

health

# Outcomes

indicators

## URINARY INCONTINENCE

Report of a working group  
to the Department of Health



## FOREWORD

The Government consultation document "A First Class Service - Quality in the new NHS", published in 1998, emphasised three essential aspects of ensuring delivery of high quality of care by the National Health Service: setting, delivering and monitoring standards. It also discussed the importance of partnership between the Government and the clinical professions and patients in achieving such quality.

This series of 10 reports concerns the third aspect - monitoring standards. It represents the culmination of work that was started several years ago under the auspices of the Clinical Outcomes Group, chaired jointly by the then Chief Medical Officer, Sir Kenneth Calman, and the Chief Nursing Officer, Dame Yvonne Moores. The work was commissioned by the former Central Health Outcomes Unit of the Department of Health. The Unit has since moved and is now called the National Centre for Health Outcomes Development (NCHOD), based jointly at the Institute of Health Sciences, University of Oxford and the London School of Hygiene and Tropical Medicine, University of London.

The background to the work was the need to ensure that the NHS is driven by considerations of quality and outcome. The Department wanted to build on an earlier set of Population Health Outcome indicators, which had been limited by the constraints of existing routine data. It therefore commissioned systematic work on ten clinical topics, to be undertaken by a Working Group on each, tasked to make recommendations on 'ideal indicators' for each condition. 'Ideal indicators' were defined as statistical measures of what should be known, and realistically could be known, about the outcomes of the condition in routine clinical practice. The Groups were asked to consider a wide spectrum of possible uses of outcome indicators, from national monitoring of NHS performance by government to the periodic assessment of local services by clinicians and users.

The work of the Working Groups was coordinated by Michael Goldacre, University of Oxford. A particular feature of the work is that the Groups have recommended definitions and technical specifications for each indicator. It is hoped that people interested in monitoring the topic covered by each indicator will use the same definitions so that comparisons can be facilitated. Moreover, the methodology adopted by the Working Groups is applicable to developing health outcome indicators for many other conditions.

The publication of these reports, however, is only one further step on a long road of quality assessment in health care. The reports present 'menus' of suggestions for ways in which outcomes might be monitored in a variety of settings, by a variety of organisations and people. It goes without saying that NCHOD will welcome feedback on the reports and on the development and use of outcome indicators.

I believe that the work described here shows the value and potential of partnerships between various parties. Each working group had members who brought together perspectives of all the relevant clinical professions plus patients, NHS managers, policy makers, researchers and others as appropriate. The recommendations of the Working groups show quite clearly how these various perspectives may contribute to a broader and more balanced monitoring of standards. I would personally like to congratulate and thank everyone who has worked so hard and well to bring this initiative to fruition.

Azim Lakhani (Director - National Centre for Health Outcomes Development)

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This report may be referenced as follows:  
 Brocklehurst J, Amess M, Goldacre M, Mason A, Wilkinson E, Eastwood A, Coles J (eds). ~~Health Outcome Indicators: Urinary Incontinence. Report of a working group to the Department of Health.~~  
 Oxford: National Centre for Health Outcomes Development, 1999.

# OUTCOME INDICATORS FOR URINARY INCONTINENCE

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# SUMMARY OF RECOMMENDATIONS

Using a variety of check lists including a health outcome model, the Group identified outcome indicators which were fully specified in a standard format and are included in this Report. Outcome indicators, whose numbers correspond to the specifications in Section 4, were grouped under four headings relating to the aim of the intervention.

Recommendations for implementation were made for each indicator using the following categories:

- A.** To be implemented generally on a routine basis.
- B.** To be implemented generally by periodic survey.
- C.** To be implemented where local circumstances allow on a routine basis.
- D.** To be implemented where local circumstances allow by periodic survey.
- E.** To be implemented following IT development on a routine basis.
- F.** To be further developed either because link with effectiveness is not clear or the indicator specification is incomplete.

