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# 1 Summary

## Statement of the problem

Urinary incontinence is the main symptom of disordered storage of urine as distinct from disordered voiding. It represents several underlying conditions within a classification of diseases of the bladder which needs further development. The two main disorders featuring incontinence are overactive bladder, involving urge incontinence, and sphincter incompetence, involving stress incontinence. However, there are substantial overlaps with conditions such as dementia and stroke, particularly in elderly people, and for those with discrete neurological disorders and long-term disabilities including MS, and learning disability.

The two most important recent issues in relation to service provision have been (i) the extent of need related to incontinence, in view of symptom prevalence reports ranging up to two-thirds of the population in women and (ii) the effectiveness of a nurse-led service crossing the primary/secondary care interface. These issues have been comprehensively addressed over the last few years by a research programme funded by the MRC with DoH support. This review includes insights from this research which is still ongoing.

The role of the GP in assessment and management of the underlying condition is hampered by a lack of information, training and experience and the lack of an integrated specialist service. Further issues, where more information is needed to develop policy, concern the best management of people with overlapping conditions, e.g. stroke, MS and learning disability, who already receive specialist input of various kinds. One of the longer-term issues concerns the merits of extending an integrated incontinence services to include all disorders of the bladder and its outlet, in view of the extensive overlap between storage and voiding symptoms and the uncertainty about the distinctions between underlying conditions and about the management of prostatic enlargement.

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## Sub-categories

*Storage disorder* signifies the totality of clinically recognised abnormal storage symptoms including incontinence, urgency, frequency and nocturia. Incontinence serves as the main epidemiological indicator and has two commonly recognised levels of severity – any and moderate/monthly. At primary care level the syndrome of *overactive bladder* is commonly represented by the symptoms of urgency, including urge incontinence, often occurring in association with frequency and nocturia. Similarly, *sphincter incompetence* is commonly represented by the symptom of *stress incontinence*.

The ICD-10 codes (*see* **Table 2**) encompass all the conditions associated with incontinence but the subcategories lack coherence. The International Continence Society reflects current thinking in re-organising the main sub-categories as *detrusor overactivity* (DO) with idiopathic and neurogenic components, and *urodynamic stress incontinence* (USI). Less common categories involving incontinence in men include chronic retention of urine with overflow, mostly due to prostatic enlargement and post-micturition dribble due to abnormal relaxation of the external sphincter.

*Health care need* is defined in terms of objectively defined abnormal storage symptoms and impact on life. *Felt need* is defined more subjectively in terms of apparent motivation to obtain help indicated by either using services or wanting help. *Health care requirement* represents felt need within the context of the defined health care need.

## Prevalence and incidence

The results of a systematic review of UK studies suggest that bladder malfunction is very common, often distressing for the individual and represents a major public health problem in the UK that may be increasing over time. Incontinence and other storage symptoms should be conceptualised as disorder of the bladder on a par with and indeed related to other organ systems of the body and deserve similar consideration for research and service development.

Across a range of UK studies, the prevalence of any incontinence averages out at around 40% for women and 10% for men. Incontinence with impact on life is estimated around 30% for women. For those aged 40 or more, storage disorder as a whole affects around 39% of women and 29% of men. This represents considerably more men than are affected by incontinence alone (Table 1). These results are consistent with findings from around the world and the current MRC programme of research. There were no published UK studies available that estimated the full extent of felt need in relation to storage disorder. We estimate this at 25% in women and 18% in men within the previous year, indicating the level of health care requirement. These levels cannot be ascribed to measurement error or uncertainty over thresholds. They appear high in relation to other individual conditions partly because incontinence/storage disorder represents several common conditions affecting the bladder. There is an overall increase in prevalence of symptoms with age in both women and men but the latter start from a lower base after childhood, increasing to similar levels in old age. Women experience a peak of prevalence around menopause, due to stress incontinence. The rise seen in elderly people is related to urge incontinence. These two types of incontinence place very different demands on services, especially with regard to surgery. Overall, the prevalence of need increases with age and the major problem is apparent in old age, equally among men and women.

	Average prevalence % (range in studies) <sup>a</sup>		
	Women	Men	
Storage disorder <sup>d</sup>	39 (-)	29 (-)	
Incontinence (minor) <sup>d</sup>	40 (16–69)	10 (8–25)	
Incontinence (monthly)	12 (8–23)	5 (3–9)	
Nocturia (2+)	15 (14–26)	15 (14–20)	
Frequency (hourly)	9 (-)	5 (-)	
Urgency (difficulty)	9 (6–9)	5 (3–5)	
Impact – any <sup>d</sup>	30 (17-44)	$12^{b}(11-12)$	
– more than a little	8 (8–30)	4 (3-6)	
Consultation	6 (2–11)	3 (1-7)	
Want help/uptake on offer <sup>c</sup>	5 (4-9)	4 (3-4)	

 Table 1: Urinary incontinence and storage disorder: prevalence, impact and use of services from UK studies – 1960–2001.

<sup>a</sup> Estimated from graphs.

<sup>b</sup> Elderly ages only.

<sup>c</sup> Indicator of unmet need.

<sup>d</sup> Indicator of health care need.

The prevalence of incontinence is 2–3 times higher in residential care and hospitals and among people with severe disabilities of various kinds than in the general population. Incontinence probably operates as a selection factor but it could deteriorate as a result of institutional care.

The incidence of incontinence suggests three distinct peaks in women – early reproductive age, menopause and old age with rates ranging between 6-22% for women and half this for men. The natural history suggests a marked tendency to fluctuation with elements of both remission and progression. There are clear associations with pregnancy/parity, obesity and cognitive impairment, and fairly consistent relationships with stroke and depression.

## Services available and their costs

Division of care between professionals is complex, with varied models of service around the country. Patients may present to GPs or go directly (or indirectly) to continence nurses in the community. They may be treated extensively within primary care with behavioural and medical therapies or be referred at an early stage to specialists, including neurologists, geriatricians, urologists and gynaecologists. In relation to health service pathways for incontinence, most younger women are referred to gynaecologists whereas most older men and women are referred to physicians for the elderly; whilst for voiding problems most men are referred to urologists. Continence nurses of various kinds play a considerable role in managing the problem but the nature and extent of provision is very variable across the country. Community nurses are often the first port of call for patients with incontinence. They may make the initial in-depth assessment and are often involved in providing some degree of behavioural therapy for the common disorders and long-term aids for intractable conditions.

## Primary care

The key issues in the provision of appropriate services to date have been the level of interest in continence on the part of the health care provider, the fragmented approach to provision of specialised services in secondary care and the variable nature of provision. This variation in service delivery affects patient outcomes. Interventions available in primary care include giving general advice, behavioural and lifestyle changes, pelvic floor muscle training, bladder training and drug treatment, all of which form the mainstay of the conservative management of urinary incontinence. Pelvic floor muscle training is usually reserved for individuals with stress incontinence and occasionally urge incontinence. The latter is more commonly treated with bladder training or drug therapy.

## Secondary care

The interventions in primary care may also be introduced in the secondary care setting, where assessment and treatment may be provided by any one of a number of clinical specialists with or without specialist nursing or physiotherapist support. It is in secondary care that facilities such as urodynamic investigation are available to diagnose the underlying abnormality, as well as a more multidisciplinary approach to care.

Surgery is clearly within the remit of secondary care and plays a major part in the treatment of urodynamic stress incontinence. Over 100 operative techniques have been described to treat this condition. Colposuspension is currently regarded as the gold standard procedure. Surgery is generally performed in those cases where conservative measures, such as pelvic floor muscle training have failed. However, surgical therapies for urodynamic stress incontinence are relatively expensive and not without complications.

## Health care utilisation

Official statistics indicate that 36/10 000 of the population per annum consult a GP for incontinence; however, this represents only 7% of adults who self-report such consultations. The corresponding level of hospital episodes is 14/10 000 p.a. and the level of surgery is 2/10 000 p.a. In primary care the pattern of recognised consultation reflects that in the community in relation to age and sex. However, hospital episode rates are disproportionately high for elderly men compared to women. Hospital episode rates remained stable overall in recent years but within this there has been a substantial increase in the rates for elderly people. Whether this reflects trends in admission or more people developing incontinence during a hospital episode is unknown. The majority of surgery is carried out on women mostly around the time of menopause. This pattern reflects the high peak in mild/moderate incontinence in the community. However, surgical rates are too small to account for much of the sharp decline in prevalence following menopause. There has been a steady increase in the number of prescriptions for drugs used exclusively for incontinence in recent years. An estimated 1.6 million such prescriptions are dispensed per year. The MRC Incontinence Study estimates 6.2% of people aged 40+ are using incontinence aids of some kind.

## Costs

The overall annual cost to the UK of urinary incontinence was estimated in 1998 by the Continence Foundation to be £353.6 million. This does not include patient-borne financial costs and estimates from elsewhere in the world would suggest considerably higher levels. However, one study has estimated NHS and patient-borne costs in women to be £37 (1995) for a three-month period. Patients also bear other types of costs such as discomfort and embarrassment, disruptions to usual activities and disruption of social life. These costs are difficult to quantify but the concept of 'Willingness to Pay' in relation to urinary

incontinence provides some indication. Estimates in the region of £18 per month for a reduction in symptoms indicate the level of importance to the individual.

## Effectiveness of services and interventions

There is clear evidence in the literature showing the benefit of pelvic floor exercises and bladder training, both in primary and secondary care. Drug treatment, which is mainly aimed at patients with detrusor overactivity, is also effective but has been hampered by unacceptable side effects. The introduction of newer, more effective drugs is addressing this problem, but they are much more expensive. As with many other areas of health care, there is very limited evidence of the cost-effectiveness of any interventions in primary care.

Surgery provides differing cure/improvement rates for urodynamic stress incontinence. Despite the large number of studies published, the quality of trials comparing different techniques has been criticised. Surgery is expensive and is associated with morbidity and mortality. It is therefore essential that treatments are evaluated properly before being introduced into everyday practice. Furthermore, outcome is related to the experience of the surgeon. Once again, there is little evidence of the cost-effectiveness of surgery for incontinence.

## Quantified models of care/recommendations

As outlined in the previous two sections, there are considerable inconsistencies in current continence care available to the population. What is lacking is co-ordination of continence care. Continence nurse practitioners can not only provide this co-ordination, but also deliver these services in primary care with effect and high levels of patient satisfaction. A new model of care is proposed based on current research. The new ideal service would span the primary and secondary care interface, with Continence Nurse Practitioners (CNPs) bridging the gap and leading and co-ordinating the service. The CNPs would provide much of the care in the community with an emphasis on conservative interventions, e.g. bladder retraining and pelvic floor muscle exercises, thereby reducing referrals to secondary care. They would be part of a multidisciplinary team along with other health care professionals, such as GPs, surgical specialists and physicians. The service would be structured around evidence-based protocols, regular audit and quality assurance systems, in order to ensure the delivery of high quality care.

Within this context there is considerable consensus about the main issues that need to be addressed in order to improve services including:

- raising public awareness to remediable symptoms of bladder disorder and overcoming the lack of knowledge and reticence of patients, particularly elderly women, with this highly stigmatising and neglected condition
- employing standard identification and assessment procedures in primary care to assist professionals in identifying and not discouraging appropriate people who need to access services, including those in residential care
- training and expansion of the primary care workforce to provide first line therapy including bladder training, pelvic floor exercises and behavioural interventions in accordance with evidence-based best practice
- developing an integrated service including specialist continence nurses, urology, uro-gynaecology and gerontology that bridges the primary/secondary interface to minimise confusion over referral pathways and to rationalise the use of expertise.

## Patient outcomes, audit tools, information and future research

Urinary incontinence is associated with significant psychological distress and poor quality of life. It is therefore necessary to assess symptoms and impact on patients' lives to establish the need for services and to evaluate outcomes. A variety of questionnaires exist which variously assess urinary incontinence symptoms, lower urinary tract symptoms and impact on quality of life, with some designed specifically for use in clinical trials.

Evidence-based audit tools have been developed to promote the quality of incontinence services in primary and secondary services.

The Working Group on Outcome Indicators for Urinary Incontinence has identified indicators that are routinely available from health care data or periodic surveys and some which require further development.

Until very recently, research concerning the bladder received very little investment in the UK or around the world. Consequently the levels of understanding and conceptual development are at an early stage. There is a lack of any long-term infrastructure to maximise contributions from around the country in building a coherent evidence base for innovative forms of management and prevention.

Future research needs to focus on providing an evidence base for preventive action; investigating mechanisms for dual diagnoses, e.g. depression as a basis for innovative therapeutic development; improving access and equality in the use of services; development and evaluation of services, especially those for elderly and disabled people; plus the development of a comprehensive classification and related non-invasive assessment and diagnostic tools.

# 2 Introduction and statement of the problem

This chapter contains an interpretation of the evidence concerning appropriate levels of NHS provision and treatment for urinary incontinence and related symptoms in adults. The broad questions addressed include:

- What is the level of need for services?
- What are the roles of primary and secondary services?
- How effective are the medical and surgical treatments available?
- What are the costs of treatment?
- What overall level of provision should be commissioned for urinary incontinence among adults?

Urinary incontinence has been defined as the involuntary loss of urine.<sup>1</sup> This concept has served to highlight a substantial but neglected, indeed taboo, subject and stimulated varied development of services across the country. In itself, however, incontinence is only one symptom of disordered storage of urine. It indicates a number of underlying conditions which are themselves only partially conceptualised at present. Nevertheless, abnormal symptoms may be useful markers of the pattern of disease in the population.

The bladder is a relatively complex system of the body because, although it operates largely autonomously, we are obliged to learn and maintain voluntary control of its functioning. Thus a wide range of neurological and mental disorders make considerable contributions to the nature of bladder dysfunction. The lower urinary tract differs markedly between females and males and is subject to the different risks of childbirth and prostatic enlargement. Physical disability and acute disorders have additional implications for maintenance of continence, even when the bladder functions within normal limits, because of the necessity of accessing a toilet and adjusting clothing. The manner in which lower urinary tract (LUT) disorder tends to be subdivided in relation to service provision is necessarily complex. It owes something to the specific underlying conditions in so far as they are perceived and to the range of client groups involved. Classifications abound, suggesting that none integrate all the various dimensions and few capture the difference in perspective between primary and secondary care. **Figure 1** represents a system based on underlying condition but arranged to illustrate the main health service orientations. All the disorders may present as incontinence and other storage symptoms. Common general conditions such as immobility and acute confusion also impinge on the overall functioning of the bladder/nervous system, particularly in old age. Currently the commonest disorders of the LUT are conceptualised in terms of function or structure rather than the inter-related pathology. This represents a relatively early stage of development compared with other systems of the body.<sup>2</sup>

NEF	RVOUS SYSTEM BLADDER		GENERAL HEALTH
-	dementia stroke	overactive bladder	frailty
	(elderly)	(elderly/urology)	(elderly)
	Parkinson's disease multiple sclerosis spinal injury	sphincter incompetence	urinary tract infection
	(neurology)	(gynaecology)	(primary care)
-	diabetes + neuropathy	prostatic enlargement	long-term disability
	(general medicine)	(urology)	(e.g. learning disability/ psychiatry)

Figure 1: Lower urinary tract disorder – a public health classification (main service orientation).

The difficulty faced by commissioners in the case of incontinence is defining what level of severity is significant and the appropriate boundaries for an integrated service. The challenges for service planning and delivery also include:

- 1 determining the extent of need, taking into account significant symptoms, the impact on people's lives and personal goals, the attendant stigma and low expectations;
- 2 getting people to come forward with their problem; and primary care recognising and responding appropriately to the problem;
- 3 identifying the appropriate structured care pathways for patients to make use of available resources;
- 4 determining the roles of the parties involved in providing care, including general practitioners (GPs), nurses and consultants and the corresponding levels of expertise and degrees of specialisation required;
- 5 organising secondary care teams and clinics to provide essential multidisciplinary advice and avoid duplication of costly resources such as cystometry;
- 6 determining the effectiveness of modern treatments;
- 7 deciding on the indications for surgery, what type of specialist should do it and what procedures should be used;
- 8 developing approaches to prevention/early intervention;
- 9 addressing priorities in terms of how far to treat those most able to benefit, those most liable to deteriorate and those in the worst state of health.

Available evidence from epidemiological research, evaluative studies and economic analysis will be presented in this chapter. This information, together with guidance on best practice, will be considered and analysed as a basis for advice on commissioning services. However, it is important to acknowledge that although a considerable amount of research has been carried out, its contribution is limited by the lack of development of appropriate conceptual frameworks (including diagnostic classification and thresholds for symptom severity and need) and well designed studies and trials. Hopefully this review will help to reduce the uncertainty, but there is still along way to go to obtain a clear picture of disorders of the bladder and appropriate services.

# 3 Sub-categories

Urinary incontinence as a whole does not have a specific code in the International Classification of Diseases (ICD). Details of the diagnostic codes of all relevant underlying conditions are shown in **Table 2**.

Code	Diagnosis
N31.0	Uninhibited neuropathic bladder, not elsewhere classified
N31.1	Reflex neuropathic bladder, not elsewhere classified
N31.2	Flaccid neuropathic bladder, not elsewhere classified
	Neuropathic bladder: atonic (motor, sensory)
	autonomous
	non-reflex
N31.8	Other neuromuscular dysfunction of the bladder
N31.9	Neuromuscular dysfunction of the bladder, unspecified
N32.2	Vesical fistula, not elsewhere classified (excludes fistula between bladder and female genital
	tract)
N39.3	Stress incontinence
N39.4	Overflow, reflex, urge incontinence
N82.0	Vesico-vaginal fistula
N82.1	Cervico-vaginal, uretero-vaginal, urethro-vaginal fistulae
R32	Unspecified urinary incontinence
	Enuresis not otherwise specified
R39	Extravasation of urine
F98.0	Non-organic enuresis

 Table 2: Relevant diagnostic ICD-10 codes.<sup>3</sup>

From the perspective of clinical management, particularly in primary care, LUT disorders are currently thought of as either a problem of storage or voiding (*see* Appendix 1). Here the notion of storage disorder includes incontinence but also the other commonly associated symptoms of urgency, frequency and nocturia.<sup>1</sup> Storage disorder includes the predominant sub-groups of patients with sphincter incompetence and overactive bladder. To a fair extent, these relate to the underlying categories of urodynamic stress incontinence (USI) and detrusor overactivity (DO), respectively. (The notion of voiding disorder includes bladder outlet obstruction with symptoms of hesitancy, straining, slow stream, spraying, terminal dribble and intermittency. It includes primarily the underlying condition of prostatic enlargement.) The division

between storage and voiding is useful, but not entirely coherent because, for example, chronic obstruction with retention of urine leads to overflow incontinence.

Storage symptoms represent an objectively defined element of normative need, as perceived by professionals.<sup>4</sup> However, there is variation in symptom severity and in the concept of normality in the general population. In this context especially, the definition of need for health care must take account of the impact on the individual. Impact is a concept we will define in two main ways: (i) overall or *general impact* using global terms such as 'problematic'; (ii) disabling or *specific* impact using *interference* with important area of life, including activities, feelings/well-being, quality of life and relationships. Symptoms and impact are indicators of the *health care need*<sup>5</sup> for therapeutic services, and may be applied to incontinence or storage symptoms as a whole. The unusual degree of stigma and coping attached to incontinence may lead this to be an underestimate of the true extent of health care need. The *felt need* for help is used here to indicate the likely motivation to use services assuming basic awareness of their existence.<sup>4</sup> It is indicated by the individual reporting that they sought or want help. In relation to symptoms and impact it represents the priority or extent of *health care requirement* for therapeutic services.<sup>6</sup>

Operation codes for procedures that may be carried out for conditions involving incontinence are shown in **Table 3**.

 Table 3: OPCS operation codes: relevant OPCS operation codes, 4th revision (April 1988 onwards).<sup>7</sup>

Code	Procedure
M51.1	Abdominoperineal suspension of urethra
M51.2	Endoscopic suspension of bladder neck
M52.1	Suprapubic sling operation
M52.2	Retropubic suspension of bladder neck
M52.3	Colposuspension
M53.1	Vaginal buttressing of urethra
M53.8	Tension-free vaginal tape insertion
M55.2	Artificial urethral sphincter insertion (female)
M56.3	Periurethral collagen injection
M64.2	Artificial urethral sphincter insertion (male)
M65.1	Endoscopic resection of prostate using electrotome
M65.2	Endoscopic resection of prostate using punch
M65.3	Endoscopic resection of prostate
P25.1	Repair of vesicovaginal fistula
P25.4	Repair of ureterovaginal fistula
A70.1	Implantation of neurostimulator into peripheral nerve (sacral nerve implant)

## 4 Prevalence and incidence

A literature search was carried out to identify all papers on the prevalence of urinary incontinence and related storage symptoms in the UK published since 1960. The electronic sources were Medline and Embase. Keywords employed were 'urinary disorders', 'epidemiology', 'prevalence' and 'UK' or 'Great Britain'. The search was limited to English language papers. Index medicus was searched for relevant publications between 1960 and 1966 using 'urinary disorders' and 'urinary incontinence' headings.

References from located publications were examined for further prevalence papers and an author search was also undertaken.

Thresholds for incontinence are based on a general consensus present in the UK literature. In essence this distinguishes minor or any leakage from moderate or monthly leakage whilst major leakage denotes a more severe level. Variations are grouped under these thresholds on the basis of either similar terminology (any, ever, yearly) or a notional average frequency  $\times$  volume (**Table 4**).

Minor (1)	Moderate (2)	Major (3)
any $\times$ leakage ever $\times$ leakage yearly $\times$ leakage	monthly × leakage any × damp/wet/soaked ever × damp/wet/soaked yearly × damp/wet/soaked	monthly × damp/wet/soaked weekly × leakage/damp/wet/soaked daily × leakage/damp/wet/soaked

Estimates for minor leakage for all adults average out at around 40% for women and 10% for men; for moderate incontinence at around 12% for women and 5% for men; and for major leakage at around 5% for women and 3% for men (**Figure 2**). Moderate incontinence shows an overall increase with age affecting around 5% in younger women and 20% in old age, compared to around 2% in younger men and 10% in old age. Major incontinence shows a similar but lower prevalence pattern. However, in women the pattern for minor leakage shows substantial increases across the reproductive period to a high peak around the time of menopause. This has no parallel with minor incontinence in men, which follows the same age-related pattern of moderate and major incontinence. The majority of studies in the UK show an increase in moderate incontinence after the age of 70, affecting around 17% of women and 12% of men. However, the prevalence in older people is probably underestimated in many cases because of exclusion of those in care homes and non-response bias.

The main methodological features of all UK studies are summarised in order of prevalence in **Table A2.1(a)**. It is most apparent that higher prevalence is associated with milder severity of incontinence both between and within studies. The average female to male ratio of prevalence for all studies was 1.9 but was higher in studies involving younger subjects (2.5) compared to those confined to old age (1.5). In order to identify methodological and other factors associated with the prevalence of urinary incontinence, univariate and multivariate meta-regression models were generated in relation to age, date, response rate, number of prompts and type of study, with prevalence weighted for study size. Models were generated separately in men and women for each severity rating using p<0.05 to indicate significance.

In addition to gender, severity and age, meta-regression identified significant associations with number of prompts and response rate. The length of time since the study was published was also significant for increasing prevalence. There was little apparent relationship with study region or sample type. In the early stages of research development, some learning and therefore increase in prevalence is to be expected. However, controlling for the number of questions or prompts on incontinence should take account of this to a large extent. Therefore, it is possible that a genuine increase has occurred over time. This would be consistent with known increases occurring to recognised co-morbidities for incontinence, e.g. obesity.

Recently, the focus has moved to include other significant storage symptoms (nocturia, urgency, frequency and bladder pain) within overall prevalence estimates. The effect is illustrated in a recent MRC study where monthly incontinence in women affected 20% whilst storage symptoms affected 39%. The prevalence also doubled for men from 9% to 20%.<sup>8</sup> Studies of storage disorder in older people suggest the

prevalence is similar in men and women and doubles between 70 and over 809. Increasingly in the future, services are likely to be oriented towards levels of storage symptoms as a whole.

The results of this review are consistent with studies of urinary incontinence from around the world. The prevalence of any incontinence across a variety of ages ranged from 10–71.9% for women and 3.4–19.6% for men. For moderate incontinence, the range was 6.5–46% for women and 8.5–15% for men (*see* Appendix 2).

Relatively few studies have included the other individual storage symptoms of nocturia, frequency and urgency.<sup>8,10–13</sup> Overall, there is some comparability between studies for each symptom but only nocturia is consistently defined across several studies (**Table A2.2**). Nocturia at the level of twice a night is reported consistently between studies and averages out at around 15% for men and women. It increases markedly between young and old, around four-fold in women and ten-fold in men. However, at age 75+ the prevalence of nocturia (twice a night) averages out similarly for men and women at around 35–40%.

Frequency was captured in several ways, length of interval between micturitions, number of micturitions in a day, as well as on the basis of change in pattern and without specification. Estimates for specified frequency suggest a slight overall increase with age in both men and women. There is inconsistency between studies as to whether the prevalence is higher in men or women. However, the largest and most recent study suggests slightly higher rates in women.<sup>8</sup>

Urgency was also defined in a variety of ways. Those that included expressions of 'difficulty' or 'inability' were grouped as more severe than those described in terms of 'hurrying' or 'having control'. Estimates for specified urgency suggest an increase with age, particularly old age, and slightly higher levels in women.

## Prevalence among elderly people in institutional care

In the UK, the prevalence of urinary incontinence is 2–3 times higher in populations in institutional care than elsewhere in the community<sup>9,14,15</sup> in line with studies from elsewhere in Europe.<sup>16,17</sup> In Britain, recent evidence suggests an overall prevalence of regular incontinence in institutional settings of around 40%, with estimates of 15–30% for those in residential homes, 30–60% for those in nursing homes and 30–70% for those on geriatric and psycho-geriatric wards.<sup>15</sup> The higher prevalence of urinary incontinence in institutional care is probably largely due to the selection of frail, incontinent individuals into this type of accommodation. Prevalence estimates are likely to vary between and within institutions over time due to differences in admission and management policies and as residents age. The threshold for defining incontinence tends to be higher in institutions because it relies on observations from carers rather than on self-reported incontinence. There is a strong correlation between the prevalence of incontinence and the level of dependency plus a suggestion of an excess observed prevalence associated with incontinence among psycho-geriatric patients (**Table 5**).

In institutions, almost half of those with urinary incontinence also experience faecal incontinence. This is a far higher proportion than in the general population, where only 1% of women aged 65 or over have regular faecal or double incontinence compared with 12% who have regular urinary incontinence.<sup>18–20</sup>

Incontinence is associated with dementia, stroke and problems of mobility and dexterity.<sup>21,22</sup> This may contribute to a tendency for staff to be more reluctant to treat incontinence as vigorously in older people as they would in younger people. It is worth noting that among all people aged 75 or more, only 20% of those with troublesome incontinence are reported as being cognitively impaired. Incontinence in older people is often a remediable condition and this age group is likely to benefit considerably from appropriate treatment. Furthermore, it has been suggested that dementia is no bar to achieving continence in elderly people.<sup>23</sup>

Among elderly people in residential and nursing homes it has been estimated that 87% of residents needed changes in the management of their condition and 57% of homes requested more help from the specialist services.<sup>24</sup>

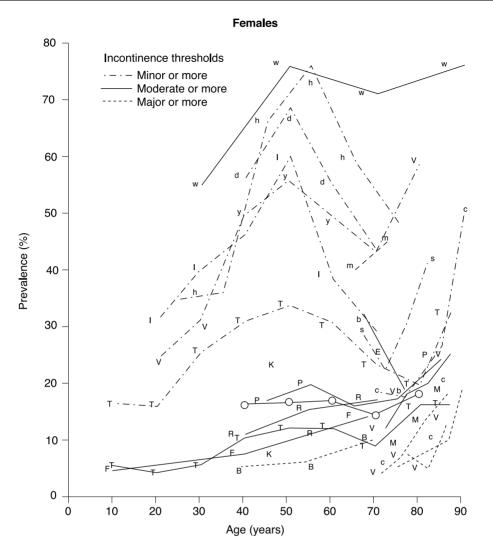


Figure 2: Prevalence of urinary incontinence by age, sex and severity (UK, 1960–2001).

