Partnership working emerged as a multi-layered concept with each of the stakeholder groups focussing on their unique interpretation of what working in partnership meant to them. The Leisure Services Managers and Health Service Managers tended to focus on strategic issues looking at partnership working in relation to government initiatives around healthy living centres and joint training initiatives to encourage more joint working. The health professionals and leisure services staff regarded partnership working as sharing ideas and referring users appropriately to provide the best possible care as smoothly as possible. Some limitations to partnership working included the navigation around the different organisational structures within health and leisure that appeared to be difficult for some of the staff.

The sub-categories that contributed to the formation of the core category ***Partnership*** are explored below.

Sub-Category Interface

The stakeholders who managed the different services felt that the opportunities for health and leisure to provide a seamless service that would complement one another were possible within the "Quay to Health". Some described how joint working between different groups had been advocated by central government with the link between physical activity and the promotion of good health included within the National Service Frameworks (2001).

P2 (4) 87-93: back to the government thinking and particularly on social exclusion, social inclusion, and departments, directorates that they have within government. It's about partnership working and I think it's about not having one thing in isolation. But it's a new concept obviously leisure and health... (Avril, Health Professional).

The stakeholders acknowledged that although they supported partnership working and felt sure that it was in fact happening at the "Quay to Health" because they were removed from the day to day running of the site they were unclear about the level of integration that had occurred.

P5 (10) 233-242: It's a good opportunity for people working in the health service to talk to people in the leisure services. I think how it evolves is coming out of that, you know.... Whether we get enough of that I don't know, or whether although we are in that facility we are still to some degree separate I'm not sure (Arthur, Planner).

The limitations imposed by health services entering into partnership with the City Council at a late stage in the development of the whole project were acknowledged as forward planning was limited, placing a degree of urgency on the negotiations for the development of the health facility.

P5 (4) 76-81: I don't think it is, it maybe not, even now, as integrated as it could be if you were starting from scratch and you knew what you were wanting from the partnership before anyone even drew anything. Whereas this was a bit different to that and that's what people have to remember in terms of looking at where we've got to because we got in quite late (Arthur, Planner).

The practitioners involved with the "Quay to Health" felt that much was to be gained by working alongside other disciplines, connected with leisure as well as with health and valued the different perspectives offered by people from other backgrounds.

P3 (7) 142-145: Oh, it's nice. It's ...I think working alongside other disciplines, although we don't get a huge interaction between the different specialities down there.

The stoma nurses do actually come and ask me for advice, or they'll refer people across and vice versa (Camilla, Practitioner).

The nature of partnership working with health and leisure services staff working together, offering different perspectives to improve patient care was recognised by one of the stakeholder managers.

P1 (6) 136-139: ...practitioners are also mixing with a different group of people, like they are mixing with hopefully, mixing with people that work at the Quays that are not health professionals, so that must add a different dimension as well (Sarah, Health Professional).

The integration of different specialities at the "Quay to Health" with the leisure services staff and external health services was best illustrated by the referrals between health and leisure staff, other continence practitioners and General Practitioners (GPs).

Sub-Category Referral

A single Continence Advisor who started the clinic in June 1999, and has continued to develop the service usually operates the continence clinic at the "Quay to Health". Referrals between the continence clinic within the "Quay to Health" and the contraception and sexual health clinic appear to be established and reciprocated.

P3 (1) 18-22: You get the girls who go for smear testing and contraceptive advice, and I work quite closely with Mary from there and she will send people across if she thinks it's appropriate. And they'll pick up leaflets and they'll come back to us, so I think from that point of view it works (Camilla, Practitioner).

Other referrals to the continence clinic had included a referral from one of the leisure services staff who worked in the gym who had suggested that one of his clients suffering from a continence problem should seek help at the clinic.

P3 (7) 153-157: Interestingly I've actually had one referral from the gym, from the, they're not physiotherapists in there, but one of the people who works in the gym. Somebody obviously confided and "well you should go round and see them and they'll sort you out" (Camilla, Practitioner).

The benefits to both patients and practitioners of being able to refer between agencies within the "Quay to Health" and beyond to the leisure services were recognised both by the stakeholders and the practitioners involved. From a continence perspective the ability to access the "Active Options" programme where a planned exercise and general fitness programme is individually tailored to each individual was a valuable addition to the continence care plan. Patients who have functional incontinence, who may find it difficult to physically reach the toilet on time, or who may be overweight can benefit from this programme. This was recognised by one of the stakeholder managers as a valuable benefit of partnership working.

P1 (4) 80-86: We can also access active options for our patients so it might be helpful for them to do some sort of exercise that actually might help their continence because it helps them get there quicker (Sarah, Health Professional).

However, not all the service providers felt that the referral between the different agencies was a two-way process that worked well for the benefit of the patients concerned. The referral pathways between health and leisure appeared to be quite straightforward with referrals made to the "Active Options" programme from the continence clinic but this did not appear to work the other way round.

P4 (10) 223-225: As regards, you know, the benefits of me having health next door, really there weren't any benefits I don't think. There are lots of benefits for them because I think sometimes all of their services have knocked the door (John, Practitioner).

The referral pathways between leisure and health services appear to be complex with physiotherapy and dietetic referrals having to be made via a GP. This was frustrating for one of the leisure service providers, as they were able to see the potential benefits of being able to refer people directly to a dietician for weight management, or a physiotherapist for musculo-skeletal problems.

P4 (9) 195-202: I was hopeful, hoping that dietetics would be in more than they are and that there would be a closer working relationship between us, so that if I had a client that needed dietary advice I could refer them into there. If they had patients that *needed exercising they could refer to "Active Options", which they do, but it's all one way. Their patients come to leisure facilities but it's very difficult for the leisure clients to be referred in to health (John, Practitioner).*

Some of the problems encountered by this new partnership between leisure and health services were exacerbated by referrals from health agencies outside the "Quay to Health". Referrals to the continence clinic by GPs were encouraged and seen as an endorsement of the quality of the service offered to patients at the clinic.

P3 (8) 166-171: We get a lot of GP referrals and I think that's quite reassuring, because if GPs think you're doing a good job they keep sending patients. As long as you send back and tell them what you're doing. That seems to be quite good. And they tend to come from the same practices so you get a sort of a bit of a rapport with the GPs (Camilla, Practitioner).

This relationship between GPs and the Continence Advisor had been developed over several years, and was still in its infancy when working with leisure services. The development of the "Active Options" programme, a partnership between leisure and health had initially proved challenging to the leisure services.

P7 (7) 154-158: Health people are very territorial; I have to say GPs are the worst. And I can understand that because there may be this perception, well there's people who are leisure muscling in on stuff that they really shouldn't be getting involved in, and I can understand that. I think we shouldn't be seen to be muscling in to areas that we shouldn't be (James, Planner).

However, by working with GPs and spending time building up their confidence in the programme gradually relationships developed and the "Active Options" programme developed.

P7 (8) 174-178: We bent over backwards to build up that confidence, which did happen, but it didn't happen straight away, it took a long time. There were one or two really good people who were really supportive and that helped, but it's just, you know, you're in new territory and it takes a long time (James, Planner).

Sub-Category Future Developments

The partnership working at the "Quay to Health" appears to be working well amongst the practitioners within the health centre. Referrals are made between the different clinics and to other practitioners for more specialist advice and treatment. Some problems had been encountered by leisure service practitioners when trying to refer to physiotherapists or dieticians as referrals to these services had to be made via the client's GP. If direct referrals to these services could be made by practitioners then this may enhance the service offered and improve partnership working.
The foundations of partnership working within the "Quay to Health" have opened up other possibilities for joint working within the city.

P5 (4) 86, 95: I think it's helped because it's built relationships with a dimension of the City Council that we weren't involved with. We've proved that we can produce something together, and now we can sort of move on to other things so that health can really get itself into the regeneration agenda in a big way (Arthur, Planner).

A new healthy living centre has been proposed for a central city site that would include leisure facilities (as yet to be decided), and the relocation of health facilities from a central health clinic. The plans had to be modified as they originally included shopping facilities, GP practices, tennis, badminton and squash courts, child health services, physiotherapy and a continence clinic. Stakeholders were keen to embrace the concept of a healthy living centre but recognised that these plans would be too expensive and are now focussing on a smaller scale project.

The foundations of partnership working were laid down with the development of the "Quay to Health" and many stakeholders saw this as an opportunity to develop joint working on future projects, whilst recognising some of the limitations imposed by different organisational structures working together. Tensions occasionally developed, as leisure service providers were unsure how health service professionals fitted into the general structure of things.

P4 (4) 85-88: I think it laid down the.. it was the first partnership working in Southampton so there are always going to be tensions involved, but I think the good thing about it was it's laid down those foundations for future partnership working (John, Practitioner).

P6 (10) 238-241: I also thought that because this was really the first key partnership between health and leisure of any significance that it would then potentially lead to others, and it has in that the Charlotte Place healthy living centre concept was born thereafter... (Verity, Planner).

The problems inherent in joint working with different cultural norms were illustrated by one stakeholder, although he felt that there had been an improvement in understanding each other's roles that would enable better joint working when moving to the healthy living centre.

P4 (4) 88-96: We're moving to the healthy living centre as well, so things should be a lot easier for us all.... because people understand each other's roles now. One of the big criticisms from leisure's point of view was that nobody knew who the people who came from health were. And nobody knew where they were in the structure of things, you know. And I'm sure that health felt the same way about us (John, Practitioner).

Integrated working between different service providers needs to have a clear structure of roles, responsibilities and accountability to facilitate clear referral pathways between health and leisure. This lack of clarity was identified by one stakeholder as a weakness of the "Peckham Pulse" healthy living centre in London.

P7 (6) 139-142: Peckham Pulse, from the inspection that we've done, haven't really worked, and that's because nobody's sure who's driving it, you know, is it the health people who are driving it or is it the leisure people who are driving it? (James, Planner).

Stakeholders also recognised that it would be difficult for healthy living centres to facilitate integrated working without considerable effort from all those involved.

P7 (7) 144-149: So it's not enough clearly to just build a building, and put people in there and provide the facilities, it's not going to work. You will still have a health bit, you'll still have leisure bit, there won't be the kind of integrated working that we're all aspiring to. I would hope that the healthy living centre will actually achieve that over time, but wouldn't sort of underestimate how difficult that would be (James, Planner).

The "Quay to Health" has clearly laid the foundations for partnership working within healthy living centres in Southampton City. Stakeholders have reflected on the positive and negative aspects of joint working between health and leisure and have planned to incorporate changes into the development of healthy living centres.

Core Category Improving Access to Care

The main philosophy behind the development of the "Quay to Health" for the Stakeholders focussed on issues that related to the opportunity to improve access to health services by specific groups (younger people and those from ethnic minorities). These groups were perceived to be less likely to access health services within traditional locations, and the informality of a leisure centre was seen as an ideal location for the provision of clinics that would appeal to these groups. The provision of health care in a non-health setting was seen as something new and less threatening than traditional medical services located within GP surgeries or hospitals. The opportunity to de-medicalise stigmatised services by locating a continence clinic and stoma clinic within the health centre was acknowledged. The advantages for people using the "Quay to Health" were that the services provided were located in the same corridor as the changing facilities so nobody would know where you were going within the building.

The additional benefits identified by the stakeholders were that people who used the "Quay to Health" would be aware of the health enhancing activities on offer within the building and would be prompted to undertake some physical activity. They also considered that leisure centre users may see the signs for the "Quay to Health" and pop in to one of the clinics on offer, thus making health care more accessible.
As the "Quay to Health" is located in the basement of the building, there is little natural light, and the atmosphere created by the nature of its location emerged as a theme for both the stakeholders and the clinic users.

Sub-Category Non-Clinical Setting

The stakeholders identified an opportunity to provide health care in a non-health setting by co-locating health and leisure facilities. This was closely linked with improving access to health services for those groups who may not access services within traditional settings such as GP surgeries or health centres.

P1 (2) 44-50: I think the main underpinning philosophy was to provide health care in a non-health setting. We're very aware of the numbers of people that don't access healthcare when it's appropriate that they should. And certainly some of the evaluations that have come out of the "Quays" have suggested that people have actually sought help/advice, whatever, whereas perhaps wouldn't have done had they have had to go to a hospital or health centre or whatever (Sarah, Health Professional).

The opportunity to access different groups appeared to focus on younger people with the numbers of women from ethnic minorities who attended the continence clinic remaining less than 5 per annum. Although the receptionist employed to organise the continence clinic was Asian and spoke 3 languages her offer to interpret for non-English speaking patients was usually declined. This may have been due to cultural influences whereby daughters would often interpret for their mothers or husbands for their wives.

The numbers of women attending the continence clinic who were under 50 years of age were not recorded but the continence advisory service responsible for the clinic felt that this particular clinic did attract a younger age group.

P1 (6) 125-129: I think if they are getting more younger people, younger clients, that must be more satisfying because, OK the elderly clients we can work proactively with them, we can improve their continence status, but younger people it improves much more quickly. I just think it's a nice place to do a clinic really (Sarah, Health Professional).

P3 (15) 341-346: I think it's a successful clinic, in that you've got fairly well motivated younger women coming through and any of the sort of people who come who are not going to be particularly going to be helped by the type of advice that I can give...I can steer them back to the correct agencies and get the district nurses to help them, or whoever might be appropriate (Camilla, Practitioner).

This opportunity to access a younger population was also identified by the city council that recognised some of the advantages of providing health care in a leisure facility. They had already identified the fact that leisure services were used by a younger age group and could see the potential of providing additional services for current centre users.

P6 (5) 114-119, 121-126: We anticipated that 55% of the people using the venue would be young people...I felt that having health services that were relevant to young people within the "Quays" would be potentially more successful in reaching those young people if they were in the building anyway...I also felt that psychologically health services were more accessible if they were within a venue that people felt comfortable going to anyway, rather than in a clinical building somewhere else where people go if they are physically or mentally ill, rather than somewhere where they go if they are feeling healthy (Verity, Planner).

Both stakeholders and clinic users identified the unique nature of the setting of the "Quay to Health" and described it as different from a hospital and an unexpected place for a clinic. Stakeholders also indicated that the total environment of the leisure centre was less intimidating than a hospital and this relaxed, informal place was a good place for people to seek health advice.

P3 (1) 4-7,(15) 337-341: I think the main idea was to take the clinician out of a health environment and put it into a more relaxed environment, so that you associated good health with promotion of health and moving away from the hospital setting
It's perhaps less formal in its setting. It's a pleasant environment. It's not a hospital although it's a purpose built health facility. It's not really set up as a, it's not threatening. It's fairly relaxed, having the music and TV playing. It's not too daunting for the patient (Camilla, Practitioner).

The hospital environment was seen by one of the stakeholders as an unpleasant place to be, with the "Quay to Health" providing a more pleasant atmosphere.

P7 (3) 50-54: It evolved that was just, you know, imaginative and fairly kind of innovative, and still the idea that if you have those clinics in a leisure type environment, well perhaps it was a bit more attractive to people than going into horrible, intimidating hospital environment, for example (James, Planner).

The women who attended the continence clinic also identified a preference for attending clinics that were held in a non-hospital environment. As incontinence is not a life-threatening condition and may not be seen as an illness it appears to be appropriate to receive help and advice in a non-clinical setting.

J1 (10) 224-225, 228-229: Yes. I'd rather it wasn't at a hospital actually. I think its better being there because it seems less intimidating, which is odd...big hospitals tend to have a long wait generally and then...it's much better, something smaller (Julie, aged 32, Service User).

D2 (5) 102-105: I think at the "Quays" it's great because it's just a health place dedicated to something like that, well I know they do other things. It is quite nice going to the "Quays", yes. It sort of feels non-medical somehow (Dawn, aged 69, Service User).

One of the other ways in which the continence clinic at the "Quays" was seen as different from other clinics was that the clinic was nurse-led and perceived as more informal than care provided in a GP or hospital setting.

J1 (13) 290-296, (18) 409-411: Seeing a nurse specialist I expected to be treated more as a person and get a bit more time really because that's what they tend to be like. That's another reason for going there...rather than. I probably would have never gone to my GP to be referred to a normal urogynaecology or whatever clinic because I wouldn't have wanted to go through all that humiliation, so the fact that it was there, the nurse at the "Quays" I went.
It's informal. It's not in a big hospital setting so it's less...and it's a nurse specialist rather than a team of doctors, which to me means more time, more interest and less investigations (Julie, aged 32, Service User).

The different approach to the delivery of health care was acknowledged by some of the stakeholders and clinic users as being strange or unusual. They indicated that some people may find it an unexpected setting for a clinic and that it may take time for people to accept clinics in different settings.

P7 (14) 319-326: It's got to be that it's not hospital or it's not the conventional health centre, it's something different...I would imagine again that people must find that quite strange. They almost expect they are going to go to.... they almost expect to go into the hospital environment and see people in white coats don't they? And all the usual paraphernalia of hospitals and someone says "well, no you go to the leisure centre". They must find that quite strange (James, Planner).

K1 (10) 222-228: Well it's all right I suppose, but I did think it was odd, but I don't know why it was odd. I suppose it's a health thing isn't it? And people go to swim, be healthy, have fun. It did seem a bit strange, but I don't know why, because it's never been in a swimming pool before. You didn't go for a doctor's appointment to a swimming pool, but why shouldn't you, you know? Yes, why not. I think it's because it's never been done, never done it before (Kate, aged 52, Service User).

However, some of the women who attended the continence clinic who either had a long standing continence problem or a chronic disability were less keen to attend a clinic in a non-medical setting. Whether the idea of mixing leisure and health together was really an unacceptable notion to them or whether they just needed more time and information about the clinic in this different setting was not clear.

M1 (8) 175-180: Well, I don't know that you want it to be very clinical but I didn't honestly think that that was...if you'd said to me, if I'd met you in the street and you'd said to me "Can you tell me where the continence clinic is?" the last place I'd think of sending you would be to the "Quays". I was surprised because I don't think it's a fit building for it, not myself, for it to be in (Mary, aged 82, Service User).

The "Quay to Health" is situated on the lower ground floor of the leisure centre with no direct access from the car park. To reach the clinic you have to walk across the main reception area of the centre (approximately 30 yards) and then either use the stairs or the lift. The process of navigating the way across the main area usually involves contact with the main leisure centre reception, the café and the toddlers' swimming pool! With a disability it can take some time to cover this area and Kate, one interviewee who had a disability felt that people were staring at her as she crossed towards the lifts. Some of the other women also felt uncomfortable about crossing this area as they felt that it was a very exposed area where you were in full view of leisure centre users.

K1 (10) 236-241: I think it's because it's nice to go somewhere where you've all got the same problem and the whole building is sort of round that problem, and you know if you talk to someone they've got that problem. But in the swimming baths you know, there's all people running around, it's more awkward if you're disabled because it's a very sort of able-bodied place, you know what I mean (Kate, aged 52, Service User).

Although stakeholders were keen to offer services to several different groups of people the tensions between running a leisure business for profit and offering health services to some disadvantaged groups became apparent during the data collection phase of the study. Some of the stakeholders were reluctant to encourage the provision of health services that would encourage people with mental health problems or drug and alcohol problems to use the centre. They felt that the families who used the swimming pool and other facilities at the leisure centre would take their business elsewhere if these stigmatised groups used the "Quay to Health" and this would have a direct impact on the feasibility of the whole "Quays" complex.

P5 (9) 197-203: That facility has to pay for itself at the end of the day as well, so when you say something like "Well, we're going to bring some people in to do work around drugs, people who are drug-takers", they say, "Woh, we don't want the word to be out that there are people on drugs in there", you know. Because people could then say "We're not going to take our kids there!" You just, it sometimes is a difficult line to walk (Arthur, Planner).

The provision of health services within a leisure setting involves choices about the nature of the services provided and some interviewees and stakeholders viewed it as more appropriate to locate some services within more traditional settings.

Sub-Category Health Promotion

Some stakeholders viewed one of the main advantages of the "Quay to Health" to be the focus on the promotion of health rather than the management of illness, shifting the boundaries of health care away from chronic disease management.

P2 (10) 225-233: I think we're looking at pro-health rather than crisis management, rather than, you know disease management. We're looking at being well and healthy and improving that, and I think that's the part of working with health and leisure, is the benefit because usually activity on the whole is about well-being and improving that quality of life. And in a hospital setting or clinical setting it's very much around disease management and orientation, so you know, the whole concept has changed and I think for patients that has been a big, big plus (Avril, Health Professional).

Stakeholders identified several cross-benefits between health and leisure services mainly focussing on an increased uptake of both health and leisure services within the building.

P6 (12) 274-278: I think fundamentally it boils down to two things and that is encouraging more people to use health services that wouldn't have done before. And encouraging more health users to use leisure facilities that wouldn't have done so before. And having access to those two different audiences (Verity, Planner).

The opportunity for people to do more than one thing whilst in the leisure centre was also recognised as a benefit of co-locating health and leisure.

P5 (9) 210-215: I think one of the benefits is that it does offer the opportunity for them to do more than one thing, you know. They can go there and they can do whatever they're doing with the health service, and they can swim or work out or whatever, so that's a benefit. It does encourage that and if it encourages that and some people pick it up it must help with their health and their general well being (Arthur, Planner).

This focus on health rather than illness was also identified by some of the women who used the clinic. It reflected a holistic approach to the management of health, encompassing the benefits of improved physical health and the impact of sporting activities on people's sense of well being. It was interesting to note that this underpinning philosophy was readily identified by some of the younger continence clinic users who appeared to see the "Quay to Health" and the leisure centre as a total health package.

L1 (21) 480-489: It's different because it's not in a clinical setting is it? It's more because it's in a sports environment and sports, there's something for everyone, you don't have to be medal winning level, and you don't have to be young. You can be any shape, and it's all, you know, sport is about healthy living the same as managing stress in your life, having an appropriate diet, meeting all your holistic needs, so having it there is just another, set of muscles that just need working, or another look at part of your lifestyle that you can manage to improve the quality of life. So that makes a difference, I think having it there (Lisa, aged 35, Service User).

B1 (13) 307-310: It's all concerned with health really isn't it? Swimming is good for you, it keeps you healthy, and the gym they've got there. The whole thing goes together doesn't it? I think it's a good place to have (Brenda, aged 68, Service User).

One of the women who attended the clinic recognised that people may attend the leisure centre for a swim and then visit the "Quay to Health" to sort out a medical problem due to its convenient location. The ability to self-refer without having to go via the GP was also seen as one of the main advantages of the clinic.

B1 (13) 310-316: And if you're going to the gym or swimming you might very well say "Oh they've got a clinic here, we can try that" You can refer yourself, which is quite good. So there's no having to go to your doctor and saying "please could you do this for me?" and so on. Which some people might not want to do. They might rather go direct (Brenda, aged 68, Service User).