Category	Page	
		<b><i>Indicators related to avoidance or reduction of risk of urinary incontinence</i></b>
<b>F</b>	<b>18</b>	<b>1.</b> Incidence and prevalence of urinary incontinence.
<b>B</b>	<b>21</b>	<b>2.</b> Prevalence of urinary incontinence in long-term care.
<b>D</b>	<b>23</b>	<b>3.</b> Incidence of urinary incontinence among women following pregnancy.
<b>F</b>	<b>25</b>	<b>4.</b> Rate of pelvic floor exercise training among pregnant women.
		<b><i>Indicators related to avoidance or reduction of adverse effects of delayed diagnosis and treatment</i></b>
<b>F</b>	<b>27</b>	<b>5.</b> Delay to presentation with urinary incontinence.
<b>D</b>	<b>29</b>	<b>6.</b> Clinical assessment rates following presentation with urinary incontinence within a GP population.
<b>D</b>	<b>31</b>	<b>7.</b> Rate of referral following presentation with urinary incontinence within a GP population.
<b>B</b>	<b>33</b>	<b>8.</b> Clinical assessment rates for those with urinary incontinence in long-term care.
		<b><i>Indicators related to treating underlying mechanisms and causes and avoiding adverse consequences</i></b>
<b>E</b>	<b>36</b>	<b>9.</b> Rate of pre-operative cystometry in women undergoing surgery for urinary incontinence.
<b>F</b>	<b>38</b>	<b>10.</b> Rate of 'one-to-one' training in pelvic floor exercises (PFE) among women with stress incontinence.

- |          |           |  |
|----------|-----------|--|
| <b>A</b> | <b>41</b> | <b>11.</b> Percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence without vaginal prolapse.   |
| <b>C</b> | <b>43</b> | <b>12.</b> Rate of re-operation in a hospital provider unit population within two years following surgical treatment for urinary incontinence.   |
| <b>C</b> | <b>46</b> | <b>13.</b> Rate of emergency re-admission (for urinary related condition and/or specific post-operative complication) within 30 days of discharge, for a hospital provider unit population which has undergone surgery for urinary incontinence. |
| <b>D</b> | <b>48</b> | <b>14.</b> Changes in urinary symptoms from before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence.   |

***Indicators related to reducing impact of urinary incontinence on general well-being***

- |          |           |   |
|----------|-----------|---|
| <b>B</b> | <b>50</b> | <b>15.</b> Use of indwelling urethral catheters in long-term care.  |
| <b>F</b> | <b>53</b> | <b>16.</b> Changes in health related quality of life as assessed before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence. |
| <b>F</b> | <b>57</b> | <b>17.</b> A measure of patient satisfaction at six months, within a hospital provider unit population which has undergone surgery for urinary incontinence.                                |
| <b>F</b> | <b>59</b> | <b>18.</b> A measure of the attainment of patient specified outcome goals, within a population receiving treatment for urinary incontinence.  |

# 1. INTRODUCTION TO THE REPORT

## **Health outcome indicators**

- 1.1** This Report is one of a series containing the recommendations of working groups set up to report on 'ideal' indicators of the health outcomes of specific conditions. The background to the work, commissioned by the Department of Health is summarised in Appendix A.
- 1.2** Health outcomes have been defined as changes in health, health related status or risk factors affecting health, or lack of change when change is expected. They may be the result of the natural history of the condition or may be the effect of interventions to prevent or treat it. The particular concern of the working groups has been to make recommendations about outcomes which may be attributable to interventions or the lack of them.
- 1.3** The term indicator has been defined as an aggregated statistical measure, describing a group of patients or a whole population, compiled from measures or assessments made on people in the group or the population. An indicator may not necessarily provide answers to whether care has been 'good' or 'bad'; but well chosen indicators, as the term implies, should at least provide pointers to circumstances which may be worthy of further investigation.
- 1.4** An 'ideal' indicator has been taken to mean what should be known, and realistically could be known, about the outcomes of prevention and care of specific conditions. The development of the recommendations has, of course, been tempered by considerations of the likely cost and availability of information. However, the working groups have tried to be reasonably far-sighted in their views about the advances in information systems.
- 1.5** For each condition the working group has developed a menu of indicators which can be used by different groups of people for a variety of purposes. In particular, an attempt has been made to recommend, within each set, indicators which reflect a population, clinical, patient, and in relevant cases, a carer perspective.

## **Urinary Incontinence Working Group**

- 1.6** The terms of reference and membership of the Group are shown in Appendix B. The Group included representatives of the major professional, managerial and patient groups involved with the prevention and treatment of urinary incontinence.

**1.7** The work of the Group had three main components:

- development of check lists including a health outcome model for urinary incontinence to assist members choose candidate indicators by which is meant potential indicators worth detailed consideration
- specification of candidate indicators
- recommendations about implementation and further development.