## Prevalence in people with disabilities

The OPCS surveys of disability in Great Britain<sup>25</sup> estimate that 14.2% of all adults have a limiting and longstanding disability, which may relate to physical, sensory, intellectual and/or social functioning. The study looks at 10 main areas of disability, including continence. Among adults with any disability, 17% of those living in private households and 44% of those resident in institutions have a disabling problem with urinary and/or faecal incontinence.

The researchers calculated a severity score of overall disability for each adult in the survey with one or more disabilities and described a positive relationship between the prevalence of incontinence and the overall severity of disability score (**Figure 3**). As people age, the prevalence of incontinence rises and multiple disabilities also become more common, with a corresponding increase in the overall severity score. It is only among people within the most severe category of disability (score 9–10) that there is a

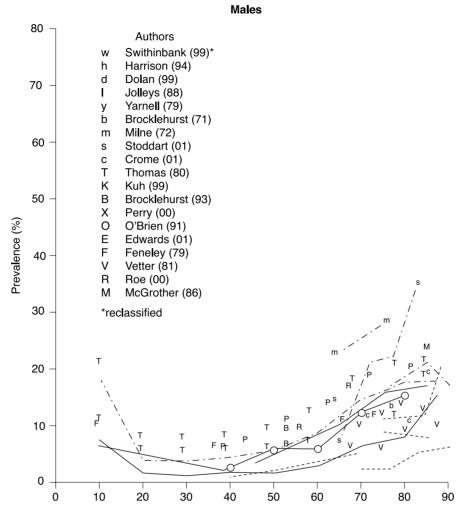


Figure 2: Continued

significant difference in the prevalence of incontinence between those living in their own households and in institutions (56% and 72% respectively).

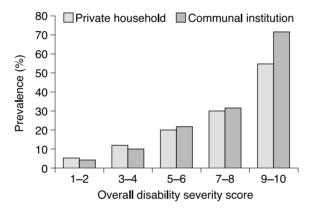
There is a paucity of information about incontinence in people with specific disabilities. A communitybased study found that survivors of stroke living in the community had double the prevalence of urinary symptoms of the non-stroke population (64% v 32%).<sup>22</sup> The prevalence among women with severe learning disability resembles that of older people in residential care more than the general population<sup>26</sup> (**Table 6**). Data from the Leicestershire Learning Disability Register shows that 23% of women and 16% of men with learning disability are wet at least once a week.<sup>26</sup>

Type of home	Urinary incontinence without faecal incontinence (%)	Total urinary incontinence with or without faecal incontinence (%)	Dependent (%)
Private nursing	30	63	70
NHS geriatric	31	58	61
NHS psycho-geriatric	28	65	47
NHS acute	21	30	35
Private residential	19	29	32
Local authority	21	35	26
Voluntary	6	10	17
Other	15	23	24
All types of home	23	41	39

**Table 5:** Prevalence of incontinence<sup>a</sup> and dependency<sup>b</sup> in older persons in residential care.<sup>15</sup>

<sup>a</sup> Incontinence: at least one episode of weekly wetting.

<sup>b</sup> Dependency: an additive score derived from ratings of mobility, washing/dressing and feeding.



**Figure 3:** Prevalence of incontinence in adults with disabilities by overall severity of disability and place of residence.

**Table 6:** Prevalence of urinary incontinence in women with learning disabilities compared with older people and the general population.

Study	Sandvik 1993 <sup>27</sup>	Peet 1995 <sup>15</sup>	McGrother 1996 <sup>26</sup>	
Subgroup	General population	Institutional care	Learning disability	
Definition	>drops weekly	leakage weekly	wet weekly	
Age group	- ·	Prevalence %		
40-49	3	_	16	
50–59	12	_	14	
60–69	6	22	27	
70–79	9	30	22	
80+	18	32	44	

## Health care need and requirement

In the UK, need for services is an important domain that relies on quality of life for disorders like urinary incontinence and other storage symptoms. This review suggests health care need should be defined in terms of the recognised *storage symptoms* having an *impact* on life. There is a large degree of consistency in the literature suggesting 'any' or 'minor' incontinence represents the lower threshold of abnormality. Impact includes general 'problems' and specific 'interference' with life. There is a fair degree of consistency in the literature suggesting 'mild' or 'little' impact represents the lower threshold of abnormality. Although impact is more subjectively defined than symptoms, it still represents an external norm rather than a felt need in Bradshaw's original sense of wanting help. Indicators of felt need identified in this review are any reported use of a relevant service, reported need for help or take-up of services when offered and represents the health care requirement or priority in the context of the overall health care need.

Urinary incontinence may interfere with activities of daily living, social activities, relationships, feelings, self-perception, general health and overall quality of life in a variety of ways.<sup>28–36</sup> Activities most commonly affected are shopping, visiting friends and sport. Travel becomes problematic, with initial avoidance of long journeys and eventually also of short journeys. Relationships may be affected, particularly sexual relationships since incontinence can occur during coitus.<sup>30</sup> Disturbance of sexual relations due to incontinence has been reported in 1.1%<sup>32</sup> and 0.1%<sup>33</sup> of community populations, i.e. in approximately 1–4% of those with incontinence. In clinic populations this proportion can be as high as 40%.<sup>35,36</sup> Incontinence tends to be more restrictive than stress incontinence.<sup>32</sup> Interference with activities, feelings and relationships is commonly reported in 1–5% of the population.<sup>8,28–31,37</sup>

Women tend to experience more bother or social restriction than men, but the prevalence shows only a slight increase with age. However, care is needed in interpreting studies of very elderly people, especially women, since non-response and admission to residential care lead to underestimation of the problem. Some people are able to modify their lifestyle to cope fairly successfully with incontinence, though the coping strategies may contribute to their becoming socially isolated.<sup>33</sup> Others experience shame, embarrassment, loss of self-esteem, anxiety and depression.<sup>35</sup>

Twelve UK studies<sup>8,9,18,28,37–44</sup> have addressed some aspects of the extent of need and are profiled in **Table A2.3**. Although there are variations in the definitions of need they are similar enough to allow some comparison. A minority of studies relate to storage disorder as a whole but most relate to incontinence. *General impact* was defined as a 'problem', 'a difficulty' or 'a bother'. Precise thresholds used had a marked effect on prevalence estimates. Four studies covering a range of ages identified a *problem* for 8–30% in women and 3.8–6.2% in men.<sup>8,40,42,45</sup> In old age, one comparable study estimated *difficulty* in control of micturition affected 12% of men and women aged 75+.<sup>9</sup> Three studies explicitly included a relatively mild problem/bother with incontinence which affected more people (17–44% of women of all ages and 17% of elderly women and 12% of elderly men).<sup>41–43</sup>

Estimates of *specific interference* with life also varied depending on the threshold used. Five studies across a *range of ages* estimated <2%–8.6% of women and <1%–2.9% of men experienced interference with their daily lives.<sup>8,18,28,37,40</sup> In *older* people similar interference was estimated to affect 5% of men and women.<sup>9</sup> However, a *little* interference with life affected substantially more people, *18%* of women and *12.2%* of elderly men.<sup>43</sup>

Reported consultation in primary care was estimated across a range of ages at 2.1-11.4% for women and 1.3-6.7% for men<sup>28,37,39,40,44</sup> and for older people at 5.1-6.2%.<sup>9,38</sup> More broadly defined use of health services was estimated at the higher level of 14% of women and 9.2% of men aged 65+.<sup>43</sup> Reported consultation confined to the last year was relatively low but was more prevalent than incontinence recorded by services.<sup>37,18</sup> Uptake of services offered was estimated across a range of ages at 6.1-9.2% of women and 3.4% in men and 4.4% for elderly men and women.<sup>9,28,39</sup> The levels of currently wanting help across a range of ages was 3.8% in women and in men at 4.4%.<sup>8</sup>

An association between the level of incontinence and level of impact or use of services has been demonstrated within the UK studies.<sup>18,37,38,41</sup> Amongst women, 69% of those with severe incontinence regard it as a problem compared with 55% with moderate and 27% with mild incontinence. In men the relationship was stronger: 86%, 65% and 27% respectively.<sup>43</sup> A similar relationship occurs with specific interference with life. The gender difference may suggest women adapt their lifestyle more than men.

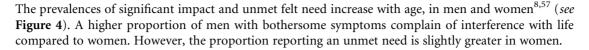
Reports in the UK are consistent with studies elsewhere in the western world in terms of overall impact,<sup>27,46–48</sup> consultation rates,<sup>29,31,46,48–52</sup> and relationship between symptoms and impact.<sup>29,31,53</sup>

Consultation reported directly by an individual is a far better measure than consultation recorded by a professional, which forms the basis of routine statistics. Reported rates vary considerably depending on the sample and the definition of incontinence. Between 9% and 32% of women with incontinence (2% to 7% of the total population) have spoken to their doctor about it.<sup>28,29,31,37,48,52</sup> Younger sufferers and those in full-time work are most likely to seek help.<sup>30</sup> Consultation rates increase with increasing severity and impact of incontinence but the association is not strong. In Reker's study,<sup>31</sup> 44% of women experiencing incontinence at least once a week sought help compared with 22% with less frequent incontinence. Even among women reporting worry about their symptoms, only a third had spoken to a doctor and among women reporting more severe restriction to their social life, only half had consulted a health professional. The relationship is stronger for use of aids: 73% of elderly people with severe incontinence used aids compared to 17% with milder incontinence.<sup>54</sup>

A major reason for not seeking professional help is a misconception of the aetiology and natural history of the condition. Many women view incontinence as the inevitable result of childbearing and ageing and consider that seeking medical attention is an inappropriate use of consulting time.<sup>55</sup> There is a general lack of awareness of the range and efficacy of treatments.<sup>28,48</sup> Some do not consult a doctor because they fear surgery.<sup>55</sup> Unfortunately, these views are often reinforced by health professionals.<sup>56</sup>

Condition	(rating)	Definition	Prevalence %				
			Women	Women		Men	
			all ages	elderly	all ages	elderly	
Impact	(>mild)	problem/bother/ difficulty	8–30	12	3.8–6.2	12	
		interference with life	<2-8.6	5	<1-2.9	5	
	(mild)	mild problem	17-44	17	_	12	
		a little interference	_	18	_	12.2	
Felt need	('met')	primary care consultation	2.1–11.4	6.1–6.2	1.3–6.7	5.1–6.2	
		use of any health service	_	14	_	9.2	
		consultation in last year	2.1	_	_	-	
		routine statistics of use	<2	_	<1	_	
	(unmet)	uptake on offer	6.1–9.2	4.4	3.4	4.4	
		currently want help	3.8	_	3.8	_	

 Table 7: Estimated prevalence of impact and felt need in relation to storage disorder/incontinence from UK studies 1960–2001.



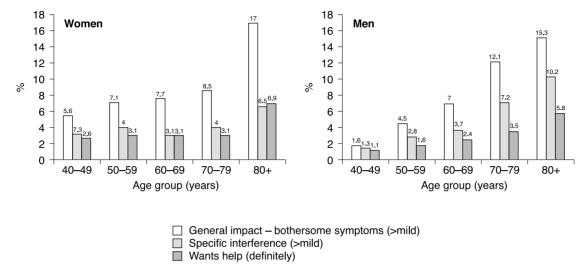


Figure 4: Prevalence of significant impact and unmet felt need in adults by age (storage symptoms).

There is limited information concerning the prevalence of incontinence among ethnic minorities in the UK. It has been suggested that white women are at greater risk<sup>58</sup> but others have found no difference between ethnic groups.<sup>59</sup> One small study in London found that fewer than 50% of women with incontinence from a range of ethnic minority groups sought help.<sup>60</sup> However, only Muslim women had a strong preference for female doctors. In general it is recognised that South Asians within the UK make greater use of GP services and less use of specialist care than the general population.<sup>61–64</sup>

In the USA prevalence rates for Caucasian women appear consistently higher than Afro-American women,<sup>65–68</sup> but consultation rates are lower.

## Prevalence by type of incontinence

In women, the most common conditions underlying incontinence are detrusor overactivity and urethral sphincter incompetence. Several studies have shown a relationship between these disorders and the symptoms of urge incontinence (leakage associated with a strong urge to void) and symptoms of stress incontinence (leakage during coughing, laughing, exercise or other physical exertion) respectively. Studies relying on standardised questions have shown moderate validity.<sup>69,70</sup> In Lagro-Janssen's study,<sup>69</sup> for example, the sensitivity and specificity of pure urge incontinence for detrusor overactivity diagnosed by cystometry are 61% and 95% respectively; and 78% and 84% of pure stress incontinence for urodynamic stress incontinence. Although symptoms of urge and stress incontinence are not sufficiently accurate predictors to be clinically diagnostic for surgical interventions, they provide markers with which to examine the different epidemiological patterns of the two leading bladder disorders.

A range of studies report on the symptomatic diagnosis of incontinence in women (**Table A2.4**). Again, the prevalence values are wide-ranging and depend on the precise definition used and the age of the population studied.

The prevalence of stress incontinence increases gradually through the reproductive years to a slight peak around the time of the menopause, followed by a possible decline. In contrast, the prevalence of urge incontinence steadily increases with age and is most pronounced in old age. These studies suggest that, to some extent, stress incontinence undergoes some degree of remission after the menopause, possibly through genuine recovery and/or through adaptation and treatment. Urge incontinence contributes primarily to the overall increase in incontinence in old age.

Overall, stress incontinence is the most prevalent type of incontinence reported by women (**Figure 5**). Stress and urge incontinence occur in combination in around a third of cases in women overall and increasingly in older women. The extent of overlap of both disorders in old age may contribute to the preponderance of severe incontinence at this stage.

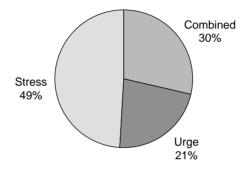


Figure 5: The overall pattern of incontinence by type of incontinence in women.<sup>37</sup>

The predominant type of urinary incontinence in men is urge incontinence. The most common condition underlying this is detrusor overactivity, with or without prostatic enlargement. Urge incontinence accounts for most of the overall increase of incontinence with age in men.

## Incidence and natural history

The *incidence rate* represents the number of new cases developed in a disease-free population in a year.\* In order to estimate the incidence rates and natural history of a condition it is necessary to conduct repeated surveys on the same large random sample of the population over several years. For this reason, very few prospective studies are available. Retrospective studies are subject to problems with recall. Episodes of incontinence may be forgotten or there may be difficulty recalling the correct year of onset, especially in the distant past. These reports are therefore likely to underestimate the true incidence, especially among older persons who may have memory defects. The only advantage of retrospective studies is that they readily provide a perspective on the pattern of incidence over a lifetime (**Figure 6**). The overall incidence of incontinence mirrors the pattern of prevalence in younger women. It highlights two distinct peaks in incidence, one in the early reproductive years and another around menopause. There is also a third peak in old age.

**Table A2.5** summarises three key prospective studies of the incidence of urinary incontinence in adults living in the community, each carried out using sound methodology on a large and representative study population.<sup>72–74</sup> Like prevalence, incidence is very dependent on the definition and severity of the

<sup>\*</sup> Incontinence incidence rate = number of new cases of incontinence at the current assessment/number of respondents who were continent at the previous assessment (non-cases).

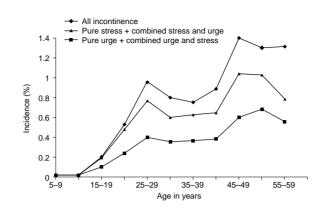


Figure 6: Incidence of urinary incontinence in women by age.<sup>71</sup>

symptom being studied, making comparison between studies difficult. Broadly, however, these studies indicate that 6–22% of middle-aged and older women who are previously continent develop incontinence each year. The incidence rates are higher where the study population is older and when the definition of symptoms studied is milder. The incidence rates in men are about half those in women, which is consistent with men's lower prevalence rates.

The *remission rate* denotes the number of cases remitted from a diseased population in a year and is not directly comparable with incidence rate.\* Results from the prospective studies<sup>72–74</sup> show remission rates in women ranging between 9% p.a. and 42% p.a. The remission rates are lower where the population is older and incontinence more severe, thus contributing to the cumulative effect of incontinence with age. Remission rates in men are higher than in women, estimated in one study at 30% compared to 12% in women.<sup>72</sup> The MRC programme estimates incidence rates for storage disorder at 15.4% p.a. for women and 12.7% p.a. for men and remission rates at 23.1% p.a. for women and 30.4% p.a. for men aged 40 and over.<sup>72</sup>

When continent people first become incontinent, they are most likely to develop a mild form of incontinence. Figure 7 shows the changes in continence and severity of incontinence for 726 women during the first year of study<sup>72</sup> (Table A2.6). A large proportion of mild and moderate incontinence appears to fluctuate in severity but severe incontinence is relatively persistent. The pattern in men is similar, with higher remission rates.

#### Associated factors

Incontinence is more common in pregnancy.<sup>75</sup> Although the problem is generally self-limiting, it may predispose women towards incontinence later in their lives, such as during a subsequent pregnancy or as they age.<sup>76</sup> Several studies have shown that nulliparous women are less likely to develop incontinence than parous women and that increasing parity is a risk. However, the precise relationship between pregnancy, parity, childbirth and incontinence needs further investigation. Similarly, there are inconsistent findings in the literature about the role of oestrogen loss around the menopause and hysterectomy in the development of incontinence and other urinary symptoms.

<sup>\*</sup> Incontinence remission rate = number of recovered cases of incontinence at the current assessment/number of respondents who were incontinent at the previous assessment (cases).

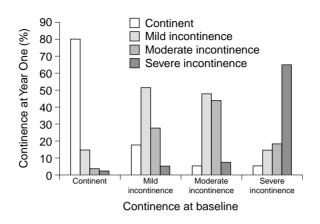
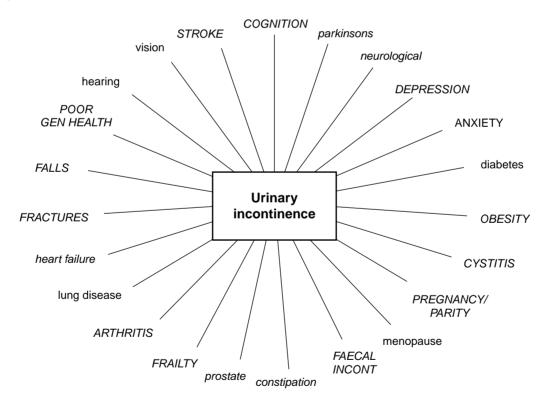


Figure 7: Changes in self-reported incontinence after one year of follow-up in women.<sup>72</sup>

There is stronger evidence for the association of incontinence with obesity and with cognitive and functional impairment, especially mobility problems. Prostatectomy is an established iatrogenic cause of male stress incontinence. Comorbidities identified in a review of the literature<sup>42,74,77–85</sup> are shown in **Figure 8**.



CAPS = consistent factors *Italics* = prospective predictors

Figure 8: Co-morbidities for urinary incontinence.

Well-controlled analyses of potential lifestyle risk factors for the development of urinary incontinence are limited.<sup>77</sup> Most of the data have been derived from cross-sectional studies of volunteers and clinical subjects. Early indications from the population-based cohort study within the current MRC programme suggest adherence to a healthy diet may offer protection.

# 5 Services available and their costs

## **Primary care**

The organisation of continence services affects patient outcomes and thus the mode of delivery in continence provision is an important factor in delivering positive outcomes.<sup>86</sup> At present, primary continence care provision shows great variation across the country and is often fragmented. There are wide variations in nursing input and a lack of continuity of care. Care may be provided by one or more health care professional, with referral from one to another, but there are no consistent care pathways. When individuals first present with incontinence or lower urinary tract symptoms, they tend to see a GP, despite the fact that continence advisors have been in existence for over 20 years in many areas. Primary care may then be provided by a continence advisor, continence link nurse, practice nurse, district nurse or health visitor.

## Continence care pathway in primary care

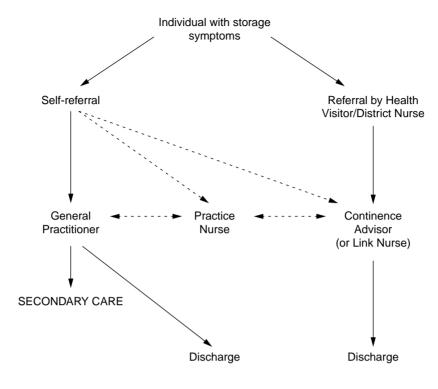
The two key continence service providers are described below in terms of role, access to provider, training and reasons for variation in care provision and costs (**Figure 9**).

## General practitioners

General practitioners (GPs) are the most likely first point of contact when patients seek formal help for their incontinence.<sup>40,87</sup> The GP usually carries out the clinical assessment, screening, giving advice, prescribing medication and arranging referral to secondary care. As with other aspects of general practice, GPs have a gate-keeping role in continence provision. They may refer their patients to other health professionals in primary care, such as a continence advisor, practice nurse or district nurse or, more commonly, to a specialist in secondary care. GPs provide this service without having undergone essential specialist training in the management of patients with urinary symptoms, as this is not available. Access to GPs is usually through self-referral.

The estimated cost of a GP consultation is £18.<sup>88</sup>

Inadequacies in incontinence care have been acknowledged for some time. In 1983, the Incontinence Action Group published a report<sup>89</sup> which identified 'the huge gap which exists between available knowledge of the causes and methods of management and that which is actually known to practising nurse and doctors.' In their review of the evaluation and treatment of women with urinary incontinence in the primary care setting, Walters and Realini found that urinary incontinence can be diagnosed accurately by family physicians using basic tests.<sup>90</sup> A later study found that outpatient geriatric assessment units were better than physicians in community based practices at identifying patients with both mild and severe incontinence.<sup>91</sup> There is evidence that there is a need for further education of health care professionals.<sup>92</sup> Brocklehurst found that less than 25% of patients with urinary incontinence were given a full examination by their GPs.<sup>40</sup> Deficits in the knowledge of GPs about urinary incontinence were found by Jolleys and



Solid lines represent most common referral pathways Broken lines represent least common pathways

Figure 9: Flow diagram of typical care pathways for individuals with storage symptoms.

Wilson in a survey of 1284 GPs.<sup>93</sup> They also found that GPs lacked confidence in their abilities to diagnose and manage urinary incontinence, although this lack of confidence was not related to length of practice as a GP. In an analysis of incontinence in the community, the action taken by many GPs was found be suboptimal, with considerable geographical variation.<sup>94</sup> Fewer than 5% of those who consulted a doctor in this survey were referred to a nurse or incontinence clinic. It also suggested that medication was often prescribed without clinical examination and probably without a diagnosis being made. In Briggs' study<sup>95</sup> 42 of 101 general practitioners surveyed never used the service of a continence advisor for older patients although the service was available to them.

## Nurses involved in continence care provision

A common model of care provision comprises a service led by a team of continence advisors, which, in turn, has a team of link nurses, largely drawn from the pool of district nurses. Some health care trusts, often covering a large geographical area, rely on a single continence advisor, with no link nurse system. Other trusts have teams of continence advisors offering expertise in the care of individuals who have, for example, learning disabilities or mental health problems as well as urinary symptoms.<sup>96,97</sup> However, continence advisors often work in isolation without expert medical support.<sup>96</sup> The majority of health authorities now have the services of a continence advisor.

Continence advisors are trained to carry out clinical examinations and complex holistic assessments to initiate treatment for individuals with urinary symptoms. The link nurse may also be able to perform some or all of these duties. A few continence advisors also perform urodynamic investigations. The specific role of each link nurse shows considerable variation throughout the country. Some continence advisors have a limited clinical remit, leaving all, apart from the most complex, clinical care to the nurse link team. Apart from clinical practice, the role of the continence advisor is to provide management, advice and education, research and audit, to co-ordinate the service and support the link nurses. Some may also have the responsibility of holding the continence budget. The amount of time spent in each activity varies enormously between continence advisors. Geographical variations in the time spent in core activities and in the type of service offered result in inconsistencies in care provision.

Training of the continence advisor includes completing an ENB 978 course. Various continence modules are available in addition, but there are geographical inconsistencies. Access to the continence advisor may be via the GP, district nurse, link nurse, practice nurse, health visitor or through self-referral.

Cost of a continence advisor – Grade F (£22 302–£27 039), G (£24 903–£28 854) and occasionally H (£27 819–£32 326).

The lack of knowledge amongst medical staff regarding urinary incontinence outlined above is mirrored within the nursing profession. In her study of nurses' attitudes towards incontinence, Cheater found that there was a need for increased education of nurses in relation to preventative care and the therapeutic and rehabilitation aspects of continence promotion.<sup>98</sup> The same author also found that qualified nurses lacked the knowledge to complete an adequate assessment of incontinent patients.<sup>99</sup> Health visitors wanted more information in a training needs analysis by Burnet *et al.*<sup>100</sup>

## Secondary care

The following groups currently provide secondary care:

- core medical professionals
- nurses
- allied health care professionals (physiotherapists/occupational therapists)
- allied diagnostic specialist professionals.

The role of each of these groups will be briefly outlined in terms of professionals involved, variation in care provision and costs.

## Core medical professionals

In the UK the vast majority of secondary care is provided from acute hospitals by consultant-led services. Most of these operate a traditional referral pathway directly from the GP and some allow referral from specialist nursing services. Unfortunately, many specialist nursing services are located in community trusts whereas hospital specialists became based in acute trusts when these were formed. This led to the further fragmentation of continence care. The formation of Primary Care Trusts may lead to further isolation of community services from those in secondary care. Consultant-to-consultant referral may also occur where the skills needed to deal with patients do not exist within a consultant's own service. Such tertiary referrals previously required GP approval, but the need for this appears to have reduced. There are direct referral pathways to urologists or gynaecological oncologists from specialities when life-threatening conditions such as renal or genital tract cancer are discovered. There are also facilities for frail elderly individuals to be specifically referred to physicians for the care of the elderly; such referrals may originate from other

secondary care specialists dealing with urinary incontinence. The trend for increasing sub-specialisation is evident in gynaecology. There are at present six recognised sub-specialty training rotations in urogynaecology, to which more are likely to be added in the near future. Such sub-specialisation has been recognised as desirable following the publication of data concerning the results of operations conducted by general gynaecologists when compared with the published results of interventions from research studies.<sup>101</sup> Urologists have also begun to recognise the need to develop their input into female urology.

Services have often been developed because of the interest of individual practitioners, with little strategic overview in any location, rather than in response to an identified need of the local population. Continence services led by physicians for the care of the elderly in particular have a large regional variation. Geriatrician membership of the International Continence Society, UK, for example, numbers approximately 20 of a total consultant population of over 700. Each of these medical specialties tends to work in isolation and care pathways vary similarly between specialties. Some regions may have clear linkage and referral pathways. There is also great variation within each medical specialty in terms of services and interventions provided. All specialists provide access to diagnostic services, behavioural therapies, medical interventions (including drugs) and surgery. There is little appreciation of the desires or needs of users in the design or delivery of secondary care services. With the advent of national service frameworks and the NHS Plan this is likely to change, with user and carer involvement becoming central to future service planning and delivery.