However, some of the women felt that the opportunity to go swimming or to use the gym was one that did not interest them. The location of the continence clinic in a leisure centre was seen as incidental, with the focus of their visit on the appointment at the clinic.

N1 (7) 150-153: I'm not going to suddenly decide to go swimming because I've gone to the health centre. I mean, to be honest it's probably put me off because I've realised how far away it is from the bus stop (Nora, aged 27, Service User).

This particular interviewee could envisage why stakeholders had thought that people who used health services would also use the leisure services because they were in the building. She thought that it was a good theory but recognised that people were lazy.

N1 (15) 339-343: It's all about the holistic approach to health and prevention of problems in the first place. Studies have shown that exercise can reduce blood pressure, reduce depression, can reduce problems associated with diabetes, heart disease. So, yes it's a fantastic theory but people are lazy (Nora, aged 27, Service User).

For some people visiting either the "Quay to Health" or the swimming pool or gym the opportunity to use some of the other facilities was recognised. Whether or not people choose to participate in other activities whilst visiting the "Quays" will be decided on an individual basis. A previous evaluation of the "Quay to Health" (Partington 2001) found that although some people used both the leisure and health facilities those people who visited the "Quay to Health" stated that they would be more likely to use the leisure facilities at a subsequent visit as they were more aware of the facilities available having attended the "Quay to Health". With all the National Service Frameworks (Department of Health 2001) advocating the benefits of physical exercise in disease prevention and management the co-location of health and leisure facilities will continue to develop with the advent of healthy living centres.

The advantages of locating a health facility within a leisure centre were focussed on its unique and relaxed approach to the promotion of health and the provision of services. It was seen by many stakeholders and clinic users as a totally different health facility from other clinic or hospital services. It was popular both because it provided a relaxed, informal environment that was seen as less intimidating than a hospital, but also because more time was available to discuss concerns with the health professional involved with the clinic.

Sub-Category Anonymity

Stakeholders saw one of the main advantages of the location of the "Quay to Health" within the leisure centre as anonymity. People could be doing any number of different activities within the leisure centre, including visiting the health facility and nobody would know where you were going.

P4 (3) 57-61: You can see why people can come in and they can lose themselves in a leisure centre, slip down to the health centre, do their business, whatever that is. Whereas if you go into a health centre everyone knows what you're going in there for, basically. That is obviously a health reason (John, Practitioner).

P1 (4) 73-76: Well, I think a big benefit is the non-health setting, you know. When you go through the doors you could be going to do anything really. You could be going swimming, you could be going to the health suite, you could be doing anything (Sarah, Health Professional).

P3 (3) 59-60: It's a nice environment, it's not threatening. You could be going for contraceptive advice. Nobody knows why you're there (Camilla, Practitioner).

One of the stakeholders felt that by locating a continence clinic in a leisure centre with a swimming pool this added to the "invisible" nature of the clinic appointment. She felt that the one place that women with continence problems did not visit was a swimming pool as if they leaked urine they would be too embarrassed to go swimming. By locating a clinic facility in the same building as a swimming pool then this enhanced the anonymity of the visit.

P3 (1) 8-10: The one place that people with continence problems don't go is swimming pools, and putting it there meant that they could go there with anonymity (Camilla, Practitioner).

The issue of anonymity was also identified by some of the women interviewed. One of the women who attended the clinic felt that nobody would know why you were in the leisure centre and visits to the clinic would be anonymous.

L1 (8) 178-184: I would not imagine for one minute that by me walking in people would think "She's got a continence problem" (Lisa, aged 35, Service User).

However, some of the other women felt that just by walking into the leisure centre people would instinctively know what their problem was. Although they were able to recognise that other leisure centre users probably had no idea why they were in the building their own beliefs prevented them from thinking logically about the situation. On reflection and in a location away from the clinic they were able to express their feelings about navigating their way to the clinic and recognised that other people would probably have no idea, or interest in their presence in the building.

K1 (9) 201-204: But walking across in front of the thing, people in the swimming baths, and I could feel, I felt really horrible. I could feel them staring at me. Like "she can't be going swimming", I don't usually feel like that (Kate, aged 52, Service User).

C2 (14) 322-324: I know why I'm coming. Do all these other people know why I'm coming? Which is, you know, perhaps it could be a cause of embarrassment for some people? (Carol, aged 49, Service User).

F1 (12) 271-277: I had mixed feelings about where it's located. I mean there's a bit of...but I think it's my paranoia you see because I think "I bet these young people behind the desk" and maybe it's because it all happens as you're becoming older as well, I guess. These young people.....they'll be thinking "There's another woman who wets her knickers off down to the incontinence clinic" And I don't think probably for 30 seconds it even crosses their minds (Fay, aged 51, Service User).

Sub-Category Drop-In

The relaxed, informal nature of the setting of the continence clinic within the "Quay to Health" was seen by stakeholders as helping people with an embarrassing condition to come forward to seek help.

P3 (14) 325-330: I think you could put a continence clinic into any health promotion environment. Anywhere where people can go and get a quick fix then you're going to find people will come and say, "Well actually I have got a problem". The idea of having to go to their GP and say, actually get the words out, you know "I leak".... I think anywhere that they can do that in a different way will help them (Camilla, Practitioner).

However, many of the women who attended the continence clinic had been referred by their GP and although they attended that particular clinic they would have attended a clinic in another setting if they had been given an alternative appointment.

The clinic at the "Quays" was convenient because of its city centre location and was geographically close to many of the women attending the clinic.

The provision of health services at the "Quays" was also seen as an opportunity to de-medicalise stigmatised services although there appeared to be some difference of opinion between the stakeholders as to the type of service that was seen as stigmatised. The contraceptive and sexual health clinic did not appear to some stakeholders as a stigmatised service although the continence clinic and stoma clinic were seen as services that people may have been embarrassed to have needed to attend.

P2 (12) 270-275: Which is a bit like your continence people, they can walk in. These are the areas, which are very, very sensitive to people and find it difficult to address, and on the whole the GP is the gateway for those things. So, if we can get more of these sort of drop-in services, getting away a little bit from the GP, I think it's much easier for the patient (Avril, Health Professional).

The drop-in nature of the continence clinic was something that was frequently cited as a main function of the clinic at the "Quays" and something that differentiated that clinic from other continence clinics held in the area. Although providing a valuable additional service enabling people to access instant advice the service was poorly advertised and as a result only approximately five people per year used this service, with the remaining clinic time used for booked appointments. People who attended the clinic for a drop-in appointment had often been using one of the leisure facilities and popped in to the clinic to seek advice for continence problems that had either not been satisfactorily resolved in the past, or had experienced frustrations with existing health services. The provision of this service may well support existing services by providing an immediate response to people's concerns, thus enhancing the satisfaction of service users.

P3 (9) 201-205: The sort of drop-in people tend to be the ones who are either desperate or have been disappointed where they've been fobbed off, told that it's something they have to put up with, "what do you expect at your age?" things like that (Camilla, Practitioner).

Core Category Location

The third part of this chapter will focus on the final core category that emerged from the data from stakeholders and service users and will explore how the women who used the continence clinic felt about the location of the continence clinic. This category was made up of two sub-categories: Geographical location and Location of the clinic in the building. The city centre location was convenient for most people, especially those who had access to private transport. The setting of the clinic within the building itself was viewed as an unfortunate location in the basement of the building with both stakeholders and users recognising that future developments should plan the location of a health facility more carefully, to provide a brighter, less concealed location.

Sub-Category Geographical Location

The accessibility of the "Quays" was good for people with access to a car, although it was not as convenient for those using public transport. The availability of parking immediately outside the building was appreciated and compared very favourably with the parking problems experienced at most hospital sites.

C1 (11) 258-259: I think it's fine, it's quite central; it's easy for me to get into. There's loads of parking and its nice modern surroundings (Carol, aged 49, Service User).

B2 (11) 253-256: It's easy to get to, you know. Everybody knows where it is which is another thing, whereas if you go to the hospital you've got the parking problem and everything (Brenda, aged 68, Service User).

N1 (15) 353-358: I think for car drivers it does because the "Quays" is a fantastic place, peak hours Monday to Friday you can park there. If you're disabled you can park there, if you've got kids you can park there. If you've got public transport it's not, you've got to get off in town and then walk through, down some horrible steps and an underpass. It's just its not very nice (Nora, aged 27, Service User).

The access to the building will improve as the area surrounding the building is fully developed.

Sub-Category Location of Clinic in Building

The location of the "Quay to Health" within the basement of the building was recognised by stakeholders as a location that was convenient at the time of its inception, but that it was not an ideal location. The only space available once the building had been completed was a small area with four consulting rooms, a waiting area, a toilet and some office space. The impression gained from the Stakeholder interviews was that the health services, leisure services and the city council were keen for this development to take place and realised that they had to work within the constraints of the space available. Future developments with the healthy living centres would plan to involve all parties at an early planning stage in order to provide appropriate facilities for health care.

P7 (10) 229-241:.but the problem with the "Quay to Health" is it's still plonked away in, down in the basement you know? Not really part of the entire complex, it's still, you know. There's the "Quay to Health" and there's the "Quays" and the two are sort of, they are in the same building, and they work together, but it doesn't send out a sort of strong message that this is something, which to be fair was never intended....Charlotte Place goes a stage further than that and I think you know that the aspiration of that's exactly what it will be. You'll go in there and it will be leisure and health totally integrated; there won't be any demarcation (James, Planner).

The location of the continence clinic and the problems that may be involved for women gaining access to the clinic were appreciated by one stakeholder who identified all the different signals that may be coming from a leisure environment and how those signals may have to be navigated by people attending the clinic. This linked well with some of the perceived messages picked up by Kate on her journey to the clinic.

P7 (15) 348-351: But still, with your sort of journey, still right through the leisure environment, right through the leisure reception, which is sending out all the leisure signals and you've almost got to fight your way through that to where you want to be (James, Planner).

The women who attended the continence clinic were divided in their opinion about the location of the clinic within the building. Some women felt that the setting was clean and modern, whereas others did not feel that it was a pleasant place to have a health facility.

B1 (2) 45-46: I was quite impressed, you know. It's all laid out in proper rooms and everything. It's very nice (Brenda, aged 68, Service User).

H1 (15) 345-348: I found it very pleasant. The waiting room was nice and there were people around and so you weren't sitting there thinking, "Oh my God, what's going to happen"...I'm not like that anyway, but some people probably are (Hilda, aged 89, Service User).

E1 (6) 131-133: It was unusual to find it there, and it was quite private, you know, not many people knew it was there so that was quite nice. So, yes I found it nice in there (Eve, aged 28, Service User).

The positive responses received to the location of the clinic may have been influenced by a number of factors. When comparing the location of the clinic to other clinics held in more traditional settings a modern, recently completed building would probably appear to be a nicer location than a clinic in a hospital or older health centre. I occasionally covered one of the continence clinics at the "Quays" so some people may have assumed that I would think it was a good location and make a positive response. However, some women found the location to be dark, dingy and unpleasant and were apparently able to honestly express their feelings about the clinic.

N1 (5) 100-106: The actual waiting room I didn't like it at all. It looked really grubby and really dark and dingy in the basement of this sports centre...The actual clinic rooms themselves are lovely, really nice, but I mean if I had come down to make an appointment I don't know if I would have. If I hadn't been feeling so desperate I don't know if I would have continued (Nora, aged 27, Service User).

J1 (11) 240-242: It's underground. It's rather dark; it's like a bit of a hovel, Santa's grotto or something when you go in there. It's a bit dark. It was quite quiet in the waiting room, which was nice I guess (Julie, aged 32, Service User).

The reception and waiting room areas of the "Quay to Health" might benefit from improved lighting, as it appeared the dark and dingy areas were not as welcoming as they could be for people who were feeling anxious about their visit to the clinic. One woman provided an even more graphic description of the clinic surroundings and suggested that the clinic should be on the upper level of the building rather than in its current location. She also described the location of the clinic as somewhere you went to be punished rather like the Tower of London, but recognised that this was psychological.

K2 (10) 250-253, 257-260: And going down like in the dungeons, that's where you go and you belong in the dungeons, don't come out. I'm terrible. Yes, but it is and when you went up it would feel better, see, it's all psychological isn't it? That's a good point, they should [locate the clinics on the same level as the main facilities].
Your punishment. Though once you were in there it wasn't bad, you know, if you're talking to people. But I didn't like waiting, there's nothing to do there, the reception I didn't know which one I had to go to. There was two people sat there and I didn't really know... (Kate, aged 52, Service User).

The stakeholders felt that the environment of the "Quay to Health" was a pleasant one that encouraged people to attend and had been designed with users in mind.

P5 (10) 215-218: I think it is a good environment. I'm not sure exactly where it is, but if you were doing it again and we were on the ground floor, it just offers a nice environment to go to for something that makes people anxious (Arthur, Planner).

P6 (6) 133-137: A high profile building also in the area, so if you were describing a health facility was at the "Quays" then most people would know where that was, it wouldn't be difficult to find. But also a building that was designed with the users in mind (Verity, Planner).

Conclusions

The stakeholders were very positive about the relationships between health and leisure. They were keen to be seen to be innovative in their approach to working in partnership across the city, but recognised some of the limitations when trying to work within different cultural norms alongside one another. To develop the concept of partnership working, joint training between health and leisure centre staff was recognised as a way forward and some joint training sessions had been organised. Many of the stakeholders were keen to try out new approaches to the provision of health services, looking at different settings for clinics and looking forward to the development of healthy living centres in the city. They did not always need to see evidence that an approach worked to "have a go" as they felt that if a new idea did not work then they could always withdraw the service and re-think the approach taken.

The interviews with the stakeholders were undertaken two years after the opening of the "Quay to Health" enabling them to reflect on the process of the development of the facility and to identify any changes they would consider for future developments.

Some of the key recommendations they made for future service development were:

- The planning of how a health centre would be incorporated into a healthy living centre should take place at the earliest possible stage.
- The types of services to be provided within the centre should be agreed and planned rather than inviting any service that was interested to be accommodated within the building.
- The position within the building of the health services would be planned so they were not tucked away in the basement.

The "Quay to Health" had helped to lay the foundations for future partnership working around the city and it has achieved some of the original aims of the stakeholders who developed the service.

This study has found that providing health care in a non-health setting appears to be acceptable to women attending the continence clinic at the "Quays". Although some of the women initially found the location of the clinic a little strange, following their first visit most did not think there was anything unusual about a clinic in a leisure centre. The clinic environment was seen as relaxing and quite pleasant by most of the women although some felt that it was a dark and dingy place that could be brightened up a little.

Many of the women who attended the clinic felt that the "Quay to Health" was in a much nicer location than a hospital clinic and that the continence clinic was less intimidating than hospital clinics with an informal atmosphere and friendly, helpful staff. It was suggested that it was easier to park and that waiting times were shorter compared to hospital clinics. One Continence Advisor who has been involved with the clinic usually operates the continence clinic at the "Quay to Health" since she developed the clinic in June 1999. She is an experienced member of staff who is very popular with the people who attend the clinic.

It was interesting to note that one of the women interviewed who had a disability felt uncomfortable in a leisure environment. From her perspective the able-bodied nature of a leisure centre reinforced her loss for the person she used to be, which was something that I had not considered would be an issue in an accessible leisure centre. She felt that the whole environment provided a painful reminder of all the activities she used to enjoy, but was no longer able to participate in. The building was a permanent reminder of past happiness, one where she had enjoyed visiting a gym and going swimming, but no longer felt able to participate in those activities. Stakeholders had commented on how they had made every effort to make the building accessible to disadvantaged groups, consulting widely during the planning stages of the building to enable wheelchair access and access to all areas by disabled people. However, for this particular woman the psychological impact of her disability together with the physical limitations resulted in a reluctance to use the building.

Another younger woman who had suffered a disability felt very comfortable within a leisure centre environment. Because she had spent so much time in hospitals and GP surgeries she welcomed the opportunity to attend a clinic in a non-medical environment. Further research is indicated into the expectations of women with disabilities about how they perceive health and illness and which environments are best suited to their care.

The following chapter will explore the pathways to care taken by the women attending the continence clinic and the impact of their incontinence on their everyday lives.

CHAPTER FOUR

The Women Who Attended the Continence Clinic

This chapter focuses on the categories identified from data collected from clinic users about their experience of incontinence and of the clinic itself. The core categories identified were ***Living with Incontinence, Prompts to Help-Seeking*** and ***Experience of Service***. The table below (Table 6) identifies both the core categories and their sub-categories.

Table 6 Categories Identified from data gathered from clinic users

Core Categories	Living with Incontinence	Prompts to Help-Seeking	Experience of Service
Sub-Categories	Impact	Worsening Symptoms	Pathway to Clinic
	Coping Strategies	Unpredictability	Advertising
		Cumulative Effects	Expectations of Visit
			Ongoing Pathways Through System
			Evaluation of Service (including questionnaire data)

The chapter will briefly describe each core category and then discuss them in detail with the sub-categories that contribute to their development. The data obtained from structured instruments, incontinence impact questionnaires and frequency/volume charts is also discussed later in this chapter.

Living with Incontinence was the first core category to be identified. This category was made up of two sub-categories: Impact and coping strategies. The impact of incontinence on women's lives can involve limitations on their social activities, relationships and compromise their self-esteem. Some women appeared to blame themselves for their incontinence as they had failed to carry out pelvic floor exercises following childbirth and interpreted this as non-compliance with medical advice and therefore their fault. The coping strategies adopted included restricting fluid intake (especially when planning a trip away from the house), wearing protective incontinence pads or sanitary towels and carrying spare pads and pants with them in case of an "accident" (unexpected urinary leakage). Interviewees were aware of the location of toilets within the city centre and planned shopping trips around the different toilet stops. The coping strategies employed, if successful, enabled women to carry on with their lives concealing their incontinence. However, if urinary leakage became unpredictable and difficult to manage then the problem could become visible to others prompting them to seek help.

Prompts to Help-Seeking emerged as a core category that described the final catalyst that prompted users to seek the help they needed. This category was made up of three sub-categories: Worsening symptoms, unpredictability and cumulative effects. The worsening of symptoms or lack of improvement appeared to prompt an attempt to seek help. Many women approached their GP as the first contact and if they received an unfavourable response it could be several years before they had the courage to approach another GP or health professional for help. The interviewees had suffered from incontinence for between one and 35 years with some having concerns about the future and how their incontinence could affect family relationships and their independence. The cost or embarrassment of purchasing incontinence pads or sanitary towels was sometimes a trigger to seek help. The unpredictable nature and strong feelings of urgency caused by an overactive bladder adversely affect some women's lives causing complicated routines to be developed to try to minimize the impact of the condition on their everyday lives. The failure of these routines to cope with the problem was another trigger to encourage women to seek help.

Experience of Service emerged as the third core category. This category was made up of five sub-categories: Pathway to clinic, advertising, expectations of visit, ongoing pathways through system and evaluation of the service (including questionnaire data). The pathways taken by users to arrive at the clinic varied with some being referred by their GP or Consultant and others via health professionals or friends. The existence of a clinic in its leisure centre location was generally unknown to all the users in this study who had either been referred to the clinic by their GP or offered an appointment following contact with the Continence Advisors main clinical base at Hythe. Some of the clinic users had visited the centre on a regular basis to use the gym or to swim but had not noticed the signs for the "Quay to Health". The lack of advertising was noted by users, some of whom felt that they would have sought help for their problem earlier had they been aware of the existence of the clinic and the ability to self-refer. The expectations of the clinic included the need to obtain advice about incontinence, a resolution of the problem and the opportunity to spend some time with a nurse specialist who would understand their problem and offer support. The ongoing pathways through the system involved referral to the main continence base at Hythe for electrical stimulation treatment, referral to the Urogynaecologist at the main hospital, liaison with the GP for medication and continuing attendance at the clinic. The service offered at the "Quays" was evaluated positively with users feeling that they had received the support and information they needed to either resolve their problem or manage their symptoms until they had contact with another health professional providing some specialist intervention.

Core Category Living with Incontinence

The category ***Living with Incontinence*** involved the impact incontinence had on women's lives and the different ways in which they coped with the problem. Many of the interviewees appeared to be embarrassed about their incontinence and were able to describe how they had limited their social activities as a result. However, some of the interviewees described how they were determined not to give up some activities they enjoyed and had devised ways of coping with their incontinence to enable them to continue to participate in sporting activities. Incontinence could have an impact on relationships, with some of the women indicating that they did not discuss their problem with partners or other members of the family. The coping strategies employed appeared to involve developing routines that would enable them to manage their incontinence, concealing the problem from others and incorporating these routines into their daily lives. The sub-categories that contributed to the formation of the main category ***Living with Incontinence*** are explored below.

Sub-Category Impact

The impact of incontinence was unique to each individual and caused some limitations to their everyday lives. Many women found their problem caused them embarrassment and affected both their social lives and their self-esteem. One woman who worked as a health professional felt very embarrassed about her problem and found it difficult to discuss the problem with her GP. She appeared to find it difficult to explain why she felt so embarrassed as she would not expect any women who consulted her to feel uncomfortable if they had the same problem.

J1 (7) 145-147: Some people aren't really embarrassed about things and... but it just feels silly because as a health professional I wouldn't feel someone was stupid if they were coming to me about it. But just being on the other end... (Julie, aged 32).

Another woman described how she had felt so ashamed when she leaked urine as bladder control is something that society expects adults to have attained.

D1 (17) 386-389: The other day when I came home and I leaked a little I felt really quite ashamed of myself, you know. I don't know why. I think it's a feeling of being out of control isn't it? And we're supposed to have got this sorted out as adults (Dawn, aged 69).

Another woman described how she was too embarrassed to buy incontinence pads from the supermarket as she felt that the girl on the checkout would know that she leaked urine. Although she was able to rationalise that the girl may not even notice the pads, her sense of acute embarrassment prevented her from buying the pads that would help her cope with her problem.

F1 (7) 158-161,180-184: I find that using sanitary towels on the whole is OK but I sometimes feel I could do with something that is slightly more absorbent. But I will not buy those.. at the supermarket. I just cannot bring myself to buy them . I can't do that. Even though I didn't know the girl and she probably isn't interested in what people are buying. But I would just feel embarrassed that she might think, "oh you wet your knickers do you?" that sounds awful doesn't it? But that's just how I feel about it. I suppose I find it so embarrassing (Fay, aged 51).

The location of public toilets had a profound impact on some of the women who felt that they had to be vigilant and within easy reach of a toilet when away from home.

L1 (2) 46-52: If you venture into a shopping centre it's a major expedition. As soon as I get there I need the loo. When everyone wants to sit down and have a drink I don't want to have one because then I know I'll be looking for the loo again. It feels like you're hampering other people's enjoyment as well especially if you have to go on public transport or even on a car journey because then you have to keep getting everyone to stop (Lisa, aged 35).