**1.8** In this Report:

- the health outcome model is described in Section 2
- work commissioned to support the model is included in Appendix C
- a glossary of medical terms used in the model is in Appendix D
- check lists for choosing candidate indicators are outlined in Appendix E
- guidelines for specifying candidate indicators are described in Appendix F
- candidate indicators chosen for specification are listed in Section 3
- candidate indicator specifications are included in Section 4
- recommendations about implementation and development are made in Section 5
- references to all sections and appendices are in Appendix G.

### **Recommendations**

**1.9** The recommendations made by the Group were categorised as those which:

- can be implemented generally throughout the NHS as there are systems available which can provide the requisite data
- could be implemented now where local circumstances allow, and more generally in the near future once expected developments are in place
- will not be possible to implement in the near future but, because of their desirability, they should be considered in the future development of clinical and management information systems
- require further work before a recommendation can be made.

**1.10** The recommendations have been further categorised as to whether the requisite indicators should be available:

- routinely on a universal and continuous basis
- from periodic surveys and/or sampling, either at different points in time nationally or in geographical areas when there is a particular need or inte

## 2. HEALTH OUTCOME MODEL FOR URINARY INCONTINENCE

### **Definitions and scope of the work**

**2.1** Urinary incontinence is defined as the involuntary or inappropriate loss of urine which may be demonstrated objectively and has an impact on social functioning or hygiene. It was agreed that:

- the scope of the project would not include children
- in reviewing causes and risk factors potential indicators would not be considered specifically for systemic diseases associated with incontinence.

### **Developing a health outcome model**

**2.2** The greater part of the material for a health outcome model came from the Royal College of Physicians' Report (1995) *Incontinence : causes, management and provision of services*. In addition, the NHS Centre for Reviews and Dissemination were commissioned by the Group to prepare short literature reviews, which are included in Appendix C, on:

- interventions to prevent incontinence following pregnancy and childbirth
- effectiveness of surgical techniques to alleviate incontinence in women
- organisation of continence services.

**2.3** The health outcome model was developed as an aid to help Group members identify potential indicators. The model contained four elements:

- an overview of the epidemiology of the condition
- a review of the causes, mechanisms, and exacerbating factors
- a review of the course, complications and consequences
- a review of relevant interventions.

### **Overview of epidemiology**

**2.4** The prevalence of urinary incontinence is difficult to measure as sufferers under-report their problems to medical services and are probably reluctant to mention them to friends because of embarrassment and lack of awareness of the available treatments. Figures derived from surveys of those living at home and in institutions vary depending on the definitions of incontinence used and the survey methods, in particular whether or not the impact on social functioning is taken into account. Exhibit 1 shows the estimated prevalence of regular urinary incontinence in men and women living at home and institutions (Royal College of Physicians 1995; Peet et al. 1995).

**EXHIBIT 1 : PERCENTAGE OF THE POPULATION WHO HAVE URINARY INCONTINENCE**

<b>Population</b>	<b>Age (years)</b>	<b>Incontinent (%)</b>
Women living at home	15 - 44	5 - 7
	45 - 64	8 - 15
	65 and over	10 - 20
Men living at home	15 - 64	3
	65 and over	7 - 10
Both sexes together living in:		
Residential homes		30
Nursing homes		60
Hospital (elderly and elderly mentally infirm)		55 - 65

**2.5** Estimates of health care costs in the USA and Sweden indicate that urinary incontinence costs about 2% of the national health care budget (Royal College of Physicians 1995). This would suggest a cost in the UK of around £1.4 billion per annum at 1990 prices. The costs are spread across several sectors and are therefore difficult to measure and monitor. The direct cost of pads and appliances used in UK hospitals and long-term care in 1986 was £50 million with a further £18 million in prescription items in England and Wales (Sanderson 1995).

**Causes, mechanisms and exacerbating factors**

**2.6** For the purposes of the Group's work the mechanisms and main exacerbating factors for incontinence were identified as:

- Mechanisms:
  - genuine stress incontinence
  - detrusor instability/hyperreflexia
  - bladder outlet obstruction with detrusor weakness or bladder underactivity
  - incomplete bladder emptying not associated with outlet obstruction due to conditions such as neurological abnormalities of bladder sensation and motor supply
  - congenital abnormality
  - genitourinary fistula.

- Exacerbating factors:
  - co-existing diseases or conditions
  - socially unacceptable toilet facilities
  - inability to achieve timely access to toilet facilities.

A glossary of the medical terms used in this section is included in Appendix D.