The percentage time that each specialty devotes to incontinence management may be calculated indirectly and hence cost calculations can be made. The Continence Foundation has estimated the cost of both urinary and faecal incontinence to an average primary care group (PCG) of 102 000 people to be approximately £737 000 per year. Similarly, the cost to the NHS in England has been estimated at £353 595 000 per year; and a total of £423 467 000 per year for the UK. This takes into account the time and services of both primary and secondary care resources but only the salary costs of staff.<sup>102</sup>

#### Nurses

The Royal College of Nurses sees clinical nurse specialists in continence care as an essential part of continence services, able to give cost-effective expert care, advice and treatment. As first line referral for people with incontinence, their services compare favourably to hospital consultants.<sup>103</sup> Hospital continence nurse specialists may originate from any of the incontinence-based backgrounds, notably from urology or gynaecology. They are, however, an ill-defined entity throughout the specialties. Within certain specialties such as urology, they may have a limited remit in continence care. Often they have a combined role in performing urodynamic studies and providing a service to the patients under the care of their department. Some specialist nurses within hospital have a remit to serve the entire hospital. There is a wide variation in the degree of collaboration between nurses from the different specialties and between hospital- and community-based specialist nurses. However, a recent survey of continence nurses suggested that the majority had both hospital and community responsibilities.<sup>104</sup> The referral pathway to these nurses is through any of the consultants from the incontinence-based specialties and, for those with a hospital-wide remit, from nursing or medical staff within the institution. The services tend to be consultant-led with the nurses providing the majority of continence care.

The differences between continence nurse specialists and continence advisors are ill-defined. Historically, providers of continence care in secondary care are involved in staff education and training, providing expert advice to staff and direct care to patients, often with involvement from an interested medical consultant. The role of the continence nurse specialists is currently variable and has been outlined in the previous section. The type of services provided includes patient assessment, diagnosis and conservative intervention such as bladder re-education and pelvic floor re-education therapies. Depending upon the role of the nurse within each department and the wider educational and training role, such nurses may be of varying grade. Nurse specialists are most often employed as a G grade (£24 903–£28 854); others may be

either F ( $\pounds$ 22 302– $\pounds$ 27 039) or even E ( $\pounds$ 18 212– $\pounds$ 22 387). The lower grade nurses tend to have a role limited to their host department and may spend a limited amount of time in continence care delivery.

## Other allied health care professionals

## Physiotherapists

Although continence care in the community is largely provided by nurses, the situation is different in secondary care. In this setting, care may be provided by either nurses or physiotherapists. Both may receive referrals from the community or hospital clinicians. Traditionally, assessment and conservative treatments used to be administered by physiotherapists, who may or may not have had a particular interest in the pelvic floor. They have been superseded by physiotherapists who do have a special interest in the pelvic floor and incontinence. More recently, the role of the physiotherapist in secondary care has been supplemented by the continence nurse, who has been trained in the management of incontinence and pelvic floor problems. One of the reasons for this is that the only remit for the nurses is incontinence and so they can be based in the relevant clinical department. This encourages a closer working relationship, especially between clinician and nurse. This is more likely to happen in the larger units where there is a greater workload. The vast majority of physiotherapists have a more general role so tend to be based in their own departments. The result is a variation in the continence service, largely determined by local circumstances. National average salary, senior 1 grade: £26 148.

## **Occupational therapists**

Occupational therapists may be involved in continence care provision by advising on techniques to improve function, or aids to maximise an individuals ability in self-toileting, thereby avoiding incontinence. They may recommend modification to clothing or alternatives to the toilet that will help to maintain continence. National average salary, senior 1 grade: £26 148.

## Allied diagnostic specialist professionals

Certain services may have access to specialists in other disciplines who are involved in the delivery of continence care, for example, uro-radiology, neuro-urology and rehabilitation physicians. Often these people exist in specialist centres and their services have evolved in an unplanned fashion, rather than as a result of any coherent plan for a continence service. In some areas, the services provided by such professionals may be provided by core specialists within urology or gynaecology.

## Summary

Division of care between professionals is complex, with varied models of service around the country. Patients may present to GPs or go directly (or indirectly) to continence nurses in the community. They may be treated extensively within primary care with behavioural and medical therapies or be referred at an early stage to specialists, including neurologists, geriatricians, urologists and gynaecologists. In relation to health service pathways for incontinence, most younger women are referred to gynaecologists whereas most older men and women are referred to physicians for the elderly; whilst for voiding problems most men are referred to urologists.

Continence nurses of various kinds play a considerable role in managing the problem but the nature and extent of provision is very variable across the country. Community nurses are often the first port of call for

patients with incontinence. They may make the initial in-depth assessment and are often involved in providing some degree of behavioural therapy for the common disorders and long-term aids for intractable conditions. The role of the GP in assessment and management of the underlying condition is hampered by lack of information concerning the long-term natural history of bladder problems and the lack of an integrated specialist service.

## Treatment in primary care

Treatment for urinary incontinence in both primary and secondary care has been the subject of a number of World Health Organization sponsored international conferences. The available data concerning treatments has been reviewed by a number of committees and recommendations published.

## Conservative therapies

#### Pelvic floor muscle training

Pelvic floor muscle training (PFMT) is the most commonly recommended physical therapy treatment for women with stress incontinence. It is also used in the treatment of women with mixed incontinence, and less commonly for urge incontinence. PFMT involves the voluntary contraction and relaxation of the levator ani muscle, which supports the vagina, bladder and urethra and which contributes to the skeletal muscle component of the urethral sphincteric mechanism. The goal of these exercises is to increase the strength and endurance of the levator, thereby enhancing the force of urethral closure under certain conditions, such as with a sudden increase in abdominal pressure.

Although the use of PFMT is the main non-surgical treatment for women with mild to moderate stress incontinence, there has been little research into how pelvic floor exercises should be taught and there is wide variation in the elements of teaching such as frequency of training, number of repetitions, duration and quality of contractions and exercise period reported in studies.<sup>105</sup> Prior to PFMT, a woman should be assessed by a person with skills in the assessment and training of pelvic floor muscles to ensure that a correct pelvic floor muscle contraction is being performed, and to determine if any facilitation techniques or adaptations are required to the recommended training programme.<sup>106</sup> On the basis of extrapolation from exercise science literature, PFMT programmes should include three sets of 8 to 12 slow velocity maximal voluntary pelvic floor muscle contractions sustained for six to eight seconds each, performed three to four times a week and continued for at least 15 to 20 weeks.<sup>106</sup>

Not all women are able to perform pelvic floor exercises correctly and so may require instruction and supervision from a nurse or physiotherapist. Adjuncts such as biofeedback and electrical stimulation are also commonly used with PFMT. Biofeedback is most commonly employed when using a perineometer to measure pelvic floor muscle strength. The use of electrical stimulation in the treatment of incontinence is described in detail by Laycock.<sup>107</sup> Use of this mode of treatment has increased in recent years, partly due to the introduction of portable equipment. The technique has been used in both neurologically and non-neurologically impaired individuals to manage both bladder and urethral dysfunction. Electrical stimulation is usually given to mimic a normal pelvic floor muscle contraction and is a treatment option for patients who are unable to produce a voluntary contraction or only a weak contraction. Such electrical stimulation recruits muscle fibres. Having been made aware of the specific pelvic floor muscle activity by means of electrical stimulation, the patient then tries to join in and reproduce the contraction. Naturally, these adjunctive treatments do require nursing or physiotherapy input.

More recently, vaginal cones have been used as an alternative form of PFMT. The use of weighted vaginal cones to assess and train pelvic floor muscles was first reported by Plevnik.<sup>108</sup> The cones are the

same size but are of different weights, usually five. When a cone of the appropriate weight is inserted into the vagina, it tends to slip out. This feeling of 'losing the cone' provides a sensory feedback which makes the pelvic floor contract around the cone retaining it. This principle can be used to exercise the pelvic floor muscles correctly.

Therapies to strengthen the pelvic floor have the advantage over other therapies in that they have no physical side effects or morbidity. Rational use of these therapies may offer treatment to women who would or could not undergo more invasive treatments.

#### **Bladder retraining**

Bladder retraining is the most commonly used behavioural treatment for patients with overactive bladder symptoms. Bladder retraining can successfully be taught and monitored in a primary care setting, but has also been employed as part of an in-patient programme for urinary incontinence. It relies on three basic concepts: (1) education, (2) voiding schedule and (3) positive reinforcements.<sup>109</sup>

Education emphasises the voluntary control over motor and sensory impulses. Distraction techniques to control urinary urgency are also incorporated. The voiding schedule includes mandatory voiding at specific intervals. These intervals are gradually extended until a reasonable time between voids is established.

## **Caffeine restriction**

Dietary advice regarding the restriction of caffeine is often given. There is evidence that theoretically supports its association with bladder overactivity.<sup>110</sup>

#### Fluid advice

Drinking excessive amounts of fluid, especially at night, may contribute to a patient's symptoms of frequency and nocturia. It may be appropriate in such circumstances to advise some sort of fluid restriction.

#### Weight reduction

There are no data on the relationship between urinary incontinence and obesity in males. In females, however, there is good evidence for a positive association of stress urinary incontinence and body mass.<sup>111,112</sup> Obese women should, therefore, be advised to lose weight.

### **Relief of constipation**

Subjects who report urinary incontinence are more likely to report constipation. Faecal impaction can lead to urinary retention, and there have been conflicting reports of an association between incontinence and constipation.<sup>7,113</sup> It would seem sensible to advise all patients, not just those with constipation, to eat a high fibre diet.

#### Smoking

An association of bladder problems with cigarette smoking has been identified for both men and women.<sup>114–117</sup> However, there are clearly many more convincing arguments for not smoking.

## Drug therapy

Drug therapy for urinary symptoms is mainly aimed at patients with detrusor overactivity (DO). Bladder contractions are mediated by the release of acetylcholine to act on muscarinic receptors in the bladder. Most drugs for detrusor overactivity work at least in part by blocking these receptors. The most commonly used drugs today are oxybutynin and tolterodine. Other drugs include trospium chloride, flavoxate hydrochloride, propiverine hydrochloride, imipramine, desmopressin and oestrogens. All of the currently available drug therapies have side effects that limit their use. At present most secondary care sites do not have the resources to provide effective behavioural therapies and so there is a reliance on drug therapy alone. The vast majority of drug prescribing occurs in the community.

All of the above interventions can be delivered in primary care, but need time and positive reinforcement.

## Continence aids

A wide variety of continence products are available in the UK, from the NHS, over the counter and by mail order,<sup>118–121</sup> but accessibility still remains a problem. Continence aids may be divided into (1) containment devices such as absorbent pads, penile sheaths and bed sheets; (2) conduction devices such as catheters; (3) occlusive devices such as clamps and urethral plugs; and (4) intravaginal devices which support the bladder neck. These aids may be used in individuals with intractable incontinence, in cases where other treatments have failed, when alternative treatments such as surgery are inappropriate or for patient preference. The product used should be tailored to the individual and all of these products are used for both the long and short term. Absorbent pads and pants are probably the most commonly used aids and are, for many, the first method of control. There are a large variety of types available. Occlusive devices and devices to support the bladder neck tend to be used the least.

In an evaluation of health interventions by primary health care teams and continence advisory services, Roe *et al.*<sup>122</sup> reported that the majority of people with incontinence felt that health services for sufferers could be improved by the supply of continence products. The most recent Department of Health Guidelines<sup>119</sup> recommend that the initial assessment of a person's continence needs at primary care level should include assessment of the need for appropriate continence products. There should be a range of pads available in all categories, consideration should be given to patient choice, there should be periodic re-assessment of those receiving long-term supplies, the provision of pads should be available equally to anyone in the geographical area, regardless of where they live, and pads should be provided in quantities appropriate to the individual's continence needs.

## Treatments in secondary care

Initial treatment of bladder problems, following an assessment in secondary care, is little different from that offered in the primary care setting. Secondary care may offer greater experience in terms of adjustment and experience with drug therapy and combinations of conservative techniques. Surgical intervention is clearly the role of secondary and, in the case of certain specialist areas, tertiary care. In secondary care the treatment of symptom clusters such as frequency, urgency, nocturia and urge and stress incontinence often gives way to treatment of underlying pathophysiology. The common conditions being diagnosed are urodynamic stress incontinence (USI), detrusor overactivity and bladder outflow obstruction. These are diagnosed using a series of invasive techniques termed urodynamic investigations based on definitions from the International Continence Society.<sup>123</sup> Symptoms have not been found to predict the underlying diagnosis accurately,<sup>124–131</sup> hence the need for investigation. Not all patients require urodynamic investigation

in order to make a diagnosis or before implementing treatment, but there is a consensus of opinion that such investigation should be performed prior to surgery. The main argument for urodynamic investigation is that it avoids unnecessary surgery in a woman complaining of stress incontinence, where the cause of urine leakage is due to detrusor overactivity and not bladder neck descent or urethral sphincter incompetence.<sup>132–134</sup>

## Surgery for incontinence

The vast majority of surgery performed in the UK is for urodynamic stress incontinence, a condition in which the bladder sphincter mechanism has failed. After behavioural and pelvic floor therapies have been tried in either primary or secondary care, the next line of treatment is often surgery. The aim of surgery is to increase closure pressure within the urethra and so prevent urinary leakage when the pressure within the bladder rises (such as when the patient coughs or exercises). The commonly performed operations include colposuspension, needle suspension, bladder sling, anterior repair and urethral buttress, Marshall-Marchetti-Krantz (MMK), all of which are usually performed under general anaesthesia, and injection of collagen or synthetic material into the bladder neck, which can be performed under general, regional or local anaesthesia. The aim of these injectables is to bulk up the junction between bladder neck and urethra, increasing pressure transmission and causing a partial obstruction. This technique is particularly useful in frail or elderly patients where more major operations are not possible. Colposuspension is still widely regarded as the gold standard surgical procedure, although tension-free vaginal tape (TVT) insertion, a new sling procedure, is rapidly gaining popularity and has the advantages of being performed under regional or local anaesthesia. There is still some uncertainty over the mechanisms of cure for some of these surgical procedures. Colposuspension, needle suspension and the MMK procedure aim to stabilise the bladder neck, so that abdominal pressure is equally transmitted to bladder and proximal urethra, and also to increase the urethrovesical angle. The older sling procedures also elevate the bladder neck, whilst the TVT insertion is thought to cause kinking of the urethra during an increase in abdominal pressure. The anterior colporrhaphy is no longer recommended as a sole procedure for the treatment of stress urinary incontinence.135

Men may also suffer with stress incontinence, although far fewer than women. Some may require insertion of an artificial urethral sphincter to treat their problem. Rarely, women may also need an artificial sphincter. A small number of surgical procedures are performed for other types of incontinence. Severe cases of detrusor overactivity in both men and women can be treated with a sacral nerve implant, which is expensive. Very occasionally there are cases of detrusor overactivity which fail to respond to all conservative interventions and surgery may become necessary. Techniques include urinary diversion, augmentation cystoplasty and detrusor myomectomy. These are complex surgical procedures, associated with not insignificant morbidity and should only be considered as a last resort.

## Health care utilisation

## Consultation

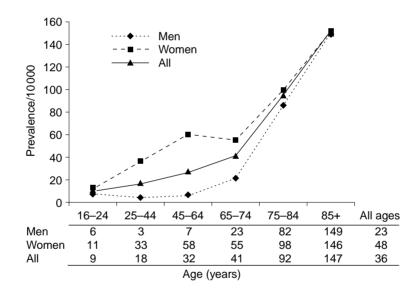
The most recent available data for urinary incontinence consultation in primary care was obtained from the Fourth National General Practice Morbidity Survey 1991–1992<sup>136</sup> on the basis of the ICD-9 codes listed in **Table 8**. The survey involved a representative cross-section of practices in England and Wales. The consultation rates were calculated using denominator data from the 1991 census. The numerator for *consultation rates* was the number of consultations for urinary incontinence during 1991/92. The number

of *patients* forms the numerator for *patient rates* consulting with urinary incontinence during the same period.

**Table 8:** ICD-9 codes for urinary incontinence included in the NationalGeneral Practice Morbidity Survey 1991–1992.

Diagnosis code from ICD-9	Description
788.3	Male and neurogenic urinary incontinence
625.6	Female stress urinary incontinence
307.6	Non-organic incontinence

The recognised level of patients presenting to primary care with urinary incontinence in 1991–1992 was  $36/10\ 000$ .<sup>136</sup> For people aged 40 or more, these rates are considerably lower than estimates based on consultations reported by patients themselves  $600/10\ 000\ (40+)\ (610/10\ 000\ for\ men\ and\ 650/10\ 000\ for\ women)$  identified by the MRC Incontinence Study. The difference may be due to urinary incontinence not registering as a presenting complaint. The sex and age pattern of distribution of urinary incontinence in primary care is consistent with that in population studies, with the rate being appreciably higher in women than men and increasing with age in both sexes (**Figure 10**).



**Figure 10:** Patient rates consulting for urinary incontinence per 10 000 population by age and sex in general practice in England and Wales 1991–1992.<sup>136</sup>

The total consultation rate for urinary incontinence in general practice was 54 per 10 000 population, with women consulting almost twice as often as men (**Table 9**). Among these patients, the average number of consultations per incontinent patient was 1.5, with similar levels in men and women, young and old.

In a typical Primary Care Trust with 150 000 population, 25 900 patients aged 40 and over with storage symptoms would be expected to be present at any one time, based on population studies. In the course of a year 6700 people will develop a condition worthy of assessment, whilst 5154 prevalent cases are likely

Sex	Age (years)							
	16–24	25–44	45-64	65–74	75–84	<b>85</b> +	All ages	
Men	8.4	6.1	10.8	40.8	153.4	202.0	36.9	
Women	16.0	44.1	84.9	86.3	160.8	216.8	70.2	
All	12.2	25.1	47.5	65.9	158.0	213.1	53.9	

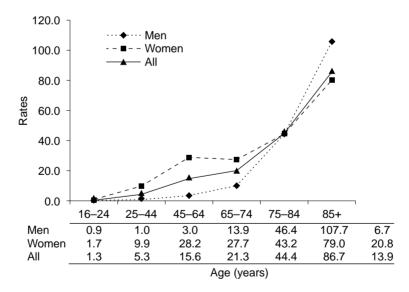
**Table 9:** Consultation rates for urinary incontinence per 10,000 population by age and sex in general practice 1991–1992.<sup>136</sup>

to remit. Self-reported annual patient consultation rates suggest 4014 will visit the GP and mention incontinence. However, official patient consultation rates suggest only around 300 (i.e. 7%) will actually be recorded by the GP; this may be due to patients reporting an incontinence problem whilst consulting for a more 'serious' medical problem.

For secondary care service utilisation, urinary incontinence data for England in the period 1999–2000 was obtained from Hospital Episode Statistics (HES). The data were based on the ICD-10 codes given in **Table 2**. Rates were calculated using the corresponding population estimates.

In that year, the overall rate of admission to hospital of patients with urinary incontinence was 13.9 per 10 000 population. These patients were not necessarily admitted because of their urinary incontinence, but a diagnosis of UI was recorded during the hospital stay.

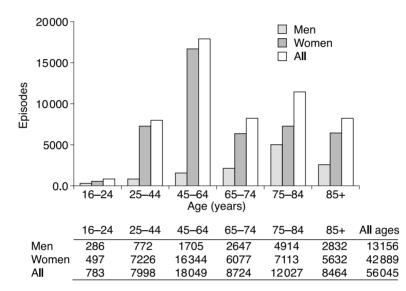
The rate of *hospital episodes* is approximately one third of patients consulting in primary care (**Figure 11**). The rate of admissions was higher in women than men and increased steadily with age for both sexes, with a slight peak for women at age 45–64 years. In old age, the admission rates in males overtook those in women, apparently.



**Figure 11:** Hospital in-patient episode rates for urinary incontinence per 10 000 by age and sex in England, 1999/2000.

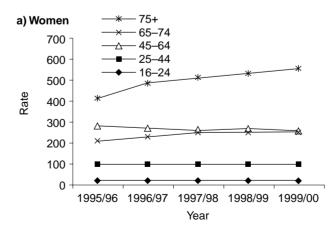
The overall pattern of use of secondary care is similar to that in primary care. However, there appears to be a disproportionate rate of hospital episodes for older men compared with older women. This may reflect a disproportionate tendency to refer elderly men rather than women, possibly related to overlapping concerns about prostate enlargement, and the development of incontinence *de novo* in hospital among men, among other factors.

It appears that 56 045 patients with urinary incontinence were admitted to hospital in England in 1999/2000 (**Figure 12**). Numerically, more women than men attend hospital at every age. There is a peak in women in the age group 45–64 years, suggesting an increased service use in this age group.



**Figure 12:** Number of hospital patient episodes with urinary incontinence by age and sex in England 1999/2000. *Source*: Hospital Episode Statistics.

The overall annual rate of hospital episodes has remained unchanged over the 5-year period 1995–2000. However, the age-specific rates increased slightly over this period for older men and women, particularly at age 75 years and over (**Figure 13**).



**Figure 13:** Hospital episode rates for urinary incontinence per 10 000 population by age and sex in England and Wales 1995–2000.

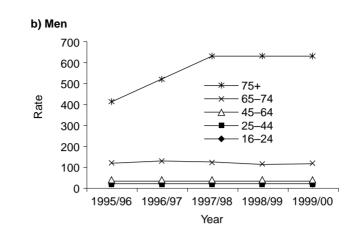
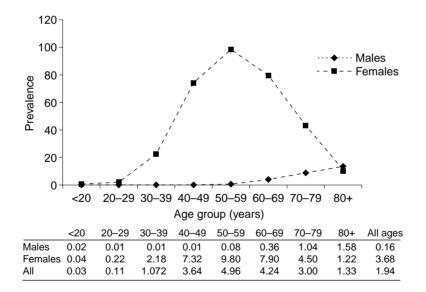


Figure 13: Continued.

The data in **Figure 14** was obtained from Hospital Episode Statistics, Department of Health, and represents surgical activity for urinary incontinence performed during 1999/2000 in England & Wales. The Office for National Statistics' Surgical Classification codes (OPCS4) for urinary incontinence were used to extract data on surgical activity for this condition (**Table 3**) (*see* **Table A3.1** for actual numbers of surgical procedures).



**Figure 14:** Surgical procedures rates for urinary incontinence per 10 000 population by age and sex in England and Wales 1999/2000.

The overall rate of surgical procedures for urinary incontinence was 1.94 per 10 000 population in 1999/2000 (**Figure 14**). For women the rate was 3.68 compared with 0.16 per 10 000 population for men. The number of surgical operations was minimal below age 20 for both women and men but thereafter, for women, the rate starts to rise rapidly to a peak of 9.8 operations per 10 000 at 50–59 years. Thereafter the frequency declines for women and rises steadily for men, arriving at comparable levels at age 80 and over.

Numerically, the vast majority of operations are undertaken in women. This is not only because of the higher prevalence of urinary incontinence in women but also because most surgery in the UK is performed for urodynamic stress incontinence, which largely affects women.

## Use of therapies and surgery

In a nurse-led continence service in Leicestershire<sup>137</sup> where male and female patients were seen and treated by nurses in the community, of 101 patients that were assessed, 37.6% had a 'weak pelvic floor' and were treated with PFE. 21.8% had urge incontinence and underwent bladder retraining. 12.9% had both conditions and therefore received both treatments. The distribution of the diagnostic groups was different in a later study carried out in Somerset.<sup>39</sup> Of those eligible for treatment, stress incontinence was diagnosed in 55%, urge incontinence in 10% and mixed stress and urge incontinence in 31%. All patients received both PFE and bladder retraining.

Among the different forms of incontinence, urge incontinence is the one most often treated with drugs, most commonly with anticholinergic drugs. Pharmacological treatment may or may not be combined with bladder retraining. These drugs may also be used to treat urinary urgency and frequency, when not accompanied by urge incontinence. Detrusor overactivity, which is a urodynamic diagnosis, is treated similarly. These drugs are increasingly being used in both primary and secondary care settings and the number of such drugs available on the market is increasing. The more modern drugs are more effective and have fewer side effects, which will lead to increased utilisation. **Table A4.2** indicates the numbers of prescriptions dispensed and the cost of four types of drug dispensed in the community in England for the three years 1998–2000. During these three years there has been a steady increase in the number of prescriptions and this is reflected by a considerable cost. The latest estimate suggests 1.6 million prescriptions dispensed each year, at a cost of over £28 million. Information regarding the number of people being treated with these drugs may be obtained from the *General Practitioners Research Database*.

The extent of use of investigations for urinary incontinence, such as urodynamic studies, and interventions such as pelvic floor exercises (PFE), bladder retraining and drug treatment may be influenced by a number of factors including the population being studied (gender, prevalence and the different types of urinary incontinence), the presenting symptoms, previous treatment for the problem, how the type of incontinence is diagnosed, the preferences of the clinician and whether surgery is being considered. With the exception of drug treatment, data on the above interventions is not routinely collected, although individual units may audit their practice. The following examples from the literature provide an illustration of the utilisation of conservative measures for urinary incontinence.

In Hilton and Stanton's study<sup>138</sup> of 100 elderly women with urinary incontinence, 29% were diagnosed with urethral sphincter incompetence and recommended oestrogen, pelvic floor exercises or surgery, whereas 56% had detrusor overactivity and were recommended drug treatment. Over a third (39%) of their sample underwent urodynamic investigation. Black *et al.*<sup>139</sup> performed a survey of the practice of clinicians in the North Thames region. 57.5% of women undergoing surgery for urodynamic stress incontinence had pre-operative urodynamic investigation. Interestingly, the likelihood of improvement was similar regardless of whether urodynamics were done before surgery.

## Use of continence aids

A wide variety of continence products such as pads, sheaths, catheters, urinals and bed sheets are available in the UK, from the NHS, over the counter and by mail order<sup>118,119</sup> but there is limited epidemiological data on their use. The MRC Incontinence Study estimates 6.2% (women 10.1%, men 1.7%) of the population are using incontinence aids of some kind. The study by Roe *et al.* in 1996<sup>122</sup> revealed that only a minority of people who were incontinent, both in a health authority with and in a health authority without a continence service, used NHS aids or appliances to manage their incontinence. The majority of incontinent people (83%) bought their own aids or appliances. This may be due to sufferers being unaware that these products are available, not knowing how to obtain them, difficulties obtaining them or some individuals having to pay for their products. In the United States, Herzog<sup>72</sup> reported that 66% of the men and women with urinary incontinence aged 60 or over living in the community used one or more aid to control leakage and 47% of these used absorbent pads.

Hellström's study<sup>16</sup> of an 85-year-old population in Sweden found that among incontinent people living in the community significantly more women (68%) used continence aids during the day than men (43%). At night, 77% of women and 62% of men used aids, the major difference during the night being the increased use of disposable sheets. Nearly half of the men living at home who had daily incontinence did not use any form of continence aid. This may be due to different attitudes towards and/or awareness of the products available between men and women. Among those incontinent people living in an institution, 92% of women and 86% of men used continence aids. Pads were the commonest form of aid used both by those living in the community and those in an institution. Indwelling catheters were used by 2% of the 85-year-old population living in an institution.<sup>16</sup> In other studies, a figure of up to 28% is cited as the proportion of patients with long-term urinary catheters in residential long-term care.<sup>140</sup> There has been a suggestion that the over-use of catheters to manage incontinence, other than for short-term periods, is a potential sign of suboptimal care and an indication that further assessment and alternative treatment could be offered.<sup>141</sup>

Among adults with a learning disability within the UK, women are more likely to use continence aids than men (**Table 10**).