K1 (6) 133-137: You've got to be near a toilet, you've got to have towels. The other day I had one "Tena Lady" left I was like a smoker "oh I want a cigarette". I had to ring up people "can you get me some?" because I can't stop it leaking before I go to the loo so I have to change (Kate, aged 52).

One woman who enjoyed dancing had to wear pads that she changed frequently to enable her to continue a leisure activity that she enjoyed. The impact of incontinence on her self-esteem was revealed in her use of language when she described her symptoms as "horrible".

C1 (14) 318-321: If I dance I have to every other dance go out and change and then I do have to wear heavy pads. It can be absolutely saturated. I can have got home sometimes and my undergarments are wringing wet, horrible (Carol, aged 49).

Sub-Category Coping Strategies

The coping strategies adopted by the women to manage these problems included planning trips out from the house and being aware of the location of the toilets in the shopping centre. Some of the women used pads when away from the house to give them the confidence that if they leaked urine it would not be visible.

H1 (14) 318-320: If I'm going to be out a long time I use a pad because that gives me confidence. It's not so much that I use it that I need it but it makes me feel confident (Hilda, aged 89).

N1 (23) 539-540, 544-545: It's part of a routine that I've developed, in the same way I always have plasters and tissues, you know. Just another thing I put in my bag. At least these days everything comes in plastic (Nora, aged 27).

C1 (2) 44-48: Most of the time it's not too bad and I just learn. I mean I'm not having to wear big pads just panty liners, but I wear them all the time and change them fairly regularly. It's all right so long as I don't cough, sneeze, jump, run, so on an average day it's not really a problem. Well a problem other than it's so uncomfortable (Carol, aged 49).

As well as being aware of the location of toilets in an area some women emptied their bladders just before leaving the house and restricted their fluid intake to try and reduce the risk of an accident in public.

H1 (2) 40-43: If I go out I make sure that I go out with an empty bladder. And I use every opportunity to spend a penny when I'm out. If I see a sign saying "ladies room" or whatever I always go (Hilda, aged 89).

L1 (3) 56-59: Yes. I do still plan because if I have to be somewhere first thing in the morning I probably have a small glass of water to get me going for the day. I wouldn't have a cup of tea or coffee and I wouldn't have a lot of fluids (Lisa, aged 35).

K1 (6) 141-142: ... we know nearly every loo everywhere. We know all of them especially if it's quite a good one to go to (Kate, aged 52).

Many women were able to cope well with their incontinence whilst they had easy access to a toilet at home but had to be adaptable in order to continue other pursuits.

B1 (8) 180-185: When I'm home it's all right because I can generally get there all right. It's when you're out walking it's a nuisance, but it has been a bit better lately. I've only had to get behind the bush once and then I was all right until I got home (Brenda, aged 68).

Core Category Prompts to Help-Seeking

The category Prompts to Help-Seeking involved the stage at which symptoms created an unacceptable impact on a woman's daily life. Whilst they were able to control bladder leakage by emptying their bladder frequently, using sanitary towels or pads and planning toilet visits when away from home, the problem was tolerated.

However, if the bladder leakage became more unpredictable and more difficult to manage and conceal this could provide the catalyst for them to seek help. Frequently women tolerated their incontinence for several years before seeking help, although the precise length of time was not directly related to their help-seeking behaviour.

The sub-categories that contributed to the formation of the core category ***Prompts to Help-Seeking*** are explored below.

Sub-Category Worsening Symptoms

The deterioration in symptoms experienced by the women was unique to each individual but generally involved limitations to activities, especially outside the house.

L1 (1) 4-10: It was causing me problems outside the house and restricting where I could go. I would have to wait until I had enough fluid to get by, but that I'd been to the loo enough times before I could go out and then I would end up panic-stricken always looking for a toilet. I had hoped that it would just miraculously get better, but it didn't. It had improved but not sufficiently to let me do what I wanted. So that's when I decided that I needed some help (Lisa, aged 35).

K1 (2) 31-36: So it has got worse. I know its five years, but it's got slowly, slowly worse. It hasn't got better. I think a lot of it is gravity because I'm more mobile now. It's a change in my posture like getting out of the car, standing up and I think "oh god", it just pours out of me. While I'm in the car I'm all right. So I think it's gradually got worse especially over the last year (Kate, aged 52).

B1 (1) 4-6, 9-11: Well. I was going through a bad patch with my bladder 'cause I've had it, it's leaked for a long time and it's been a nuisance but I've more or less kept it under control. I was living with it. But then it suddenly got really a nuisance (Brenda, aged 68).

C1 (1) 12-16: About last September it got noticeably worse and although I may not have been doing the exercises non-stop all the time it started to get quite serious. It wasn't making any difference, whereas last time, in the past I've been able to control it with the exercises (Carol, aged 49).

Two of the women were worried about how their incontinence may deteriorate as they became older and gave this as one of the main reasons they had sought help at this stage. A close friend of one of the women had become incontinent and needed to be cared for by her son. This appeared to have shaken the interviewee as she felt that she did not want to be a burden to her family when she became older, and would also have been embarrassed at having to ask her son for help with such a personal and distressing condition.

D1 (8) 168-172: A lot of women I know do have problems and some older women sort of smell. It's natural but it's something you know, like life but it's something I'd be very embarrassed about. I wouldn't like my sons to have to deal with that (Dawn, aged 69).

F1 (6) 128-134: I look to the future and I feel worried that it's going to continue to get worse. Because if it's a muscular problem I have this vision of it getting worse and worse. I really would quite like to get it sorted out while I still feel able to (Fay, aged 51).

Sub-Category Unpredictability

An interviewee found travelling in a car difficult, as she was unable to predict when she would need to empty her bladder and traffic queues caused her to experience some stress. Waiting in a queue for a public toilet also appeared to generate some anxiety with the concern that a total loss of urine was possible, something that would have been unacceptable.

L1 (17) 406-409, 437-443: At the first hint of a traffic jam I'd be panic stricken thinking "oh god we're miles from anywhere and I don't think I can go much further". So that was it for me, then I realised that I really couldn't manage it on my own. I've just had small leaks, I haven't actually let go of the whole thing but I've come very close to it where I'm practically in tears because I can't get in there. Then your legs are shaking and everything else because it's so stressful and it wears you out. You just feel like "oh please don't I'd rather die on the spot than that happen". But just thankfully I haven't completely let go so it must be worse for people that do (Lisa, aged 35).

One of the interviewees who had an unstable bladder found it difficult to wait for a suitable moment before passing urine. If she met a neighbour in the street and needed to go she was anxious that she would be able to wait long enough without leaking any urine. This unpredictability had been a factor that prompted her to seek help as it was affecting her relationships with others.

J1 (3) 49-54: It's more needing to go and not being able to hold on in awkward situations. Like if I met someone on the street and started talking and thought I needed the loo and was trapped there, and that really made it a problem. So it was situations like that rather than the frequency itself, it was holding on that was the problem, rather than the frequency (Julie, aged 32).

Another interviewee had to respond immediately to the signal to pass urine and found this limiting.

H1 (2) 39-40: I can't wait to go, I just have to run. And if I'm late I have an accident (Hilda, aged 89).

One of the interviewees had found that by wearing pads she had some protection if she had an unexpected leakage of urine. The unpredictable nature of her incontinence appeared to cause her some anxiety and this may have been one of the factors that prompted her to seek help for her problem.

F2 (6) 123-130: The incontinence that I have is terribly unpredictable, you know I could just, [leak] if I needed to go to the toilet. If I come home from work and I'm desperate for the toilet I can hold it even until I get to the, it's not a problem, but another time I could have gone to the toilet, walked down the stairs and across the road and I've wet my knickers. And it's that unpredictability of it that's actually quite difficult, so having got used to the idea of wearing pads it essentially means that you are prepared for anything (Fay, aged 51).

Sub-Category Cumulative Effects

Many of the women had tolerated their incontinence for several years before seeking help. If they received the advice they needed then they were prepared to continue as they were as long as things had improved to some extent. It was often several more years before they asked for help again. The reasons why people waited for several years before seeking help were unclear, as it appeared that as a group, their incontinence varied in its severity and impact on their lives. Women appeared to minimise the importance of the problem and perhaps this enabled them to tolerate symptoms over many years.

B1 (7) 165-171: But then it got more of a nuisance so I went to my own doctor here. Which I suppose must have been 25 years ago. I probably left it for about ten years. About 25 years ago and it's been going on ever since. But the fact that they gave us some tablets helped and that did help quite well for a long time. But then I think my mind must have overcome the tablets or something and it was being more of a nuisance again (Brenda, aged 68).

J1 (1) 4-10: It had been going on probably over ten years and I just got to the point, it was probably getting a little bit worse. I'm not sure, but it certainly wasn't getting any better. I'd been saying to myself for years "oh I must do more pelvic floor exercises and it'll be all right". And it wasn't getting any better. I got to the point where I wanted to get some help, even though it's a bit of an embarrassing problem (Julie, aged 32).

D1 (5) 104-105: I suppose it's been like this for about 15 or 16 years really, feeling that my bladder is much weaker than it used to be (Dawn, aged 69).

C1 (17) 389-390: It's only because I'm beginning to feel that it is intruding on my life that therefore I've come to get some help with it (Carol, aged 49).

One of the women had suffered from incontinence since she was a child but had still waited until she was 26 years old before seeking help for the problem.

N1 (2) 39-40, 44-45: It's been off and on since I was a little girl really. I was very old before I was reliably dry and clean. I was about six or seven years old, so I was always having accidents (Nora, aged 27).

Another prompt to help seeking identified by a younger clinic user was the cost of the continence pads, together with the impact the problem was having on her life.

N1 (1) 4-7: It was the cost of the "Tena Lady" pads, and also my age you know. I'm 27 and having your knickers smell of urine and always worrying about it wasn't a good idea (Nora, aged 27).

Other interviewees raised the cost of the "Tena Lady" incontinence pads as an issue. While this wasn't identified as a specific prompt to help-seeking it may have contributed to it.

K2 (5) 119-121, 129-130: Tesco's own one they've just got folded in the packet, and they've just got a strip down them, you haven't got to, and they're very soft and they're nice. I can't afford "Tena Lady" now as they're dear, £2.50 or so (Kate, aged 52).

B1 (9) 179-180, 195-196: I would wear pads and things, but they're very expensive to have to buy if you're wearing them all the time. I usually use "Boots" because they're the cheapest, and they do various sizes (Brenda, aged 68).

If women were using pads on an occasional basis the cost of the pads did not appear to be an issue for them. However, those women who needed to use pads on a regular basis identified cost as an important consideration when deciding the type of urinary leakage protection to use. This had prompted them to seek out pads that provided comfortable protection at the best price and had appeared to indicate that when women became fed up with their incontinence and the need to use pads this prompted them to seek help.

Core Category Experience of Service

The category ***Experience of Service*** involved the pathways taken by women to access the clinic, how the clinic was advertised, their expectations of clinic attendance, the referral pathways followed by some women on to more specialised services and their evaluation of their experience of the "Quays". Although all the women shared accessing the clinic, their expectations of the clinic itself and their evaluation of the experience, only some women were referred on to either a Urogynaecologist or to the main continence base at Hythe for an eight-week course of electrical stimulation treatment.

The clinic users did not always have a clear picture of what was going to happen to them at their first appointment. They all indicated that one of the main purposes of their visit was to gain a clearer picture about what was happening to them and how they could eliminate or reduce the impact of their symptoms. The evaluation of the service at the "Quays" appeared to be positive with users feeling that their problem had either resolved or that they had been given the advice they needed to cope with the problem. The sub-categories that contributed to the formation of the category ***Experience of Service*** are explored below.

Sub-Category Pathway to Clinic

The pathways taken by women to reach the clinic could involve some personal perseverance, as it appeared that other clinics and hospitals within the Southampton area were not always aware of the existence of the clinic. One woman had heard about a clinic at the "Quays" from a friend but found that finding out how to access the clinic was not straightforward.

D1 (1) 11-20: A friend of mine she found out about a clinic. Now I don't know whether it was the same one it doesn't sound like it was but she said, "oh why don't you find out about that?" so I went to my doctor for something else and asked her. She said, "oh I've never heard of such a thing" and the receptionist hadn't heard of it either. I thought it was something to do with the hospital so they rang them and they gave me the number of a clinic in East Park Terrace. They eventually gave me the number of the clinic at the "Quays" (Dawn, aged 69).

Another woman had approached her GP for help with incontinence and found that the pathway involved contact with different health professionals and a delay of six months before she was able to obtain an appointment at the "Quays".

N1 (1) 6-11: I went to my GP and he referred me by letter to the gynaecology physiotherapist. He got a letter back saying they no longer accepted referrals so he told me to see the nurse, practice nurse. So I saw her and she told me to see the district nurse and then she came and did an assessment, then I found out about the clinic (Nora, aged 27).

Some GPs were aware of the existence of the clinic and referred women to the clinic. It appeared that when they had used the clinic before for referrals they continued to refer women with continence problems for help.

G1 (1) 4-6: I went to my doctors because I was having a coil check and I spoke to the sister there, and she said to make an appointment with my doctor and my doctor suggested coming to the clinic (Geraldine, aged 35).

F1 (1) 24-26: I went down to Lymington hospital and had a scan on my tummy and things. I then had to go back following that and then that was when the GP referred me to this clinic (Fay, aged 51).

One of the Consultants at the local hospital regularly referred women to the "Quays" who he felt would benefit from advice about the management of bladder problems. These referrals appeared to involve women with chronic bladder problems who had seen several health professionals over many years.

M1 (5) 111-115: He wanted me to come to the clinic because he said when I went to see him "are you happy with that?" and I said "the only thing I do find I have a bit of a problem holding my water". He then said "well, we've got this clinic going and I'd like you to go there". So that's why I came down there (Mary, aged 82).

K1 (1) 186-189: He said "what I could do is perhaps get some, get in contact with the incontinence nurse and they could perhaps come to your house and tell you about operations and things like that". So my impression was that people were going to come to the home. I didn't know I was going to have to go to the clinic (Kate, aged 52).

One woman had arrived at the clinic having spoken to a nurse at the continence foundation. The help-line number had been included in a stroke foundation magazine and enabled her to access the service.

L1 (4) 72-80: I did speak to a nurse on the advice line for the continence foundation and she explained that in all likelihood it was part of the damage from the bleed and that there was a good chance of being able to manage it properly. She sent me some information and the contact number for the service which when I phoned that's when I *found out that the clinic was at the "Quays". I hadn't realised before or I might have got myself down there (Lisa, aged 35).*

The local NHS walk-in centre had also referred women to the clinic and the nurses at the centre appeared to be aware of all the continence clinics in the area and were able to offer alternative venues to people that suited where they lived.

B1 (1) 16-27: I thought "I've got half an hour to spare, I'll pop in" [to the walk-in centre] they didn't seem to be busy. So then she said "have you been to an incontinence clinic?" and I said "no, only to the specialist at the hospital". She then said, "would you like to try going to one?" and looked it up and suggested the one at the "Quays". She then gave me the 'phone number and I rang them up and made an appointment (Brenda, aged 68).

Only one woman had arrived at the "Quays" having seen a notice in a GPs surgery for a continence clinic in a nearby town. Although she was unable to secure an appointment at her nearest clinic, by persevering she found out about the "Quays".

H1 (1) 4-8: I saw a notice in the doctors' surgery saying there was a clinic in Milford-on Sea so I rang them and they couldn't give me a date for months so I rang around. I tried Totton and finished up with Southampton and they gave me a date in a reasonable time. So there I went (Hilda, aged 89).

Accessing the continence clinic at the "Quays" appeared to involve some determination to seek help on the part of the sufferers. Some GP surgeries and other NHS clinics did not appear to know how to access the continence service and this may have an impact on the number of referrals to the "Quays".

Sub-Category Advertising

The existence of a continence clinic at the "Quays" appeared to be largely unknown. Although some of the women were aware of other clinics taking place within the "Quay to Health" many were surprised to find a continence clinic in a leisure centre location. There appeared to be an expectation that a clinic that dealt with bladder problems would be located in a more traditional setting such as a hospital outpatients department or a health centre. This location remains new and unusual and may indicate a different approach to the provision of health care.

B1 (3) 54-55: I knew there was a clinic of some sort there but I didn't know there was an incontinence one there (Brenda, aged 68).

D1 (9) 190-191: No. I had no idea it was even there. And nobody I've spoken to knows. I keep telling my friends about it. No. I didn't know. I thought probably I'd be going to a hospital or something, outpatients or something like that (Dawn, aged 69).

L1 (4) 83-86: I knew that there was a health clinic there. I knew there was a contraception clinic for anyone who needed to go there and that it was based in the centre. But I didn't realise there were other services as well (Lisa, aged 35).

The "hidden" nature of the clinic was closely linked with the lack of advertising. The existence of the different clinics within the "Quay to Health" was advertised by "word of mouth" with the women attending the continence clinic hearing about the service by contact with friends who had attended the centre for other clinics.

G1 (27) 629-632: I didn't actually know there were any clinics there at all until the teacher that I work for, she goes to the coeliac clinic down there and my friend does a clinic down there. So then I did start to know that there are actual clinics going on there (Geraldine, aged 35).

Although some of the women were members of the health club at the centre and used the building on a regular basis they were unaware of the continence clinic. The gym is located immediately next door to the "Quay to Health" with the changing rooms in the same corridor. One of the women felt that people tended to focus on one thing at a time and was not surprised that the clinic could go unnoticed.

C1 (12) 264-267: I have been in this building before a couple of times and didn't notice it though I didn't have any trouble finding it when I did arrive 'cause it's well signposted. It depends what you're looking for doesn't it? (Carol, aged 49).

Users felt that the clinic was poorly advertised and suggested that the first place women would go to seek help would be their GPs surgery. They felt that many more women could benefit from attending the clinic but because it was not publicised widely people were unable to access the service.

G1 (28) 639-644: If they had leaflets in doctors' surgeries and places like that, yes things like that. If it was advertised more widely then obviously people would get to know about it more (Geraldine, aged 35).

E1 (12) 268-274: In doctors' surgeries, definitely because you know, mothers and their babies are in there for the first couple of months with their babies getting checked and injections. All it takes is for a notice to be up on the board to say that this clinic is available and I think that more people would come forward. Because if you've got a health visitor who doesn't mention things like that to you, or you don't talk about it like mine did, then I don't think mothers would know about it (Eve, aged 28).

B2 (9) 204-207: It should be advertised a bit more, perhaps in doctors' surgeries. "Just pop in and see us", or "give us a ring and make an appointment" you know. "Just come and have a chat", not to feel that you're going to a medical thing, "drop in and have a chat with us" (Brenda, aged 68).

Different venues were suggested for advertising and included libraries, women's groups and posters on the back of doors in women's toilets. There was also some awareness that not all GPs may know about the clinic thereby reducing the number of referrals to the service.

J1 (5) 99-100: I think if it was publicised it would be great because it's a brilliant service. But nobody knows about it I don't think (Julie, aged 32).

D1 (22) 511-516,527-528: I suppose it's getting the doctors knowing. Advertising. I mean I don't know how much you advertise like on posters, like the library, you know the place for posters. In women's groups. I suppose it's targeting people. A poster in a doctors' surgery because when I sit there there's posters all round the place. And you're sitting there for ages reading them all over and over. Yes, and some places like *toilets, like in the university or something, in the women's toilets. That would be the ideal place wouldn't it really? (Dawn, aged 69).*

Sub-Category Expectations of Visit

Two of the women who attended the clinic explained that they did not know what to expect from their initial appointment. Although some information is enclosed with their appointment advising them to complete a bladder diary for three days and to bring a urine sample, details of what may happen are not included.

E1 (2) 45-48: I didn't really know what to expect when I went. I wasn't sure what was going to happen and what they were going to do. I was just hoping for someone to give me a cure really. Just like that you know (Eve, aged 28).

G1 (3) 66-68: I didn't really know what to expect the first time. I thought I'd be given exercises to do and basically just find out how bad things were and whether there was anything I could do to improve myself (Geraldine, aged 35).

The need for information about how their incontinence could be managed appeared to be important to the women together with some encouragement to carry out suggested treatments to resolve or alleviate the problem.

B1 (5) 113-114: Bit more advice on how to cope with it really and any more suggestions, anything new that's come along since I went before (Brenda, aged 68).

E1 (3) 61: A little bit of encouragement really to get me going to start doing it. (Eve, aged 28).

C1 (12) 278-282: Well. I don't know really. Presumably some help with the problem I have. Fairly open-minded about what they had to offer as I said last time I'd been looked at it was going to be fairly major surgery and I'd got to a stage where I was prepared to entertain that. So it was a move towards getting whatever was needed to get it sorted out really (Carol, aged 49).

N1 (18) 411-412: I suppose the person I see listens to me and gives me relevant information and encourages me to do whatever I'm supposed to do (Nora, aged 27).

The opportunity to talk to someone who would understand their problem and show some empathy was important to some of the women. Because incontinence can be embarrassing they felt that they needed to talk to someone who would look at them as a whole person and help them with any additional problems they may have.

D1 (6) 134-137, 137-139: I just thought it would be nice to talk to someone about it, you know, someone who was a specialist or whatever. Who would listen, be sympathetic and talk to you as a human being, with all your other problems as a whole person really (Dawn, aged 69).

Women felt that they wanted to resolve their incontinence problem and recognised that it was something that should not normally occur. They were keen to try exercises and bladder retraining before considering surgery and wanted to feel in control of their problem.

L1 (19) 448-450: I wanted to know what was the best way to go about trying to sort it out. I'm not keen on doing anything that requires tablets or intervention if I can manage it for myself (Lisa, aged 35).

H1 (5) 116-117: I wanted the knowledge of how to stop this. I mean it's not, I haven't had it all my life it's not something that should be there (Hilda, aged 89).

The pathways followed by the women through the system were individual and unique to them. The following section explores the sub-category ***Ongoing Pathways through System***.

Sub-Category Ongoing Pathways through System

Of the twelve women who consented to participate in the study two were referred to the Consultant at the hospital for further assessment and treatment. Eight were not referred to other agencies and their incontinence was managed by attending the clinic at the "Quays".

Referrals to the main continence base at Hythe only involved two women who attended an eight-week course of mild electrical stimulation treatment, with one of these women receiving this treatment and also being referred to the consultant. This treatment was unavailable at the "Quays". There was a waiting list for this treatment that could delay the start of it by several weeks. This delay appeared to cause some frustration as many of the women expected to start the programme as soon as they received their first appointment at Hythe.