- 2.7** In women genuine stress incontinence is the most common cause (Royal College of Physicians 1995). Stretching and damage to pelvic floor muscles and nerves associated with childbirth is an important risk factor for genuine stress incontinence. Muscular weakening and tissue thinning after the menopause may also be associated with stress incontinence. Anything that increases intra-abdominal pressure such as coughing, chronic constipation or pregnancy is likely to increase symptoms of urinary leakage.
- 2.8** For the majority of women with stress incontinence, leakage occurs for the first time either during pregnancy or after vaginal delivery. The cause is probably multi-factorial. Frequently, but not always, there is coexistent prolapse of the anterior vaginal wall.
- 2.9** Detrusor instability is the commonest cause of incontinence in men and the second most common cause in women. It may occur in up to 10% of young and middle aged adults, although for most people it causes few problems. It is not uncommon in women for stress incontinence and detrusor instability to co-exist and this may make accurate diagnosis difficult (Royal College of Physicians 1995).
- 2.10** In older men the commonest cause of incontinence is detrusor instability co-existing with benign prostate obstruction. Overflow incontinence may occur when the bladder outlet is obstructed and this may be complicated by bladder overactivity and chronic retention (Royal College of Physicians 1995).
- 2.11** Incomplete bladder emptying may occur because of:
- poor bladder contractility
  - bladder outlet obstruction
  - overdistension injury
  - urethral or vaginal inflammation
  - medication
  - prolapse or pelvic mass
  - anaesthesia or immediately following surgery
  - pregnancy and childbirth.

**2.12** Genitourinary fistula is uncommon in the United Kingdom but may result from complications of pelvic surgery, cancer or radiotherapy. In the developing world fistula secondary to obstructive labour is still a common cause of urinary incontinence. Congenital abnormalities are also rare causes of incontinence in the UK.

**2.13** Co-existing disease and conditions which may exacerbate incontinence include:

- chronic constipation or faecal impaction
- urinary infection
- confusion as a feature of acute delirium or in chronic confusional states
- drugs, in particular the loop diuretics
- diabetes either through an autonomic neuropathy or the mechanism of glycosuria requiring a high urine output
- any cause of an increased solute load including renal failure and hypercalcaemia
- cardiovascular diseases
- psychiatric disorders
- neurological disorders.

**2.14** Among old people living in institutions, where the prevalence of urinary incontinence is high, detrusor instability may lead to urgency and nocturia in the absence of other co-existing diseases. A failure to concentrate urine may also lead to excessive urinary output and precipitate nocturnal incontinence. To remain continent in these circumstances old people require:

- full assessment and examination to look for conditions noted in paragraph 2.13
- access to private and comfortable toilet facilities
- help from carers and staff.

**2.15** Access to a toilet may be difficult for someone who is not fully mobile and if timely help with walking or wheelchair access is not available then incontinence may result. If toilets are not near living areas and clearly labelled then some residents may find continence difficult to achieve. If toilets are uncomfortable for the arthritic because they are too low, or they are cold or unclean then some may prefer not to use them and suffer incontinence instead. Lack of private toilet facilities may be a source of embarrassment to some people who might prefer discomfort to the indignity of using a commode close to their peers.

### **Course, complications and consequences**

**2.16** Urinary incontinence is unpleasant for the sufferer. It results in discomfort and irritation of the skin which may contribute to infection and ulceration. Clothes and bedding may become soiled or ruined. The smell of stale urine adds to social embarrassment and isolation, which is likely to lead to low morale. The difficulties for family and carers may prove to be too much and urinary incontinence is often a contributing factor to the institutionalisation of a patient.

**2.17** Urinary incontinence is a symptom and may be the consequence of any one of many underlying diagnoses. The clinical course of a patient will be related to that diagnosis. Untreated urinary outflow obstruction may with time lead to progressive kidney damage and renal failure, especially in the presence of infection. Stress incontinence and detrusor instability, with complete bladder emptying, are unlikely to lead to any serious complications other than the social disruption already described.

### **Relevant interventions**

**2.18** The Group reviewed the relevant interventions for urinary incontinence using the following classification of types of intervention aimed to:

- reduce or avoid risk of urinary incontinence
- reduce or avoid adverse effects of delayed detection and treatment
- treat underlying mechanisms, causes and avoid adverse consequences
- reduce impact of incontinence on general well-being.