Age group	Prevalence of weekly wetting <sup>a</sup> (%)		Using continence aids (%)		Total felt need for aids (% – met and unmet need)	
	Men	Women	Men	Women	Men	Women
20–29	20	34	3	34	7	39
30–39	15	20	1	23	2	25
40-49	15	15	16	21	16.5	22
50-59	10	23	15	27	15	29
60–69	20	16	23	34	26	39
70–79	25	31	36	39	36	42
80+	14	44	14	33	14	33
All ages	16	23	19	27	20	30

**Table 10:** Prevalence of incontinence and use and need for incontinence aids in adults with learning disability living in Leicestershire (Leicestershire Learning Disability Register 1994–1999).

<sup>a</sup> Wetting on one or more days/nights a week.

## Overall estimates of the cost of urinary incontinence

Cost of illness studies aim to estimate the total amount of societies' resources involved with the care or treatment of a condition, or that arise because of that condition. There are a number of cost of illness studies which deal with urinary incontinence. Probably the most comprehensive estimate of the cost of urinary incontinence (urinary incontinence) was made for the USA,<sup>142</sup> subsequently updated to 1995 US dollars, <sup>143</sup> and the later study estimated the cost of urinary incontinence to be \$26.3 billion in 1995 US dollars, of which \$704 million were indirect costs. These estimates were derived for the over-65s and included costs associated with extended hospital stays, urinary incontinence as a reason for admission to

nursing homes and residential care, and indirect costs relating to loss of earning due to urinary incontinence. Wilson and colleagues also estimated the direct cost of urinary incontinence for the USA, this was £16.3 billion in 1995 US dollars.<sup>144</sup> Doran and colleagues estimated the cost of urinary incontinence for Australian women aged over 18 to be \$710.44 million Australian dollars in 1998<sup>145</sup> (equivalent to \$439.76 million US dollars) equating to \$387 dollars per person with incontinence. An estimate of the cost of urinary incontinence to Italy in 1998<sup>146</sup> was based on a survey of 229 Italian women over 40 years of age. Focusing only on direct expenditure for the health service, i.e. costs associated with diagnosis, hospitalisation for detrusor overactivity, diapers and drugs, and excluding the cost of GP visits, the cost in 1998 was 351 800 billion lira, equivalent to 255 519 lira (\$158 1998 US dollars) per person. An estimate was also made for Sweden that suggested that urinary incontinence costs comprised 2% of the total health care costs in 1993.<sup>147</sup>

There have been a number of estimates of cost for urinary incontinence in the UK. The most recent was made for the year 1998.<sup>102</sup> This included drugs and prescription appliances, containment products, the proportions of time spent by various staff on urinary incontinence and surgery. The estimated cost for the UK was £353.6 million. There were also two earlier estimates that focused on equipment, pads and appliances.<sup>102,148</sup> An estimate of the cost of urinary incontinence to health authorities was produced as part of an study carried out by the Social Policy Research Unit, York University.<sup>149</sup> The authors produced estimates of the costs of continence services to two health authorities, labelled as area 2 and area 3. The cost for area 2 was £2.72 per person and for area 3 £4.71 per person (1993/4 UK pounds). Both areas included urodynamic investigations, a continence advisory service, issue of products, drugs, and urinary appliances and stoma appliances, but area 2 also included the involvement of health care professionals in continence management while area 3 included outpatient clinic and social services.

Work has also been carried out to estimate the costs of urinary incontinence on an individual basis. Clayton and colleagues<sup>150</sup> surveyed 118 women, of whom 28 were disabled. The costs of NHS and patientborne costs for a three-month period had a mean value of £37 in 1995 prices. An earlier study estimated the cost for people with multiple sclerosis as £1.53 per week in 1977/8 prices.<sup>151</sup> This author also found that mothers of severely handicapped children spent 10 hours a week on incontinence care. Utilisation of services due to urinary incontinence was examined by Roe and colleagues.<sup>122</sup> The authors found that those with incontinence were more likely to have contacted their GP and also any other health care providers compared to individuals without urinary incontinence.

One common feature of these studies is that they are limited to financial costs of urinary incontinence. They typically look at health service or provider costs. Some studies also consider financial costs borne by individuals such as purchases of pads. None of these studies estimate the non-resource-related costs of urinary incontinence. Examples of these types of cost would be discomfort and embarrassment of urinary incontinence, disruptions to usual activities and disruption of social life. These costs are not easily quantifiable but they represent a burden of urinary incontinence to individuals and society. Wagner and Hu recognised the lack of any estimate of these costs in their work but at the time of publication they felt there was no way to quantify these costs.<sup>143</sup> However, one tool that could be used to estimate these non-financial costs is willingness to pay (WTP). In this method a respondent is asked how much they would be prepared to pay for a defined change in their health. For example, a change in an individual's continence level would be defined and that individual may be asked to identify how much they would pay a month for this change. Alternatively, they might be given a series of amounts and asked to say whether they would pay these amounts, a technique used in the field of urinary incontinence.<sup>152</sup> In a study using this technique, respondents were asked about their willingness to pay for a reduction in their urinary symptoms. Responses were consistent with prior expectations in that they increased with severity of symptoms and with the ability to pay of the respondent. The mean willingness to pay for a respondent in the middle of their severity range was 530 Swedish krona per month (1996 prices). This equates to approximately £35 per month (UK pounds with an exchange rate of 15 krona to  $\pm 1$ ). In an evaluation of these results Kobelt<sup>153</sup> found that willingness to pay was correlated with improvements in health, urinary incontinence symptoms and income. A similar method was used on a sample of US respondents<sup>154</sup> where 257 respondents completed a WTP survey in 1997. The mean WTP was US\$87.7 for a 25% reduction in micturitions and leakages. These results show that the non-financial part of the burden of urinary incontinence is potentially very important to those with the condition.

These studies are very mixed in that they use varying methodologies on different populations from different countries and in different time periods, but as a whole demonstrate that urinary incontinence has large resource implications, both to societies and to individuals. Any planned change in services for urinary incontinence should consider the wider costs associated with any change in level of function, as they are likely to be important.

# 6 Effectiveness of services and interventions

#### Primary care

Overall rates of cure and improvement resulting from primary care services are estimated at around 44%.<sup>122</sup> The presence of a Continence Advisory Service appeared to have little effect on the condition but a marked difference on levels of satisfaction with services.

#### Pelvic floor muscle training

Although therapies designed to strengthen the pelvic floor muscles and enhance closure of the bladder under stress have been extensively investigated, studies report markedly different results. These differences may be the result of different methods in applying the interventions, differences in the patients undergoing them, differences in compliance or differences in measuring the effects of treatment. Most studies have investigated small numbers of patients and few have used any form of satisfactory control group.

There is some evidence to support the effectiveness of bladder re-education, pelvic floor exercises and drug therapies in primary care. Hall<sup>137</sup> set up a team of trained district nurses supervised by a continence advisor in Leicestershire and found that 59–65% of patients were cured or improved. Short and longer term cure/improvement rates vary from 65–74%.<sup>39,94,155,156</sup> In a review of the literature by Williams *et al.*,<sup>157</sup> the authors concluded that studies varied in their design, the exercise programmes implemented, the person undertaking the training programme and the measures used to test effectiveness. This is reflected in the cure/improvement rates of 25–84% in the studies reviewed. A recent Cochrane review of the literature<sup>121</sup> showed that PFMT appeared to be an effective treatment for adult women with stress or mixed incontinence. PFMT was better than no treatment or placebo treatments. 'Intensive' appeared to be better than 'standard' PFMT programmes for women with stress incontinence and postnatal women with symptoms of urine leakage. There is insufficient evidence to determine if: PFMT is better or worse than other treatments; e.g. electrical stimulation or weighted cones in women with stress incontinence; or whether adding PFMT to other treatments for women with SI (e.g. electrical stimulation or behavioural therapy) is effective. Evidence of the effect of adding other adjunctive treatments to PFMT (e.g. vaginal cones, intravaginal resistance devices) is equally limited. On the basis of the evidence available, there does not appear to be any benefit of biofeedback-assisted PFMT over PFMT alone.

There have been very few trials comparing PFMT with pharmacological therapy or surgery. In a recent review of the literature, in women with stress and mixed incontinence, there may be no difference between PFMT and phenylpropanolamine (an alpha-adrenergic antagonist), but in women with detrusor over-

activity, with or without stress incontinence, PFMT may be better than oxybutynin. In women with urodynamic stress incontinence, PFMT may be better than topical oestrogens, but surgery may be better than PFMT.<sup>106</sup>

Long-term outcomes of PFMT are unclear. Most studies have reported a follow-up of no longer than 12 months. The best quality and most complete data comes from the follow-up study by Lagro-Janssen and Van Weel.<sup>158</sup> The number of continent women (25%) was the same after five years, but a significant number of women reported their condition had worsened. Women with urge or mixed incontinence were less likely to be satisfied with the outcome of treatment at five years, although two-thirds of all the women followed up remained satisfied with the outcome of treatment and did not want any further intervention. Nearly half (43%) of the women who had received PFMT were no longer training at all. For women with stress incontinence, continued training was the only significant predictor of outcome at five years. Five years after an intensive exercise program, Bø and Talseth<sup>159</sup> found that 70% of women were satisfied with treatment, despite a significant increase in urine loss over this period. This may reflect the fact that women became more empowered over their condition and accepted greater urine loss. O'Brien<sup>160</sup> evaluated non-specialist nurse continence classes using pelvic floor exercises and bladder retraining and showed that 68% of patients were improved or cured, compared with 5% in the GP control group. When the treated group was followed up four years later<sup>161</sup> 69% had either maintained their original improvement or cure or had improved further.

The role of PFMT for women with urge incontinence alone remains unclear.<sup>121</sup> There is level 1 evidence that PFMT is better than placebo treatments for women with urge incontinence.<sup>106</sup> In their review of the literature of pelvic floor exercises for the treatment of overactive bladder, Bø and Berghmans found that because of the lack of evidence, no firm conclusion can be drawn on the effect of pelvic floor muscle exercise on the overactive bladder.<sup>162</sup> In a review of 15 randomised controlled trials to assess the efficacy of physical therapies for first line use in the treatment of urge urinary incontinence in women, Berghmans *et al.* concluded that although almost all studies included reported positive results in favour of physical therapies, there were too few studies to evaluate the effect of pelvic floor muscle exercise with or without biofeedback in this group of women.<sup>163</sup>

#### Electrical stimulation (ES)

Electrical stimulation for the treatment of urinary incontinence in women is currently the subject of a Cochrane review.<sup>164</sup> A previous review of the literature by Wilson *et al.*<sup>106</sup> found that due to a lack of good quality trials, there is insufficient evidence to judge whether ES is better than no treatment for women with urodynamic stress incontinence or detrusor overactivity. With regard to ES versus placebo ES, the findings of two good quality trials are contradictory.<sup>165,166</sup> For women with detrusor overactivity, there is a trend in favour of active stimulation over placebo stimulation.<sup>106</sup> When reviewing ES trials in general, and trials comparing ES protocols in particular, it appears that some ES protocols may be more effective than others and/or some populations of women receive more benefit from ES than others. Both these variables require further investigation.<sup>106</sup> With only single small trials comparing ES with medication, there is insufficient evidence to determine if ES is better than vaginal oestrogens in women with urodynamic stress incontinence, or better than anticholinergic therapy in women with detrusor overactivity.<sup>106</sup>

#### Weighted vaginal cones

A Cochrane review has provided some evidence that weighted vaginal cones are better than no active treatment in women with stress incontinence and may be of similar effectiveness to PFMT and ES.<sup>167</sup> The authors suggest that this conclusion must remain tentative until further larger, high quality studies are carried out using comparable and relevant outcome measures. Some women treated with cones, PFMT or

ES drop out of treatment early. Therefore, cones should be offered as one option so that if women find them unacceptable there are other treatments available.

#### Behavioural and lifestyle changes

#### **Bladder retraining**

Evidence for the efficacy of lifestyle changes in the management of urinary incontinence is lacking. Much of current practice is based upon expert opinion and a 'common sense' approach. Such measures include advice relevant to the maintenance of general health and therefore should not be neglected. It appears that, when taken as a whole, the basket of interventions is effective in reducing the subjective severity of bladder problems as assessed by sufferers. The evidence for bladder retraining is a little more robust and data suggest that, in certain groups, bladder retraining can gain as much improvement as drug therapy. When employed as part of a package of measures, bladder retraining appears to be as effectively delivered on an outpatient as an in-patient basis,<sup>168,169</sup> but remote delivery, by telephone, does not work.<sup>170</sup> This suggests that the therapeutic relationship and direct contact with their clinician or therapist is important in achieving success. In many studies the technique is used as part of a package of other lifestyle measures (diet and fluid advice, caffeine restriction) with or without pelvic floor therapy and medication.<sup>171,172</sup> Studies of bladder retraining alone indicate that among incontinent women successfully undertaking a bladder retraining programme 60–80% will be improved in terms of urine loss and urinary frequency.<sup>173–176</sup>

A number of trials of this technique, which aims to control urinary frequency and increase functional bladder capacity, have been performed and have recently been the subject of a Cochrane Review. This noted that many of the available studies were flawed and that limitations on the available data led the reviewers to issue a guarded positive recommendation based upon the available evidence.<sup>177</sup> Where the patient is confused and unable to participate in bladder retraining then there are other toileting regimens which have been found useful in care homes in the US. These techniques have also been the subject of a Cochrane review.<sup>178</sup>

#### Effect of caffeine restriction

There has been a short-term, urodynamic study using oral caffeine, which has shown minimal effect on the bladder while retrospective analyses have found an association between high caffeine intake and a diagnosis of detrusor overactivity.<sup>110,179</sup> Clinical trials, most of which assessed fluid intake and caffeine, have found no sustained benefit,<sup>81</sup> although a recent trial of caffeine reduction in a predominantly elderly group of women reported that reduction in caffeine intake with maintenance of total fluid intake led to a reduction in urinary frequency.<sup>180</sup> However, the practicality of meaningful caffeine reduction and the achieved magnitude of resolution of symptoms may not result in this being a worthwhile option for most patients.

#### Fluid advice

Limiting or reducing overall fluid intake is not effective for managing incontinence and may lead to adverse effects especially in the elderly, who are likely to be taking other medication, who have a decreased total body water and are more susceptible to volume depletion. There are no randomised trials of fluid intake adjustment alone on which to base management. Retrospective studies have shown that nurse intervention is useful in achieving appreciation of fluid requirements<sup>181</sup> and a study examining the association of caffeine and fluid intake resulted in improvements in continence status.<sup>180</sup>

#### Weight reduction

There are no data on the relationship between urinary incontinence and obesity in males. In females, however, there is good evidence for a positive association of stress urinary incontinence and body mass.<sup>111,112</sup> In community surveys a greater number of women with incontinence reported themselves as obese, or being too heavy for their height.<sup>59</sup>

There is also evidence that being obese is associated with a poorer result from operation for stress incontinence.<sup>182</sup> However, the evidence that weight reduction might be able to correct some of this disadvantage is limited to two studies of women who had undergone surgery for their obesity with consequent massive weight reduction.<sup>183,184</sup> The latter study reported that, in women losing at least 50% of their excess weight, the prevalence of urinary incontinence was reduced by 50%. An association of obesity with types of incontinence other than stress incontinence is seldom reported<sup>185</sup> and the single report which did, did not control for age.<sup>186</sup> It seems that the weight loss achieved by advice from physicians is unlikely to have a significant impact upon urinary incontinence.

#### **Relief of constipation**

There has been one community-based study in women of 60 years and older which has examined the relationship between self-reported urinary incontinence and constipation. Subjects who reported urinary incontinence were more likely to report constipation. A relationship between straining and impaired function of rectal emptying is hypothesised but there are no studies which systematically evaluate the effect of relieving constipation on urinary incontinence.<sup>187</sup> Faecal impaction can lead to urinary retention, and there have been conflicting reports of an association between incontinence and constipation.<sup>113</sup>

#### Smoking

An association of bladder problems with cigarette smoking has been identified for both men and women.<sup>114,116</sup> The odds ratio of men suffering lower urinary tract symptoms was 1.47 for current smokers and 1.38 for former smokers when compared with men who had never smoked.<sup>114</sup> For women, smokers were 1.9 times more likely to suffer from incontinence.<sup>115</sup> However, studies in other populations have found no association.<sup>66,84</sup> As with other adverse effects of smoking, this association weakened following cessation of smoking and appeared to reach baseline after 40 years of abstinence. In men, the association of smoking appeared to be strongest with the occurrence of detrusor overactivity. An association with both stress and urge incontinence is found in women, smoking-related cough thought to be a precipitating factor in the development of stress incontinence.<sup>188</sup>

There are no prospective intervention trials of smoking cessation on improving bladder symptoms. However, there is little doubt that smoking should be discouraged in view of the cardiovascular risk, regardless of its effect upon lower urinary tract function.

Lifestyle interventions for the treatment of urinary incontinence have been a subject of the Cochrane review process.<sup>189</sup>

#### Drug therapy

Drug therapy for urinary symptoms is mainly aimed at patients with detrusor overactivity. All of the currently available drug therapies have side effects that limit their use. At present the most effective drug therapies with the most favourable side effect profiles are controlled release oxybutynin and tolterodine. These drugs, although of proven efficacy, have limited clinical effects (about 50% reduction in urinary

frequency and incontinence episodes) and should not be started without ensuring that simple behavioural therapies have been started. The costs of the drugs vary with the compound and dose used (**Table A4.1**).

Details of the individual drug studies and the evidence of benefit may be found in Appendix 4.

#### Economic evidence

To be considered an economic evaluation a study must consider both the costs of any intervention and also some measure of benefits produced. These must be combined; for example, cost per quality adjusted life year, cost per case cured etc.

Although there is some evidence for the effectiveness of primary care interventions for lower urinary tract symptoms, there is very little evidence of the cost-effectiveness of interventions. One study investigated the use of tolterodine for overactive bladder<sup>190</sup> and estimated quality of life using a rating scale; this was used to generate quality-adjusted life years (QALYs). Costs measured related to drug costs, pad usage and visits to a GP. Costs in the tolterodine arm were SEK (Swedish Krona) 5309 higher than in the control arm. The improvement in quality of life was 0.025 equating to a cost per QALY of SEK 213 000, which equates to US\$28 000 or UK£14 200. There are also two studies which consider the costs of urinary incontinence interventions in primary care,<sup>191,192</sup> but neither of these studies combined an estimate of costs with any measure of whether the interventions studied were effective.

#### Secondary care

#### Drug therapy

The main indication for pharmacological therapy is detrusor overactivity, whether idiopathic or secondary to a neurological cause. Whatever the indication, drug therapy appears to maximally improve or cure approximately 50% of patients in terms of urinary frequency or urgency, with a lesser effect on the number of incontinence episodes. The main limitation of antimuscarinic drugs for this indication has been the relatively high incidence of side effects, notably dry mouth, leading to withdrawal from medication. The newer, once daily, formulations of both oxybutynin and tolterodine are an attempt to minimise the effect of these and to maximise the effective dose of medication. Although drug therapies are in common use in secondary care many patients will not have undergone behavioural therapies before starting medication. There is little evidence that drug therapy is superior to behavioural therapies<sup>172</sup> but some suggestion that a combination of drug therapy with behavioural therapy is advantageous.<sup>193</sup> In fact most studies investigating the efficacy of drug therapy in secondary care do not allow any of the patients to receive concurrent behavioural therapies. It therefore seems appropriate to make sure that behavioural therapies have been applied appropriately before starting medication. The evidence supporting the use of antimuscarinic medication has been subject to recent Cochrane reviews.<sup>194–196</sup>

#### Oxybutynin

Oxybutynin is the most established antimuscarinic drug in use today. Trials comparing oxybutynin to placebo have consistently shown a reduction in symptoms and urodynamic parameters with the active drug (**Table A4.5**). Oxybutynin is thus the drug against which all new preparations are compared. Drug-related unwanted side effects occur in the majority of patients taking standard doses of oxybutynin and these can result in about 1 in 4 patients discontinuing treatment.<sup>197,198</sup> It has been suggested that oxybutynin should be started at a low dose and gradually increased, titrating the dose against side-effects and efficacy. Inevitably this will lead to more hospital appointments with associated cost.<sup>199</sup>

Recently controlled-release oxybutynin has been studied. This modified release, once daily preparation avoids large peaks in plasma levels of the drug and its active metabolite.<sup>200</sup> Trials seem to show an improved side effect profile with this preparation (**Table A4.6**).

#### Tolterodine

Tolterodine has functional selectivity for muscarinic receptors in the bladder compared to the salivary gland. Given in a dose of 2 mg twice per day, there seems to be similar efficacy between oxybutynin and tolterodine, but tolterodine had a more favourable side effect profile in terms of unwanted dry mouth and gastrointestinal effects resulting in less patients needing to stop therapy. Controlled-release tolterodine may have less adverse side effects (**Table A4.7**).

#### **Trospium chloride**

There is limited evidence that trospium chloride is useful in the treatment of detrusor overactivity. Randomised controlled trials have shown improvements in urodynamic parameters and subjective symptomatic improvement.<sup>201,202</sup> Trospium (20 mg bd) seems to be better tolerated than oxybutynin (5 mg tds) and as the compound does not cross the blood-brain barrier, very few CNS side effects have been reported.

#### Flavoxate

This tertiary amine has not been shown to have any clear advantages over placebo in double blind controlled studies.<sup>203,204</sup>

#### Imipramine

Imipramine is a tricyclic antidepressant with anticholinergic side effects. It may also have some bladder anaesthetic and adrenergic properties that may aid bladder filling. There is some evidence that imipramine may be useful in children with nocturnal enuresis,<sup>205</sup> but the only double blind controlled trial in adults was small and inconclusive.<sup>206</sup>

#### Propiverine

This drug, with combined antimuscarinic and calcium channel blocking properties, has been shown to be superior to placebo in controlled clinical trials. It appears to be as effective as oxybutynin in the treatment of detrusor overactivity. There are no data comparing the drug to behavioural intervention. Approximately 20% of users develop some adverse side effect but dry mouth is less common and milder than with oxybutynin.

#### Desmopressin

This synthetic vasopressin analogue can be used to suppress diuresis overnight. It has been shown to be useful in nocturnal enuresis in children<sup>205</sup> and in reducing nocturnal frequency in adults.<sup>207</sup> There are potential problems in producing worsening daytime frequency due to increased daytime diuresis and fluid overload may be a problem, particularly the elderly.

#### Oestrogens

Although oestrogen therapy has been advocated for the treatment of urinary frequency and incontinence in randomised controlled trials, no beneficial effect was shown on bladder function.<sup>208,209</sup> The only symptom that appears to be reduced with oestrogen therapy is urinary urgency.<sup>210</sup>

#### Alpha-adrenergic agents

Alpha-adrenergic receptor agonists have been used for the treatment of stress incontinence. Where the urethral sphincter is incompetent, they are thought to increase the intrinsic tone of the sphincter and so prevent incontinence on pressure. Currently there is no recommended indication for this type of drug in stress incontinence.<sup>211</sup>

#### Surgery

As might be expected when there are such a large number of operations for one condition (**Table A4.8**), there is variable efficacy and morbidity associated with each. Until recently there were few trials comparing these procedures and evidence for efficacy of recent techniques, such as the tension-free vaginal tape (TVT), is still being generated. Evaluation of the efficacy of this operation in particular is part of the 6th work program of the National Institute for Clinical Excellence.

Jarvis, in 1994, completed a systematic review of surgery for urodynamic stress incontinence.<sup>212</sup> This showed that some procedures had only limited efficacy (which is usually unacceptable when considering major surgery for a non-life threatening disease). Others, although efficacious, had high levels of morbidity associated with them.

Anterior repair with bladder buttress has been evaluated in a recent Cochrane review.<sup>213</sup> This procedure, when done for stress incontinence alone, was shown to have low initial cure rates with high recurrence and repeat operation rates compared to colposuspension. Although morbidity is low with this operation, it is significantly higher than the minimally invasive procedures that are now available. No such procedures should now performed for significant incontinence in the absence of prolapse.

Marshall-Marchetti-Krantz procedures have generally been abandoned as there is a high incidence of osteitis pubis (2.5%) following the procedure. When this occurs the patient has severe pain, often necessitating further surgery. All other rates of efficacy and morbidity are similar to colposuspension.

Many different types of needle suspension have been described. All involve minimal access surgery inserting (with the use of needles) stitches between the abdominal wall and the anterior vaginal wall. Although associated with minimal short-term morbidity, long-term success rates have been disappointing and fewer numbers of these procedures are performed. Bladder neck needle suspension surgery is probably not as good as open abdominal retropubic suspension for the treatment of primary stress urinary incontinence in terms of lower cure rates and higher morbidity.<sup>214</sup>

Traditional suburethral sling procedures were originally designed for recurrent stress incontinence but have recently been used for patients with severe primary disease. A recent systematic review showed no increased efficacy over colposuspension but there was a longer in-patient stay.<sup>215</sup> Suburethral sling procedures are usually associated with high rates (37%) of postoperative voiding disorder and subsequent repeat operation (28%) to release the sling. They involve a relatively large abdominal incision resulting in moderate short-term morbidity.

The tension-free vaginal tape (TVT) for primary treatment of stress incontinence has become fashionable. It is based on the suburethral sling but this is sited at the mid-urethra under no tension. Using angled needles, a specially developed sling (polypropylene tape) can be inserted with minimal dissection. The tape should be inserted without tension so that minimal obstruction of the urethra occurs. Large case series seem to

show that this operation has reduced short- and long-term morbidity compared to a colposuspension.<sup>216</sup> In particular the in-patient stay is dramatically reduced. There is comparable reduction in symptoms for up to five years compared to a colposuspension. A randomised controlled trial has been conducted comparing TVT with colposuspension. The unpublished results of this trial in the short term seem to be encouraging. The major disadvantage of this operation is the cost of the tape. However, this is more than outweighed by the reduced costs of hospitalisation.

Any decision about which operation to perform will usually take into account the chance of cure, the likelihood of surgical complications, the severity of the patients' condition, medical comorbidities and what previous therapies have been tried. The ideal surgery should be effective, have few risks and be long-lasting. At present the gold standard operation is the colposuspension despite a failure rate of 10% in the short term and 20% in the long term. The operation is also associated with a 10% incidence of genitourinary prolapse, a 10% incidence of voiding disorder and a 10% incidence of *de novo* detrusor overactivity. This 'gold standard' is far from ideal.<sup>217</sup> Colposuspension may be performed either as an open operation or using a laparoscope. Currently there are exponents of each technique and no clear consensus as to whether one is superior in terms of cure or improvement. The long-term performance of colposuspension is uncertain. Currently available evidence suggests that laparoscopic colposuspension may be poorer than open colposuspension. Like other laparoscopically performed operations, laparoscopic colposuspension leads to a quicker recovery, but takes longer to perform and may be associated with more surgical complications. These matters should hopefully be answered in the near future as the results of a randomised controlled trial sponsored by the MRC become available. If laparoscopic colposuspension is performed, two paravaginal sutures appear to be more effective than one.<sup>218</sup>

There is conflicting evidence from trial data of effectiveness versus the real-life experience of women undergoing these operations, the results seldom reaching those attained in clinical trials.<sup>101,219</sup>

Injection of various different materials into the bladder neck has been described.<sup>220</sup> The aim of these procedures is to bulk up the junction between bladder neck and urethra, increasing pressure transmission and, although unclear, probably causing a partial obstruction. The operation is minimally invasive and can be performed under local anaesthetic. There is little associated morbidity and most patients will be treated as day cases. This has the advantage of allowing frail elderly patients to receive treatment where more major operations are not possible. The short-term success rate is acceptable but may fall to as low as 40% by four years. There is no strong evidence that any agent has a marked increased success rate but they vary considerably in their cost.