J2 (3) 71-76: The disappointing thing was I'd been told that it'll take a few weeks to do the TENS [electrical stimulation] treatments in October. I was eventually seen in February thinking that'll be a few weeks, and then it was like, oh well just measure the pelvic floor and make the appointment rather than actually starting the treatment then. I think it was connected to this waiting list thing because I'd been seen. And then it was June I think, anyway it was another few months before I actually got started (Julie, aged 32).

F2 (12) 276-283: What was disappointing on reflection was that it takes an awful long time to actually go down this pathway, call it a care pathway, what you like. You just sort of toddle down it forever and a day and it's almost as if you have to be quite determined to actually progress it. You feel you're kind of on your own, which I suppose to some extent I'm well able to be actively responsible for my health care but I feel like that (Fay, aged 51).

Having been referred on to another health professional for a course of treatment women's expectations appeared to be high, hoping for a complete resolution of their continence problem within a few weeks. Although they accepted that the treatment might not resolve the problem, they appeared to be disappointed when this was not the outcome.

F2 (11) 259-263: I suppose I felt when the "Quays" referred me to Hythe I felt hopeful that it might produce some change. Although I suppose in my heart of hearts I knew actually it wasn't making any difference (Fay, aged 51).

J2 (2) 32-35: I've been having TENS treatments. I've got the last one tomorrow so I'm a bit disappointed that it hasn't really done anything. I think my pelvic floor is better which has helped a little bit, but the bladder hasn't really changed I don't think (Julie, aged 32).

One woman indicated that she had expected to receive a course of treatment at Hythe but was frustrated that she had been given a portable treatment unit to use at home. As she was unsure how to use the unit and did not like using it she had discontinued the programme and felt disappointed that things had not improved.

G2 (1) 15-21: I suppose I was under the false impression that when I went to Hythe lots of things were going to have been done and basically it wasn't. All the things I was told were going to happen didn't and I've been given a machine to do it at home. I've just been left with it and I don't like it. There's nobody to talk to about it so I'm not doing anything at the moment (Geraldine, aged 35).

Some of the referral pathways appeared to be less straightforward than they should have been. Before a referral can be made to a consultant at the main hospital the patient's GP needs to initiate the process. Although one of the women had been advised that she was being referred to the hospital she did not realise that she needed to make an appointment with her GP before the referral could be activated.

C2 (9) 214-225: The "Quays" were going to refer me to the hospital but it had to go back via my GP who got the letter and was then expecting me to make an appointment, and I didn't realise that. I thought he would get the letter and refer me. I then spoke to him on the 'phone and said, "have you heard anything? Has anything happened?" and he said, "well, I'm waiting to see you" and I said, "well what do you want to see me for? "Do you want to be referred then?" well, yes actually. "Oh, I'll do it then". It probably took three months before I thought "that's funny, I haven't heard anything" and 'phoned him (Carol, aged 49).

Whilst their incontinence was being managed at the "Quays" most of the women appeared to be satisfied with their treatment. However, once the management of their condition was passed to another health professional the outcomes appeared less clear. The evaluation of the service at the "Quays" enabled women to reflect on their experience and to describe the change in their condition following attendance at the clinic.

Sub-Category Evaluation of Service

One of the aspects that women appreciated was the opportunity to attend a clinic in an informal setting where they were seen on time and given enough time to discuss their concerns.

Women also felt that they had been given the information they needed to understand their incontinence and to implement the appropriate treatment to resolve the problem. Although some of them had some understanding of their problem before coming to the clinic their coping mechanisms and confidence in their ability to manage their incontinence appeared to improve following visits to the clinic.

*B2 (7) 152-155: I did understand it before but I got better ways of coping with it when I saw you** *[the continence service]. I understood it before, I knew what it was but I felt that I could cope with it better when I spoke to the people at the clinic (Brenda, aged 68).*

*L2 (5) 104-107: I can have some control over it by what I've learnt from the services you've** *[the continence service] provided. I've actually got more confidence whereas before I just felt as if my bladder controlled my life and it was miserable, really quite miserable (Lisa, aged 35).*

J2 (5) 130-135: The most useful thing I've found is that I thought the tablets would be something you either take forever, or you manage without. And what she said was that if I took it for a few months I might be able to bladder train and then not need to take anything, which was quite encouraging (Julie, aged 32).

The women's confidence in the advice they had been given was enhanced by the trust they had in the practitioner who provided the service. They acknowledged that a nurse specialist would know as much as a doctor about the problem and valued the specific appointment dedicated to their incontinence problem.

L2 (6) 135-141: The thing about the "Quays" is the appointment is specifically for the problem and you know that because that's what the service is set up for. You feel almost straight away that you can trust the advice you're being given rather than

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* Some of the women in this study had seen me at the clinic as a continence advisor, but when they referred to 'you' in the text they were referring to the continence service rather than me personally.

having to go and see the GP. I'm not saying the GP wouldn't know but I never really discussed it in great detail with him (Lisa, aged 35).

One woman felt that by attending the clinic she had been able to openly admit that she had a problem, something she had been unable to do before.

J2 (5) 125-127: It helped bringing it out into the open because I hadn't really talked about it apart from with my husband before. And yes just getting some help really, some advice (Julie, aged 32).

Some of the women felt that the support they had received at the clinic had enabled them to monitor the progress of their treatment and feel that their problem was being taken seriously. Women who had asked for help with their problem in the past indicated that their problems had been dismissed as irrelevant causing them to delay seeking help again for several years.

F2 (11) 240-242, 244-246: When I'd been to the GP previously it was almost as if it's a women's problem and "you should have done your exercises when you had your baby" and all this stuff. What was different when I went to the "Quays" and that was nice that it was, I felt, it was taken more seriously and there was some attempt made to test and measure what the problem might be (Fay, aged 51).

L2 (12) 267-273: I think it's been helpful to be able to go at regular intervals and see what's going on because it's helped monitor how effective the treatment has been. I do feel like it's been reviewed very thoroughly and I haven't just been left to it, which is important (Lisa, aged 35).

D2 (3) 54-62: I suppose it's just that someone's interested in my problem. Someone's got the time to listen and be interested and give me advice. It's like having support for what I'm trying to do; its not just "here's a prescription and bye, bye". It's like an ongoing support and talking about how my bladder works that was helpful. And talking about various things that come up like last time the woman I spoke to said this isn't necessarily a problem of old age, which I thought it was (Dawn, aged 69).

One woman had been unable to buy incontinence pads from the supermarket before attending the clinic. Following attending the clinic she felt more optimistic about her improving continence problem and had managed to overcome this psychological hurdle.

F2 (13) 309-319: I mean, I'm selective as to what supermarkets I go to and I buy these things and I get them in the bottom of my basket. I make sure I go to a checkout where there's not a young bloke or a young girl. I look for a middle-aged lady as you assume they will be more sympathetic. And it does, it affects your life. I suppose twelve months ago I couldn't have laughed about it, I suppose I've accepted it more and feel that the problems going to be much better, I feel much better about it (Fay, aged 51).

Only one woman felt that attending a clinic in a leisure centre had been a negative experience. Although she valued the personal contact and the treatment offered she held negative views about the building itself and may have preferred to attend a clinic in a more traditional setting.

K2 (16) 437-439: The actual, the personal contact I'd recommend. But I wouldn't recommend the "Quays" the whole building with all the barriers there, It's not very welcoming (Kate, aged 52).

Overall women appeared to appreciate attending a clinic that enabled them to discuss their incontinence in a friendly and supportive atmosphere. Although some dissatisfaction was expressed at the service provided following referral on to other services, the "Quays" as a setting appeared to be acceptable with only two of the interviewees preferring to attend a clinic in a more traditional setting. The time allowed for consultations facilitated the exploration of the problem in a sensitive and caring way and the ongoing support and monitoring of their condition appeared to enhance both their knowledge of their problem and their coping skills.

Of the thirteen women who consented to participate in the study five indicated that they felt their incontinence had either completely resolved or improved to a degree whereby they could tolerate their symptoms. Data were incomplete from one woman who had died from an unrelated condition and six indicated that their symptoms had either not improved or had worsened. Three of the interviewees had been referred on to a Consultant Urogynaecologist for surgical intervention. One had been referred back to her GP for management of her urinary tract infections and two had been referred to the main continence service base at Hythe for electrical stimulation treatment.

Outcomes: Interview and Questionnaire Data

Complementary data providing some element of a framework used particularly with the second interviews involved two incontinence impact questionnaires and frequency/volume charts. These were used to facilitate exploration of incontinence impact on women's lives during the interviews and with the frequency/volume charts to provide an objective clinical measure of their voiding patterns. The "Incontinence Impact Questionnaire-Short Form" (IIQ-SF) developed and validated by Uebersax *et al* (1995) and the "International Consultation on Incontinence Questionnaire-Short Form" (ICIQ-SF) (Donovan *et al* 2001) were sent to women prior to their initial appointment, together with a frequency/volume chart (bladder diary). These measures were repeated six to twelve months later.

The data have been presented in four tables that indicate the type of incontinence suffered by each interviewee together with their scores out of a possible 21(highest impact) for both incontinence impact questionnaires. The four categories of incontinence described in the tables include Stress (4 women), urge (3), mixed stress and urge (4) and neuropathic (1). Where frequency/volume charts were completed the results have been included and a summary at the end of each table discusses the findings in relation to the reported incontinence impact and the difference in the two scores six to twelve months later. The results are discussed for each of the women.

Stress Incontinence

The difference between the 1st and 2nd incontinence impact questionnaires for Eve appeared to indicate that the impact of incontinence on her daily activities had reduced following attendance at the "Quays". It was interesting to note that the 2nd ICIQ-SF score had only reduced from 11 to 9 even though she reported leaking urine on an infrequent basis and considered her incontinence resolved. The score for impact on interference with everyday life remained the same at 5 on both questionnaires suggesting that although she felt her incontinence had resolved it was still having an impact on her everyday life.

Table 7 Stress Incontinence Questionnaire Data (including frequency/volume charts where available)

Maximum Scores of the IIQ-SF and ICIQ-SF = 21

Frequency/Volume Charts are not scored

	1st IIQ	1st ICIQ	2nd IIQ	2nd ICIQ	1st Frequency/ Volume	2nd Frequency/ Volume
Eve (aged 28)	11	11	1	9	Not Available	Not Available
Dawn (aged 69)	0	0	0	1	8-10 voids daily, 50-300mls.	5-6 voids daily, 150-500mls.
Geraldine (aged 35)	2	8	4	9	20 voids daily, 25-400mls.	6-9 voids daily, 200-700mls.
Nora (aged 27)	6	13	1	8	5 voids daily, 150-400mls.	Not Available

Dawn had scored 0 on the 1st questionnaires and scored 1 on the 2nd ICIQ-SF as she continued to leak urine when jumping around indicating that incontinence had little if any impact on her life. She had followed a pelvic floor exercise programme supervised by the "Quays" and had increased her fluid intake, reflected in her improved bladder capacity and reduction in the number of times she needed to pass urine daily. Following attendance at the "Quays" she indicated that her incontinence problem had been resolved, and by avoiding vigorous exercise on a full bladder was able to control her symptoms.

Geraldine's scores on both the questionnaires had increased with her bladder problems having a greater impact on her everyday life over time. Her frequency/volume charts indicated a reduction in the number of times daily she needed to pass urine together with an improvement in the volume of urine passed. However these improvements were not reflected in the questionnaire scores. When I discussed the scores with Geraldine she indicated that she was feeling "fed up" with her incontinence and this was reflected in the scores. Her fluid intake exceeded four and a half litres daily and comprised of water and juice with only 150-300mls of caffeine daily. Having followed the advice given at the "Quays" she reduced her fluid intake to two and a half litres daily thereby reducing the number of voids to six to nine daily.

Although initially she had experienced problems with urine leakage only when exercising, her worsening symptoms affected travel away from home and feelings of frustration. Following attendance at the "Quays" a rectocele (bulging of the rectum into the vagina) was found and referral to the consultant at the hospital was made. It is unlikely that the impact of incontinence on Geraldine's life will improve until she has had surgery to correct the rectocele.

The difference between the 1st and 2nd questionnaires for Nora indicated that her incontinence was having less of an impact on her everyday life. She felt that incontinence had no impact on her travelling, going to a movie or household chores but felt an impact on her emotional health and feeling frustrated. The score on the 1st ICIQ-SF for interfering with everyday life was 7 and this had reduced to 2 on the 2nd questionnaire. Although she was still leaking urine several times a day she indicated that she felt that her symptoms were improving and she continued to receive support from the "Quays".

Of the four interviewees who had stress incontinence two had felt that their incontinence was resolved following attendance at the "Quays", one had experienced deterioration in symptoms and one felt that things were improving. The scores for both questionnaires indicate the impact on quality of life on women with stress incontinence, with those experiencing worsening symptoms scoring higher in the areas of impact on interference with daily life and emotional health and frustration.

Neuropathic Incontinence

Table 8 Neuropathic Incontinence Questionnaire Data (including frequency/volume charts where available)

Maximum scores of the IIQ-SF and ICIQ-SF = 21

Frequency/volume charts are not scored

	1st IIQ	1st ICIQ	2nd IIQ	2nd ICIQ	1st Frequency/ Volume Chart	2nd Frequency/ Volume Chart
Kate (aged 52)	20	19	21	20	Not Available	Not Available

Kate had been unable to complete a frequency/volume chart as she had a disability that affected her movement. Her urine leakage appeared to be having a significant impact on all aspects of her daily life, something that did not improve over a one- year period. She leaked urine several times a day and needed to wear incontinence pads to protect her clothing from urine. She scored 9 on the 1st ICIQ-SF for interference with daily life and 10 (the maximum) on the 2nd questionnaire. She had received a diagnosis of a neuropathic bladder following urodynamic investigation and was awaiting surgery to try to improve her problem. As a direct impact of her problems with manual dexterity and obesity she was unable to self-catheterise and until her surgery is completed (and if successful) the impact of her incontinence on her life may remain severe.

Urge Incontinence

Table 9 Urge Incontinence Questionnaire Data (including frequency/volume charts where available)

Maximum scores of the IIQ and ICIQ = 21

Frequency/volume charts are not scored

	1st IIQ	1st ICIQ	2nd IIQ	2nd ICIQ	1st Frequency/ Volume Charts	2nd Frequency/ Volume Charts
Brenda (aged 68)	9	9	7	7	6-9 voids daily, 50-300mls	6 voids daily, 150-400mls
Julie (aged 32)	4	7	7	9	7-12 voids daily, 80-300mls	7-10 voids daily, 20-400mls
Lisa (aged 35)	9	13	6	16	9-10 voids daily, 150-450mls	Not Available

The difference between the 1st and 2nd questionnaires for Brenda indicated an improvement in the impact of incontinence on her everyday life. Although her incontinence remained unpredictable following attendance at the "Quays" she had tried bladder retraining and pelvic floor exercises, moving on to prescribed medication from her GP that appeared to have improved her symptoms and reduced the impact of her incontinence. Her 1st frequency/volume chart indicated that she was passing 50-300mls of urine 6-9 times daily, but following the treatment she was passing urine 6 times a day and passing 150-400mls (an improvement). The minimum and maximum volumes of urine passed daily indicate an improvement together with the frequency of voids reduced to six a day.

The scores for both questionnaires had increased for Julie reflecting her lack of improvement in the symptoms she was experiencing. Her 1st questionnaires indicated a slight impact on travelling, going to a movie or leaving the house with urine leakage two or three times a week. Although the degree of impact of her incontinence had not increased by the 2nd questionnaires she had become more frustrated and the urine leakage had increased to several times a day. She had received an eight-week course of electrical stimulation treatment and had also tried several different tablets to reduce the irritability of her bladder, without a significant effect. The frequency/volume charts indicated that she was passing urine 7-12 times a day and passing 20-400mls, there appeared to be no improvement in the number of times she passed urine daily or the volume of urine passed. The incontinence impact questionnaires and the frequency/volume charts appeared to reflect the lack of improvement in her symptoms over a one-year period, with the frustration expressed by an increase in the scores. It is unlikely that surgery will improve the symptoms experienced by Julie and until different drugs have been developed that may reduce her bladder irritability she may have to continue to manage her incontinence. The indications suggest that Julie may have to tolerate her incontinence until new treatments have been developed and this may continue to have an adverse impact on her quality of life.

Although the IIQ scores for Lisa improved from 9 in the 1st questionnaire to 6 in the 2nd the ICIQ-SF scores increased from 13 in the 1st to 16 in the 2nd. Her incontinence had a moderate impact on travelling, going to a movie and social activities with a slight impact on emotional health. The impact of interference on everyday life scored 10 in the 1st ICIQ-SF but had fallen to 3 by the 2nd questionnaire. The increased ICIQ-SF score overall appears to be misleading as Lisa indicated in the 2nd interview that following advice on fluid intake, bladder retraining and the use of medication to reduce the urge to pass urine her symptoms had improved. The 1st frequency/volume chart indicated that she was passing urine frequently (9-10 times daily) with the amount passed from 150-450mls. Her fluid intake included approximately five mugs of coffee each day with only a litre of water daily. She had been unable to complete a 2nd frequency/volume chart as hospital appointments and holidays away from home took up most of her time. Lisa had reduced her caffeine intake to one mug of coffee daily and had managed to increase her water intake to two and a half litres daily. The objective measure of the frequency/volume chart would have demonstrated any improvement in her incontinence. However, by discussing her symptoms at the 2nd interview I was able to clarify with Lisa that the number of voids had reduced to six a day, although the volume of urine passed was not known. The value of a 2nd frequency/volume chart when assessing any change over time in symptoms is that an objective measure of incontinence is available that may differ from the perceived symptoms experienced by sufferers.

Of the three women who had urge incontinence two had noticed an improvement in their symptoms and impact on their daily lives, with one indicating she had not improved.

Mixed Stress and Urge Incontinence

Table10: Mixed Stress and Urge Incontinence Questionnaire Data (including frequency/volume charts where available

Maximum scores of the IIQ-SF and ICIQ-SF = 21

Frequency/volume charts are not scored

	1st IIQ	1st ICIQ	2nd IIQ	2nd ICIQ	1st Frequency/ Volume Charts	2nd Frequency/ Volume Charts
Fay (aged 51)	9	14	8	17	4-6 voids daily, 200-650mls	4 voids daily, 250-500mls
Carol (aged 49)	5	9	8	14	Not Available	7-9 voids daily, 30-400mls
Hilda (aged 89)	2	6	N/A	N/A	6-8 voids daily, 150-500mls	Not Available
Mary (aged 82)	12	11	11	12	6-8 voids daily, 50-200mls	Not Available

The difference between the 1st and 2nd questionnaires for Fay indicated that the incontinence impact had reduced from 9 to 8 in the IIQ-SF but had increased from 14 to 17 with the ICIQ-SF. The 1st questionnaires showed a greater impact on social activities and exercise and a high level of frustration. She was leaking urine several times a day and this was interfering with her life. The 2nd questionnaires showed a reduced impact on social activities but the ICIQ-SF indicated a greater impact on everyday life. The frequency/volume charts remained similar with 4-6 voids daily of 200-650mls. She had suffered from stress incontinence for 23 years and urge incontinence for 9-10 years. The frustration and impact of incontinence on her everyday life were described in the interviews with the impact questionnaires used as a discussion tool. They appeared to reflect the frustration and adverse impact incontinence was having on her life and this may not improve until she receives surgical treatment for a small anterior vaginal prolapse.

The difference between the 1st and 2nd questionnaires for Carol indicated that the impact of her incontinence on her everyday life had not improved. She had to wear an incontinence pad all the time and was leaking urine when walking, jumping, coughing or sailing. Her caffeine intake was high having 8-10 mugs of coffee daily and although she was trying to reduce this she was finding it difficult. She had been referred by the "Quays" for urodynamic tests to the hospital and was waiting to have surgery. Only one frequency/volume chart was available and this showed that she was passing urine 7-9 times daily and passing 30-400mls. She felt that the reason the scores were higher on the 2nd questionnaires was that she was getting fed up with being incontinent and this was reflected in the scores.

Only the 1st questionnaires and one frequency/volume chart were available for Hilda, as she died six months after first attending the "Quays" (in unrelated circumstances). She leaked a small amount of urine once daily and felt that it did not really interfere with her everyday life. She had experienced only a slight impact on her life when going to a movie or travelling by car and had started pelvic floor exercises and bladder retraining following her appointment at the "Quays". Although the incontinence impact questionnaires indicated that her incontinence had little impact on her everyday life she appeared to have identified incontinence as a problem, something that she wanted to address. The frequency/volume chart indicated that she passed urine 6-8 times daily, between 150-500mls but also indicated that she had nocturia 2-3 times a night that may have disrupted her sleep. The incontinence impact questionnaires focus on activities that occur during the day, so sleep disruption is not included in the questions.

There was little difference between the scores of the 1st and 2nd questionnaires for Mary who scored 12 in the 1st IIQ-SF and 11 in the 1st ICIQ-SF. In the 2nd questionnaires she scored 11 in the IIQ-SF and 12 in the ICIQ-SF. She felt that incontinence had a slight impact on household chores, going to a movie and the ability to travel and a moderate impact on social activities, walking and emotional health. She was very frustrated and felt that she leaked urine all the time. The main difference between the first and second questionnaires was the reported impact on her emotional health with feeling frustrated and an interference impact score increasing to 5 (out of 10). Mary had suffered from recurrent urinary tract infections over a long period and was becoming fed up with taking antibiotics that did not appear to work. Although she had attended the clinic at the "Quays" she had found it difficult to increase her fluid intake and to carry out pelvic floor exercises. The questionnaires appeared to reflect her frustration with the impact incontinence was having on her life and following further discussion with Mary following the interview I suggested she go back to the continence advisor as I was concerned about her emotional symptoms.

Of the four women with mixed stress and urge incontinence, the incontinence impact scores suggested that the impact on their daily lives was greater than those with stress incontinence. Two of the women were waiting for surgery, one had died from an unrelated condition, and one had deterioration in her mental health.

Conclusions

All the women in this study appeared to have had some difficulty finding out about the clinic. By talking to friends and colleagues some of them were aware that other clinics were being held in the building but many did not realise that these included a continence clinic. If their own GP was aware of the service then they were likely to be referred, but if the GP was unaware of the clinic then a referral was not made from that source.

Although the clinic is advertised on the back of the information leaflet about the leisure centre none of the women had noticed the advertisement. Information about the clinic needs to be displayed within the leisure centre itself and circulated to health centres and GP practices. All the women indicated that they would like to see the clinic advertised on posters in GP surgeries and also suggested some additional venues where information could be circulated. Leaflets and posters could be displayed in libraries and on the back of toilet doors both in GP surgeries and in public toilets. To obtain a balance between encouraging people with embarrassing conditions like incontinence to seek help and maintaining a level of service is a difficult issue. However, if the demand for the service increased then the Primary Care Trust responsible for that area would need to review and increase the level of service provision offered to meet that need.