**2.19** The most important risk factors for incontinence in younger women are associated with pregnancy and childbirth. Relevant interventions are reviewed in Appendix C. Research results support the use of pelvic floor exercises for the treatment of stress incontinence. However, there is insufficient evidence to identify the precise way in which exercises should be taught.

**2.20** For men the most frequent risk factors are ageing and prostate enlargement.

**2.21** Operations which have incontinence as a particular complication are:

- pelvic floor repairs and other pelvic surgery
- some gynaecological cancer procedures
- prostatectomy.

- 2.22** The early detection and treatment of urinary incontinence requires knowledgeable health professionals and patients willing to admit to an embarrassing condition. A postal questionnaire of general practitioners in 1992 concluded that only 8% of GPs in practice for more than five years had received undergraduate training in continence prevention, compared with 51% of GPs in practice for less than five years (Jolleys, personal communication).
- 2.23** Embarrassment and unawareness of effective treatments makes it likely that many patients delay consulting with health service staff about their incontinence. National Continence Week in 1994 involved media coverage, local events and 1.7 million leaflets, posters and stickers to promote the message 'Don't suffer in silence'. The impact of this campaign was difficult to evaluate as people may present to many different professionals (Royal College of Physicians 1995).
- 2.24** Because of the embarrassment factor and acceptance of incontinence, people with urinary incontinence are often unlikely to tell their doctor about it. Systematic enquiries of the 'at risk' population may be a useful way of helping patients admit to this condition.
- 2.25** Before underlying causes can be treated, a careful clinical and social assessment must be carried out. This will include (Royal College of Physicians 1995) investigations such as urine culture. Further tests such as diagnostic imaging and urodynamic tests may be indicated following the preliminary screen or lack of response to appropriate treatment. Before surgery patients should have cystometry in order to make a precise diagnosis and to anticipate post-operative problems.
- 2.26** Interventions other than drug therapy and surgical operations include:
- improving access to toilet facilities particularly in residential care settings
  - regularly taking elderly patients who are disabled or have cognitive impairment to the toilet
  - implementation of bladder retraining regimens
  - strengthening the pelvic floor muscles
  - supplying appropriate continence aids.
- 2.27** Incontinence caused by pelvic laxity may respond to pelvic floor re-education. Aims for the treatment of stress incontinence are to reduce urethral hypermobility and to increase urethral closure pressure. A strong pelvic floor contraction can also aid inhibition of detrusor overactivity. Pelvic floor muscles can be strengthened by regular pelvic floor exercises, and enhanced by biofeedback. Neuromuscular electrical stimulation can inhibit detrusor overactivity and help patients who cannot contract their pelvic floor muscles adequately (Royal College of Physicians 1995).

**2.28** Medical interventions include (Royal College of Physicians 1995):

- anticholinergic drugs such as Oxybutynin and Imipramine which may lessen detrusor contractility but can impair bladder emptying leading to urinary retention
- alpha-adrenoreceptor blocking drugs which may alleviate urinary tract outflow obstruction but may also lower blood pressure
- Desmopressin which acts by reducing the formation of urine.

**2.29** The relative effectiveness of surgical procedures to treat stress incontinence is reviewed in Appendix C. From the identified literature to date there is insufficient evidence to recommend any specific surgical procedure although there is evidence of colposuspension being more effective in the short term.

**2.30** Urinary outflow obstruction by the prostate gland may be relieved by surgery, most commonly by transurethral resection. While urinary flow may be improved by this operation, detrusor instability may take months to settle, if ever (Royal College of Physicians 1995). Surgery may be complicated by damage to the sphincter mechanism causing permanent incontinence. The risk of this is likely to decrease with the experience of the operator.

**2.31** Insertion of an artificial urinary sphincter is a highly specialised operation, which is only appropriate for a few people and should be carried out in a centre with the appropriate expertise.

**2.32** Interventions to reduce the impact of incontinence include (Royal College of Physicians 1995):

- odour controls and skin care
- absorbent products
- urine collection devices
- occlusive devices
- clean intermittent catheterisation
- indwelling catheters
- advice about fluid intake
- bowel control
- review of medication
- treatment of co-morbidities such as diabetes.

**2.33** Odour controls and skin care are both important aspects in the management of incontinence. They contribute to personal hygiene, social acceptability and comfort. Several proprietary deodorants are listed in the drug tariff, as are products to prevent and treat dermatitis caused by contact with urine.