Surgical therapies for urodynamic stress incontinence are relatively expensive in terms of health service usage. Most have significant associated morbidity and mortality. Effectiveness will depend on patient selection and the skill and experience of the surgeon.<sup>101</sup> It seems reasonable that surgery should only usually take place where conservative measures, in particular pelvic floor therapies, have already been tried and failed. In view of the possible adverse consequences of surgery, all patients should undergo a detailed expert assessment to confirm the diagnosis and assess the severity of disease. Where surgery is necessary it should ideally be performed by a small team of experienced surgeons in each locality. This will allow development of expert local expertise and allow local figures for success and complication rates to be quoted.

Urinary incontinence after prostatectomy is a common problem. Conservative management of this condition includes pelvic floor muscle training, biofeedback, electrical stimulation using a rectal electrode, transcutaneous electrical nerve stimulation, or a combination of methods. Conservative management is often combined with lifestyle adjustments including: decreased intake or elimination of caffeine, physical exercise, cessation of smoking, and bladder retraining. A Cochrane review of six randomised trials, each evaluating different treatments, concluded that the value of the various approaches to manage this particular problem remains uncertain.<sup>221</sup>

#### Economic evidence

There is very limited evidence relating to the economic evaluation for surgery for lower urinary tract symptoms. Two studies were found which could be categorised as economic evaluations. Open and laparoscopic colposuspension were evaluated by Kohli in a cost-minimisation study, using intra-operative complications, postoperative haematocrit change and estimated blood loss as the outcome measures.<sup>222</sup> The authors found no statistically significant differences in outcome between the groups, although the total hospital charges were found to be higher for the laparoscopic group, \$4960 versus \$4079. In Canada, Kung<sup>223</sup> carried out a cost-effectiveness analysis of laparoscopic Burch procedures compared to an abdominal Burch procedure. This time the measure of effectiveness used was the percentage cure rate for the surgical procedure. The costs of the surgical procedure were also estimated. The hospital costs *per case cured* were \$3029 for laparoscopy and \$6325 for Burch and open surgery.

Although there have also been a number of studies that have considered costs relating to surgery, they were not combined with a measurement of outcomes,<sup>224–229</sup> therefore these studies are of limited use as decisions cannot be made on the basis of cost only. For example, if an intervention is more expensive than an alternative it may still be preferable if it is also more effective. Whether it is indeed preferable will depend on the degree of extra cost and extra effectiveness.

# 7 Models of care and recommendations

Minimal evidence exists on the effectiveness of current UK service provision. Such evidence as does exist has tended to have been generated by the more motivated, specialist centres and probably does not reflect the more general experience. As noted above, there are large inconsistencies in care provision, with many areas either having a consultant-led or a continence nurse-led service. Considerable scope for improvement lies in supplementing primary care teams with special expertise and resources. However, there are a number of problems in comparing the merits of the different models of service provision using the results of existing studies. First, it is probable that, due to selection factors, the severity and type of condition treated varies substantially between hospital clinics, district nurse clinics and GP sessions. Second, the age distribution of patients is different. For example, attendance at non-specialist nurse clinics declines with age. Third, no standard definition of cure or improvement has been applied. Finally, the number of patients seen and the levels of improvement achieved have not been related to the resources used.

Rhodes *et al.* carried out a two-phased feasibility study which aimed (i) to examine continence services in three district health authorities (to reflect different approaches to continence management), (ii) to examine costs to the health and social services, (iii) to determine policy and provision and (iv) to explore professionals' perceptions of quality in service delivery.<sup>230</sup> The different services ranged from a very limited community continence service to an integrated continence service covering both the acute and community sectors. However, problems were identified in each service, with all three exemplifying many of the problems in providing a truly integrated service. In none of the three areas had GPs shown any real enthusiasm or interest in continence service was controlled by GPs. Even in the most well-established continence service, the service was integrated more in name than in practice. Hospital and community services operated virtually autonomously, largely as a result of management structures. Consultants seemed to know very little about the community service. Continence advisors and the nursing management saw integration as a potential loss of autonomy. Furthermore, there seemed to be little incentive for co-operation, with different hospital departments and community services competing for business from GPs. Other concerns raised included insufficient medical input to the service, routes of referral from

primary to secondary sector and varying paths of clinical decision making. One solution proposed by medical staff would be for all patients to be channelled through a hospital department, the route of referral being from GP to hospital consultant. A single gateway service may avoid loops in the system but would swamp hospital clinics.

The researchers were also unable to report any interprofessional consensus on best practice issues or the structure of a continence service. They suggested that in defining a good quality service it is necessary, first, to identify various professionals and services which make a contribution and, second, to extricate a continence service from other services. Should continence promotion and continence care be an integral part of all health professionals or should there be a separately defined continence service?

There were clear difficulties in identifying the costs of providing continence services at local levels. Identifying the input of health care professionals in the community was particularly difficult. Variations between individual health authorities were exposed in terms of the allocation of resources between the acute and community sectors.

The second phase of the study looked at the costs of incontinence to individuals and to services, and users' perceptions of quality and effectiveness of services.<sup>231</sup> On the whole patients did not find it easy to describe their referral route through the service. Patients also had difficulty in identifying the links between assessment, intervention and review and in describing the outcomes they might expect from service contact. The most common difficulty for patients was recognition of the role and responsibility of the professionals they met. Members of the continence advisory service in one area were frequently praised for their patience, understanding and support but were not readily recognised as part of that service. As a result the authors suggested that a 'care management' (multi-referral) model may be more effective in meeting the needs of incontinence sufferers. Continence advisors or specialists could act as sole 'care managers' where they assess a patient, directing and monitoring the appropriate path(s) of care. This may involve referral to GPs for drug treatment or to other professionals for assessment for continence aids, to physiotherapists for pelvic floor exercises or other specialists for urodynamics. The continence care manager would then be responsible for case review to ensure that the patient is successfully moved through the system with outcomes which can be readily evaluated. Where no continence advisor is in post, the team model would be applied, with one individual (a key worker) taking overall responsibility for the management of care of that individual, ensuring progress through the system. The study concluded that district-wide comparative studies of the cost-effectiveness of different service models are not feasible, given the current rate of change of service structures and the fact that continence services are made of many disparate elements which may not be related in the coherent way that the word 'model' suggests. They proposed that it would be more valuable to study the cost-effectiveness of particular interventions or specific service innovations.

Another study of continence services<sup>122</sup> compared the health needs and use of health services by people who suffered from incontinence compared to a background population who were not incontinent. Comparisons were also made between individuals who were incontinent within two health authorities to provide an evaluation of their health interventions and patient outcomes in relation to a health authority with a continence advisory service and one without. There was some evidence that people in the health authority with a continence service received more appropriate treatment and care for their incontinence than those in the health authority without a continence service. Despite significant differences between the health interventions undertaken in the two health authorities, these findings did not transfer through to people's perceptions of their continence status. Only 44% of incontinent people in the health authority with a continence service felt that their incontinence was cured, improved or better managed, compared to 43% in the health authority without a service. However, the difference in health interventions did follow through to satisfaction with services and health care, with significantly more incontinent people in the authority without a service reporting that they were satisfied compared to those in the authority without a service.

The researchers also felt that type and severity of incontinence are important factors that should be considered when evaluating health care and services in relation to their outcomes. Using The Short Form 36 as a measure of health status, people who were incontinent had a significantly lower health status than those who were not incontinent. Women who were incontinent tended to have a better health status than men who were incontinent. Using the Incontinence Impact Questionnaire (IIQ) as a measure of the impact of incontinence, there were no significant differences between the IIQ scores of people whose incontinence was effectively or ineffectively managed. People who were incontinent in the health authority without the continence service had significantly lower mean scores for their self-esteem than those in the authority with a continence service. Furthermore, people whose incontinence was successfully managed.

People who sought help early for their incontinence were considered to be successfully managed and the vast majority of sufferers who sought help early lived in the health authority with the continence service. Establishing management techniques that suited individuals and evaluating their health gains and outcomes were important indicators identified by the authors as contributing to the successful management of incontinence. People who had participated in decisions taken about the management of their incontinence were generally considered as being successfully managed.

There was some evidence that multiple referral to members of the multidisciplinary team which focused and targeted their particular health intervention skills was associated with incontinence being successfully managed. Greater flexibility of services was considered as being important by a number of sufferers, and related to the acceptability and appropriateness of health services. A person's incontinence was considered successfully managed when their views were considered and their expectations were met.

In 1997, a report of a working group to the Department of Health highlighted a number of aims that a continence service should strive for, including:

- given the possibility of cure or improvement, a continence service should not have provision of products as its primary focus;
- acute and community services need careful co-ordination across trust boundaries and across the primary care/hospital interface.

The group concluded that given the paucity of research evidence, any care which provides a systematic approach to the management of incontinence may improve outcomes.

The Leicestershire MRC Incontinence Pilot Study has evaluated a new nurse-led continence service.<sup>232</sup> This involves specially trained continence nurse practitioners delivering pre-defined, evidence-based treatment interventions. The service was shown to be effective in reducing urinary symptoms (60% reported cure or improvement), with high levels of patient satisfaction (99%). This service is currently being evaluated in a comparison with care provided by GPs in a randomised controlled trial. Further work from the Leicester team showed that an informal, friendly approach by nurses with good communication skills relieved patients' embarrassment and anxiety, giving them confidence and trust in the nurses, thus facilitating information exchange and effectiveness of care.<sup>233</sup> Good communication skills conveyed the nurses' specialist technical skills and knowledge, encouraging patient compliance with treatments. An RCT of the new service is now published.\*

The following model of care describes an ideal service that may overcome some of the variability in continence care available to the population. This proposal is based on analysis of available evidence and consensus within the main groups concerned. The principles underlying an integrated continence service have been outlined in a Department of Health document *Good Practice in Continence Services* (March 2000), which has recommended an evolutionary approach to service development from the existing local

Williams KS *et al.* Clinical and cost-effectiveness of a new nurse-led continence service: a RCT. *Brit J Gen Prac* 2005; **55**: 696–703.

provision. The ideal new service for continence care would span both primary and secondary care and would comprise a large volume, community-provided service which would include a number of key elements:

- All patients with bladder symptoms would be eligible to enter the service.
- There should be a defined method of entry into the service regardless of the original source of the referral.
- Service co-ordination would be provided by a multidisciplinary team.
- The service, whilst provided by a multidisciplinary team, is likely to be led by the specialist continence practitioners.
- The service would be structured around evidence-based protocols.
- There would be clear patterns of referral to specialist secondary care providers.
- The service would have access to medical and surgical consultants with a special interest in continence.
- Secondary care provision would be provided by trained specialist professionals.
- Nurse prescribing of limited medications would be implemented using a patient group directive following appropriate training.
- Continence specialist clinicians (either nursing or physiotherapy background) would take part in secondary care clinical sessions to ensure continuity and consistency of approach throughout the service.
- Regular user satisfaction surveys and analysis of performance indicators.
- Well defined and regular audit and quality assurance systems.
- The service would undertake training of other health care professionals and would promote continence awareness.
- The service would involve consumers in its evaluation.

A comprehensive list of elements of an ideal continence service follows:

- There should be a defined method of entry to the service regardless of the original source of the referral, whether this be from medical or nursing practitioners or by self-referral.
- Service co-ordination would be provided by an interdisciplinary team: a specialist continence nurse or physiotherapist with specialist continence training and a consultant.
- The service, whilst provided by an interdisciplinary team, is likely to be led by the specialist continence practitioners within primary care, whether they have a nursing or physiotherapy background.
- Effective liaison with GPs would be essential.
- User and carer involvement would be invited, not only as a part of clinical governance of the service, but as an integral part of service planning, development and delivery.
- Regular user satisfaction surveys and analysis of performance indicators would be necessary for the effective governance of the service.
- There would be well defined and regular audit and quality assurance systems.
- All patients with bladder problems, SS or VS would be eligible to enter the service.
- Assessment and screening procedures would be in place to enable case-finding exercises to be a core element of activity, regardless of where a potential patient might have contact with a health professional.
- The service would be based on evidence-based protocols, and timed elements of care provision would be built into the protocols.
- There would be clear patterns of referral to specialist secondary care providers where when the initial assessment led to specified diagnoses (for example, significant prolapse would be referred to a urogynaecologist).
- The service would have access to medical and surgical consultants with a special interest in continence; these might exist as a virtual continence centre with clear pathways of referral between specialists.
- The service would clearly define successful or unsuccessful treatment rooted in subjective and objective outcome measures.

- Diagnostic urodynamic investigation would be available at a defined point in treatment provision. This would require central organisation of primary and secondary care to avoid duplication of testing and the avoidance of unnecessary tests.
- Secondary care provision would be provided by trained specialist professionals who would undertake intensive physiotherapy and provide treatment for bladder overactivity based on an evidence-based protocol.
- Nurse prescribing of limited medications including antibiotics, relevant antimuscarinic medication and topical oestrogen would be implemented using a patient group directive following appropriate training.
- The service would target high risk groups and people with special needs.
- The service would undertake training of other health care professionals and would provide general health promotion information and advice.
- Specialist continence practitioners (as defined above) would take part in secondary care clinical sessions to ensure continuity and consistency of approach throughout the service.
- Specific groups would be targeted for health promotion.
- The service would participate in general continence awareness promotion.
- The service would have an integrated multidisciplinary record, which is freely accessible to all members of the team. All members would be expected to record care interactions cumulatively.
- The team database would form the basis for audit and research.

The document recommends that continence services should be organised as integrated continence services. This will include a locally provided service comprising continence nurse specialists as well as medical and surgical specialists. Furthermore, each primary care and community team should have available professionals trained to carry out initial assessments and care, and arrangements that ensure that patients are identified, assessed and reviewed. There is no research evidence regarding the optimal way to provide a primary care continence service, but three distinct approaches have emerged:

- creating posts which include the specific responsibility and time provision for the delivery of continence services (continence co-ordinators) and giving them appropriate training;
- providing a basic level of training to many members of a primary care team who provide continence services as part of their job;
- referring all patients with continence problems to a specialist continence service for initial assessment and treatment as well as more complex problems.

The ideal service would incorporate all three elements. The result would be a continence nurse practitioner who would become the leading health care professional responsible for the provision of primary continence care. The continence nurse practitioner will accept referrals from other primary care health professionals and be responsible for patient education and advice, clinical assessment, investigation (e.g. urodynamic investigation) diagnosis and conservative treatment (e.g. pelvic floor exercises, behavioural therapy) as a member of an expert clinical team, based in secondary care. The continence nurse practitioner will also help develop and maintain care pathways to and from primary care and specialist services. A nurse practitioner would also be able to provide continuity of care, which is currently lacking. By taking part in secondary care clinical sessions, this continuity and consistency can be ensured. The continence nurse specialists will therefore play a vital role in the new service as they span the interface between primary and secondary care.

Referral mechanisms would incorporate the following features:

• A core consultant team including a nominated urologist, gynaecologist and gerontologist would meet regularly with the remit of accepting direct referrals from the primary care portion of the continence service. The core team would implement an evidence-based protocol for failures of secondary care, specifying where joint management needs to be implemented for continuing care.

- Patients who were found to be obstructed would be referred directly to the core consultant team urologist.
- Patients who failed conservative treatment for urodynamic stress incontinence would be referred directly to the core consultant team gynaecologist or urologist. All surgical interventions would be evidence-based and regularly audited. Rare conditions, e.g. fistulae would be referred to designated specialist centres.
- Patients who failed treatment for detrusor overactivity would be referred directly to the core consultant team.
- Patients with prolapse would be referred directly to the core consultant team for pelvis floor assessment and management.
- Patients with complex medical needs or chronic comorbidity with an impact upon continence status would be referred directly to the core consultant team physician/elderly care physician for initial assessment and management.
- All patients would have clear pathways of care back into the community team for the long-term monitoring of management.

## Quantitative comparison of two models of care

The main difference between the recommended model and the existing model of care is that in the new model there is an emphasis in primary care on PFE and bladder training managed by continence nurse practitioners (CNPs). This results in a reduction in the number of patients who go through to secondary care. The service in secondary care remains similar to the current service.

#### Future service configuration and associated costs

The Leicestershire MRC Incontinence Study has evaluated a new nurse-led continence service,<sup>232</sup> which may be the principle upon which continence services will be based in the future. **Figure 15** shows the structure of part of the study and patient flow through the service. An economic evaluation of this new service will be compared to that of an existing continence service.

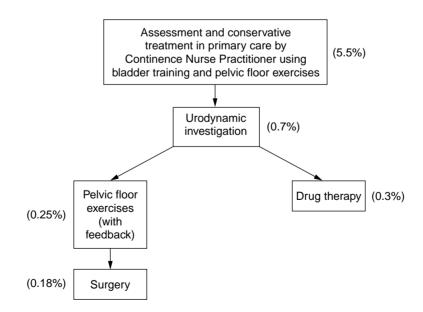


Figure 15: New model of care based upon a nurse-led continence service (prevalence).

The prevalence of individuals eligible for assessment and treatment in primary care for this model was based upon screening the local population through a postal questionnaire and home interview to establish severity of symptoms. In the new model, management in primary care would be provided in the main by CNPs with support from the GP in the first instance and referral to secondary care as appropriate.

All costs for these services are based on costing work carried out as part of the evaluation of the nurse-led continence services. These evaluations of the nurse-led continence services are ongoing, so the published costs may be revised in subsequent publications. All costs are in UK pounds for the year 2000. Although it is proposed that these costs should provide an estimate of the costs of this type of service, there are a number of caveats that need to be considered. The services evaluated were set up as part of a research project so workload and patterns of working may differ from those to be found in normal practice. Also, although the entry criteria for these services were based on symptoms relating to urinary incontinence, some of those admitted to the services would also have symptoms that related to voiding problems. Therefore, not all the resource used necessarily relates to urinary incontinence. In addition, these services were aimed at those over 40 years of age and so do not address the needs of those below this age.

All patients were seen by the CNP over an eight-week treatment period, with three planned visits, together with additional visits depending on the interventions provided and the degree of support deemed necessary by the nurse. Each patient underwent a one-hour assessment visit, which included taking a clinical history, physical examination, urinalysis, a mid-stream specimen of urine (MSU), a bladder scan to estimate post-void residual volume of urine, blood pressure, weight, height and, in women, vaginal examination. All patients were instructed in how to complete a urinary diary and pad test. Patients were seen one week after provision of the diary and pad test, which were then reviewed and a treatment regime was begun. A battery of clinical interventions could be implemented by the nurses, including bladder reeducation for frequency, urgency and urge incontinence, Canesten for vaginal candida, pelvic floor awareness for stress incontinence, antibiotics for urinary tract infection, topical oestrogen for atrophic vaginitis, medication change for symptoms caused by loop diuretics, and advice on diet and fluid intake. Each CNP had a maximum caseload of 60 patients. Up to three visits could be scheduled over the subsequent five weeks, before a final assessment. Preliminary results of the costs for these services for older adults are given in **Table 11**.

	Total number of contacts (% of study population)	Unit cost	Cost per 1000 people in Leicestershire over 40
Treatment in primary care	7,147 (5.5%)	£163	£9,008
Urodynamics	906 (0.7%)	£154	£1,076
Pelvic floor	329 (0.25%)	£293	£745
Drug therapy (oxybutynin)	390 (0.3%)	£418	£1,261
Surgery**	237 (0.18%)	£1,966	£3,602
Total			£15,691

**Table 11:** Costs\* for the new model of care as developed in the Leicestershire MRC Incontinence Study for people aged 40 or over.

\* For the year 2000 (preliminary results subject to revisions); \*\*This value is taken from HRG and OPCS data.

The total cost for the new service is estimated at £15 691 per 1000 per annum. This is likely to be an overestimate for several reasons:

- The services evaluated were set up as part of a research project, so workload and patterns of working may differ from those to be found in normal practice.
- Although the entry criteria for these services were based on symptoms relating to urinary incontinence, some of those admitted to the services would also have symptoms that related to voiding problems and this is likely to result in an *overestimate* of resource use.

#### Estimate of current service costs

Costs for the conventional incontinence service were estimated from a survey carried out as part of the Leicestershire MRC Incontinence Study. Respondents were asked for details of services they had used in the last year. The survey was carried out on 29 268 community residents over the age of 40. The percentages of respondents who used each category of service are given in **Table 12**. Since this was a snapshot of patients' experiences in just one year, none reported any surgery therefore an estimate of this was made using average rates and cost for surgery for the over 40s in the UK, calculated using OPCS statistics. Preliminary results of the costs for these services for older adults are given in **Table 12**.

Table 12: Estimate of costs <sup>a</sup> with conventional pattern of care based on survey of service contacts of
29,268 community dwelling adults aged 40 and over.

	Proportion using this service	Unit cost	Average cost per 1000
Any health care professional	11.2%		
GP	8.7%	$\pounds 18^{88}$	£1,566
Hospital doctor	2.9%	$\pounds 61^{234}$	£1,769
Physiotherapist	1.5%	$\pounds 16^{88}$	£240
Specialist continence nurse	1.2%	$\pounds 17^{88}$	£200
Other nurse	1.2%	$\pounds 17^{88}$	£200
Antibiotics	4.0%	$\pounds 2^{234}$	£91
Other medications	2.2%	$\pounds 60^{235}$	£1,323
Surgery <sup>b</sup>			£975
Pelvic floor exercises urinary diary	1.5%	$\pounds 293^{236}$	£4,493
Total			£10,856

<sup>a</sup> For the year 2000 (preliminary results subject to revision).

<sup>b</sup> This value is taken from HRG and OPCS data.

The total cost for existing services is estimated at £10 856 per 1000 per annum. This is likely to be an *underestimate* for several reasons:

- Costs are based on just the previous year's experience of a sample of respondents.
- Costs were used for a single contact as there is no data on the numbers of times respondents contacted a service.
- Costs for urodynamics are not included, as only values for consultations with a hospital doctor were available.

# 8 Outcome measures

This section summarises the results of a review of the literature in relation to outcome from the patient's perspective, audit tools and the information that is relevant for monitoring the effectiveness of intervention and care for urinary incontinence and an outline of future research.

#### Patient outcome

Urinary incontinence is associated with serious psychological suffering and poor quality of life.<sup>237</sup> It is therefore necessary to measure symptoms of urinary incontinence and the impact on patients' lives as part of the process of establishing the need for services and evaluating outcomes.<sup>238,239,240</sup> Symptom assessment helps determine the type, frequency and quantity of urinary leakage, and the extent of psychological and social disruption caused by these.

A wide range of questionnaires has been developed and used for symptom assessment. Most of these are designed either for men (often secondary to benign prostatic hyperplasia and surgical treatment of it) or for women, with very few for both. There are variations in the length and content of these questionnaires depending on whether they are developed for clinical or research purposes.

Some of these questionnaires were recommended in the First International Consultation on Incontinence<sup>241</sup> and elsewhere;<sup>242,243</sup> commonly used examples include the King's Health Questionnaire, the Bristol Female Lower Urinary Tract Symptoms Questionnaire (BFLUTS), the ICS male Questionnaire and the Quality of Life in Persons with Urinary Incontinence (I-QOL). Further details of these and other questionnaires are given in **Table A5.1**.

The King's Health Questionnaire and the BFLUTS were developed in the UK for assessing urinary incontinence symptoms in women. The former is also used to measure the impact on the quality of life. For men, the ICS male Questionnaire is used to assess lower urinary tract symptoms. It contains five questions concerning incontinence symptoms including urge and stress.

The Quality of Life in Persons with Urinary Incontinence (I-QOL) is designed for use in clinical trials to measure the impact of urinary incontinence on men and women. It contains 22 items and is scored on a four-point categorical scale.

A new questionnaire, the ICIQ-SF, has been launched in the second edition of the International Consultation on Incontinence, published in 2002.<sup>244</sup> The ICIQ-SF is aimed to provide a brief and robust tool for measuring frequency, severity and impact on quality of life of incontinence symptoms in all patient groups: 'men and women, young and old, in the developed and developing'. Preliminary data on its scores suggest that it is valid, reliable and responsive to change.

## Audit tools

A number of audit tools have been published to promote the quality of urinary incontinence services in the UK. These are briefly described below.

The Royal College of Physicians has produced a clinical audit scheme for collecting information in relation to urinary and faecal incontinence in primary and secondary care settings.<sup>245</sup> The purposes of the scheme are to educate staff and to identify areas that need change and improvement. It offers three instruments for three types of audit: single patient audit, multiple patient audit and facility audit.

Single patient audit comprises a comprehensive checklist of good practice for one or two patients. It is intended that a completed questionnaire should provide the basis for discussion and decision making for improved management of incontinence.

Multiple patient audit was developed from a review of standards of good practice among larger groups of incontinent patients. The aim is to give an overview of current practice and the extent to which standards of good practice are being achieved. Facility audit covers policy, procedures and staff education in relation to incontinence management.

Cheater *et al.*<sup>246</sup> have developed an evidence-based audit protocol for primary health care teams. The protocol proposes two levels of audit. Audit-one comprises a set of minimum criteria or must-do criteria (**Table 13**). The authors propose that each practice needs to undertake audit-one because there is strong research evidence in support of that.

Audit-two comprises the must-do criteria in audit-one and should-do criteria in relation to additional risk factors that are modifiable such as obesity and smoking. For the should-do criteria there is some research evidence of their importance but the impact on outcome is less certain. The protocol includes instructions and advice regarding the organisation of the audit, collection of data and implementation of change.

Table 13: Urinary incontinence: summary of audit criteria.

#### 'MUST DO' CRITERIA

These are the minimum criteria that practices need to audit, as there is firm research evidence to justify their inclusion. Every practice must include these criteria in the audit.

- 1 The records show that a patient with urinary incontinence has had an initial assessment that includes a history and/or completion of a continence chart and physical examination.
- 2 The records show that a patient with urinary incontinence has had a urine dipstick examination or microscopy or a mid-stream specimen of urine for culture and sensitivities.
- 3 The records show that there has been an estimation of the post-void residual (PVR) urine volume when indicated by the history/continence chart or physical examination.
- 4 The records show that the type of incontinence has been identified as either stress incontinence, urge incontinence, mixed incontinence, overflow incontinence (voiding disorder) or if the type of incontinence is unclear, appropriate specialist referral has been made.
- 5 The records show that at presentation a medication review has been undertaken to identify drugs which can cause or contribute to urinary incontinence; and in post-menopausal women an examination has been made for atrophic vaginitis/urethritis.

#### 'SHOULD DO' CRITERIA

#### These are additional criteria for which there is some research evidence of their importance but where the impact on outcome is less certain.

The records show that at presentation modifiable risk factors of obesity, chronic constipation and smoking have been sought and appropriate action taken if indication

Source: Cheater et al. 246

The Royal College of Obstetricians and Gynaecologists has produced a report on effective procedures in gynaecology that are suitable for audit.<sup>247</sup> Section 10 of the report deals with auditable procedures in urogynaecology that are relevant for female urinary incontinence. The section presents seven evidence-based statements of audit standards. For each statement a suggestion for audit is made, followed by a list of the research studies or reports on which the standard was based.