Many women had tolerated their problem for several years before seeking help and whilst they were able to manage their incontinence by emptying their bladder frequently, restricting fluid intake and wearing protective pads they coped without help. The prompts to seek help for their incontinence included a worsening of their symptoms and unpredictability of their bladder behaviour. One woman had waited 25 years before seeking help and five had asked for help 10-15 years ago and then managed the problem until the symptoms had become apparent to others and increasingly embarrassing to the women themselves. Personalised continence management strategies were important for many of the women whereby they carried spare incontinence pads or sanitary towels with them when they left the house, planning shopping trips around the location of toilets and trying to minimise the impact of their incontinence with these measures. These strategies enabled women to cope with their incontinence and to normalise these routines, incorporating them into their everyday activities. However, if their incontinence became unpredictable and visible then these strategies had little impact, prompting them to seek help for their problem.

The main impact of incontinence on the women appeared to be the embarrassment they felt about the problem. It could restrict their ability to continue to do the things they enjoyed and the leakage of urine necessitated the use of incontinence pads and frequent changes of clothing. Some of the women felt that they smelled of urine and appeared reluctant to discuss their problem with their partners.

Women who enjoyed dancing and tennis described how they needed to "pad up" before starting the activity and how they had to change their underclothes at frequent intervals during the activity. This may have been embarrassing for them as others could question why they needed to "disappear" so frequently.

The pathways that women followed to reach the clinic included referrals from Practice Nurses, Health Visitors, GPs, Consultants and via friends and an NHS Walk-In Centre. The opportunity for women to be referred appeared to depend upon which health professional they had contacted as some were unaware of the clinic and were unable to offer advice. The walk-in centre had information about continence clinics across the area and was able to offer a choice of clinic venue to incontinence sufferers. However, some GP surgeries appeared to be unaware of the clinic and referred women to the practice nurse or district nurse for advice and treatment. Although this may have been appropriate for the initial conservative management of incontinence unless the nurses recognised when referral on to a continence advisor or back to the GP was necessary women could be offered inappropriate advice for their problem. This could affect how women felt about their incontinence and may mean that they are not able to resolve the problem until they seek help from an alternative source at a later date. To reach the clinic two of the women had been referred by health professionals who had identified their incontinence problem. The remaining ten women had approached health professionals and requested help for their problem, taking responsibility for their own health and the management of their problem.

A majority of the group were unclear about what to expect from the clinic prior to their first appointment but their overriding needs were for more information about incontinence, support and encouragement from someone who would understand their problem and treatment that would enable them to resolve the problem. Some women were unsure about what to expect from the clinic but felt more confident following their initial appointment about what would happen in the future.

Some of the women needed to be referred to other health professionals for more specialist treatment. The pathways through the system once women had left the "Quays" could be time-consuming and frustrating with long waiting lists for electrical stimulation treatment carried out at the main continence base at Hythe (located 12 miles from the centre of Southampton). Women were disappointed that the treatment did not commence at their initial appointment at Hythe as the delay in commencing the eight-week programme could mean that treatment lasted for several months. Some women were referred to the consultant at the main hospital if surgery was indicated and this could mean a delay of several months in the resolution of their problem. For the referral to be activated the Continence Advisor writes to the patient's GP requesting a referral. In one example presented here the GP then expected the woman to make an appointment to see him/her to request the referral before it was activated. This would appear to be an unnecessary step in the overall referral process and in this case was the cause of further delay on the individual who waited for a few months before discovering that the referral had not been passed through the system. With plans to move towards a more integrated continence service this problem should be rectified. Locally within the Southampton area continence advisors and physiotherapists are conducting joint clinics and assessments, with plans to prioritise all continence referrals through the continence advisors. In future if a woman presents with a continence problem at the GPs surgery the referral would be passed to the Continence Advisor who would decide whether the woman could be managed within primary care or whether referral to a consultant was necessary. Although this system could provide an improved service to incontinence sufferers, speeding up the time taken to reach the appropriate health professional some GPs may not be willing to pass the initial assessment to other health professionals.

The incontinence impact questionnaires may be useful as a quick and simple tool to enable incontinence sufferers to reflect on the impact incontinence has on their daily lives. They were used in this study to provide data on incontinence impact for each individual and changes over time and were a useful discussion tool during the interviews. The two questionnaires look at different aspects of incontinence impact, with the IIQ-SF focusing more on impact on specific individual activities such as walking, going to a film and travelling away from home. The ICIQ-SF focuses on when and how often urine leaks with a single impact score for interference with all aspects of everyday life. In some cases the scores from the questionnaires were higher the second time. Although this should indicate that the impact of incontinence on women's lives was greater, with perhaps deterioration in symptoms this did not appear to always be the case. Having the opportunity to discuss the questionnaires with the interviewees permitted further exploration with them how they felt about their incontinence, the impact of the treatment they had received, and why they thought the scores might have been higher with the second questionnaires. The interviewees felt that the responses given to the questionnaires would vary depending on when they were completed. This was because they felt that their incontinence could vary in its severity from one day to the next, together with how they were coping with their problem on that particular day. If the interviewees were feeling fed up with their incontinence, or they failed to see any improvement in symptoms then they indicated that they would score higher than if they were having a good day and things appeared to be improving. This is clearly an important issue for the sensitivity of the instruments in detecting real change.

The frequency/volume charts were sent out with the initial appointment for the “Quays” and are routinely used in continence clinics to provide a picture of the frequency someone is passing urine, the volume of urine passed and whether they leak urine. In this study a second chart was sent by post to the interviewees six months to one year after their first appointment. However only five of the interviewees completed both charts five others completed the initial chart only and two failed to complete either chart. Where both charts were completed they provided an objective measure of incontinence and demonstrated whether there had been any improvement in the women’s symptoms. It was interesting to note that where the interviewees felt their incontinence had worsened or not improved this was reflected in their charts. However for one woman although the frequency/volume charts reflected an improvement in her symptoms she felt that there was no improvement. It was perhaps because her expectations of what was going to happen with her incontinence had changed as a result of seeking help and she expected the problem to be resolved. When she found that her incontinence had not been resolved she appeared to be disappointed and frustrated at the lack of progress she had identified.

Although women welcomed the opportunity to evaluate the clinic, if they felt they had received the help and advice needed to enable them to cope with their incontinence or to regain continence they gave positive feedback about the clinic consultation and quality of perceived service. However those women who experienced worsening symptoms or little improvement in their continence problem were more critical of the service offered following referral from the “Quays” to other services or treatments. The information they had received at the clinic afforded them an improved understanding of how their bladder worked and helped them to understand what was happening to their bodies. The ongoing support offered by a knowledgeable health professional who understood problems of incontinence and responded to them appropriately was welcomed by all, with many women feeling that without that support they would not have been able to continue with treatment programmes and improve their continence. Some women indicated that during the clinic consultation they felt that it was the first time that their problem had been taken seriously and examination and tests carried out to identify exactly what the problem was. The time allowed for an initial appointment was one hour and this was appreciated by the users as they felt that they had been given enough time to discuss their concerns without feeling pressured or guilty that someone else was waiting for them to finish. The relaxed and informal atmosphere of the "Quays" appeared to be a popular location for a clinic with easy access and the anonymity of a leisure centre.

Key Points Identified in this Chapter

- As long as the women in this study were able to manage and conceal their incontinence from others they were able to tolerate the problem. The impact on their social lives and personal relationships could be limiting with some social isolation experienced.
- The main prompts to help seeking involved a worsening of their symptoms, often with their incontinence becoming unpredictable and difficult to manage. A cumulative effect from a combination of these symptoms could indicate the "last straw" and this prompted them to seek help.
- The pathways to the clinic and through the system need to be simplified as women could experience delays of several months in the instigation of treatment or assessment by a Urogynaecologist.
- What women wanted from the clinic consultation included empathy, understanding and a resolution of their continence problem.
- Women were keen to try conservative methods of treating their incontinence before embarking on referral to a Urogynaecologist and the prospect of surgery.
- The incontinence impact questionnaires were quick to complete and reflected the perceived impact of incontinence on their quality of life on that particular day. As all the women indicated their symptoms could vary from one day to the next, the scores could vary and were influenced by both their incontinence symptoms and how they were coping on that day.

- The frequency/volume charts provided an objective measure of incontinence and where a second was completed provided an accurate voiding picture over time. However, women appeared to be reluctant to complete a second chart, as measuring and recording urine output can be inconvenient, interfering with activities outside the house.

CHAPTER FIVE

Discussion of Findings

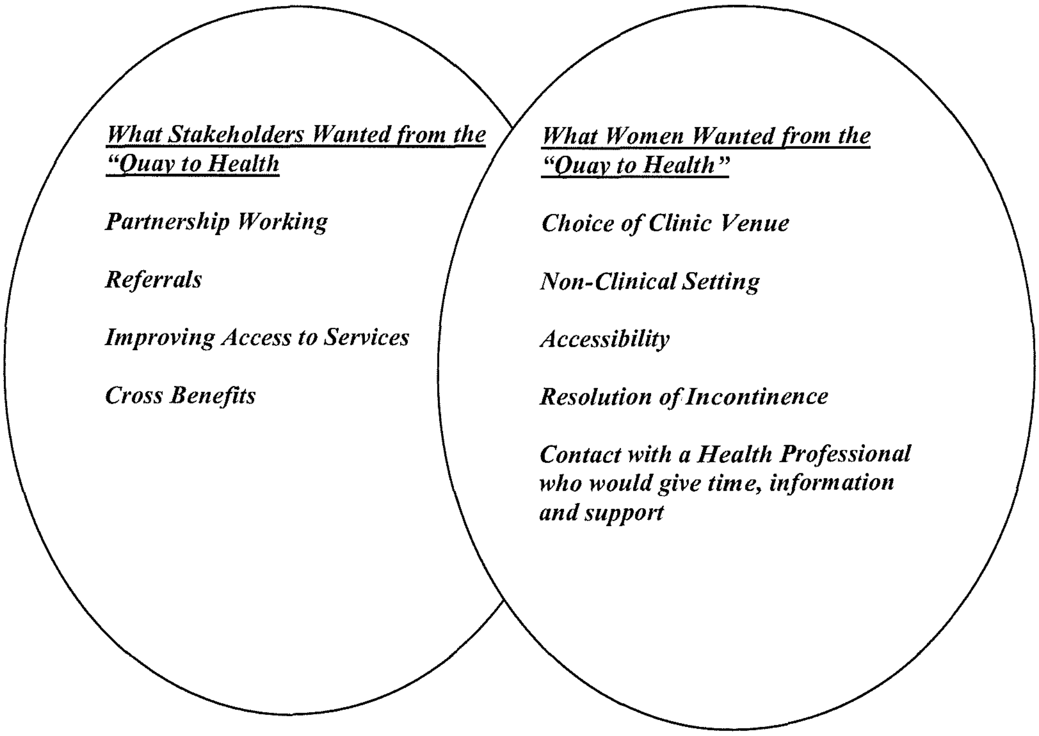
Theoretical Observations

This study was not designed to promote the development of new theories relating to the experience of incontinence and continence care but to elicit the experiences of stakeholders and women of the continence clinic held at the "Quays". Theory development was not a specific aim of the study that identified implications of locating a continence clinic in a non-clinical setting with recommendations for future practice.

This chapter discusses the outcomes of the study under three main headings:

1. ***What Stakeholders wanted from the "Quay to Health"***
2. ***What Women wanted from the Continence Clinic***
3. ***How well the clinic is working from both the stakeholders and users perspective.***

Diagram 3: What Stakeholders and Women wanted from the "Quay to Health"



What Stakeholders wanted from the "Quay to Health"

Partnership Working

The stakeholders involved with the "Quay to Health" shared a common aim of partnership working influenced by government initiatives to encourage agencies and communities to work together (Department of Health 1997,1998a,1999a). They were aware that the concept of health and leisure working together in the same building was unique with only two other centres in London offering a similar facility (Peckham Pulse, Bromley by Bow). When the project was in the early planning stages and during the process of applying for lottery funding the PCT had not been involved and joined the project when the building was nearing completion. This appears to have had a significant impact on some aspects of partnership working especially between the PCT managers and leisure managers who would have preferred a partnership agreement between the two agencies rather than a commercial lease held by the PCT. The city council were accountable to both the government and to the lottery funding for the success of the venture whereas the PCT although accountable to government, held no accountability to the lottery funding agency.

Both groups of stakeholders were keen to be seen to be working in partnership, but some tensions between the different service providers emerged relating to organisational structures and accountability. If the PCT had been involved in the planning of the leisure facility from the outset, there may have been an opportunity for the development of shared common goals, with new accountability structures that would have enabled health and leisure services professionals to collaborate more efficiently to provide appropriate services for users. Threats to partnership working have been identified in studies by Kanter (1994) and Huxham (1996) who found that differences in cultures, goals and agendas could lead to problems in understanding one another, impacting on the partnership.

Referrals

The practitioners who were directly involved with delivering the services both within the leisure sector and the "Quay to Health" suggested that there could be problems when referring people between different services. Referrals between health practitioners at the "Quay to Health" appeared to work well with referrals to the continence clinic from the contraceptive and sexual health clinic and stoma clinic occurring on a regular basis. Referrals to the leisure services from the continence clinic under the "Active Options" programme were straightforward, with a verbal request for input. However, referrals from the leisure services to health could be problematic with direct referrals to the physiotherapist or dietician requiring a GP to complete the referral. This appeared to be inequitable and could diminish the positive attitude to partnership working fostered between the different groups of practitioners.

The Physiotherapy service together with the fitness centre could provide some excellent opportunities for joint working with sports injuries directed to the Physiotherapists and exercise programmes to the fitness centre. The Physiotherapy and Dietetics services are currently no longer based at the "Quay to Health" reflecting the dynamic and changing nature of the service, although negotiations are ongoing to reinstate the services. To facilitate smoother referrals between agencies at the "Quay to Health" joint training, encouraging the recognition of roles and the building of trust between practitioners may assist this process. An early evaluation of the partnership at the Quays suggested that this would lead to an understanding of different roles and enable staff to share the principles on which the centre was operating. A further recommendation was made to improve referral away from depending on the goodwill of staff towards improved procedures (Speller 1999). Following this report little appears to have changed with referrals initiated on an informal basis and joint training occurring once or twice a year.

Working in partnership presents many challenges to all the stakeholders involved with tensions apparent relating to who is driving the "Quay to Health" forwards. A joint steering committee used to meet on a regular basis, but the frequency of meetings appears to have reduced. There appears to be a real enthusiasm among the stakeholders to work together to provide health and leisure services in the same location, to promote better health but pressures exist to meet targets. These pressures may result in health and leisure focussing on their core functions rather than seeing partnership working as a core function. A study by Charlesworth (2001) suggested that paradoxically although government policy is encouraging partnerships between statutory and voluntary agencies the pace of change and the need to meet targets may be counterproductive to partnership working.

Although the "Quay to Health" was seen by stakeholders as an integral part of the leisure centre there were concerns from some stakeholders that the health element of the package could be seen as a "bolt on" to the main leisure centre rather than part of a health promoting environment. These concerns may have arisen from the late arrival of health to the development of the centre, and the lack of planning that went into the type of health services offered. Impressions gained from discussions with stakeholders were that elements of the partnership at the "Quays" worked well with stakeholders viewing the complex as a "first step" towards increased partnership working across the city. The stakeholders appeared to be cognisant with the problems associated with working in partnership and committed to continuing to work with other statutory and voluntary agencies. For services to continue to develop stakeholders will need to work together to formulate shared aims and objectives, with a clear plan of how they propose to deliver agreed targets.

Improving Access to Services

Stakeholders also identified improving access to services for groups that were less likely to access health services in traditional settings. They expected more young people and those from ethnic minorities to access health services within the "Quay to Health" partly due to its location and the non-clinical setting. In an evaluation of "The Quays Partnership" by Partington (2001) 48% of 498 users of the "Quay to Health" were aged between 18 and 34. The sample was identified from all users of the "Quays" and the "Quay to Health" over a two-week period who completed a questionnaire. However, the number of users from black and ethnic populations was only 9% and appears low considering the overall population in the area; two of the city centre wards have a combined black and ethnic population of 37.1%. The continence clinic appeared to attract a younger population although no figures were available for the age distribution of those attending the clinic. The number of people from ethnic minorities attending the clinic appeared to be of the order of five per annum suggesting that the continence clinic was no more successful than the other clinics at the "Quay to Health" in attracting people from ethnic minorities. These figures were suggested by the Continence Advisor at the clinic as no figures were available to confirm this finding.

Stakeholders had also indicated an expectation that the relaxed and informal environment of the "Quay to Health" would enable potential users of services to feel more comfortable in accessing health services such as continence care in the leisure centre environment. There appears to be no literature exploring this issue in relation to continence services, but the women in this study recognised and valued the anonymity of attending a clinic in this setting. They acknowledged that as incontinence is an embarrassing condition, by locating the clinic in this setting they could be visiting the gym or going for a swim and nobody would know they were actually attending the continence clinic. The stakeholders had described continence clinics, stoma clinics, and services for people with drug dependence and mental health problems as "stigmatised" services. This implies a negative attitude by stakeholders who appeared to reinforce the misconception that incontinence is something to be ashamed about. They appeared to be selective about the services provided at the "Quay to Health" and reluctant to provide services to other groups as they felt this might have a negative impact on the other users of the leisure centre. Some tensions appeared to exist between running the leisure centre as a business and opening up the "Quay to Health" to people with drug dependence or mental health problems.

A number of studies have looked at acceptability of continence clinics in other settings to women. For example, a study by Harrison and Memel (1994) looked at whether the management of urinary incontinence could be undertaken in a health promotion clinic within general practice. Findings indicated that of 167 women identified as suffering from incontinence offered an appointment at a clinic only 13 attended. Attempts to enable the clinic to be more user friendly had included the use of women staff and flexible appointments, with the option of a home visit. They suggested that there might be a psychological problem for people in admitting that incontinence is a problem and seeking help. However, they did not explore why the remaining 154 women with incontinence had not taken the opportunity to receive help, suggesting that they may have spontaneously improved. Whilst some of the women may have improved it seems unlikely that they all did. It was not known how much of a problem the women perceived it to be suggesting that minimal improvement in their symptoms may have been enough to prevent them from seeking additional help. They indicated that although urinary incontinence could be managed successfully in general practice, it could probably be better managed within other women's health clinics rather than in a clinic dedicated to continence management.

When providing services for people with incontinence it would seem appropriate to ascertain why the offer of an appointment had been declined or ignored.

Although some women may have experienced an improvement in their symptoms, they may have opted out of the system because they felt embarrassed about having to ask for help, or admitting that they need further advice and support. If women had been dissatisfied with the service received then they may choose to withdraw from the system rather than complain. However, in practice it is often difficult to obtain this type of information if women choose not to attend.

Cross Benefits

Stakeholders and users indicated that the "Quay to Health" and the leisure centre aim to provide a total health package with physical activity influencing the sense of well being experienced by service users. Stakeholders indicated that they felt that people using the "Quay to Health" would be more likely to use the gym or the swimming pool at the centre, as they would notice the activities and be motivated to participate. Evaluations of the services provided at the "Quay to Health" (Partington 2001) have indicated that some of the participants (numbers not stated) felt that the location of the "Quay to Health" in a leisure centre had increased their levels of physical activity. However, it appeared that although a few of the women who attended the continence clinic also used the leisure facilities the majority focused on their appointment alone and did not use any of the other facilities.

In view of the lack of physical exercise undertaken by adults in the UK and the rising obesity and associated morbidity there will be continuing encouragement by the government for people to increase their levels of activity and to adopt a more direct role in the management of their own health (Department of Health 2004). It would seem ideal to locate health facilities within leisure centres to encourage people to consider their own health and fitness as a total package rather than seeing health care as a separate issue. When visiting the "Quay to Health" advice can be given to actively promote healthier lifestyles that may be easier for people to adopt if they are currently attending another activity in the leisure centre. Nevertheless it may be necessary to use more pro-active strategies to encourage such interaction and take up of opportunities provided.

The integration of health and leisure facilities has been widely supported by the current government with the promotion of healthy living centres (Department of Health 1998b). These centres are a high profile example of how money from the "New

Opportunities Fund" has been invested in deprived areas to address health inequalities. The missing element from the centres appears to be a paucity of published evaluations making the effectiveness of the centres difficult to ascertain. The use of qualitative evaluations with different criteria for measuring the success of a project may have to be developed as these centres involve small groups of people in distinct geographical areas. The effectiveness of a healthy living centre may encompass all aspects of persons' well being including mental and physical health, self-esteem and quality of life, so evaluations that focus on certain measurable elements may not reflect the success of the project. The evaluations of the "Quays" (Farebrother and Partington 2000, Partington 2001) have shown that only 22% of health service users were also using leisure facilities during their visit, although 82% of the "Quay to Health" users who had not used leisure services on that day intended to do so at their next visit to the "Quays". The responses to these evaluations may indicate that people responded in a way they thought was expected rather than admitting they would not use a leisure facility at a future visit. These evaluations indicate that the findings from this study would appear to be similar with clinic users intending to do something about their levels of physical activity, but contemplating change to behaviour rather than actually taking action.

What women wanted from the "Quay to Health"

Choice of Clinic Venue

Women wanted a choice of clinic venue to enable them to receive advice and treatment in a setting that was suited to their individual needs. Some of the women had not attended a continence clinic before so although they may have visited a clinic in a GP's surgery or hospital setting a continence clinic was a new experience for them. It may be difficult for people to request an appointment in a different setting as they may not automatically be offered a choice of clinic venue and may be too embarrassed to ask for something different. Patient choice has become the new focus of the NHS with people being given the power to make decisions about their health care. A recent public consultation by the Department of Health (2003) developed a statement (Patient Experience Definition) that will be used in the future as a measure of quality of care. The statement is as follows: "We want an NHS that meets not only our physical needs but emotional ones too. This means getting good treatment in a comfortable, caring, and safe environment, delivered in a calm reassuring way. Having information to make choices, to feel confident, and to feel in control. Being talked to and listened to as an equal. Being treated with honesty and dignity." The consultation included over 110,000 people including nurses and nursing organizations and asked people to identify the changes they would like to see in the NHS and the type of patient experience they would like to have. However, how patient experiences will be assessed according to the statement is far from clear, perhaps consigning it to the realms of a mission statement.

Other initiatives that may impact on patient choice about the choice of clinic include the recommendations of the guidance document "Good Practice in Continence Services" (2000a). Within the good practice guidance the first level of contact is seen as primary care with incontinence sufferers being assessed at that level and only referred on to a Continence Advisor or for more specialist treatment and investigation following this. However, Thomas (2003) found in a national survey of continence services that GPs tend to refer all continence problems to the Continence Advisory Service rather than carrying out an initial assessment or referring them to another health professional within the Primary Health Care Team. This can overload the Continence Advisory Service and result in the patient encountering referral back to the Primary Health Care Team, with additional appointments and a delay in obtaining help. Clinic services may be offered in hospital environments where the Consultant and Physiotherapists are based rather than in places with more relaxed and accessible environments like leisure centres.

Non-Clinical Setting

The majority of women in this study preferred to attend a continence clinic in a non-clinical setting. This may be because many women see incontinence as a "nuisance" and something that has to be tolerated rather than a legitimized medical condition. Because incontinence may not be seen as an illness, the coping strategies adopted by sufferers included "normalizing" incontinence, so that it became part of their everyday routine. Studies by Dowd (1991), Ashworth & Hagan (1993), Skoner & Haylor (1993) and Shaw (2001) all suggest that women manage their symptoms and develop routines to cope with everyday life in as normal a way as possible. Attending a clinic in a leisure centre can be viewed as a reinforcement of normalizing incontinence in comparison to attending a clinic in a traditional setting which suggests that you may be suffering from a medical problem.

Accessibility

The accessibility of the "Quay to Health" with good car parking facilities and bus links was identified by the women in this study as an advantage over clinics held in traditional settings. They felt that the environment of the clinic was more relaxed and informal than others although its location within the basement of the building was dark and dingy with little natural light. The anonymity afforded by the location of the "Quay to Health" indicated that other people would remain unaware of the reason why they were in the building, something the women had identified as a positive aspect of the clinic. It was interesting to note that one of the women who had a disability felt that the leisure centre was associated with able-bodied people and that by locating a health facility within such a centre this heightened her sense of loss for the activities she was no longer able to complete. The stakeholders indicated that they had considered the needs of disabled users and had incorporated fittings that would enable disabled users to access the services in the same way as able-bodied users. However, a summary of Implementation Section 21 of the Disability Discrimination Act (1999b) found that "the most significant barrier cited by the majority of disabled people was that of inappropriate staff attitudes and behaviours". To date there is a lack of any literature that explores disabled users experiences of using health facilities located in leisure centres, and this may indicate the need for future research in this area

Resolution of Incontinence

Women wanted a resolution of their continence problem and were keen to try conservative, non-invasive treatments before considering surgery. Compliance with pelvic floor exercise programmes appeared to be good although following initial assessment of pelvic floor strength, confirmation of the success of the programme tended to be verbal with no objective measures used to monitor pelvic floor strength. Studies by Lewey, Billington & O'Hara (1997) and Sander *et al* (2000) found that most women with stress incontinence were successfully managed with conservative treatment.

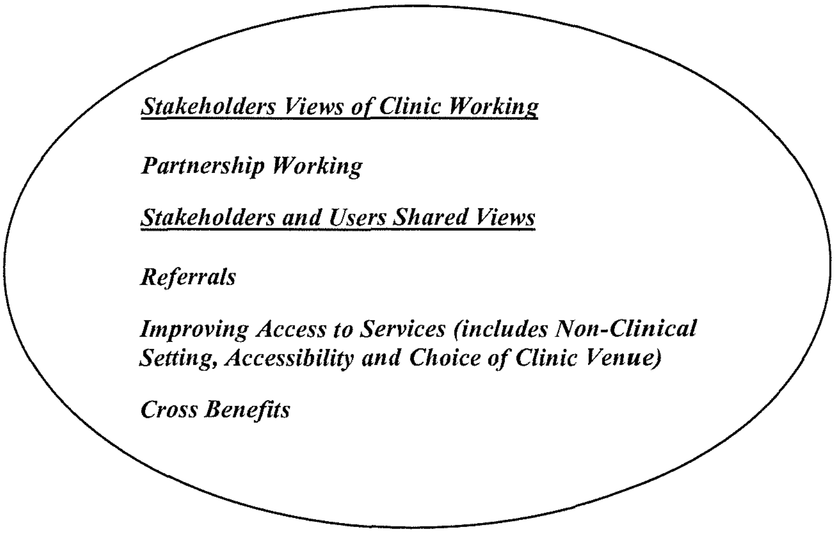
Contact with a Health Professional who would give Time, Information and Support

If women were unable to resolve their continence problem in addition to wanting contact with a health professional who would be empathetic, give them time, information and support they also needed someone whom would guide them through the pathways beyond the "Quays". The communication skills of the Continence advisor at the clinic were crucial in providing the support and encouragement to the women to carry out treatments and to monitor progress towards the resolution of their problem or referral to others for further treatment. The referral pathways beyond the "Quays" could involve three to six month delays in seeing a consultant or starting electrical stimulation treatment. The clinic tended to be run by the same continence advisor enabling a continuity of care from a practitioner who was familiar with the problems suffered by the women. The embarrassing nature of incontinence and the psychological impact it can have demands that a trained practitioner should offer support and encouragement to incontinence sufferers. Studies looking at evaluations of nurse-led clinics in incontinence have found that incontinence can be successfully managed in Primary Care by nurses with additional training in the assessment and management of incontinence (O'Brien *et al* 1991, McGhee *et al* 1997, Button *et al* 1998, Bignell & Getliffe 2000, Shields *et al* 2001, Williams *et al* 2002).

How well the clinic is working

The following section explores how both stakeholders and women indicated how they felt the clinic was working from their perspective. The specific topics selected reflect those previously identified by both stakeholders and women with only two categories, partnership working and resolution of incontinence identified by stakeholders and women alone. The shared views on clinic working included referrals, improving access to services, non-clinical setting, accessibility, choice of clinic venue and cross benefits.

Diagram 4: How well the clinic is working



Stakeholders Views of Clinic Working

Partnership Working

Stakeholders and Users Shared Views

Referrals

Improving Access to Services (includes Non-Clinical Setting, Accessibility and Choice of Clinic Venue)

Cross Benefits

Partnership Working

The ongoing evaluations of the "Quay to Health" although exploring the impact of the centre on the health of its users may not be able to demonstrate the effectiveness of the project for many years. One of the first healthy living centres at Bromley By Bow in London suggested that it had taken them fourteen years to judge the outcomes of the centre indicating that timescales for these project evaluations may need to be rather more generous than for some other projects (Trimble 1998). The development of a healthy living centre appears to be a rapidly changing, dynamic enterprise encompassing complementary therapies, user involvement and a plethora of activities that may include theatre workshops and community gardens as well as fitness centres and health facilities. To enable the evaluation of the continence clinic at the "Quay to Health" to truly represent the opinions of users, user groups will need to develop that will feed into the ongoing development and total evaluation of the project.

Referrals

Access to the continence clinic still appears to depend on referral from a GP or other health professional. If the woman's GP is aware of the service at the "Quays" then a referral may be offered, but alternative clinic venues may not be discussed. The choice of clinic available may depend on the personal preference of the GP or simply on their awareness of the clinic facilities available. The "ad hoc" nature of referral to different clinics is something that will need to be addressed in future, but with the move towards more integrated continence services the choice of clinic venue could be more explicit. If contact is made with the continence advisory service at Hythe either directly by the patient or health professional an appointment is offered at the nearest geographical location to the patient. This may be inappropriate as some people feel more comfortable attending a clinic in a non-clinical setting, with the "Quay to Health" currently the only clinic offering this facility. Continence sufferers should be offered the opportunity to attend a clinic in a location of their choice and informed if they may have to wait for an appointment.

One of the benefits of locating health and leisure services together that had been identified by the stakeholders, but not by the women was the ease of referral between different groups at the "Quay to Health". Examples had been identified where people who had disclosed continence problems in contraceptive and stoma clinics had been offered an appointment at the continence clinic. Although referrals between clinics at the "Quay to Health" appeared to be well established there appeared to be few referrals between health and leisure, or leisure and health (see page 129).

Improving Access to Services

The continence clinic at the "Quays" appears to be poorly advertised with no visible posters in the leisure centre and a small advertisement on the back of the swimming timetable for the "Quay to Health". All the women in this study indicated that they had not seen any advertisements for the clinic and may have approached the clinic at an earlier stage had they been aware of its existence. Studies that have explored access to continence clinics in primary care suggest that women are usually referred to these clinics by their GP or other health professional, with direct access uncommon (Nolan 1997, Mc Ghee *et al* 1997, Shields *et al* 1998,O'Brien *et al* 1991, Williams *et al* 2000). The continence clinic at the "Quays" had been identified as different from other clinics in more traditional settings by the "drop-in" facility whereby people could access the continence advisor without an appointment for immediate advice. Although this was seen as part of the service offered only five people a year used it, and they had found the clinic by chance. The opportunity to offer a service for an embarrassing condition with immediate access needs to be developed and promulgated, rather than leaving access to chance.

The stakeholders wanted to improve access to services for people with stigmatized conditions (see page 131). Although they were keen to improve access they appeared to be limited by the availability of resources and the lack of space within the "Quay to Health". There appeared to be some tensions between expanding the health services offered and continuing to provide a quality service. Stakeholders were concerned that they may be unable to cope with the demand for services if the clinics were advertised and this would affect the relaxed and informal atmosphere within the centre. It may be difficult to actively promote the services available at the "Quay to Health" whilst improving access and retaining the unique aspects of the centre. These tensions have been identified by Drinkwater (1998) who described the "West End Health Resource Centre", a healthy living centre in Tyne and Wear. He found that many people from outside the area wanted to use the facilities at the centre, that would have increased the income available. However, a decision was made to limit the use of the facilities to only those who lived or worked in the area to enable local people to have easier access to facilities. Difficult decisions about access to health facilities have yet to be encountered at the "Quays" but if the demand for services in non-traditional settings increases then these decisions will have to be made.

Cross Benefits

It can be difficult to ascertain whether or not women attending the continence clinic have been motivated to use the other facilities at the leisure centre as a direct result of having attended the clinic at the "Quay to health". This information does not appear to have been collected from this clinic alone but evaluations of the whole of the "Quay to Health" (Partington 2001) have surveyed all users over a two week period at six monthly intervals over a two year period. Findings from the quantitative data suggest that users of the "Quay to Health" are more physically active because they attend a leisure centre based health service, and this was also reflected in the qualitative interviews undertaken in a sample of 25 users. In the report, examples were given from two interviewees demonstrating they had increased their activity, but it was not possible to determine how many of the 25 people interviewed had expressed similar views. The Continence Advisor can provide information about weight loss and exercise, with the location of the continence clinic providing the opportunity for people to participate in leisure activities.

Resolution of Incontinence

Women wanted a resolution of their continence problem and if this was not possible they wanted support and information to help them manage their problem. The clinic at the "Quay to Health" appeared to be meeting their needs with positive evaluations given about the quality of care they had received. However, there appeared to be no follow up when women discharged themselves from the clinic and although the continence advisor assumed that their problem had resolved this may not be the case. Because incontinence is embarrassing condition women may not be inclined to admit they still have a problem and may find it difficult to ask for help. Although a contact telephone number was given to people attending the clinic and they were invited to contact the continence advisor if they had any concerns, if they were dissatisfied with the service they may simply opt out of the system and choose not to attend appointments. When evaluating service provision it could be useful to know what is good and bad about the current service to enable changes to be made that would improve the quality of the service.

Summary of Main Conclusions

- Women wanted a choice of clinic venue, with ten of the twelve women who were interviewed indicating a preference for clinics in non-clinical settings. The relaxed and informal atmosphere of the continence clinic, with advice and support from a continence advisor who gave them time to discuss their concerns was identified as one of the main advantages of this particular clinic.
- The cross benefits associated with locating a continence clinic in a leisure environment were identified by both stakeholders and clinic users who suggested that the setting could encourage increased levels of physical activity, something they all supported to improve general health and well-being.
- Stakeholders had identified partnership working as one of the key strengths of the "Quays" and although there appeared to be some tensions between different service providers relating to organisational structures and accountability the day to day operation of the "Quay to Health" appeared to work well.
- Stakeholders had also identified improving access to services as one of the reasons for developing the joint working at the "Quays". However, the continence clinic at the "Quay to Health" was poorly advertised making it difficult for people to access the service without referral from others. Some tensions appeared to emerge relating to the expansion of health services and the ability to provide a quality service within limited resources.
- One woman with a disability had felt that the leisure centre was associated with able-bodied people, and by locating a health facility within such a centre this reminded her of activities she was no longer able to complete. Future research could explore the needs of disabled clinic users to inform future practice and development of the service.

The following section explores the implications for practice of the research findings.

The implications for practice suggested by this study

The implications of some of the findings from this study are discussed under the headings used earlier in this chapter.

Partnership Working

This study suggests that partnership working is a dynamic, constantly changing set of relationships between people from different disciplines and employing organizations. To facilitate effective partnership working, regular joint training between health and leisure services, with an induction programme for new staff should help all staff to promote good health and appropriate referrals between health and leisure. The development of integrated continence services will involve partnership working between health, social services and voluntary organizations where joint training, shared goals and patient care plans will need to be introduced. The positive aspects of partnership working, to the benefit of the patients' involved could be transferred from the "Quays" to other settings.

Referrals

Referral pathways need to be clarified between leisure and health services so that direct referrals can be made by leisure services staff to other health professionals. When the physiotherapy service is re-established at the "Quay to Health" leisure services staff may be able to discuss concerns they have about exercise induced injuries and refer directly to the Physiotherapist for assessment and treatment. The Continence Advisor could consider joint clinics with the Physiotherapist (if they are appropriately experienced in continence care) to enable the additional assessment of pelvic floor muscle function in complex cases or to facilitate clinical supervision for both the Continence Advisor and the Physiotherapist.

When people are referred to "Active Options" to encourage weight loss and improvement in general fitness, it could be beneficial for the Continence Advisor to have some input into the programme. Information could be given about normal bladder and bowel function, together with a pelvic floor exercise programme that could be included in the overall exercise schedule. This would also enhance the leisure services and health services staff working together as a team for the benefit of the consumer. Health promotion could become an integral part of a continence clinic appointment in any continence clinic promoting weight loss and improving general fitness levels.

When women are referred back to the main continence services base at Hythe for electrical stimulation treatment it may be helpful to keep them informed about where they are in the system. If women were likely to have to wait eight weeks before their first appointment it would be good practice to inform them how long they may have to wait. Copies of referral letters should automatically be sent to patients to enable them to have written information about their problem, and the name of the person to whom they have been referred.

Improving Access to Services

The continence clinic at the "Quay to Health" needs to be advertised to enable people to make an informed choice about where they can seek help for their incontinence. Women in this study indicated that they had not seen any posters or leaflets advertising the clinic in their local GP surgeries or health centres, with only a few GPs being aware of the location of the clinic at the "Quays". With the development of integrated continence services the initial assessment and management of incontinence will occur in primary care, indicating that people attending surgeries should be given a contact within the surgery to initiate that assessment. Access to the continence clinic at the "Quay to Health" should continue to be available to people either on a "drop in" basis or by direct referral. This would enable people who are reluctant to discuss their incontinence with a GP the opportunity to seek help in a more relaxed atmosphere.

The clinic could be promoted through advertisements in local papers or articles discussing incontinence in a clear and simple way, with contact details provided. Posters and leaflets advertising the clinics at the "Quay to Health" could be displayed in GP surgeries, health centres, libraries and on the inside of toilet doors in public toilets. This study suggests that all continence clinics need to be advertised to enable people to seek help for their incontinence and empowering them to take responsibility for their own health.

The facilities available at the "Quay to Health" and the "Quays" could be promoted by further outreach work conducted by the joint development worker and a health promotion specialist. This work appears to have been suspended since the health promotion specialist moved away, but could perhaps be transferred to a Health Visitor or similar Public Health Specialist Nurse.

Cross Benefits

To facilitate opportunities for leisure and health service users to benefit from all the facilities available at the "Quays", the nature of the facilities themselves within the building could be promoted more actively. More obvious signs to the "Quay to Health" could be erected with details given of the clinics available and how to access them.

Discounted rates could be offered for the swimming pool, badminton, squash and the fitness suite to "Quay to Health" users. Although people attending the "Quay to Health" would not be given membership of the leisure club it may motivate some of those attending the clinic to try some of the other facilities available with the introduction of discounted rates.

Information about different activities going on in the "Quays" could be displayed in the "Quay to Health" and health promotion advice could be more actively promoted within clinic consultations. For example; if a woman asked for some advice about dieting the practitioner could give her written information about suitable diets and discuss the value of exercise in the management of weight loss. She could then be encouraged to attend one of the "healthy walks" around the city or perhaps one of the gentle "aqua exercise" programmes in the pool. Continence advisors in other clinics should be able to refer people directly to supervised exercise programmes at local leisure centres, to facilitate weight loss and improve the severity of stress incontinence symptoms where excess weight may be a contributing factor.

Choice of Clinic Venue

Women should be offered a choice about whether they would prefer to attend a clinic in a non-clinical setting. All the appointments for the clinic at the "Quay to Health" are currently made from the main continence base at Hythe. People are usually offered an appointment at the nearest clinic geographically to their home, but could be offered an appointment at the "Quay to Health". The receptionists at Hythe could simply ask whether they would prefer to attend a clinic in a hospital or GP surgery or the leisure centre.

Because women may not have attended a continence clinic before it would be beneficial if they find that they are uncomfortable with the clinic they are attending that they could be offered an appointment at an alternative location.

Non-Clinical Setting

The majority of women in this study expressed a preference for attending a clinic in a non-clinical setting. If the continence advisory service finds that the majority of new patients request a clinic appointment in a non-clinical setting then they will need to review their current service provision. The number of clinics at the "Quay to Health" may need to be increased from once weekly, although resources including the lack of available space may preclude this. Continence clinics could be based in healthy living centres but it may be difficult to find suitable accommodation for more clinics. If suitable space for additional clinics is not available then conversion of existing health service premises into more relaxed and informal environments may be a way forward.

Accessibility

The accessibility for disabled users of the "Quay to Health" could be improved with a ground floor entrance to the complex. Although stakeholders had indicated that the disabled access to the building was good the findings from this study suggest that disabled people still had to navigate past the café and main reception area before reaching the lift. This appeared to be embarrassing and magnified the sense of distress experienced by one of the women.

Resolution of Incontinence

It was assumed that if women failed to attend for a continence appointment this indicated that their incontinence had resolved or was no longer a problem for them. If women who had missed an appointment were followed up by telephone then it would be possible to offer them another appointment or discuss any issues that may have affected their incontinence. The quality of the service provided appears to be good but it can be difficult to identify areas for improvement if people simply choose not to attend. Some women may not be satisfied with the service received but are unable to express their concerns except by missing appointments.

The Continence Advisor

The development of the continence clinic at the "Quay to Health" will need to facilitate the formation of a user group to influence the type of service provision needed. This group at the "Quay to Health" could feed information into other user groups that are being developed at Hythe. Patient feedback on the quality of service provided can enhance the Continence Advisors role.

The principles of "Essence of Care" (Department of Health 2001a) encourages patient involvement in a partnership which includes setting goals and assisting the continence advisor to benchmark standards of care. It could be beneficial to implement this more formally at the "Quay to Health" to facilitate the apparent good progress that is being made, providing a good quality service.

The study has indicated areas for further research and these will be identified in the following chapter.

CHAPTER SIX

Conclusions and Recommendations

This chapter examines the methodological issues and limitations of the methodology employed in this study. The recommendations for future research are explored together with the conclusions, including the preference expressed by women for attending a continence clinic in a non-clinical setting and the contact with an empathetic health professional who would give them a clear treatment plan and support to manage their problem.

Methodological Issues and Limitations

The methodology chosen was a single case study which enabled the exploration of the continence clinic within the "Quay to Health". Although the use of a single case study was appropriate to examine this unique clinic because of its setting, a comparative study also looking at continence clinics in more traditional settings may have identified differences between the "new" clinic and the traditional clinics more clearly. It would not have been possible to employ a multiple case study design because as far as the researcher is aware there are no other continence clinics in leisure centres that could be used for a study.

It was not the intention to undertake this study in order to develop an appropriate theory of women's perception of their incontinence but elements of a grounded theory approach were used in the data collection and analysis of this study, including theoretical sampling, a constant comparison of the data, open coding and category development. Thematic analysis of the data provided a valuable framework for interpretation of data gathered.

The women in this study were recruited opportunistically from those who attended the continence clinic for the first time. Initially the Continence Advisor invited participation but recruitment to the study improved when the researcher was also present at the clinic and available to give more information about the study and to answer any questions. Issues identified during preliminary interviews with women attending the clinic informed subsequent theoretical sampling. It was suggested that health and fitness could be seen as a total healthy package and it was decided that subsequently sampling should include a range of stakeholders involved with the "Quay to Health". The researcher identified the stakeholders involved with the development of the "Quay to Health" and explored with them their philosophy behind the development of this new service and what they hoped to achieve.

Although no new data emerged to develop the properties of a category after thirteen interviews, it is possible that saturation of categories may not have been achieved and new data might have emerged from further recruitment.

The incontinence impact questionnaires provided a measure of how women were feeling about their incontinence on the day they completed the questionnaire. In the subsequent interviews women suggested that their incontinence could vary in severity from one day to the next so a low score on the questionnaires did not necessarily reflect the impact incontinence was having on their lives. By using the incontinence impact questionnaires as a discussion tool during the interviews it was possible to explore further the impact of incontinence for them and to clarify what incontinence meant to them as an individual. If the impact questionnaires had been used in isolation without further clarification this important issue of dynamic variation in symptom severity from day to day could have been missed and the picture of incontinence impact on their lives much less explicit.

The use of frequency/volume charts provided an objective measure of the women's fluid intake, urinary output and urine leakage. The initial charts were completed prior to attending the clinic for their first appointment and all the women in this study had managed to complete the chart for five days. The charts provided a useful baseline and contributed to initial assessment of their incontinence and to the exploration of the impact of incontinence on their lives. The second chart, sent by post prior to the second interview six months after their initial appointment, provided a useful indication of how their incontinence was progressing, although was not always completed. Although all the women completed the first chart at the time of assessment of their continence problem, many were less keen to complete a second chart possibly due to the inconvenience and embarrassment of having to measure urinary output in a plastic jug. This made it difficult to draw robust conclusions on progress in improvement of continence symptoms.