# 9 Information and research requirements

## Information

This section summarises the health outcome indicators from the report of the Working Group on Outcome Indicators for Urinary Incontinence.<sup>141</sup> An outcome indicator is an aggregated statistical measure that can be used to describe a group of people or a population in terms of a change in health, health-related status or risk factors to health. The change may be the result of intervention or the lack of it.

The group's report was based on a health outcome model. There were 18 indicators recommended in it. The aim of the group was to develop a set of ideal indicators that could be used for gathering information from the patient, doctor and population perspectives by a variety of professionals. An ideal indicator refers to what should be known or could realistically be known about an outcome of prevention and care of incontinence. **Table A5.2** gives a complete list of these indicators, their characteristics and implementation.

For a number of the indicators, information can be obtained from existing sources such as routine health care data or periodic surveys at national or local levels. For the other indicators, the availability of information depends on further developments in relation to the indicator or to other aspects such as information technology.

The indicators that depend on routine sources of information are:

- percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence
- rate of re-operation in a population (provided by a hospital provider unit) within two years following surgical treatment for urinary incontinence
- rate of emergency re-admission (for urinary-related condition and/or specific post-operation complication) within 30 days of discharge for a hospital provider unit population which has undergone surgery for urinary incontinence.

Those that depend on further development before information for deriving them is available are numbered 5, 9, 10, 16, 17 and 18 in **Table A5.2**.

## **Future research**

The level of knowledge about urinary incontinence and related conditions is very limited compared with, for example, the cardiovascular system. Recent investment in the MRC Incontinence Programme is addressing the essential epidemiology, including associated dietary and lifestyle factors, together with the cost of illness and the effectiveness and cost of a nurse-led service including behavioural and drug therapies. These results have established the extent of health care need and requirement and suggest a significant effect from treatment in primary care. However, considerable further investment is needed to reach a firm foundation for the development of future services as a whole. The priorities for further research include:

- 1 the natural history and prognosis relating to incontinence and other lower urinary tract symptoms
- 2 environmental and occupational factors along with diet and lifestyle determinants as a basis for prevention
- 3 investigation of disease mechanisms and management particularly relating to dual diagnosis e.g. depression, MS, diabetes and hormonal determinants

- 4 the association with pregnancy, particularly the mode of childbirth
- 5 development of the genetic basis of incontinence
- 6 evaluation of innovative approaches to improving access to appropriate services, especially in primary care
- 7 evaluating the long-term outcomes of treatment and support services in the community
- 8 evaluation of services for frail and elderly people with incontinence in and out of care homes
- 9 extent of incontinence, need and services for children and teenagers
- 10 development of a standard classification of urinary disorders based on an improved understanding of structure in relation to function and natural history
- 11 development of appropriate assessment and categorisation tools.

# Appendix 1: Lexicon for the definition and classification of lower urinary tract function in adults

The following functional classification is largely derived from work produced by the Urodynamic Society<sup>248</sup> and the International Continence Society Standardisation Committee<sup>123</sup> as applied in practice.<sup>249,250</sup>

The lower urinary tract (LUT) comprises the bladder and urethra. These form a functional unit and their interaction cannot be ignored. For simplicity, however, the functions of the bladder (to store and to void) and those of the urethra (to control and to convey) may be considered separately. Similarly, since the bladder and urethra may behave differently during the storing and voiding phases of *micturition* (a term for the whole process), these phases should also be considered separately. Thus, LUT function may be classified using a dichotomy of anatomical site by phase of micturition (Figure A1.1).

	В	ladder		Urethra
	Detrusor activity	<ul> <li>normal</li> <li>overactive: net idic</li> </ul>	irogenic pathic	Urethral closure <ul> <li>competent</li> <li>incompetent</li> </ul>
Storage phase	Bladder sensation	<ul> <li>normal</li> <li>increased</li> <li>reduced</li> <li>absent</li> <li>non-specific</li> </ul>		
	Bladder compliance			
	Bladder capacity	• normal • low	[4.1]*	[4.2]*
Voiding phase	Detrusor activity	<ul><li>normal</li><li>underactive</li><li>acontractile</li></ul>		Urethral opening <ul> <li>normal</li> <li>obstructive: overactive mechanical</li> </ul>
			[4.3]*	[4.4]*

\*reference to the relevant sections of this appendix

Figure A1.1: Factors affecting LUT function.

LUT function may be described in terms of symptoms, syndromes, signs, urodynamic observations and conditions:

1	Symptoms	the subjective indicators of a disease or change in condition as perceived by the individual, carer or partner that may lead him/her to seek help from health care professionals
2	Syndromes	constellations or varying combinations of symptoms that form functional abnormalities for which a precise cause has not been defined (after routine assessment has excluded obvious local causes)
3	Signs	observations by the physician including simple means to verify symptoms and quantify them
4	Urodynamic observations	the observations made during urodynamic studies
5	Conditions	the presence of urodynamic observations associated with characteristic symptoms or signs and/or non-urodynamic evidence of relevant pathological processes

# 1 Lower Urinary Tract Symptoms (LUTS)

LUTS may be volunteered or elicited during history taking. They are usually qualitative; and can seldom be used to make a definitive diagnosis. LUTS may indicate pathologies other than LUT dysfunction such as urinary infection. LUTS are grouped into storage, voiding and post-micturition symptoms.

#### 1.1 Storage symptoms

These are symptoms experienced during the storage phase of the bladder:

- Increased daytime frequency (pollakisuria): The complaint by the individual who considers that he/ she voids too often by day.
- Nocturia: The complaint that the individual has to wake at night one or more times to void.
- **Night-time frequency:** Differs from *nocturia* in that it includes voids which occur after the individual has gone to bed, but before he/she has gone to sleep; and voids which occur in the early morning that prevent the individual from getting back to sleep as he/she wishes.
- Urgency: The complaint of a sudden compelling desire to pass urine which is difficult to defer.
- Urinary incontinence: The complaint of any involuntary leakage of urine; this should be further described by specifying relevant factors such as the type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life, the measures used to contain the leakage and whether or not the individual seeks or desires help because of urinary incontinence.
- Stress urinary incontinence: The complaint of involuntary leakage on effort or exertion or on sneezing or coughing.
- Urge urinary incontinence: The complaint of involuntary leakage accompanied by or immediately preceded by urgency; may present as frequent small losses between micturitions or as a catastrophic leak with complete bladder emptying.
- **Mixed urinary incontinence:** The complaint of involuntary leakage associated with urgency and also with effort or exertion or with sneezing or coughing.
- Enuresis: Any involuntary loss of urine.
- Nocturnal enuresis: The complaint of loss of urine occurring during sleep.
- Continuous urinary incontinence: The complaint of continuous leakage.
- Situational urinary incontinence: Such as during giggling or sexual intercourse.
- Bladder sensation: Defined during history taking by five categories:
  - normal
  - increased
  - reduced
  - absent
  - non-specific.

#### 1.2 Voiding symptoms

These are symptoms experienced during the voiding phase of the bladder:

- **Slow stream:** The individual's perception of reduced urine flow, usually compared with previous performance or in comparison with others.
- Splitting or spraying: The individual's report of splitting or spraying of the urine stream.
- Intermittent stream (intermittency): The individual describes urine flow which stops and starts, on one or more occasions, during micturition.

- **Hesitancy:** The individual describes difficulty in initiating micturition, resulting in a delay in the onset of voiding after the individual is ready to pass urine.
- **Straining:** Straining to void describes the muscular effort used to initiate, maintain or improve the urinary stream (suprapubic pressure may be needed to initiate or maintain urine flow).
- **Terminal dribble:** The individual describes a prolonged final part of micturition, when the flow has slowed to a trickle/dribble.

#### 1.3 Post-micturition and other symptoms

Post-micturition symptoms are those experienced immediately after micturition; other symptoms may occur at varying times during the micturition cycle:

- Feeling of incomplete emptying: A feeling of incomplete emptying experienced by the individual after passing urine.
- **Post-micturition dribble:** The involuntary loss of urine immediately after he/she has finished passing urine, usually after leaving the toilet in men or after rising from the toilet in women.
- **Symptoms associated with pelvic organ prolapse:** These include feeling a lump ('something coming down'), low backache, heaviness, dragging sensation and the need to replace the prolapse digitally in order to defaecate or micturate.
- Symptoms associated with sexual intercourse: In women, symptoms include dyspareunia, vaginal dryness and incontinence during or after sexual intercourse; these should be described as fully as possible, defining whether leakage of urine occurs during penetration, during intercourse or at orgasm.
- Genital and LUT pain: Pain, discomfort or pressure; should be characterised by type, frequency, duration, precipitating and relieving factors and by location as defined below:
  - bladder pain
  - urethral pain
  - vulval pain
  - vaginal pain
  - scrotal pain
  - perineal pain
  - pelvic pain.

# 2 Syndromes suggestive of LUT dysfunction

These are grouped into genito-urinary pain syndromes and symptom syndromes. In all cases, it is presumed that routine assessment (history taking, physical examination and other appropriate investigations) has excluded obvious local pathologies such as those that are infective, neoplastic, metabolic or hormonal in nature.

#### 2.1 Genito-urinary pain syndromes

These are all chronic in nature. Pain is the major complaint but concomitant complaints are of a LUT, bowel, sexual or gynaecological nature:

• **Painful bladder syndrome:** Suprapubic pain related to bladder filling, accompanied by other symptoms such as increased daytime and night-time frequency, in the absence of proven urinary infection or other pathology such as carcinoma-in-situ and endometriosis.

- Urethral pain syndrome: Recurrent episodic urethral pain, usually on voiding, with daytime frequency and nocturia, in the absence of proven infection or other obvious pathology.
- Vulval pain syndrome: Persistent or recurrent episodic vulval pain, which is either related to the micturition cycle or associated with symptoms suggestive of urinary tract or sexual dysfunction; no proven infection or other obvious pathology.
- Vaginal pain syndrome: Persistent or recurrent episodic vaginal pain which is associated with symptoms suggestive of urinary tract or sexual dysfunction; no proven vaginal infection or other obvious pathology.
- Scrotal pain syndrome: Persistent or recurrent episodic scrotal pain which is associated with symptoms suggestive of urinary tract or sexual dysfunction; no proven epididimo-orchitis or other obvious pathology.
- **Perineal pain syndrome:** Persistent or recurrent episodic perineal pain which is either related to the micturition cycle or associated with symptoms suggestive of urinary tract or sexual dysfunction; no proven infection or other obvious pathology.
- **Pelvic pain:** Persistent or recurrent episodic pelvic pain associated with symptoms suggestive of LUT, sexual, bowel or gynaecological dysfunction; no proven infection or other obvious pathology.

#### 2.2 Symptom syndromes

In clinical practice, empirical diagnoses are often used as the basis for initial management after assessing the individual's LUT symptoms, physical findings and the results of urinalysis and other indicated investigations.

- Overactive bladder syndrome (urge syndrome) (urgency-frequency syndrome): Urgency with or without urge incontinence, usually with frequency and nocturia; no proven infection or other obvious pathology.
- LUTS suggestive of bladder outlet obstruction: In men, predominately voiding symptoms in the absence of infection or obvious pathology other than possible causes of outlet obstruction.

Overactive bladder syndrome is suggestive of urodynamically demonstrable detrusor overactivity but can be due to other forms of urethro-vesical dysfunction. In women, voiding symptoms usually suggest detrusor under-activity rather than bladder outlet obstruction.

# **3 Signs suggestive of LUT malfunction**

## 3.1 Measuring the frequency, severity and impact of LUTS

Asking the patient to record micturitions and symptoms for a period of days provides invaluable information. Validated questionnaires are useful for recording symptoms; their frequency, severity and bother; and the impact of LUTS on the quality of life. The instrument used should be specified. The recording of micturition events can be in three main forms:

- Micturition time chart: Records only the times of micturitions, day and night, for at least 24 hours.
- Frequency volume chart (FVC): Records the volumes voided as well as the time of each micturition, day and night, for at least 24 hours.
- **Bladder diary:** Records the times of micturitions and voided volumes, episodes of incontinence, pad usage and other information such as fluid intake (allowing for eating significant quantities of

water-containing foods such as fruit or vegetables), diuretic use, the degree of urgency and the degree of incontinence.

The following measurements can be abstracted from frequency volume charts and bladder diaries:

- **Daytime frequency:** The number of voids recorded during waking hours, including the last void before sleep and the first void after waking and rising in the morning.
- Nocturia: The number of voids recorded during a night's sleep; each void is preceded and followed by sleep.
- **24-hour frequency:** The total number of daytime voids and episodes of nocturia during a specified 24-hour period.
- **24-hour production:** Measured by collecting all urine for 24 hours; usually begun *after* the first void produced after rising in the morning and completed by *including* the first void on rising the following morning.
- **Polyuria:** The measured production of more than 2.8 litres of urine (based on a 70 kg adult voiding >40 ml/kg), usually in 24 hours, though it may be useful to look at output over shorter time frames.
- Nocturnal urine volume: The total volume of urine passed between the time the individual goes to bed with the intention of sleeping and the time of waking with the intention of rising (this excludes the last void before going to bed but includes the first void after rising in the morning).
- Nocturnal polyuria: Present when an increased proportion of the 24-hour output occurs at night, normally during the eight hours whilst the patient is in bed (the night-time urine output *excludes* the last void before sleep but *includes* the first void of the morning); values vary with age, from >20% in young adults to >33% in those aged over 65 years.
- **Maximum voided volume:** The largest volume of urine voided during a single micturition as determined from the frequency volume chart or bladder diary.
- **Minimum voided volume:** The smallest volume of urine voided during a single micturition as determined from the frequency volume chart or bladder diary.
- **Mean voided volume:** The average volume of urine voided during a single micturition as determined from the frequency volume chart or bladder diary.

## 3.2 Physical examination

Physical examination is essential in the assessment of all patients with LUT dysfunction. It should include abdominal, pelvic, perineal and a focused neurological examination. For patients with possible neurogenic LUTS, a more extensive neurological examination is needed.

#### Abdominal examination

The bladder may be felt by abdominal palpation or by suprapubic percussion. Pressure suprapubically or during bimanual vaginal examination may induce a desire to pass urine.

#### Perineal/genital inspection

This allows the description of the skin, for example the presence of atrophy or excoriation; any abnormal anatomical features; and the observation of incontinence:

- Urinary incontinence (sign): Urine leakage seen during examination; this may be urethral or extraurethral.
- Stress urinary incontinence (sign): The observation of involuntary leakage from the urethra, synchronous with effort or exertion or with sneezing or coughing; stress leakage presumed to be due to raised abdominal pressure.

- Extra-urethral incontinence (sign): The observation of urine leakage through channels other than the urethra.
- Uncategorised incontinence (sign): The observation of involuntary leakage that cannot be classified into one of the above categories on the basis of signs and symptoms.

#### Vaginal examination

This allows the description of observed and palpable anatomical abnormalities and the assessment of pelvic floor muscle function:

- **Pelvic organ prolapse:** The descent of one or more of the anterior vaginal wall; the posterior vaginal wall; the apex of the vagina (cervix/uterus) or vault (cuff) after hysterectomy; absence of prolapse is stage 0 support; prolapse can be staged from stage I to stage IV.
- Anterior vaginal wall prolapse: Descent of the anterior vagina so that the urethro-vesical junction (a point 3 cm proximal to the external urinary meatus) or any anterior point proximal to this is less than 3 cm above the plane of the hymen.
- **Prolapse of the apical segment of the vagina:** Any descent of the vaginal cuff scar (after hysterectomy) or cervix, below a point which is 2 cm less than the total vaginal length above the plane of the hymen.
- **Posterior vaginal wall prolapse:** Any descent of the posterior vaginal wall so that a midline point on the posterior vaginal wall 3 cm above the level of the hymen or any posterior point proximal to this is less than 3 cm above the plane of the hymen.
- Pelvic floor muscle function: Can be qualitatively defined by the tone at rest and the strength of a voluntary or reflex contraction as strong, weak or absent or by a validated grading system (such as Oxford 1–5); a pelvic muscle contraction may be assessed by visual inspection, palpation, electromyography or perineometry, noting factors such as strength, duration, displacement and repeatability.

#### **Rectal examination**

This allows the description of observed and palpable anatomical abnormalities and is the easiest method of assessing pelvic floor muscle function in men.

#### 3.3 Pad testing

Pad testing may be used to quantify the amount of urine lost during incontinence episodes. The methods range from a short provocative test to a 24-hour pad test.

# 4 Urodynamic observations

In general, a urodynamic observation may have a number of possible underlying causes and does not represent a definite diagnosis of a disease or condition. There are two main techniques:

- **Conventional urodynamic studies:** usually take place in the urodynamic laboratory and involve artificial bladder filling:
  - Artificial bladder filling: Filling the bladder via a catheter with a specified liquid at a specified rate.
  - Provocative manoeuvres: Techniques used during urodynamics in an effort to provoke detrusor overactivity, for example rapid filling, use of cooled or acid medium, postural changes and hand washing.

- **Ambulatory urodynamic studies:** A functional test of the LUT using natural filling and reproducing the subject's everyday activities; monitoring usually takes place outside the urodynamic laboratory.
- Natural filling: The bladder is filled by the production of urine rather than by an artificial medium.

Both filling cystometry and pressure flow studies of voiding require the following measurements:

- **Intravesical pressure:** The pressure within the bladder.
- Abdominal pressure: The pressure surrounding the bladder; in current practice, estimated from rectal, vaginal or, less commonly, from extraperitoneal pressure or a bowel stoma; the simultaneous measurement of abdominal pressure is essential for the interpretation of the intravesical pressure.
- **Detrusor pressure:** That component of intravesical pressure that is created by forces in the bladder wall (passive and active); estimated by subtracting abdominal pressure from intravesical pressure.

#### Storage phase

**Filling cystometry** is the method by which the pressure/volume relationship of the bladder is measured during bladder filling. The storage phase begins when filling starts and ends when the patient and urodynamicist decide that 'permission to void' has been given. During filling, bladder and urethral function need to be defined separately (Figure A1.1). The rate at which the bladder is filled is divided into:

- **Physiological filling rate:** a filling rate less than the predicted maximum, where the predicted maximum is the body weight in kg divided by 4 expressed as ml/min.
- Non-physiological filling rate: a filling rate greater than the predicted maximum filling rate as defined above.

#### 4.1 Bladder storage function

Bladder storage function should be described according to detrusor activity, bladder sensation, bladder compliance and bladder capacity.

Detrusor activity may be normal or overactive; and the latter may be associated with incontinence:

- Normal detrusor function: Allows bladder filling with little or no change in pressure; no involuntary *phasic* (wave form) contractions occur despite provocation.
- **Detrusor overactivity:** Characterised by involuntary detrusor contractions during the filling phase which may be spontaneous or provoked; certain patterns and causes may be noted:
  - **Phasic detrusor overactivity:** Defined by a characteristic wave form; may or may not lead to urinary incontinence.
  - Terminal detrusor overactivity: Defined as a single involuntary detrusor contraction occurring at cystometric capacity that cannot be suppressed and results in incontinence, usually due to bladder emptying.
  - Detrusor overactivity incontinence: Incontinence due to an involuntary detrusor contraction; in a patient with normal sensation, urgency is likely to be experienced just before the leakage occurs.
  - Neurogenic detrusor overactivity: The cause is a relevant neurological condition.
  - Idiopathic detrusor overactivity: There is no defined cause.

**Bladder sensation** assessed by filling cystometry is a subjective process. It is not possible to quantify measures such as *low bladder volume*. The assumption that this technique measures sensation from the bladder alone without urethral or pelvic components may be false. Bladder sensation may be categorised as follows:

• Normal bladder sensation: Can be judged by three defined points noted during filling cystometry and evaluated in relation to the bladder volume at that moment and in relation to the patient's symptomatic complaints.

- First sensation of bladder filling: The feeling the patient has during filling cystometry when he/she first becomes aware of the bladder filling.
- First desire to void: The feeling during filling cystometry that would lead the patient to pass urine at the next convenient moment, but voiding can be delayed if necessary.
- Strong desire to void: During filling cystometry, a persistent desire to void without the fear of leakage.
- Increased bladder sensation: During filling cystometry, an early first sensation of bladder filling (or an early desire to void) and/or an early strong desire to void, which occurs at low bladder volume and which persists.
- Reduced bladder sensation: During filling cystometry, diminished sensation throughout bladder filling.
- Absent bladder sensation: During filling cystometry, the individual has no bladder sensation.
- Non-specific bladder sensations: During filling cystometry, these may make the individual aware of bladder filling, for example abdominal fullness or vegetative symptoms.
- Bladder pain: Pain during filling cystometry; always an abnormal finding.
- **Urgency:** During filling cystometry, a sudden compelling desire to void (motor urgency and sensory urgency have little intuitive meaning and are no longer used).
- Vesical/urethral sensory threshold: The least current which consistently produces a sensation perceived by the subject during stimulation at the site under investigation.

**Bladder compliance** describes the relationship between change in bladder volume and change in detrusor pressure. It is calculated by dividing the volume change ( $\Delta V$ ) by the change in detrusor pressure ( $\Delta pdet$ ) during that change in bladder volume (C= V. $\Delta pdet$ ); and expressed in ml/cm H<sub>2</sub>O.

Bladder compliance may be measured in various ways, but should include at least two standard points:

- the detrusor pressure at the start of bladder filling and the corresponding bladder volume (usually zero)
- the detrusor pressure and corresponding bladder volume at cystometric capacity or immediately before the start of any detrusor contraction that causes significant leakage.

Bladder capacity measured during filling cystometry may be normal or reduced:

#### • Cystometric capacity:

- in patients with normal sensation, the bladder volume at the end of the filling cystometrogram, when 'permission to void' is usually given
- if there is uncontrolled voiding, the volume at which the voiding begins

- in the absence of normal sensation, the volume at which the clinician decides to terminate filling in all cases, the end point and reason(s) for terminating filling should be specified (such as a high

detrusor filling pressure, large infused volume or pain):

cystometric capacity = urine voided + any residual urine

- **Maximum cystometric capacity:** In patients with normal sensation, the volume at which the patient feels he/she can no longer delay micturition (has a strong desire to void).
- **Maximum anaesthetic bladder capacity:** The volume to which the bladder can be filled under deep general or spinal anaesthetic; this should be qualified according to the type of anaesthesia used and the speed, length of time and pressure at which the bladder is filled.

#### 4.2 Urethral closure mechanism

The urethral closure mechanism during the storage phase may be competent or incompetent; and an incompetent mechanism may result in incontinence:

• Normal urethral closure mechanism: Maintains a positive urethral closure pressure during bladder filling even in the presence of increased abdominal pressure, although it may be overcome by detrusor overactivity.

- Incompetent urethral closure mechanism: Allows leakage of urine in the absence of a detrusor contraction.
- Urethral relaxation incontinence: Leakage due to urethral relaxation in the absence of raised abdominal pressure or detrusor overactivity.
- Urodynamic stress incontinence: The involuntary leakage of urine during increased abdominal pressure, in the absence of a detrusor contraction.

In patients with stress incontinence, there is a spectrum of urethral characteristics ranging from a highly mobile urethra with good intrinsic function to an immobile urethra with poor intrinsic function. Any delineation into categories such as *urethral hypermobility* and *intrinsic sphincter deficiency* may be simplistic and arbitrary, and requires further research.

The assessment of urethral function may include the following measurements:

- Urethral pressure: The fluid pressure needed to just open a closed urethra.
- Urethral pressure profile: A graph of the intraluminal pressure along the length of the urethra.
- Urethral closure pressure profile: The urethral pressure minus the intravesical pressure.
- Maximum urethral pressure: The maximum pressure of the measured profile.
- **Maximum urethral closure pressure:** The maximum difference between the urethral pressure and the intravesical pressure.
- Functional profile length: In women, the length of the urethra along which the urethral pressure exceeds intravesical pressure.
- **Pressure 'transmission' ratio:** The increment in urethral pressure on stress as a percentage of the simultaneously recorded increment in intravesical pressure.
- Abnormal leak point pressure: The intravesical pressure at which urine leakage occurs due to increased abdominal pressure in the absence of a detrusor contraction; this should be qualified according to the site of pressure measurement (rectal, vaginal or intravesical) and the method by which the pressure is generated (cough or valsalva).
- **Detrusor leak point pressure:** The lowest detrusor pressure at which urine leakage occurs in the absence of either a detrusor contraction or increased abdominal pressure.

#### Voiding phase

Voiding is described in terms of detrusor and urethral function and assessed by measuring urine flow rate and voiding pressures. The voiding phase begins when 'permission to void' is given or when uncontrollable voiding starts, and ends when the patient considers voiding has finished.

*Urine flow* is defined either as *continuous* (without interruption) or *intermittent* (an individual states that the flow stops and starts during a single visit to the bathroom in order to void). The continuous flow curve is defined as a smooth arc-shaped curve or, when there are multiple peaks during a period of continuous urine flow, fluctuating. The precise shape of the flow curve is determined by detrusor contractility, the presence of any abdominal straining and by the bladder outlet. Measurements are made of:

- Flow rate: The volume of fluid expelled via the urethra per unit time (ml/s).
- Voided volume: The total volume expelled via the urethra.
- Maximum flow rate: The maximum measured value of the flow rate after correction for artefacts.
- Voiding time: Total duration of micturition, including interruptions.
- Flow time: The time over which measurable flow actually occurs.
- Average flow rate: Voided volume divided by flow time.

• Time to maximum flow: The elapsed time from onset of flow to maximum flow.

*Pressure flow studies* of voiding are the method by which the relationship between pressure in the bladder and urine flow rate is measured during bladder emptying. Pressure measurements may be made for intravesical, abdominal and detrusor pressures as follows:

- **Pre-micturition pressure:** The pressure recorded immediately before the initial isovolumetric contraction.
- **Opening pressure:** The pressure recorded at the onset of urine flow (consider time delay).
- Opening time: Elapsed time from initial rise in detrusor pressure to onset of flow.
- Maximum pressure: The maximum value of the measured pressure.
- Pressure at maximum flow: The lowest pressure recorded at maximum measured flow rate.
- **Closing pressure:** The pressure measured at the end of measured flow.
- **Minimum voiding pressure:** The minimum pressure during measurable flow; not necessarily equal to either the opening or closing pressures.
- Flow delay: Time delay between a change in bladder pressure and corresponding change in measured flow rate.

#### 4.3 Detrusor function during voiding

Detrusor activity may be normal or underactive. A normal detrusor contraction will be recorded as *high pressure* if urethral resistance is high; *normal pressure* if it is normal; or *low pressure* if it is low.

- Normal detrusor function: Achieved by a voluntarily initiated continuous detrusor contraction that leads to complete bladder emptying within a normal time span and in the absence of obstruction; for a given detrusor contraction, the magnitude of the recorded pressure rise will depend on the degree of outlet resistance.
- **Detrusor underactivity:** A contraction of reduced strength and/or duration, resulting in prolonged bladder emptying and/or a failure to achieve complete bladder emptying within a normal time span.
- Acontractile detrusor: A detrusor that cannot be demonstrated to contract during urodynamic studies.
- **Post-void residual:** The volume of urine left in the bladder at the end of micturition.

#### 4.4 Urethral function during voiding

Urethral functioning may be normal or obstructive:

- Normal urethra function: A urethra that opens and is continuously relaxed to allow the bladder to be emptied at a normal pressure.
- **Abnormal urethra function:** May result from obstruction due to urethral overactivity or from the urethra being unable to open due to anatomical abnormality such as an enlarged prostate or a urethral stricture.
- **Bladder outlet obstruction:** In men, generic term for obstruction during voiding characterised by increased detrusor pressure and reduced urine flow rate; usually diagnosed by studying the synchronous values of flow rate and detrusor pressure in women, not yet adequately defined.
- **Dysfunctional voiding:** Characterised by an intermittent and/or fluctuating flow rate due to involuntary intermittent contractions of the periurethral striated muscle during voiding in neurologically normal individuals.

- **Detrusor sphincter dyssynergia:** A detrusor contraction concurrent with an involuntary contraction of the urethral and/or periurethral striated muscle; occasionally flow may be prevented altogether.
- Non-relaxing urethral sphincter obstruction: Characterised by a non-relaxing, obstructing urethra resulting in reduced urine flow; usually related to a neurological lesion.

# 5 Conditions

In the absence of inflammation, infection and neoplasia, LUT dysfunction may be caused by:

- a disturbance of the pertinent nervous or psychological control system
- disorders of muscle function
- structural abnormalities:
  - congenital lesions (such as epispadias, ectopic ureter, spina bifida)
  - fistulae (vesico-vaginal, uretero-vaginal, urethro-vaginal)
  - urethral diverticula.

The underlying conditions may be presumed or definite. Presumed conditions are documented clinically. Definite conditions are documented by urodynamic techniques. When reporting results, it should be clearly stated whether the conditions causing urinary incontinence are definite or presumed; and the techniques by which the conditions are documented should be specified.

The following conditions are specifically defined for LUT dysfunction:

- Acute retention of urine: A painful (usually), palpable or percussable bladder, when the patient is unable to pass any urine.
- Chronic retention of urine: A non-painful bladder, which remains palpable or percussable after the patient has passed urine; but excluding transient voiding difficulty, for example after surgery for stress incontinence; the patient may be incontinent.
- **Benign prostatic obstruction:** A form of *bladder outlet obstruction*, which may be diagnosed when the cause of outlet obstruction is known to be benign prostatic enlargement, due to histological benign prostatic hyperplasia.
- **Benign prostatic hyperplasia:** A term used (and reserved for) the typical histological pattern which defines the disease.
- **Benign prostatic enlargement:** Prostatic enlargement due to histological benign prostatic hyperplasia; the term *prostatic enlargement* should be used in the absence of prostatic histology.

**Functional incontinence** may result from difficulties with mobility, environmental impediments (such as the location and accessibility of toilet facilities), sedation, confusion, depression or other psychiatric problems. Other related factors such as poor manual dexterity, impaired eyesight and unsuitable clothing and footwear may also predispose to incontinence.<sup>248</sup>

Other conditions related to LUT dysfunction include:

- Faecal incontinence: Involuntary or inappropriate passage of faeces.
- Double incontinence: Urinary and faecal incontinence occurring together.
- **Encopresis:** The repeated passage of faeces into inappropriate places (such as in clothing or on the floor), whether involuntary or intentional.

# **Appendix 2: Prevalence and incidence**

## **Population prevalence**

Prevalence studies with a rigorous methodology carried out on a total population are summarised in **Table A2.1**. The precise prevalence depends upon the definition of incontinence, the study population, the sampling procedure and the research instruments, which may or may not include an objective validation of reported symptoms. Variations due to study design are confounded by problems of differential reporting and a scarcity of validated scales. Incontinence is clearly a common problem but the precise prevalence depends upon the definition used.

Author/Year	Location	ocation Sample	Response	Study type	Prompts	Age	Respondents	Thresholds and (ratings)†	Prevalence %	
								<b>3</b>	Female	Male
Swithinbank <sup>251,252</sup> 1999, 2000	Bristol	GP – total	<sup>a</sup> 80%	Postal Q	++++	19+	F: 2,075	Ever <damp (1)<br="">Reclassified – from monthly <damp (2)<="" td=""><td>69</td><td></td></damp></damp>	69	
Harrison <sup>28</sup> 1994	Bristol	GP – random	<sup>a</sup> 83%	Postal Q (2 stage)	++	20+	F: 314	Any <damp (1)<="" td=""><td>53.2</td><td></td></damp>	53.2	
Kuh <sup>42</sup> 1999	Britain	Birth cohort	°93%	Postal Q	++	48	F: 1,378	Yearly <damp (1)<br="">Monthly <damp (2)<br="">Monthly × damp (3)</damp></damp>	55 23 8	
Yarnell <sup>37</sup> 1981	S Wales	Electoral register	<sup>a</sup> 95%	Interview	++	18+	F: 1,000	Yearly <damp (1)<="" td=""><td>45</td><td></td></damp>	45	
Milne <sup>13,253</sup> 1972 1971	Edinburgh	GP – random	<sup>a</sup> 65%	Interview + exam	++	62– 90	F: 272 M: 215	Ever <damp (1)<="" td=""><td>42</td><td>25</td></damp>	42	25
olleys <sup>55</sup> 1988	Leicester- shire	GP – random	<sup>u</sup> 89%	Postal Q	+++	25+	F: 833	Any <damp (1)<="" td=""><td>41</td><td></td></damp>	41	
Dolan <sup>44</sup> 1999	N Ireland	GP – random	<sup>a</sup> 66%	Postal Q	+++	35– 74	F: 689	Any <damp (1)<br="">Monthly <damp (2)<="" td=""><td>33.5 23.4</td><td></td></damp></damp>	33.5 23.4	
Stoddart <sup>43</sup> 2001	Bristol	GP – stratified	79%	Postal Q	++	65+	F: 740 M: 781	Any <damp (1)<="" td=""><td>31.6</td><td>23</td></damp>	31.6	23
Thomas <sup>18</sup> 1980	London/ S Wales	GP – random	<sup>a</sup> 89%	Postal Q	++	5+	F: 9,323 M: 8,761	Ever <damp (1)<br="">Monthly <damp (2)<="" td=""><td>25.1 8.5</td><td>8.7 3.3</td></damp></damp>	25.1 8.5	8.7 3.3
Brocklehurst <sup>10</sup> 1971	SE England	GP – total	<sup>u</sup> 85%	Interview	+	65+	F: 375 M: 182	Ever wet (2)	25	16
Edwards <sup>254</sup> 2001	UK	Population – random	94%	Interview	++	65+	F: 1,695 M 1,099	Ever wet (2)	24.2	8.6
Crome <sup>255</sup> 2001	Wales	Population – random	76.9%	Interview	+	70+	F: 1,010 M: 598	Occasionally (1) Frequently (3)	21.6 8.0	17.2 8.5
Perry <sup>8</sup> 2000	Leicester- shire	GP – random (excl. residential)	<sup>a</sup> 70%	Postal Q	++++	40+	F: 5,544 M: 4,682	Monthly <damp (2)<="" td=""><td>20.2</td><td>8.9</td></damp>	20.2	8.9

Table A2.1(a): Prevalence of incontinence, UK Studies 1960–2001: Summary of methodological features in relation to ranked overall	
prevalence of incontinence.	

138 Continence

Table A2.1(a): Continued.

Author/Year	Location	Sample	Response	Study type	Prompts	Age	Respondents	Thresholds and	Prevalence %	
								(ratings)†	Female	Male
Vetter <sup>38</sup> 1981	S Wales	GP – random	<sup>?</sup> 95%	Interview	++	70+	F/M 1,280	Ever × damp (2) Daily × damp (3)	18.1 6.7	7.3 2.5
Yarnell <sup>45</sup> 1979	S Wales	GP + total (incl. residential)	<sup>a</sup> 98%	Interview	+	65+ *	F: 219 M: 169	Yearly <damp (1)<="" td=""><td>17</td><td>11</td></damp>	17	11
O'Brien <sup>39</sup> 1991	Somerset	GP – random	<sup>a</sup> 79%	Postal Q	+	35+	F: 3,165 M: 2,496	Monthly <damp (2)<="" td=""><td>16.4</td><td>7.4</td></damp>	16.4	7.4
Brocklehurst <sup>40</sup> 1993	Britain	Electoral stratified, random (MORI poll)	[not reported]	Interview (highly structured)	+	30+	F: 2,124 M: 1,883	Ever damp (2) Yearly damp (2) Monthly damp (3) Weekly damp (3)	14.0 9.3 7.5 5.7	6.6 3.8 2.8 2.2
McGrother <sup>9,22,256,257</sup> 1986, 1987, 1987, 1990	Melton Mowbray	GP – total (incl. residential)	<sup>a</sup> 95%	Interview	+	75+	F: 820 M: 381	Monthly $\times$ damp (3)	12	12
Roe <sup>258</sup> 2000	England	GP – random	<sup>a</sup> 53%	Postal Q	+++	18+	F: 2,699 M: 3,409	Monthly $\times$ damp (3)	11.3	5.3
Feneley <sup>259</sup> 1979 Akhtar <sup>260,261</sup> 1973, 1972	Bristol Scotland	GP – total Population (3 samples)	<sup>?</sup> 93% 70–80%	Postal Q Interview + exam	++ +	5+ 65+	F/M: 6,510 F: 490 M: 318	Monthly <damp (2)<br="">Monthly × wet (3)</damp>	8 1.6	3.3 2.2

Denominator: <sup>a</sup> adjusted for ineligibles and <sup>u</sup> unadjusted. o Overestimate of true response rate. <sup>?</sup> Unknown. <sup>†</sup> (1) minor, (2) moderate, (3) major. \* Selected ages 65/66 and 75+.

Author/Year	Location	Sample	Response	Study type	Age	Respondents (N)	Thresholds and	Prevalence	e %
							(ratings)	Female	Male
MacLennan <sup>262</sup> 2000	Australia	Population – random	73.3%	Home interview	15–97	F: 1,546 M: 1,464	Yearly <damp (1)<="" td=""><td>35.3</td><td>4.4</td></damp>	35.3	4.4
Simeonova <sup>56</sup> 1990	Sweden	Visitors to GP/ nurse	82%	Question- naire	18+	F: 451	Ever <damp (1)<="" td=""><td>44</td><td></td></damp>	44	
.ara <sup>263</sup> 1994	New Z.	Electoral – random	54%	Postal Q	18+	F: 556	Yearly <damp (1)<br="">2 × month <damp (2)<br="">daily <damp (3)<="" td=""><td>34.0 25.2 12.6</td><td></td></damp></damp></damp>	34.0 25.2 12.6	
Chiarelli <sup>185</sup> 1999	Australia	Health database – random	47%	Question- naire	18–23, 45–50, 70–75	F: 41,724	continuously Yearly <damp (1)<="" td=""><td>3.0 27.5</td><td></td></damp>	3.0 27.5	
Hagglund <sup>264</sup> 1999	Sweden	Total population	88%	Postal Q	18–70	F: 3,076	Monthly <damp (2)<="" td=""><td>25.6</td><td></td></damp>	25.6	
Samuelsson <sup>265</sup> 2000	Sweden	Women having health check	77%	Postal Q	20–59	F: 382 (who received follow-up)	Any <damp (1)<br="">Monthly <damp (2)<br="">weekly <damp (3)<br="">daily <damp (3)<="" td=""><td>23.6 6.5 4.1 1.0</td><td></td></damp></damp></damp></damp>	23.6 6.5 4.1 1.0	
amuelsson <sup>48</sup> 1997	Sweden	Women scheduled for gynae exam	77%	Postal Q	20–59	F: 491	Any <damp (1)<br="">Monthly <damp (2)<br="">weekly <damp (3)<br="">daily <damp (3)<="" td=""><td>27.7 12.5 8.4 3.5</td><td></td></damp></damp></damp></damp>	27.7 12.5 8.4 3.5	
Sommer <sup>57</sup> 1990	Denmark	National register random	69%	Postal Q	20–79	F: 414	Any <damp (1)<="" td=""><td>40</td><td></td></damp>	40	
Peyrat <sup>266</sup> 2002	France	Hospital employees	61%	Question- naire	22–62	F: 1,700	Any <damp (1)<br="">Daily <damp (3)<="" td=""><td>27.5 2.2</td><td></td></damp></damp>	27.5 2.2	
Makinen <sup>50</sup> 1992	Finland	Total population	71%	Question- naire	25–55, cohort	F: 5,247	Any <damp (1)<br="">daily <damp (3)<="" td=""><td>20.1 3.5</td><td></td></damp></damp>	20.1 3.5	
Vinker <sup>267</sup> 2001	Israel	GP list	84%	Question- naire	30–75	F: 418	Any <damp (1)<br="">weekly <damp (3)<br="">daily <damp (3)<="" td=""><td>36.0 18.7 13.3</td><td></td></damp></damp></damp>	36.0 18.7 13.3	

Table A2.1(b): Summary of population studies of the prevalence of urinary incontinence from around the world.

Table A2.1(b): Continued.

Author/Year	Location	Sample	Response	Study type	Age	-	Thresholds and	Prevalence %		
						(N)	(ratings)	Female	Male	
Fultz <sup>268</sup> 2000	USA	Population sample	58%	Postal Q	40+	F: 930	Yearly <damp (1)<="" td=""><td>12.2<sup>s</sup> 23.6<sup>1</sup></td><td></td></damp>	12.2 <sup>s</sup> 23.6 <sup>1</sup>		
Bortolotti <sup>84</sup> 2000	Italy	GP random	$\sim 100\%$	Telephone interview	40+ F, 50+ M	F: 2,767 M: 2,721	Yearly <damp (1)<="" td=""><td>11.4</td><td>3.4</td></damp>	11.4	3.4	
Moller <sup>75</sup> 2000	Denmark	Population – random	71.7%	Postal Q	40–60, cohort	F: 2,860	Any <damp (1)<br="">weekly <damp (3)<br="">daily <damp (3)<="" td=""><td>71.9 16.1 5.3</td><td></td></damp></damp></damp>	71.9 16.1 5.3		
Ueda <sup>269</sup> 2000	Japan	Population – random	52.5%	Postal Q	40-80	F: 968 M: 818	Ever <damp (1)<="" td=""><td>53.7</td><td>10.5</td></damp>	53.7	10.5	
Muscatello <sup>270</sup> 2001	Italy	Telephone list random – area stratified	97%	Telephone interview	41+	F: 262 M: 232	Monthly <damp (2)<="" td=""><td>46.0</td><td>15.0</td></damp>	46.0	15.0	
Hording <sup>271</sup> 1986	Denmark	Total population	84%	Interview	45	F: 515	Ever <damp (1)<="" td=""><td>22.1</td><td></td></damp>	22.1		
Malmsten <sup>272</sup> 1997	Sweden	Population – random	74%	Postal Q	45+, cohort	M: 7,763	Monthly <damp (2)<br="">weekly <damp (3)<br="">daily <damp (3)<="" td=""><td></td><td>9.2 7.9 5.9</td></damp></damp></damp>		9.2 7.9 5.9	
Sherburn <sup>78</sup> 2001	Australia	Telephone numbers – random	94.8% (not clear)	Telephone interview	45–55	F: 1,897	Monthly <damp (2)<="" td=""><td>15.3</td><td></td></damp>	15.3		
Milsom <sup>273</sup> 1993	Sweden	Population – random	74.6%	Postal Q	46–86, cohorts	F: 7,459	Ever <damp (1)<br="">Any <damp (1)<="" td=""><td>21.1 14.8</td><td></td></damp></damp>	21.1 14.8		
Holtedahl <sup>274</sup> 1998	Norway	Population – random	72.6%	Gynae exam	50-74	F: 507	Any <damp (1)<br="">2+ × month <damp (2)<="" td=""><td>47.3 30.6</td><td></td></damp></damp>	47.3 30.6		
Kok <sup>275</sup> 1992	N'lands	Electoral – random	69%	Postal Q	60+	F: 719	$2 \times \text{week} < \text{damp}(2)$ daily $< \text{damp}(3)$	23.5* 13.4		
losif <sup>276</sup> 1984	Sweden	Population random	75%	Postal Q	61	F: 902	Any <damp (1)<="" td=""><td>29.2</td><td></td></damp>	29.2		

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Bogren <sup>277</sup> 1997	Sweden	Total population	91%	Postal Q	65	F: 220 M: 238	Any <damp (1)<="" th=""><th>28.0</th><th>9.0</th></damp>	28.0	9.0
Damian <sup>46</sup> 1998	Spain	Population – representative sample	71.2%	Home interview	65+, stratified	F/M: 589	Monthly <damp (2)<="" td=""><td>16.1</td><td>14.5</td></damp>	16.1	14.5
Tseng <sup>278</sup> 2000	Taiwan	Residents – random	80%	Home interview	65+	F: 256 M: 248	Ever <damp (1)<="" td=""><td>27.7</td><td>15.0</td></damp>	27.7	15.0
Maggi <sup>279</sup> 2001	Italy	Population	73.3%	Home	65+,	F: 1,531	Yearly <damp (1)<="" td=""><td>21.6</td><td>11.5</td></damp>	21.6	11.5
	-	random		interview	stratified	M: 867	Monthly <damp (2)<="" td=""><td>14.4</td><td>8.5</td></damp>	14.4	8.5
							weekly <damp (3)<="" td=""><td>11.4</td><td>6.8</td></damp>	11.4	6.8
							daily < damp (3)	7.3	5.2
Brown <sup>81</sup> 1996	USA	Population-	95%	Question-	65 +	F: 7,949	Monthly <damp (2)<="" td=""><td>41.3</td><td></td></damp>	41.3	
		based listings		naire			daily <damp (3)<="" td=""><td>14.2</td><td></td></damp>	14.2	
Harris <sup>280</sup> 1986	USA	Total	95%	Home	65 +	F: 3,346	Any <damp (1)<="" td=""><td>10.0</td><td>7.0</td></damp>	10.0	7.0
		population		interview		M: 2,291	daily <damp (3)<="" td=""><td>7.3</td><td>5.3</td></damp>	7.3	5.3
Tilvis <sup>281</sup> 1995	Finland	Population register	81.6%	Postal Q + exam	75–85, cohort	F: 478 M: 171	Any <damp (1)<="" td=""><td>20.3</td><td>16.3</td></damp>	20.3	16.3
Lagaay <sup>17</sup> 1992	N'lands	Total population	94%	Home interview	85+	F/M: 937	Any <damp (1)<="" td=""><td>27.9</td><td>19.6</td></damp>	27.9	19.6

\* Weighted mean. s = short questionnaire, l = long questionnaire.

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Author	Nocturia	Prevalence	Frequency	Prevalence	Urgency	Prevalence		
Brocklehurst <sup>10</sup> 1971 (ages 65+)	Do you get up at night to pass urine?	Females: 28% Males: 33%	Can you go longer than 2 hours in the day time without having to pass urine?	Females: 9% Males: 14%	Do you have to go to pass urine in a hurry?	Females: 32% Males: 28%		
Milne <sup>13</sup> 1972 (ages 62+)	Do you rise to pass urine at night (2 or more times)?	Females: 26% Males: 19%	Has there been a change in how often you pass urine in a day?	Females: 23% Males: 33%	Do you have control of your bladder if unable to go to the lavatory as soon as you need to pass urine?	Females: 21% Males: 21%		
McGrother <sup>9,257</sup> * Do you feel the need to <i>Females: 4.</i> 1986, 87 (ages 75+) get up during the night to <i>Males: 5.69</i> pass urine (2 or more times)? (+ <i>difficulty in</i> <i>control</i> )		Females: 4.8% Males: 5.6%	How often do you go to the toilet to pass urine in the day usually (more than once every 2 hours)? (+ <i>difficulty in control</i> )	Females: 4.3% Males: 5.0%	How long can you hold your water once you feel the urge to go (unable to wait for an occupied toilet)? (+ <i>difficulty in</i> <i>control</i> )	Females: 6.2% Males: 3.3%		
Hunter <sup>11</sup> *** 1994 (ages 55+)			Frequency** – (level unspecified) more than half the time	Males: 9%	Urgency – (level unspecified) more than half the time	Males: 8%		
Jolleys <sup>282</sup> 1994 (ages 40+) Kuh <sup>42</sup> 1999 (age 48)	Nocturia at least twice a night How often passed urine during the night (2 or more times)	Males: 14% Females: 14.6%	Frequency at least 9 times a day How often passed urine during the day (more than once very 2 hours)	Males: 12% Females: 9.9%	Urgency unspecified	Males: 48%		
Swithinbank <sup>12</sup> 2000 (ages 18+)	Night-time voiding (2 or more times)	Females: 18%	Frequency unspecified	Females: 15%	Urgency – unspecified	Females: 61%		
Perry <sup>8</sup> (ages 40+)	How often do you feel the need to get up at night to pass urine usually (2 or more times)?	Females: 21% Males: 20%	How often do you go to the toilet to pass urine usually (hourly or more)?	Females: 9.1% Males: 6.1%	Do you have difficulty holding urine once you have the urge to go, usually (most of the time or urge overwhelming)?	Females: 8.8% Males: 5.4%		

Table A2.2: Definitions and prevalence of nocturia, frequency and urgency in the UK: studies 1960–2001.

\* Threshold question (difficulty in control) applies to all symptom estimates; these estimates exclude residential care; two-stage study with 2% prevalence (of difficulty in control) drop-out between stages.

\*\* AUA symptom index, modified for UK population (Barry MJ, Fowler FJ et al. J Urol 1992; 148: 1549-57).

\*\*\* Random sample from eight GP practices in NW Thames Region. 1905 male respondents. Postal questionnaire, response 78% adjusted, minimal bias.

Author	Group	General impact	Specific interference	Consultation/Uptake
Thomas <sup>18</sup> 1980	Males/Females, age 15+		Moderate or severe incontinence with some restriction of activities 22% of those with regular incontinence, i.e. <2% prev in females and <1% prev in males	Recognised incontinence known to health and social services in 1 year <i>Females:</i> 15–64: 0.2% 65+: 2.5% <i>Males:</i> 15–64: 0.1% 65+: 1.3%
Vetter <sup>38</sup> 1981	Males and females, age 70+			Seen GP in past month Males and females: 6.2%
Yarnell <sup>37</sup> 1981	Females, age 18+	Problem with 'waterworks' and incontinent <i>Females: 9.4%</i>	Interferes with social or domestic life: <i>Females: 3.5%</i> Causes continual embarrassment <i>Females: 1.3%</i>	Consulted a GP in last 12 months <i>Females: 2.1%</i>
McGrother <sup>9,256</sup> 1986, 87	Males and females, age 75+	Difficulty in controlling water Females: 12% Males: 12%	Interference with one or more social activity including daily, social life, relationships, feelings and quality of life <i>Males and females: 3.6% ?</i>	Communicated the problem to GP or nurse Males and females: 5.1% Took up offer of service Males and females: 4.4%
O'Brien <sup>39</sup> 1991	Males and females, age 35+			Discussed with GP or district nurse at some time <i>Females: 2.8%</i> <i>Males: 1%</i> Took up treatment when offered <i>Females: 9.2%</i> <i>Males: 3.4%</i>
Brocklehurst <sup>40</sup> 1993	Males and females, age 30+	Bladder problems e.g. leaking, wet pants, damp pants, in the previous 2 months <i>Females: 9.3%</i> <i>Males: 3.8%</i>	Effect on life style Any effect – 77% cases (M&F); prevalence: <i>Females: 7.2%</i> <i>Males: 2.9%</i> A fair amount/great deal of effect – 34% F cases and 45% M cases; prevalence: <i>Females: 3.2.%</i> <i>Males: 1.7%</i> Concerned or worried = 60% of cases	Consulted GP 80% of cases (M>F) Prevalence: 6.7% for males and females combined

Table A2.3: Definitions and prevalences of need associated with urinary incontinence and related symptoms in UK studies 1960–2001.

## Table A2.3: Continued.

Author	Group	General impact	Specific interference	Consultation/Uptake
Harrison <sup>28</sup> 1994	Females, age 20+		Worry or affects social life and activities <i>Females: 8.6%</i>	Spoken to GP <i>Females: 3.2%</i> Took up offer of advice and treatment <i>Females: 6.1%</i>
Swithinbank <sup>41</sup> 1999	Females, age 19+	A bit or more of a problem with incontinence <i>Females:</i> 40%		
Dolan <sup>44</sup> 1999	Females, age 35–74			Consulted their GP <i>Females: 11.4%</i>
Kuh <sup>42</sup> 1999	Females, age 48	Bothered by incontinence in everyday life. <i>A little: 43.9%</i> <i>A lot: 29.9%</i>		
Perry <sup>8</sup> 2000	Males and females, age 40+	Incontinence and related symptoms described as a lot of bother or a moderate or severe problem <i>Females: 8%</i> <i>Males: 6.2%</i>	Interferes a lot: with daily activities, social life, relationships or quality of life or upsets or distress <i>Females: 3.2%</i> <i>Males: 2.2%</i>	Want help (not offered) <i>Females: 3.8%</i> <i>Males: 3.8%</i>
Stoddart <sup>43</sup> 2001	Males and females, age 65+	A little or more of a problem with incontinence <i>Females: 16.7%</i> <i>Males: 11.7%</i>	A little or more interference with life <i>Females: 18%</i> <i>Males: 12.2%</i>	Used health services Females: 14% Males: 9.2%

Study Population prevalence	Study sample	Definition of types of incontinence studied	
Maclennan 2000 <sup>262</sup> Australia	1,544 women, 15–97	Stress: lost urine when coughed, laughed or sneezed	20.8%
		Urge: felt urge to go to toilet but accidentally wet themselves before reaching the toilet	2.9%
		Mixed: stress and urge combined	11.6%
Yarnell 1981 <sup>37</sup> South Wales	1,060 women, 18+	Stress: loss of urine without urgency at any time	22.0%
		Urge: loss of urine with urgency at any time	9.0%
		Mixed: both types combined	14.0%
Holst 1988 <sup>49</sup> New Zealand	851 women, 18+	Stress: not specifically stated	16.5%
		Urge: not specifically stated	7.7%
262		Mixed: both types combined	7.2%
Lara 1994 <sup>263</sup> New Zealand	556 women, 18+	Stress: loss when performing manoeuvres which increased intra-abdominal pressure e.g. coughing, exercising	16.3%
		Urge: sudden involuntary loss	9.2%
		Mixed: stress and urge combined	7.1%
		Other: not specified	1.4%
Simeonova 1990 <sup>56</sup> Sweden	451 women, 18+	Stress: voided into clothes when coughing or laughing	16.2%
		Urge: could not avoid leakage when feeling urge to void	12.2%
		Mixed: stress and urge combined	15.5%
Samuelsson 1997 <sup>48</sup> Sweden	487 women, 20-59	Stress: leakage during effort	15.8%
		Urge: leakage with a sense of urge	2.1%
		Mixed: both types combined	5.3%
		Other: leakage, not during effort or with sense of urge	4.7%
Samuelsson 2000 <sup>265</sup> Sweden	382 women, 20–59	Stress: leakage during effort	14.7%
		Urge: leakage with sense of urge	1.6%
		Mixed: stress and urge combined	2.1%
		Other: non-specific	5.2%
Peyrat 2002 <sup>266</sup> France	1,588 women, 20–62	Stress: involuntary urethral loss associated with coughing laughing, sneezing or physical exercise	12.5%
		Urge: involuntary urethral loss preceded by a sensation of urgency or by rapid uncontrollable voiding with little or no warning	1.5%
		Mixed: stress and urge combined	13.4%
Sommer 1990 <sup>57</sup> Denmark	414 women, 20–79	Stress: not defined	15.3%
		Urge: not defined	13.3%
		Mixed: stress and urge combined	11.5%

 Table A2.4:
 Summary of population studies of the prevalence of stress and urge incontinence.