The first interviews completed within a month of the initial appointment at the clinic elicited valuable data about women's expectations of the clinic, the impact of their incontinence on their lives and their thoughts about attending a health clinic in a leisure centre. The categories and supporting sub-categories that emerged from the data analysis of these first interviews formed the bulk of the findings of the study with the second interviews emerging as an opportunity for the women to reflect on their incontinence and their visits to the clinic. If repeating the same study the value of the second interviews six months after their initial appointment may be questionable, with a follow-up telephone interview providing a similar opportunity for reflection in a more cost effective way. However, because of the embarrassing nature of incontinence it appeared to be more appropriate to conduct face to face interviews with the women rather than telephone interviews thereby establishing personal contact before exploring potentially sensitive issues.

Interviews with stakeholders were conducted on one occasion only as they were able to reflect on how the "Quay to Health" had developed following its opening in 1999 to the present day. Seven stakeholders were interviewed (these included two City Council Leisure Services Managers, one Primary Care Trust Manager, one Continence Advisor, one Development Worker, one Continence Services Manager and the Manager of the "Quay to Health"). It was not possible to interview two other former City Council employees who had been involved in the early development of the "Quay to Health" who had moved out of the area.

Reflexivity within the study may have been enhanced by the researcher adopting a non-clinical role. Although the women in this study were aware of my researcher role, because I covered the occasional continence clinic at the "Quay to Health" they could have contact with me in a clinical context, that may have influenced their perception of the researcher role. This is discussed further under "reflexivity"(page 52).

Recommendations for Future Research

Findings from this study suggest that incontinence remains an embarrassing condition for women, one that may not be seen as a medical problem. The preference expressed by the women in this study to attend a clinic in a non-clinical setting needs to be further explored to determine what it is about a less clinical environment that is appealing.

One of the key areas identified for future research was the need to explore why some disabled women feel uncomfortable attending a clinic in an able-bodied environment (a leisure centre). It would be interesting to compare whether or not disabled people using the other facilities at the leisure centre felt that it was exclusively an able-bodied place, somewhere where they too did not feel comfortable. Stakeholders appeared to be more than satisfied with the access for disabled people at the "Quays" but perhaps the issue of access is not the most important issue for some people. An executive summary of "Implementing Section 21 of the Disability Discrimination Act 1995 in the NHS" (Department of Health 1999b) looked at access to health care by disabled people. They conducted physical access audits of over sixty NHS premises, focus groups of disabled service users and a postal questionnaire to 500 disabled people. Although some of the barriers to access included car parking, signage and poor physical access generally, the most significant barrier cited by the majority of disabled people (numbers not stated) was concerned with inappropriate staff attitudes and behaviours. This may suggest that although the city council had provided appropriate physical access to the leisure centre for disabled people further consideration may need to be given to staff training in disability issues.

The findings from this study may be transferable to other continence clinics in leisure centres or healthy living centres. Although the continence clinic at the "Quay to Health" is a unique case, user experiences of clinic attendance and the location and environment of a clinic could be relevant to any other clinic. The preference expressed by the women in this study to attend a clinic in a non-clinical setting may suggest that if people are given a choice of attending a clinic in a traditional setting or a leisure centre the number of clinics in these alternative venues may need to increase to meet the consumer demand.

Conclusion

This study has explored both stakeholders and users views of a nurse-led continence clinic held in the unusual setting of a leisure centre. The non-clinical setting of the clinic appeared to be popular with both the women who used the clinic and the stakeholders involved in the development of the project. The partnership working at the "Quay to Health" seems to have laid the foundations for future joint working across the city with two healthy living centres planned.

The women indicated that they had valued contact with a health professional that had given them the time they needed to discuss their problem, together with a clear treatment plan and follow-up appointments. They wanted contact with a health professional who would give them support to manage their incontinence and who would also be empathetic to the embarrassing nature of their incontinence problem.

By providing a continence clinic in this setting the Continence Advisor suggested that it tended to attract a younger population. Although no figures were available for the age spread of people attending the clinic the women in this study ranged from 25-89, suggesting that it may appeal to all age groups.

To truly build on the advantages of locating a continence clinic in a leisure centre the focus of the clinic needs to change to become a health promotion clinic rather than a treatment clinic for incontinence. Health promotion advice could be provided by the Continence Advisor with information given about healthy eating, exercise, prevention of falls in the elderly and skin care (to prevent excoriation of the skin in the genital area).

The cross benefits of locating health and leisure in the same setting could be developed more, providing a wonderful opportunity for people to improve their own health. When visiting the continence clinic the other facilities available at the "Quays" may prompt people to consider combining a visit to the clinic with a leisure activity. This could also be encouraged within the continence clinic by the Continence Advisor.

Some of the benefits of attending a continence clinic in a leisure centre could be incorporated into other settings, namely the relaxed informal atmosphere and non-clinical setting. However, these alternative settings that could include shopping centres would not have the additional benefits of leisure facilities in the same building.

The continence clinic at the "Quay to Health" needs to be advertised more, to facilitate improved access to services. Posters need to be placed in GP surgeries, libraries and public toilets, together with some joint advertising to establish the link between the leisure centre and health.

The stakeholders at the Primary Care Trust and the City Council need to be looking at a shared budget for future partnership working. This would necessitate close working relationships with clearly defined goals and measurable outcomes enabling the ongoing development of healthy living centres across the city.

The continence clinic at the "Quay to Health" has the potential to continue to evolve into a clinic not only promoting continence but promoting good health by capitalizing on its unique location and partnership working.

EXPLANATION OF DIAGRAMS 1 & 2 (Pathways to Continence Care and Alternative Pathways to Continence Care)

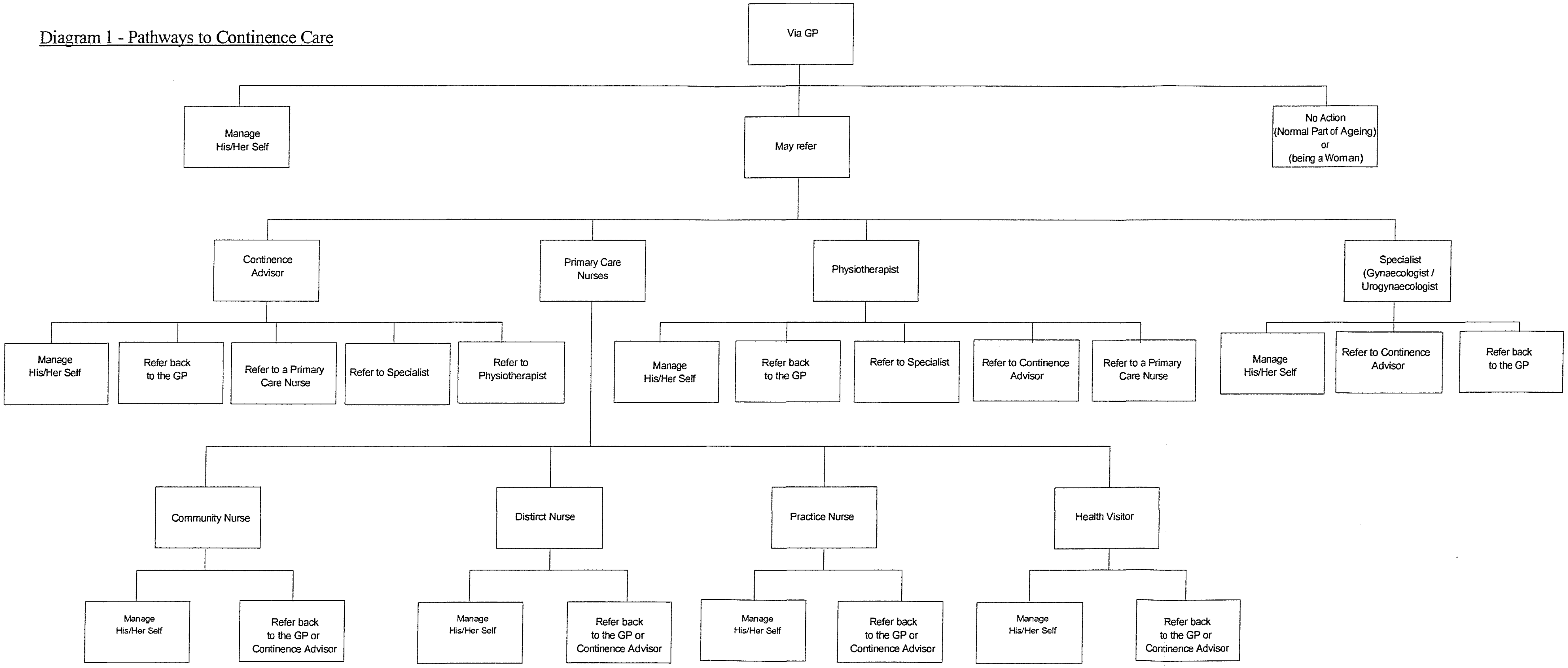
Diagram 1 Pathways to Continence Care

Diagram 1 indicates the pathways that may be taken by women who initially approach their GP for advice and treatment for their incontinence. The GP may either decide to manage their condition, refer on to other health professionals or may take no further action, dismissing their incontinence as a "normal" part of ageing or being a woman. The Continence Advisor, Primary Care Nurses, Physiotherapist or Urogynaecologist may also manage the incontinence or refer to each other to provide the appropriate care for the patient.

Diagram 2 Alternative Pathways to Continence Care

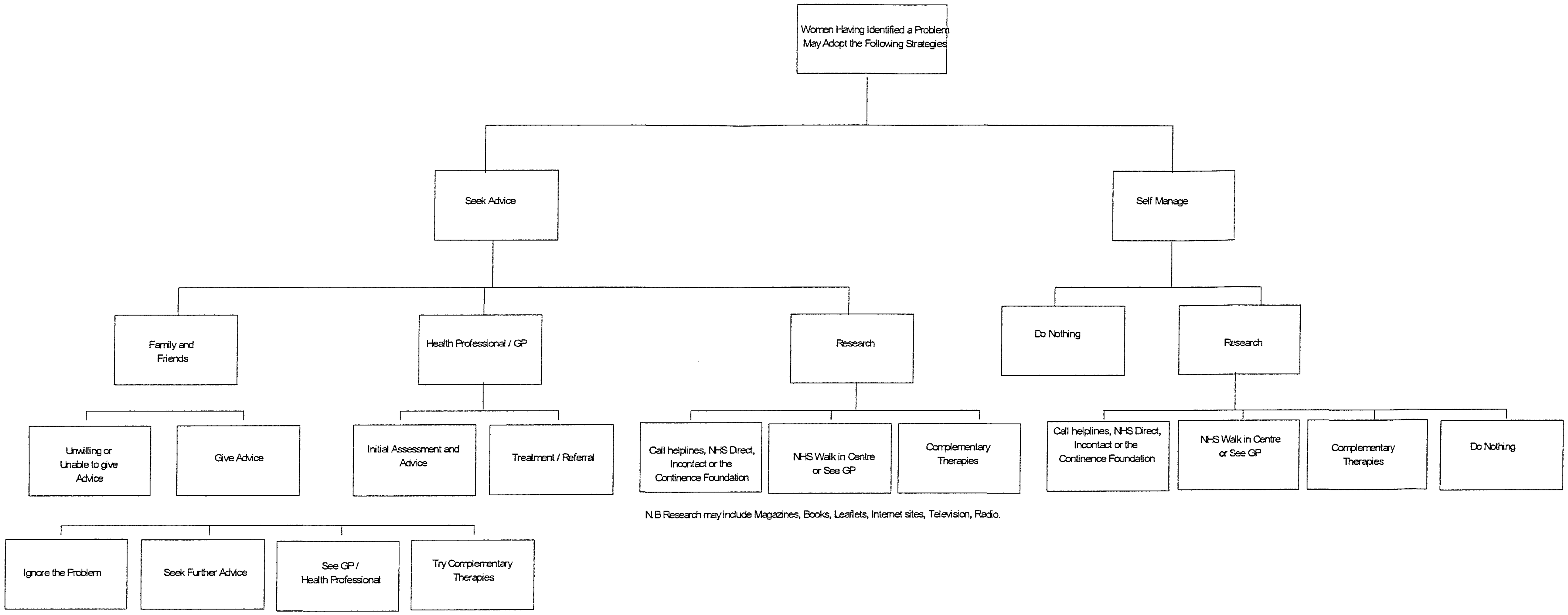
Diagram 2 indicates the alternative strategies that may be adopted by women with a continence problem. They may decide to manage the problem by seeking advice from friends and family, looking for information about incontinence in magazines, the internet or radio and television. They may approach a health professional for advice, or may do nothing.

Diagram 1 - Pathways to Continence Care



(Donnelly, 2003)

Diagram 2 - Alternative Pathways to Continence Care



N.B Research may include Magazines, Books, Leaflets, Internet sites, Television, Radio.

(Donnelly, 2003)

APPENDIX ONE

Line By Line Coding

The first analytic phase of the study involved coding the data, studying each interview line by line to enable the development of categories. Each line of data was examined and named, enabling the researcher to interact closely with the data and to frame the codes using terms that clearly described what was happening. An example of line by line coding is given below with the initial codes displayed in Italics to the left of the text.

Extract from initial interview with Brenda ***(B1 p10 220-226)***

Haven't let it have impact: I haven't let it have an impact as far as I can.

Problem could be used as an excuse not to go walking: I mean I could have given up going walking on Sundays quite happily. If I didn't like going walking it would have been a good excuse not to go.

Kept walking as likes to go, keeps you fitter in spite of it being a nuisance: But it keeps you fitter and I like to go walking so I've kept it up even though it's been a nuisance.

Control it, go to toilet before going out: You try and control it by going to the toilet before you go out and so on.

Knew location of all toilets in town: And I was a real expert on where all the toilets were in town.

These initial codes were compared with other codes from other interviews to facilitate open or focused coding.

APPENDIX TWO

Open Coding

An example of open coding is given below where the codes ‘last straw’ and ‘social isolation’ were identified to capture and understand the main themes in this statement.

Extract from initial interview with Lisa *(L1 p.1 4-10)*

Social isolation: ‘It was causing me problems outside the house and restricting where I could go and I would have to wait until I had enough fluid to get by but that I’d been to the loo enough times before I could go out and then I just would end up panic stricken, always looking for a toilet.

Last straw: And I had hoped that it would just miraculously get better but it didn’t and it had improved, but not sufficiently to let me do what I wanted so that’s when I decided that I needed some help.

APPENDIX THREE

Example of Memo-Writing

'The location of the clinic within the leisure centre appears to be a central issue for both stakeholders and women who attend the clinic. Women have indicated the relaxed and informal atmosphere of the clinic together with the non-clinical setting is preferable to attending a clinic in a hospital or GP surgery. Stakeholders have also suggested that people may prefer to attend a clinic in a non-clinical setting as they may be prompted to use some of the other facilities available at the leisure centre as a direct result of attending a clinic in the building. This suggests there may be some cross benefits for people attending the continence clinic in improving their physical well being.'

APPENDIX FOUR

Theoretical Sensitivity

The development of the core category ***Prompts to Help-Seeking*** and the sub-categories ***Worsening Symptoms, Unpredictability and Cumulative Effects*** were formed following questioning of the data. Initially the core category had been labelled ***The Last Straw*** with the sub-categories labelled as ***Duration of Problem, Coping Strategies and Impact.*** To illustrate the development of one of the sub-categories ***Worsening Symptoms*** applying theoretical sensitivity a small section of data is included together with the questions generated for the researcher by the data.

B1 (1) 4-6, 9-11: *Well. I was going through a bad patch with my bladder 'cause I've had it, it's leaked for a long time and it's been a nuisance but I've more or less kept it under control. I was living with it. But then it suddenly got really a nuisance (Brenda, aged 68).*

Questions and comments generated from the data

Interesting use of language referring to bladder as 'It'. Did this enable Brenda to disassociate herself from her own body? The bladder is also referred to as something that has to be controlled or mastered, something outside the body and visible to others. The bladder itself is referred to as a 'nuisance' rather than the urinary leakage that was causing the problem.

The worsening symptoms prompted Brenda to seek help for her incontinence and assisted in the formation of the sub-category ***Worsening Symptoms***. The questions and comments generated by the data underpinned the development of that category.

APPENDIX FIVE

University of Southampton | School of Nursing and Midwifery

LREC no: 287/01

Questionnaire Covering Letter

The two enclosed questionnaires form part of a research study being undertaken to look at how you feel about your bladder problems and the impact they have on your everyday living activities. They should only take a few minutes to complete by circling the answers or ticking the boxes.
It would be really helpful to the development of the continence services if you feel able to complete them. All information will be confidential with a code number given to each, no names will be used. Please bring them with you to your first appointment at the clinic.

After six months you will be sent the same questionnaires through the post to see if by attending the clinic at the leisure centre you feel there has been some change in your condition.

I do hope you will feel able to help with this study. Thank you very much for taking the time to read this letter.

If you have any questions about this study then please contact either myself Liz Donnelly Tel. 023 80597998 or e-mail emd1@soton.ac.uk (Researcher) or talk to your Continence Advisor.

Version 2 9/10/01

APPENDIX SIX

INCONTINENCE IMPACT QUESTIONNAIRE (IIQ-7)

HAS URINE LEAKAGE AFFECTED YOUR:

1. Ability to do household chores (cooking, housecleaning, laundry)?

   Not at All   Slightly   Moderately   Greatly

2. Physical recreational activities such as walking, swimming, or other exercise?

   Not at All   Slightly   Moderately   Greatly

3. Entertainment activities such as going to a movie or concert?

   Not at All   Slightly   Moderately   Greatly

4. Ability to travel by car or bus for distances **greater than 30 minutes away from home**?

   Not at All   Slightly   Moderately   Greatly

5. Participating in social activities outside your home?

   Not at All   Slightly   Moderately   Greatly

6. Emotional health (nervousness, depression, etc.)?

   Not at All   Slightly   Moderately   Greatly

7. Feeling frustrated?

   Not at All   Slightly   Moderately   Greatly

Scoring: 0=not at all, 1 = slightly, 2= moderately, 3 = greatly

APPENDIX SEVEN ICIQ-SF

☐☐ ☐☐ ☐☐ ☐☐
Initial number

ICIQ-SF
CONFIDENTIAL

☐☐ ☐☐ ☐☐
DAY MONTH YEAR
Today's date

Many people leak urine some of the time. We are trying to find out how many people leak urine, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1 **Please write in your date of birth:** ☐☐ ☐☐ ☐☐
DAY MONTH YEAR

2 **Are you** *(tick one)*: Female ☐ Male ☐

3 **How often do you leak urine?** *(Tick one box)*

never ☐ 0
about once a week or less often ☐ 1
two or three times a week ☐ 2
about once a day ☐ 3
several times a day ☐ 4
all the time ☐ 5

4 **We would like to know how much urine you think leaks.**
How much urine do you usually leak (whether you wear protection or not)?
(Tick one box)

none ☐ 0
a small amount ☐ 2
a moderate amount ☐ 4
a large amount ☐ 6

5 **Overall, how much does leaking urine interfere with your everyday life?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

ICI-Q score: sum scores 3+4+5 ☐ ☐

6 **When does urine leak?** *(Please tick all that apply to you)*

never – urine does not leak ☐
leaks before you can get to the toilet ☐
leaks when you cough or sneeze ☐
leaks when you are asleep ☐
leaks when you are physically active/exercising ☐
leaks when you have finished urinating and are dressed ☐
leaks for no obvious reason ☐
leaks all the time ☐

Thank you very much for answering these questions.

APPENDIX EIGHT FREQUENCY/VOLUME CHART

FREQUENCY VOLUME CHART. Name ....

Instructions for filling in this chart are on the reverse

	Monday		Tuesday		Wednesday		Thursday		Friday		Saturday		Sunday	
Day Time	Time	mls	Time	mls	Time	mls	Time	mls	Time	mls	Time	mls	Time	mls
Night Time														
Total														

Ref: freq.vol (gm)

APPENDIX EIGHT (Continued)

HOW TO FILL IN THIS CHART:

1. Every time you pass urine, please collect it in a measuring jug and measure it.
2. Record the amount of urine passed and the time you passed it.
3. Please measure and record ALL the urine you pass for 7 complete days (if you start in the middle of the week, start the chart on that day then go to the beginning of the week to complete the whole week).
4. There should be a time in the first column of each day and an amount in the second column.
5. If you leak urine, please record the time and mark with a W in the amount column.

NB. Day time is when you are up. Night-time is when you are in bed.

APPENDIX NINE

University of Southampton | School of Nursing and Midwifery

LREC no: 287/01

INVITATION LETTER FOR PATIENTS

Dear Patient,

A MULTIMETHOD EVALUATION OF WOMEN'S EXPERIENCES OF A "DROP-IN" CONTINENCE CLINIC.

I am a Ph.D student at the University of Southampton who has worked as a Health Visitor and Continence Advisor for several years. You are being invited to take part in the above study. Before deciding whether to take part it is important you understand why this study is being carried out and what is involved.

The Purpose of this Study

Continence problems affect many millions of women nationally. It is a common problem which can be successfully treated or symptoms relieved to enable people to have an improved quality of life.
Southampton Community Services NHS Trust provide continence services in your area with a range of treatments available and this study plans to examine your views of these services. The study will last 15 months and will be conducted in the Southampton area.

Please take time to read the patient information leaflet and discuss it with family, friends and myself if you wish. If there is anything you are unsure about then please discuss this with me before agreeing to take part.

If you require any further information please do not hesitate to contact me on tel. 023 80597998 or ask your continence nurse to contact me. Thank you for taking time to read this letter and considering taking part in the study.

Yours faithfully,

Liz Donnelly

Research student / Health Visitor

Version 2 *8/10/01*

APPENDIX TEN

University of Southampton | **School of Nursing and Midwifery**

LREC no: 287/01

PATIENT INFORMATION LEAFLET WOMEN'S CONTINENCE RESEARCH STUDY

Continence problems are common and many people delay seeking help for several years. The aim of this study is to investigate your experience of the continence services you have received or are currently receiving. Southampton Community Services NHS Trust supports the study and approval for the study has been given by the local Research Ethics Committee.

You are being invited to take part in this study. Please read the following information which may help you decide whether you wish to take part.

Why should I agree to participate?

Participating in this study will enable you to influence health services.
Anticipated outcomes of your involvement include improved continence services for patients together with the opportunity to influence service provision.

What is this study planning to look at?

Following your initial assessment appointment with the Continence Advisor you will be given an Incontinence Impact questionnaire to complete. This is a 7-point index which measures the impact incontinence has on everyday activities from social activities to household chores. After a period of six months you will be asked to complete the Incontinence Impact questionnaire again and to keep a fluid intake/output diary for a week (as you did when you were first assessed). By looking at the differences over a six-month period I aim to examine what effect if any, the clinic has had on your problem.