## Table A2.4: Continued.

Study Population prevalence	Study sample	Definition of types of incontinence studied	
Temml 2000 <sup>47</sup> Austria	1,262 women, 20+	Stress: how often does urine leak when	10.5%
		you are physically active, cough or sneeze? Urge: how often does urine leak before you can	1.8%
		get to the toilet? Mixed: not specifically defined	12.6%c
		Other: nocturnal incontinence	0.1%
Harrison 1994 <sup>28</sup> UK	314 women, 20+	Stress: leak when cough, laugh or exercise	24.5%
	514 women, 20 $\pm$	Urge: not defined	4.5%
		Mixed: stress and urge combined	22.6%
Hannestad 2000 <sup>283</sup> Norway	27,936 women, 20+	Stress: leak when coughing, sneezing, laughing, lifting heavy items	12.5%
,		Urge: leakage accompanied by sudden and strong urge to void	2.8%
		Mixed: stress and urge combined	9.0%
		Other: not classified	0.7%
Makinen 1992 <sup>50</sup> Finland	5,247 women 25–55	Stress: involuntary loss occurring during physical activity, such as coughing, heavy lifting, walking	14.7%
		Urge: such a very strong urge to pass water that you cannot hold on until you reach a toilet	0.8%
		Mixed: stress and urge combined	4.1%
-		Other: other types of incontinence	0.5%
Elving 1989 <sup>71</sup> Denmark	2,631 women 30–59	Stress: ICS	5.7%
		Urge: ICS	0.9%
		Mixed: both types combined	6.1%
Moller 2000 <sup>75</sup> Denmark	2,860 women 40–60	Stress: ICS	13.0%
		Urge: ICS	7.2%
1 1 2000 <sup>269</sup> 1	0.00	Other: continuous, nightly or sexual	5.8%
Jeda 2000 <sup>269</sup> Japan	968 women, 40–80	Stress: do you ever leak urine when you cough, sneeze or laugh?	33.9%
		Urge: do you have difficulty holding your urine until you can get to the toilet?	6.9%
		Mixed: stress and urge combined	12.9%
Muscatello 2001 <sup>270</sup> Australia	262 women, 40+	Stress: in the last month, how often did urine leak when you were physically active, exerted yourself, coughed or sneezed, during the day or night?	17.0%
		Urge: in the last month how often did urine leak before you could get to the toilet, during the day or night?	11.0%
		Mixed: stress and urge combined	18.0%
Burgio 1991 <sup>66</sup> USA	486 women, 42–50	Stress: leakage with physical activity	28.0%
-		Urge: loss associated with running water, urge to void, and being able to reach a toilet in time	6.8%
		Mixed: stress and urge combined	21.0%
Hørding 1986 <sup>271</sup> Denmark	515 women, 45 only	Stress: loss of urine on coughing, running etc (ICS)	16.5%
		Urge: loss of urine after strong desire to void (ICS)	2.4%
		Mixed: both types combined	3.1%

Roberts 1998 <sup>51</sup> USA	756 women, 50+	Stress: leakage of urine when coughed or sneezed in last year	6.4%
		Urge: in last year, when leakage occurred, were you aware of the need to urinate before the leakage occurred?	2.6%
		Mixed: stress and urge combined	37.9%
		Other: neither stress or urge	1.7%
Diokno 1986 <sup>83</sup> USA	1,150 women, 60+	Stress: loss at time of physical exertion	10.0%
		Urge: loss after urge to void or uncontrollable	3.4%
		voiding with little or no warning	
		Mixed: stress and urge combined	20.9%
Iosif 1984 <sup>276</sup> Sweden	902 women, 61 only	Stress: involuntary loss of urine when coughing, laughing, lifting heavy objects, climbing/descending stairs or in rapid movement on level ground	11.7%
		Urge: usually get such a very strong urge that you cannot hold back until you reach a toilet	8.0%
		Mixed: stress and urge combined	9.5%
Bogren 1997 <sup>277</sup> Sweden	225 women, 65 only	Stress: loss of urine due to physical exertion	$9.2\%^{a}$
Damian 1998 <sup>46</sup> Spain	<b>5</b> 00	Urge: loss preceded by an urge to void	$18.4\%^{a}$ $2.0\%^{b}$
Dannan 1998 Spann	589 men + women, 65+	Stress: escapes connected with exertion movements	2.0%
	031	Urge: escapes connected with specific triggering situations	2.2% <sup>b</sup>
		Mixed: stress and urge combined	9.9% <sup>b</sup>
		Other: neither stress or urge	2.0% <sup>b</sup>
Koyama 1998 <sup>284</sup> Japan	1,448 women, 65+	Stress: loss caused by coughing, sneezing, exercise	6.5%
		Urge: loss with urgency	6.8%
		Other: including abdominal pressure, during sleep	5.9%
Nygaard 1996 <sup>74</sup> USA	2,025 women, 65+	Stress: leak when cough, sneeze or laugh	41.4% <sup>a</sup>
78		Urge: how often have difficulty holding urine until reach a toilet	37.1% <sup>a</sup>
Tseng 2000 <sup>278</sup> Taiwan	256 women, 65+	Stress: loss associated with physical exertion Urge: loss because of inability to delay voiding following a micturition urge	10.9% 6.6%
		Mixed: stress and urge combined	6.3%
		Other: undetermined	3.9%
Stoddart 200143 UK	740 women, 65+	Stress: leak after cough or sneezing	15.0%
		Urge: 'before I can get to the toilet'	16.0%
Liu 2002 <sup>285</sup> Australia	2,272 men + women, 70+	Stress: accidentally pass urine	29.0% <sup>a,b</sup>
		Urge: have any difficulty holding urine until get to the toilet	41.4% <sup>a,b</sup>
Hellstrom 1990 <sup>16</sup> Sweden	658 women, 85 only	Stress: involuntary loss precipitated by coughing, sneezing or physical exertion, etc	9.0%
		Urge: involuntary loss preceded by the urge to void or uncontrollable voiding with little or no warning	19.9%
		Mixed: stress and urge combined	14.2%

a Fixures may include mixed incontinence; b Women only; c Approximately.

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**Table A2.5:** Summary of key prospective studies of the incidence of lower urinary tract symptoms (LUTS) in adults living in the community.

Study	Study population/ sample size/ (response rate)	Methodology	Definitions of symptoms studied	Prevalence at baseline (95% CI)	Incidence rate (95% CI)	Remission rate of cases (95% CI)
Møller 2000 <sup>73</sup> Denmark	Women, 40–60 Random sample from civil registers in 1 urban	Postal questionnaire at baseline (1996) and year 1	Stress incontinence: leakage caused by exertion	13.1 (11.7–14.4) %	4.0 (3.2–4.9) %	41.4 (39.2–43.6) %
	and 1 rural county Sample: 4,000 Baseline: 2,860 (72%)		Urge incontinence: leakage associated with urgency	7.3 (6.3–8.4) %	2.7 (2.2–3.4) %	42.0 (39.8–44.1) %
	Year 1: 2,284 (80%)		Any urinary incontinence	16.4 (14.9–17.9) %	5.8 (4.7–6.8) %	37.7 (35.5–39.9) %
			Any LUTS occurring weekly or more	28.5 (26.7–30.4) %	10.0 (8.5–1.4) %	27.8 (25.6–30.0) %
Nygaard 1996 <sup>74</sup> Iowa, USA – part of EPESE project (Establishment of Populations for	Women, 65+ (65–104) total population of non- institutionalised women in 2 rural counties	Annual home interviews for 6 years; incontinence at baseline (1981/2), year 3 and year 6.	Stress incontinence (SI): leaking urine when cough, sneeze or laugh	41.4%	3-year rates: baseline-year 3: 22.9% [7.6% pa]	3-year rates: baseline-year 3: 27.0% [9.0% pa]
Epidemiologic Studies of the Elderly )	Sample: 2,541 Baseline: 2,025 (80%) of which SI 1,714 (68%) UI 1900 (75%) Year 3: 1,861 alive of which SI 1,550 (83%) UI 1,736 (9,3%)	6 year results omitted here (do not correct for effects of ageing) Rates corrected for deaths	Urge incontinence (UI): difficulty holding urine until get to a toilet – occurring at least some of the time	37.1%	19.6% [6.5% pa]	30.0% [10.0% pa]
Herzog 1990 <sup>72</sup> Michigan, USA – part of MESA project (Medical, Epidemiologic and Social Aspects of Aging	Persons 60+ selected by multistage stratified area probability sampling of non-institutionalised residents in Washtenaw Sample: 2,968 Baseline: 1,956 (66%) Year 1: 1,333 (69%) Year 3: 662 (72%)	Annual home interviews for 2 years (baseline 1983/4); clinical evaluation + stress test in a subset persons at baseline Rates omit non- responders from denominator	Any uncontrolled urine loss in the past 12 months	women: 37.7% men: 18.9%	women: year 1: 22.4% year 2: 22.2% men: year 1: 9.0% year 2: 10.6% Adjusted for remissions: women: 19% men: 8%	women year 1: 11.2% year 2: 13.3% men year 1: 26.7% year 2: 32.3%

Baseline status	Baseline total	Year 1 status			
		Continent	Mild incontinence	Moderate incontinence	Severe incontinence
Women	470	374	68	18	10
Continent					
Mild incontinence	117	21	60	31	5
Moderate incontinence	85	3	41	36	5
Severe incontinence	54	2	7	10	35
Total	726	400	176	95	55
Baseline status	Baseline total	Year 1 status			
	totai	Continent	Mild incontinence	Moderate incontinence	Severe incontinence
Men	438	402	29	7	0
Continent					
Mild incontinence	55	6	32	7	0
		6	6	7	2
Moderate incontinence	21	6	6	/	4
Moderate incontinence Severe incontinence	21 9	6	6 1	2	4

 Table A2.6: Changes in self-reported continence and severity of incontinence during one year.

# Appendix 3

Age	und	ler 20	20-	24	25-	-29	30-	-34	35-	-39	40-	-44	45-	49	50-	-54	55–	59	60-	64	65–69		70-	-74	75–	79	<b>80</b> +		All age groups		
	М	F	М	F	М	F	М	F	М	F	М	F	М	F	Μ	F	М	F	М	F	М	F	М	F	М	F	М	F	М	F	All
A701	0	0	0	0	0	0	0	0	0	2	0	2	0	1	0	0	0	0	0	2	0	0	0	1	0	0	0	0	0	8	8
M511	0	0	0	1	0	3	0	21	0	47	0	75	0	84	0	120	0	98	0	97	0	65	0	52	0	41	0	11	0	715	715
M512	0	0	0	0	0	2	0	4	0	9	0	12	0	43	0	33	0	40	0	19	0	21	0	36	0	11	0	13	0	243	243
M521	0	2	0	2	0	3	0	10	0	20	0	33	0	67	0	67	0	60	0	61	0	52	0	24	0	15	0	12	0	428	428
M522	0	3	0	0	0	0	0	0	0	6	0	16	0	8	0	9	0	11	0	8	0	2	0	5	0	3	0	1	0	72	72
M523	0	6	0	3	0	35	0	137	0	435	0	745	0	908	0	1,085	0	796	0	597	0	378	0	201	0	85	0	27	0	5,438	5,438
M531	0	0	0	0	0	2	0	8	0	26	0	41	0	68	0	91	0	82	0	68	0	62	0	54	0	26	0	8	0	536	536
M538	0	0	0	1	0	2	0	21	0	46	0	82	0	106	0	133	0	121	0	81	0	77	0	56	0	51	0	20	0	797	797
M552	0	1	0	0	0	3	0	2	0	0	0	3	0	0	0	0	0	1	0	1	0	1	0	1	0	0	0	0	0	13	13
M563	0	11	0	3	0	8	0	34	0	45	0	86	0	129	0	203	0	198	1	178	2	184	0	174	1	137	0	81	4	1,471	1,475
M642	12	0	0	0	4	0	5	0	0	0	2	0	0	0	1	0	1	0	10	0	8	0	13	0	7	0	1	0	64	0	64
M651	1	0	0	0	0	0	0	0	0	0	0	0	2	0	4	0	9	0	7	0	17	0	39	0	30	0	41	0	150	0	150
M652	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	1
M653	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1	1	10	0	18	0	22	1	34	0	52	0	64	0	202	2	204
P251	0	2	0	1	0	3	0	8	0	21	0	16	0	14	0	16	0	2	0	7	0	2	0	13	0	3	0	4	0	112	112
Total	13	25	0	11	4	61	5	245	1	657	2	1,111	2	1,428	6	1,758	20	1,409	36	1,119	49	845	86	617	90	372	107	177	421	9,835	10,256

Table A3.1: Actual numbers of operations by age group and sex for 1999–2000 (Source: Hospital Episode Statistics, Department of Health).

# Appendix 4: Treatments in primary and secondary care

Drug	Dose	Cost per month (28 days)*
Oxybutynin	2.5–5 mg tds	£8.48-£18.43
Oxybutynin XL	5–10 mg once daily	£8.86-£17.71
Tolterodine	2 mg bd	£30.56
Trospium	20 mg bd	£23.33
Propiverine	15 mg bd – qds	£30.56-£61.12

Table A4.1: Drug treatment.

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**Table A4.2:** Drugs, numbers of prescriptions dispensed in the community and cost for 1998–2000 (figures are rounded to the nearest 100 or £100).

1998			
Drug name	Prescription items dispensed	Net cost (£)	Cost per item dispensed (£)
Flavoxate hydrochloride	77,700	765,300	9.85
Oxybutynin hydrochloride	1,015,800	12,291,000	12.10
Propiverine hydrochloride	1,000	31,400	30.13
Tolterodine tartrate	1,141	3,862,100	33.83
Total	1,208,700	16,950,000	
1999			
Drug name	Prescription items	Net cost (£)	Cost per item
	dispensed		dispensed (£)
Flavoxate hydrochloride	71,200	717,800	10.09
Oxybutynin hydrochloride	1,004,900	11,658,300	11.60
Propiverine hydrochloride	18,300	602,600	32.98
Tolterodine tartrate	329,300	11,189,200	33.98
Total	1,423,700	24,168,600	
2000			
Drug name	Prescription items	Net cost (£)	Cost per item
	dispensed		dispensed (£)
Flavoxate hydrochloride	64,900	681,200	10.49
Oxybutynin hydrochloride	1,003,400	9,397,300	9.37
Propiverine hydrochloride	40,400	1,402,700	34.71
Tolterodine tartrate	516,200	16,789,000	32.53
Total	1,624,900	28,270,200	

Source: Prescription Cost Analysis (Department of Health website: www.doh.gov.uk).

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nce

	Type of study and size	Condition studied	Interventions	Incontinence reduction	Patient subjective cure	Further treatment needed
Burgio <sup>172</sup> 1998	RCT N=197	Detrusor overactivity in fit elderly	Behavioural vs	80.7%	74.1%	14%
		,	oxybutynin vs	68.5%	50.9%	75.5%
			placebo	39.4%	26.9%	75.5%
				Number of patients cured		
Burgio <sup>193</sup> 2000	Crossover from failed treatment in 1998 trial: N=8+27	Detrusor overactivity resistant to previous therapy	Addition of oxybutynin to failed behavioural therapy (8 patients)	4/8		
			Addition of behavioural to failed oxybutynin (27 patients)	13/27		

 Table A4.3:
 Trials comparing bladder re-education to drug therapy.

	Type of study and size	Condition studied	Interventions	Reduction in episodes of incontinence per week	Patient subjective cure	Reduction in micturition frequency
Szonyi <sup>287</sup> 1995	RCT, N=57	Detrusor overactivity in fit elderly	Behavioural + oxybutynin vs Behavioural +	4.75 4.75	86%	1.9/day 0.4/day
			placebo			
				Reduction in incontinence episodes		
Ouslander <sup>288</sup> 1995	RCT, N=75	Urge incontinence in institutionalised elderly	Prompted voiding + oxybutynin vs	2.8%		
			Prompted voiding + placebo	6.3%		
				Cure rate		
Castleden <sup>206</sup> 1986	RCT, N=33	Detrusor overactivity elderly clinic attenders	Bladder retraining + imipramine vs	14/19		
		clinic attenders	Bladder retraining + placebo	6/15		
				Continence	No symptoms	
Jarvis <sup>289</sup> 1981	RCT, N=50	Detrusor overactivity	In-patient bladder retraining vs	84%	76%	
			Flavoxate 200 mg tds + imipramine 25 mg tds	56%	48%	

**Table A4.4:** Trials comparing combinations of behaviour and drug therapies.

**Table A4.5:** Trials comparing oxybutynin with placebo.

	Type of study and size	Population	Intervention	Increase in maximum urodynamic capacity	Increase in volume at first desire to void
Madersbacher <sup>290</sup> 1999	Multi-centre (32) RCT, N=366	Secondary and tertiary centres	Propiverine 15 mg tds vs	89 ml	67 ml
			Oxybutynin 2.5 mg bd vs	96 ml	71 ml
_			placebo	52 ml	27 ml
				Subjective improvement	
Thuroff <sup>291</sup> 1991	Multi-centre RCT, N=169	Secondary and tertiary centres	Propantheline 15 mg tds vs	44.7%	
			Oxybutynin 5 mg tds vs	58.2%	
			placebo	43.4%	
				Symptoms improved	Reduction in frequency
Moore <sup>292</sup> 1990	RCT, N=53	Secondary centre	Oxybutynin 3 mg tds vs	60%	35%
			placebo	2.3%	9%
				Stable urodynamics	Reduction of incontinence
Tapp <sup>293</sup> 1990	RCT with crossover, N=37	Tertiary centre	Oxybutynin 5 mg qds vs	62%	40%
			placebo	42%	25%
				Incontinence profile reduction	
Zorzitto <sup>294</sup> 1989	RCT with crossover, N=24	Elderly institutionalised	Oxybutynin 5 mg bd vs	24%	
			placebo	27%	

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	Type of study and size	Population	Intervention	Daytime continence	Side effects
Birns <sup>200</sup> 2000	RCT multicentre, N=130	Patients already stabilised on	Oxybutynin 5 mg bd vs	58%	Less with controlled release tablets
		oxybutynin. Secondary and tertiary centres	Oxybutynin CR 10 mg om	53%	
				Reduction of urge incontinence	
Versi <sup>199</sup> 2000	RCT multicentre, N=226	Patients responsive to oxybutynin. Tertiary	Oxybutynin vs	83%	In efficacious doses there was no difference
		centres	Oxybutynin CR (dose titrated against side effects and efficacy)	76%	in side effect profiles
				Reduction of urge incontinence	
Anderson <sup>295</sup> 1999	RCT multicentre, N=105	Secondary and tertiary centres	Oxybutynin vs	88%	Slight reduction in dry mouth with CR
			Oxybutynin controlled release (variable dose)	84%	oxybutynin

## Table A4.6: Controlled release oxybutynin.

Table A4.7: Controlled release tolterodine.

	Type of study and size	Population	Intervention	Reduction in voids per day	Reduction in incontinent episodes per 24 hours
Millard <sup>296</sup> 1999	RCT, multicentre, N=316	Tertiary centres	Tolterodine 2 mg bd vs	2.3	1.7 NS
	11 510		Tolterodine 1 mg bd vs	2.3	1.7 NS
			placebo	1.4	1.3
Larson <sup>297</sup> 1999	Pooled phase II efficacy data, N=319	Tertiary centres	Tolterodine 4 mg bd vs	1.4	1.7
			Tolterodine 2 mg bd vs	1.5	1.6
			Tolterodine 1 mg bd vs	1.0	0.8
			Tolterodine 0.5 mg bd vs	0.8	1.2
			placebo	0.5 p=0.043	1.4 p=0.18
Abrams <sup>298</sup> 1998	brams <sup>298</sup> 1998 RCT, multicentre, N=293	Tertiary and secondary centres	Tolterodine 2 mg bd vs	2.7 p=0.002	1.3 p=0.22
			Oxybutynin 5 mg tds vs	2.3 p=0.06	1.7 p=0.023
			placebo	1.6	0.9
Appell <sup>299</sup> 1997	Pooled phase III efficacy data, N=1,120	Tertiary and secondary centres	Tolterodine 2 mg bd vs	2.25 p<0.05	1.55 p<0.05
			Tolterodine 1 mg bd vs	2.10 p<0.05	1.65 p<0.05
			Oxybutynin 5 mg tds vs	1.95 p<0.05	1.75 p<0.05
			placebo	1.35	1.05
Appell <sup>197</sup> 2001	RCT, multicentre, N=378	Tertiary and secondary centres	Oxybutynin 10 mg Controlled release	3.5 p<0.05	3.1 p<0.05
			VS Taltana dina 2 mg h d	2.0	2.5
Kerrebroeck <sup>300</sup> 2001	RCT, multicentre,	Tertiary and secondary	Tolterodine 2 mg bd Tolterodine 2 mg bd	2.9 3.3 p<0.005	2.5 1.5 p<0.05
Kenedroeck 2001	N=1,529	centres	vs Vs	5.5 p<0.005	1.5 p<0.05
			Controlled release 4 mg om	3.5 p<0.005	1.7 p<0.05
			VS	2.2	1.0
			placebo	2.2	1.0

**Table A4.8:** (adapted from Jarvis 1994<sup>212</sup>).

Procedure	<b>Cure</b> (%)
Anterior repair and urethral buttress	67.8
Marshal-Marchetti-Krantz (MMK)	89.5
Colposuspension	89.9
Needle suspension	70-86.7
Bladder sling	93.9
Bladder neck injection	45.5
TVT	84.7

# **Appendix 5**

**Table A5.1:** Recommended questionnaires for the assessment of urinary incontinence symptoms and impact on the quality of life of patients.

Questionnaire	Items developed from	Sample	Content
York Incontinence Perceptions Scale (YIPS)	Open-ended questions	Female, community sample, all types of urinary incontinence, age range 29–98 years	8 items; control, acceptance, coping, knowledge, sleep, QOL, family
Incontinence Impact Questionnaire (IIQ)	Literature, qualitative interviews, experts (modification of previous scale)	Female, community sample, USI, DO, >44 years	30 items; activities, feelings relationships
Quality of Life of Persons with Urinary Incontinence (I-QOL)		Male and female, community sample, mixed UI	28 items; worry, emotions, self-image
Incontinence Stress Index	Literature review	Female nursing home residents, mean age 85.3 years	41 items; agitated depressive symptoms, retarded depressive symptoms, feeling of abandonment, somatic concerns and activities
ICS male Questionnaire	Interviews with men with lower urinary tract symptoms, discussion experts	Men, community and clinic samples, lower urinary tract symptoms	22 items; urge, stress, nocturnal incontinence, post-micturition dribble, degree of impact of symptoms
Incontinence Impact Questionnaire	Literature, qualitative interviews, experts (modification of previous scale)	Female, community sample, USI, DO, >44 years	30 items; activities, feelings relationships
Urogenital Distress Inventory	Literature review, qualitative interviews, experts	Female, community sample, USI, DO, >44 years	19 symptoms and related bother
Kings Health Questionnaire	Literature review, experts	Female, community sample, mixed UI	Role limitations (2 items), physical/social limitations (4 items), personal relations (3 items), emotions (3 items), sleep/ energy (2 items)
Bristol Female LUTS	Discussion with patients, experts, literature review	Female	Sex (4 items), activities (7 items)
Urge Incontinence Impact Scale (URIS-24)	Focus groups with older people with urge incontinence	Male and female, community sample, mean age 74 years, urge incontinence	24 items; self-image, emotions, worry
ICIQ-SF (developmental)	Literature review, experts, patient interviews	All ages, males, females	10 items covering frequency, severity and impact on quality of life of incontinence symptoms in all patient groups

USI = urodynamic stress incontinence, DO = detrusor overactivity, UI = urinary incontinence

Avoidance or reduction of the risk of urinary incontinence		
1 Incidence and prevalence of urinary incontinence	Specificity: generic Perspective: population Time frame: cross-sectional Relation to outcome: direct	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
2 Prevalence of urinary incontinence in long-term care	Specificity: condition-specific Perspective: population Time frame: cross-sectional Relation to outcome: direct	To be implemented generally by periodic survey
3 Incidence of urinary incontinence among women following pregnancy	Specificity: condition-specific Perspective: population Time frame: cross-sectional Relation to outcome: direct	To be implemented where local circumstances allow by periodic surveys
4 Rate of pelvic floor exercise training among pregnant women	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
Avoidance or reduction of adverse effects of delayed diagnosis or treatment		
5 Delay to presentation with urinary incontinence	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
6 Clinical assessment rates following presentation with urinary incontinence within a GP population	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented where local circumstances allow by periodic surveys
7 Rate of referral following presentation with urinary incontinence within a GP population	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented where local circumstances allow by periodic surveys

Recommendation for implementation

Table A5.2: Summary of outcome indicators for urinary incontinence recommended by the NCHOD Working Group reporting for the Department of Health.

## Avoidance or reduction of adverse ef diagnosis or treatment

Indicators (grouped by the aims of intervention to which Characteristics

they relate)

diagnosis or treatment		
5 Delay to presentation with urinary incontinence	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
6 Clinical assessment rates following presentation with urinary incontinence within a GP population	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented where local circumstances allow by periodic surveys
7 Rate of referral following presentation with urinary incontinence within a GP population	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented where local circumstances allow by periodic surveys

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Continence

## Table A5.2: Continued.

Indicators (grouped by the aims of intervention to which they relate)	Characteristics	Recommendation for implementation
8 Clinical assessment rates for those with urinary incontinence in long-term care	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented generally by periodic survey
Treating underlying mechanisms and causes and avoiding adverse consequences		
9 Rate of pre-operative cystometry in women undergoing surgery for urinary incontinence	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented following IT development on a routine basis
10 Rate of one-to-one training in pelvic floor exercises among women with stress incontinence	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
11 Percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented generally on a routine basis
12 Rate of re-operation in a hospital provider unit population within two years following surgical treatment for urinary incontinence	Specificity: generic Perspective: clinical Time frame: cross-sectional Relation to outcome: direct	To be implemented where local circumstances allow on a routine basis
13 Rate of emergency re-admission (for urinary-related condition and/or specific post-operation complication) within 30 days of discharge, for a hospital provider unit population which has undergone surgery for urinary incontinence	Specificity: generic Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented where local circumstances allow on a routine basis
14 Changes in urinary symptoms from before treatment to six months afterwards within a provider unit population receiving treatment for urinary incontinence	Specificity: condition-specific Perspective: clinical Time frame: longitudinal Relation to outcome: direct	To be implemented where local circumstances allow by periodic surveys

# Reducing impact of urinary incontinence on general well-being

15 Use of indwelling catheters in long-term care	Specificity: condition-specific Perspective: clinical Time frame: cross-sectional Relation to outcome: indirect	To be implemented generally by periodic survey
16 Changes in health-related quality of life as assessed before treatment to six months afterwards within a	Specificity: generic Perspective: patient	To be further developed either because the link with effectiveness is not clear or because the indicator
provider unit population receiving treatment for urinary incontinence	Time frame: longitudinal Relation to outcome: direct	specification is not complete
17 A measure of patient satisfaction at six months within a hospital provider unit population which has undergone surgery for urinary incontinence	Specificity: surgery-specific Perspective: patient Time frame: cross-sectional Relation to outcome: direct	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete
18 A measure of attainment of patient-specified outcome goals, within a population receiving treatment for urinary incontinence	Specificity: generic Perspective: patient Time frame: longitudinal Relation to outcome: direct	To be further developed either because the link with effectiveness is not clear or because the indicator specification is not complete

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