If you attend the multidisciplinary clinic at the Quays I would value the opportunity to interview you to discuss your experiences. The interviews will take no more than an hour and can take place either in your own home or at the clinic, the choice is up to you. Some patients feel more comfortable in their own surroundings and they are usually completed within an hour. By interviewing you at the start of your treatment and again six months later I will be able to see whether the expectations you had both of the clinic and your continence condition have been met. The interviews will be tape recorded to enable me to produce a typed record I can constantly refer to when analysing the results. Each tape will be given a code number and your name will not appear in any written report in order to maintain confidentiality. The tapes will be stored in a locked draw in a locked office and will be destroyed on completion of the research.

When will the research happen?

The research is planned to start in January 2002 for 15 months completed by May 2003.

How do I take part?

Participation in the study is entirely voluntary. If you consent to be involved then you will be given a return slip by your Continence Advisor together with a consent form. I will then contact you within two weeks .At any stage of the research process you are free to withdraw from the study. Your treatment will be unaffected by whether you choose to take part in the study or not.

What implications are there for me becoming involved in this study?

If you agree to take part, I will send a letter to your General Practitioner to inform him/her of your involvement in the study with a copy of your consent form. At the end of the study I will produce a newsletter outlining the outcomes of the project and I will send you a copy. Aspects of the research will be presented to interested practitioners in continence care. Any information collected during the study will be treated as confidential. Findings will be anonymised to prevent recognition of individuals in publications or presentations.

Who can I contact for further information?

Please contact me (Liz Donnelly) if you require any further information. I will be happy to answer any questions you may have. My contact number is 023 80597998 or email emd1@soton.ac.uk.

Thank you for taking the time to read this information sheet.

APPENDIX ELEVEN

University of Southampton | **School of Nursing and Midwifery**

LREC no: 287/01

PATIENT RETURN SLIP

A Multimethod Evaluation of Women`s Experiences of a "Drop-In" Continence Clinic.

This is to notify me that you have consented to participate in this study. Please would you kindly complete and give to the receptionist. I will contact you as soon as I receive the form (within two weeks). Thank you.

Name:……………………………………………………………………

Address:……………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………

Tel no……………………………………… **(Home)**
Tel no……………………………………… **(Work if applicable)**

Name of General Practitioner and Phone number……………………
……………………………………………………………………………

Address of Doctors Surgery…………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………

If you have any questions please do not hesitate to contact:
Liz Donnelly,
Tel. 023 80597998.
School of Nursing and Midwifery, University of Southampton, Highfield,
Southampton, SO17 1BJ.

Version 2 *8/10/01*

APPENDIX TWELVE

University of Southampton | **School of Nursing and Midwifery**

In conjunction with Southampton Community Services NHS Trust

LREC no: 287/01

A MULTIMETHOD EVALUATION OF WOMEN`S EXPERIENCES OF A "DROP-IN" CONTINENCE CLINIC.

CONSENT FORM

Please complete this form in full by ringing the answer that you think applies. It is a statement that you are willing to take part and fully understand the study.

1. Have you read the invitation letter? YES/NO

2. Have you had a chance to discuss the study and ask questions?

YES/NO

3. Have you had satisfactory answers to all your questions?

YES/NO

4. Who have you spoken to?

Dr/Mr/Mrs……………………………………………………………..

5. I have agreed to the tape recording of the interview YES/NO

5. Do you understand you are free to withdraw from the study:

At any time
Without having to give a reason.

YES/NO

Signed:…………………………………………………………

Name
(BLOCK LETTERS)……………………………………………

Date:……………………………………………………….

Should you need guidance on the completion of this form please contact Liz Donnelly, Research Student on tel. 023 80597998, who will be happy to answer any questions.

Version 3 *8/10/01*

APPENDIX THIRTEEN

LREC no: 287/01
Dr.
Practice
Address 1
Address 2
Town
County
Postcode

Date

Dear

RE: A MULTIMETHOD EVALUATION OF A WOMEN`S EXPERIENCES OF A "DROP-IN" CONTINENCE CLINIC.

This letter and attached documents informs you that a patient at your practice.................... Has agreed to participate in the above research study. This study forms the content of a PhD programme undertaken by Liz Donnelly at the University of Southampton.
Taking part involves the completion of an "Incontinence Impact Questionnaire Short Form" and the "International Consultation on Incontinence Questionnaire Short Form". Two interviews will also be undertaken in the patient's own home.

Please find attached a copy of the information sheet given to the patient and a copy of their signed consent for your records. Women volunteer to take part following a direct invitation from the Continence Advisor who conducts the clinic.

I have worked as a Health Visitor and Continence Advisor in the community since 1982. If you have any further questions please do not hesitate to contact me either on tel. 02380 597998 or e-mail emd1@soton.ac.uk.

Yours sincerely

Liz Donnelly (Mrs)

APPENDIX FOURTEEN

University of Southampton | School of Nursing and Midwifery

LREC no: 287/01

HEALTH PROFESSIONALS INFORMATION LEAFLET WOMEN'S CONTINENCE RESEARCH STUDY

The aim of this study is to investigate women's experiences of continence services provided within Southampton Community Services NHS Trust. This study has been approved by the local Research Ethics Committee.

Why study continence services?

An integrated approach to continence services is strongly advocated in the Department of Health "Good Practice in Continence Services" (2000). Following recent research conducted as part of the South Thames Evidence-based Practice Project (STEP) a new model of continence services was developed (Bignell, V and Getliffe, K 2000). The researcher plans to evaluate services at the Quays clinic from a users' perspective.

What is involved?

To elicit the users views on continence service provision subjective and objective measures will be used. The "Incontinence Impact Questionnaire" and frequency volume chart completed at initial assessment and repeated six months later.

In-depth interviews will be conducted by the researcher at the clinic soon after an initial appointment and repeated six months later. These will be used to elicit expectations of the service and interviewee's experiences of incontinence.

How will this study affect me?

Continence Advisors working at the Quays Clinic.
If you are willing to assist me with this study it will involve you:
Approaching women and giving them information about the research.
Obtaining signed consent from participants.
Collecting frequency/volume charts and "Incontinence Impact Questionnaires" after initial assessment and at six months for collection by researcher.
Identifying 5 women from each of the following three groups to see if they consent to being interviewed by the researcher.
1. Stress incontinence.
2. Urge incontinence.
3. Mixed incontinence.

What are the benefits?

The outcomes of the research will reflect the quality of the continence services provided and may influence the development of the service. I would like to discuss my research with you in more detail and would be happy to meet you at a time and day to suit you.

Patients will be able to contribute to the future development of services. Outcomes will provide evidence to purchasers and participants of the impact of incontinence on women's lives and the value of the services you provide to improve their continence problem.

When will it happen?

The research will commence in January 2002 with the data collection completed by May 2003.

Who can I contact for further information?

Please contact me (Liz Donnelly) if you require any further information. My contact number is 023 80597998.

Thank you.

References

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APPENDIX FIFTEEN

University of Southampton | School of Nursing and Midwifery

LREC no: 287/01

Interview Schedule for Initial Interview

First Stage

Introduction of researcher and summary of project: To include a brief summary of the background to the research project, the coverage of topics during the interview and anticipated length of time. Participants will be reminded that participation is entirely voluntary and the interview can be terminated or interrupted at any time they choose.

Proposed questions to be covered during interview:

Reasons for seeking help

What prompted you to seek help for your continence problem?

How long have you waited before seeking help?

Who did you talk to about your bladder problems?

How did you find out about what help was available for your problem?

Access to the continence clinic

How long have you waited to receive an appointment?

Do you feel that your appointment arrived quickly enough?

Is the clinic venue convenient for you?

Expectations

What do you expect from the clinic?

What would you like to happen as a result of attending this appointment?

Impact on lifestyle

Tell me about your bladder problems.

Have your bladder problems affected your life in any way?

Describe the way in which things have changed as a result of your problem?

Patient perceptions

Could we have improved the service the service you have received so far?

Second Phase:

Six months after initial clinic appointment.

Participants will be reminded of their voluntary participation and the option to withdraw from the study. Confidentiality will be assured. The following questions will be asked in addition to those used in the first phase.

Reflections on the service provision

How do you feel about the treatment you have received for your bladder problems?

Do you think that your bladder problems have improved since coming to the clinic?

Are there any other issues or concerns you would like to discuss about your bladder treatment that have not been covered during the interview?

Thank you very much for agreeing to be interviewed.

APPENDIX SIXTEEN

Interview Schedule for Second Interview

1. **Thanking participant for continuing involvement in the research, together with a brief update on the progress of the study. Participants will be reminded that participation is entirely voluntary and the interview can be terminated or interrupted at any time they choose.**

2. **Proposed questions to be covered during the interview:**

Impact on lifestyle

Describe the impact your bladder problems have had on your life to date?

How would you describe your bladder problems at the moment?

Expectations

Have your bladder problems changed from when you first came to the clinic?

If so: In what way have things changed?

Why do you think your bladder problems have improved?

If not: Why do you think things are still the same or worse?

Clinic Evaluation

Several people I have spoken to were unaware of the clinic at the Quays: Can you remind me how you found out about the clinic?

How have you found your visits to the clinic?

What information were you given about your problem?

Did you feel you had a better understanding of your problem as a result of the information you received at the clinic?

Would you have liked any contact with other sufferers? ie. information about support groups?

Some of the original ideas behind setting up this clinic at the Quays included providing services in a "healthy" environment where people who would not usually visit leisure centre would feel able to visit. What do you think?

How would you feel if you bumped into someone you knew in the waiting room?

If you had any bladder problems in the future would you be happy to come back to the Quays clinic rather than a clinic in a GP`s surgery or a hospital?

If you have attended a continence clinic in the past:

Do you feel there is anything different about attending a clinic in a leisure centre rather than a hospital or GP`s surgery?

Can you suggest any improvements that could be made to the type of service offered at the clinic?

Is there anything else you'd like to add about your experience of attending the Quays clinic?

APPENDIX SEVENTEEN

Example of field notes completed following an initial interview

Julie, aged 32,service user

Urge incontinence. Health Professional works part-time. Incontinence not exacerbated by birth of child (one year ago).

Able to manage problem by frequent voiding 8-15 times daily. Finds it difficult to control bladder when has the urge to pass urine and needs to find a toilet quickly. Feels embarrassed by problem and dislikes having to cut a conversation short in the street with a friend or to leave a lecture on a study day because she needs to pass urine. No signs of stress incontinence. Doing pelvic floor exercises regularly and had bought 'Aquaflex' cones and was able to retain heaviest weight with no problem at all. Had problems at school with irritable bladder but only recently problem has become worse. Works as a health professional but did not want to talk to own GP as concerned would be: a) referred through to surgeon when inappropriate, b) felt embarrassed at discussing problem with GP, c) felt may be subjected to a battery of extensive urodynamic tests that would be very uncomfortable and embarrassing. Concerned not to have any surgery as wants to manage problem conservatively. Selected the clinic at the 'Quay to Health' as had picked up a leaflet when went swimming and threw it away, but remembered there was a clinic there. Didn't want to see anyone she knew at the clinic as would have been very embarrassed if she had seen any of her patients at the clinic. Wouldn't have attended a clinic in a hospital as a) she may have seen someone she knew, b) she was concerned how the doctors would treat her, c) long waiting times at busy hospital clinics. Liked the quiet waiting room at the 'Quays'. Had decided that seeing a specialist nurse was preferable to a doctor as she would probably have more time and would be more familiar with the problems she was experiencing. Impressed that the continence advisor quickly sorted out what the problem was although commented that she wasn't asked re medical history or medication. Felt that the continence advisor was a little unnerved by her because of her professional status. Did not want to see a doctor as thought they would expect her to know what was wrong and would neglect to take a thorough history leading to an incorrect diagnosis.

Following the first appointment at the clinic had a bladder scan and decision taken to reduce/eliminate caffeine (now drinks decaffeinated tea). To start 'Tolteradine' once daily. Had to write a letter to GP requesting them and felt uncomfortable at own GP practice as receptionist questioned her about the requested medication which made her feel very uncomfortable. Plans to take tablets for 3-6 months then discontinue and review. Also using bladder training techniques and can wait 3 hours.

Thought it was good that had a follow-up appointment to review progress. Commented that the clinic was poorly advertised and that other colleagues did not know about it. Interesting point: Did not disclose she had a problem to them and then said she had referred a patient there who had liked it.

APPENDIX EIGHTEEN

Dear

Re: "A Multimethod Evaluation of Women's Experiences of a "Drop-In" Continence Clinic"

I would like you to feel that you can speak openly to me about your thoughts relating to the philosophy behind the development of the clinics at the "Quays". The contribution you will be able to make will really enhance my research study by providing the perspective of the clinic developers as well as the patient's perspective.

I would like to tape-record the interview, which should take about half an hour. The tape will contain no identifying characteristics and will be allocated an initial. By recording the interview I will be able to gather more information and any quotes used will remain anonymous with only the initial letter allocated to the interview used. Any sections of the interview, which could identify you, will not be used to protect your anonymity.

I do hope you will feel able to consent to this interview as your opinion provides a valuable piece of the puzzle looking at how the "Quays" clinics were developed. If you have any questions then please do not hesitate to contact me either by phone: tel. 02380 597998 or by e-mail: emd1@soton.ac.uk

If you would rather I didn't record the interview then just let me know when we meet as I will still value any contribution you are able to make to my research looking at users views.

Thanking you in anticipation

Yours sincerely

Liz Donnelly (Mrs) Postgraduate Research Student/Health Visitor

APPENDIX NINETEEN

Interview Schedule for Health Professionals

1. Thank participant for agreeing to be interviewed and give outline of study to date. Participants will be reminded that participation is entirely voluntary and the interview can be terminated or interrupted at any time they choose.

2. **Proposed questions to be covered during the interview:**

Philosophy underpinning Clinic Development

What was the original idea of providing clinic services at the "Quays"?

What do you feel was the underpinning philosophy behind the development of clinics in this setting?

Can you describe the development of a clinic facility within the "Quays"?

Who were the key stakeholders involved in the development of the project (names and contact details would be good)?

Comparative Data

What do you see as the benefits for patients attending this clinic?

Outline the benefits for practitioners working in this setting.

What, in your opinion are the differences between a clinic provided in this setting and conventional clinics?

Practical Aspects

Have you encountered any problems in providing a clinic within the "Quays"?

If so: Describe some of the issues you have had to deal with and how you feel they have been resolved.

On reflection, would you continue to support the provision of clinics within a different setting?

Would you need to see some evidence that supported the provision of new clinics and if so what form would that take?

Is there anything else you would like to add about the development of clinic services at the "Quays"?

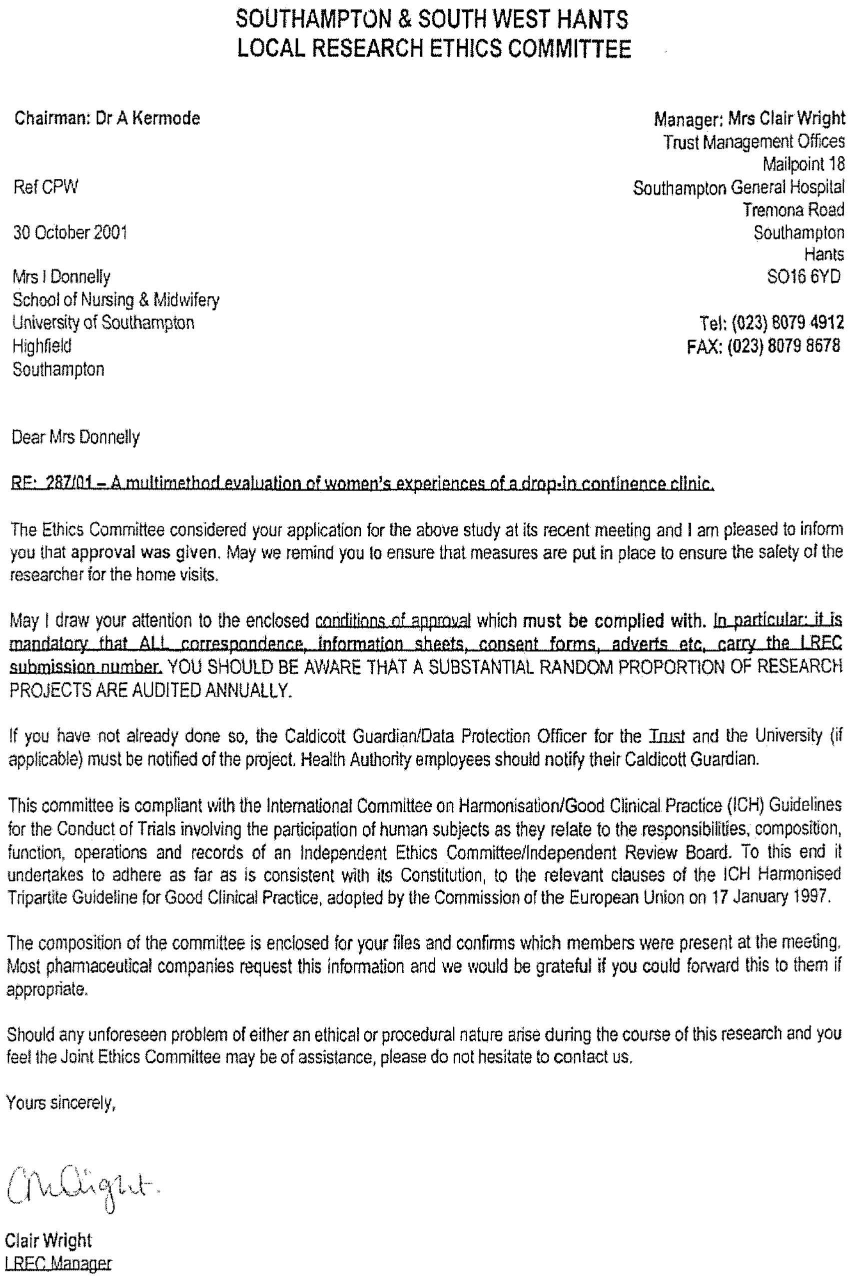
APPENDIX TWENTY

Extract from researcher diary

Jan 2004

Discussion with colleague about the progress of the study. Emerging category around the holistic approach to health care and the cross benefits of attending a clinic in a leisure centre. There appears to be a different philosophy from the providers of health services to the service users i.e. service providers think the leisure centre a good place to have a clinic because the leisure centre itself is associated with healthy behaviour. Therefore people will choose to attend a clinic because of the unique environment. Service users present a different picture in that they like the relaxed and informal setting of the clinic but wouldn't necessarily choose to attend a clinic because they could then use the leisure facilities. Suggestion from colleague that women are embarrassed about their incontinence and will attend a clinic anywhere where they are able to get their problem sorted. They may attend the clinic at the 'Quays' as it offers reduced waiting times for appointments compared with clinics in more traditional settings. To explore the data further to see what it is about the clinic at the 'Quay to Health' the women themselves identify as being important and if this differs from the stakeholder's views.

APPENDIX TWENTY ONE



SOUTHAMPTON & SOUTH WEST HANTS
LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Dr A Kermode

Manager: Mrs Clair Wright
Trust Management Offices
Mailpoint 18
Southampton General Hospital
Tremona Road
Southampton
Hants
SO16 6YD

Tel: (023) 8079 4912
FAX: (023) 8079 8678

Ref CPW

30 October 2001

Mrs I Donnelly
School of Nursing & Midwifery
University of Southampton
Highfield
Southampton

Dear Mrs Donnelly

RE: 287/01 – A multimethod evaluation of women's experiences of a drop-in continence clinic.

The Ethics Committee considered your application for the above study at its recent meeting and I am pleased to inform you that **approval was given**. May we remind you to ensure that measures are put in place to ensure the safety of the researcher for the home visits.

May I draw your attention to the enclosed conditions of approval which **must be complied with**. In particular: it is mandatory that ALL correspondence, information sheets, consent forms, adverts etc, carry the LREC submission number. YOU SHOULD BE AWARE THAT A SUBSTANTIAL RANDOM PROPORTION OF RESEARCH PROJECTS ARE AUDITED ANNUALLY.

If you have not already done so, the Caldicott Guardian/Data Protection Officer for the Trust and the University (if applicable) must be notified of the project. Health Authority employees should notify their Caldicott Guardian.

This committee is compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

The composition of the committee is enclosed for your files and confirms which members were present at the meeting. Most pharmaceutical companies request this information and we would be grateful if you could forward this to them if appropriate.

Should any unforeseen problem of either an ethical or procedural nature arise during the course of this research and you feel the Joint Ethics Committee may be of assistance, please do not hesitate to contact us.

Yours sincerely,

CWright.

Clair Wright
LREC Manager

GLOSSARY

Biofeedback : Is a technique whereby information about muscle contraction is presented to the patient and/or the therapist as either a visual, auditory or tactile signal.

Care Pathways : The steps taken by people to access advice and treatment.

Conservative Treatment : Any therapy not involving medical or surgical intervention.

Continence Advisor : A nurse with additional specialist training in the promotion and management of continence problems.

Continence Clinic : A clinic for the promotion of healthy bladder and bowel function.

Electrical Stimulation : Is the application of a mild electrical current to stimulate pelvic muscles or their nerve supply.

Frequency/Volume Chart : Records the volumes of urine passed together with the time of each over at least 24 hours.

Incontinence Impact Questionnaires : Quality of Life Measures that indicate the impact of urinary incontinence on people's lives.

Integrated Continence Services : Continence services led by a director of continence services including continence advisors, physiotherapists, community nurses, GPs, urologists and urogynaecologists working together to provide appropriate services for patients.

Mixed Urinary Incontinence : Is the involuntary leakage of urine associated with urgency and also with sneezing, coughing, exertion or effort.

Non-Clinical Setting : A setting that excludes hospitals, health centres or surgeries.

Pads : Externally worn protection to minimise urine leakage on to clothing.

Pelvic Floor Exercises : Exercises to improve pelvic floor muscle tone.

Primary Care Organisation : Organisation providing health care to a designated population.

Primary Care Trust : Organisation providing health care to a designated population.

Primary Health Care Team : Staff working in primary care including GPs, practice nurses, district nurses, health visitors and other community nurses.

Quality of Life : Encompasses general "life satisfaction" and can be interpreted on an individual basis.

"Quays" : The name of the leisure centre complex.

"Quay to Health" : The name of the health centre within the leisure centre.

Stakeholders : Health professionals, city council leisure services staff and Primary Care Trust managers.

Stress Incontinence : Involves the involuntary leakage of urine following sneezing, coughing or effort on exertion.

Urge Incontinence : Is the involuntary leakage of urine preceded or accompanied by urgency.

Urodynamic Clinic : This is a clinic where bladder capacity, muscle tone and function is measured often involving catheterisation of the bladder.

Urologist : Consultant surgeon who has specialised in bladder problems.

Urinary Incontinence : Is the complaint of any involuntary loss of urine.

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