- 2.34** Absorbent products may either be worn under the clothing or used as pads, usually in bed. These products are available as single use disposable products or reusable washable products. A huge variety of absorbent products are available and the NHS purchased 80 million pads in 1990 (Royal College of Physicians 1995). There is a wide variation in the number and type of products supplied by different health agencies. Very few comparative trials of the performance of these products or of their cost effectiveness have been published.
- 2.35** Urine collection devices are available for men but there is no satisfactory collection device available for women. Penile sheaths or condom urinals may be self-adhesive or stuck in place with adhesive strips. These then lead to a collecting bag attached to the leg or a suitable frame. Urinal systems consist of a more rigid cone or funnel with straps and bags in a wide variety of configurations, but these only drain urine effectively when the man is upright.
- 2.36** Occlusive devices such as vaginal tampons and urethral, vaginal and penile clamps may be used in some cases to prevent leakage. For women they are of varying effectiveness and for men carry the risk of personal injury.
- 2.37** Clean intermittent catheterisation is a simple and effective treatment for patients with incomplete bladder emptying. The patient must understand the principles and be physically capable of performing the technique or live with someone capable and willing to do it for them.
- 2.38** Indwelling catheters are generally the last resort in managing intractable urinary incontinence. In selected instances they may make a positive contribution to quality of life or even allow someone to remain at home who might otherwise need institutional care. Urinary by-passing of the catheter is common, about 40% in one study, and complications include infection, pain and catheter blockage.
- 2.39** The effectiveness of the overall organisation of continence services is reviewed in Appendix C. There is little or no evidence available to identify the most effective way of providing them. It seems likely that any care which provides a systematic approach to the management of incontinence may improve outcomes.

### 3. CHOICE OF CANDIDATE INDICATORS

**3.1** To ensure that all potentially useful aspects of outcomes were considered the matrix shown in Exhibit 2 was drawn up using the following dimensions:

- aims of intervention (see paragraph 2.18)
- perspectives of measurement (see paragraph E6).

**3.2** For each part of the matrix, consideration was given to possible indicators. The following paragraphs describe which indicators were chosen, grouped together by the aim of the health intervention. The numbers in the text relate to the Exhibit and to the indicator specifications in Section 4.

**3.3** In view of the relative lack of firm evidence on specific risk factors it was agreed that measures of the occurrence of incontinence would be used as proxies for the **reduction and avoidance of risk**. The following candidate indicators were specified:

- 1:** incidence and prevalence of urinary incontinence
- 2:** prevalence of urinary incontinence in long-term care
- 3:** incidence of urinary incontinence among women following pregnancy.

**3.4** One risk factor, pregnancy, was considered to have an intervention for which evidence is accumulating of its effectiveness. A candidate indicator was thus specified related to the provision of pelvic floor re-education associated with pregnancy as follows:

- 4:** rate of pelvic floor exercise training among pregnant women.

**EXHIBIT 2 : MATRIX FOR URINARY INCONTINENCE  
OUTCOME INDICATORS**

<b>Aim of health intervention</b>	<b>Primary measurement perspective</b>		
	<b>Population</b>	<b>Clinical</b>	<b>Patient</b>
* Reduce or avoid risk of urinary incontinence	<b>1,2,3</b>	<b>4</b>	
* Reduce or avoid adverse effects of delayed detection and treatment		<b>5,6,7,8</b>	
* Treat underlying mechanisms, causes and avoid adverse consequences		<b>9,10,11, 12,13,14</b>	
* Reduce impact of incontinence on general well-being		<b>15</b>	<b>16,17,18</b>

**3.5** With respect to the **reduction of the adverse effects of delayed detection** it was agreed to develop indicators related to the carrying out of diagnostic assessments and the delay time before presentation to health services. The following candidate indicators were thus specified:

- 5:** delay to presentation with urinary incontinence
- 6:** clinical assessment rates following presentation with urinary incontinence within a GP population
- 7:** rate of referral following presentation with urinary incontinence within a GP population
- 8:** clinical assessment rates for those with urinary incontinence in long-term care.

**3.6** Three areas in which to develop proxy measures related to **treatment** were considered. The importance of carrying out cystometry particularly before a surgical procedure was noted. Pelvic floor exercises are an important treatment for stress incontinence. Evidence is building of the likely superior effectiveness of some surgical procedures for women with stress incontinence and, in particular, the ineffectiveness of anterior repair. The following candidate indicators were thus specified:

- 9:** rate of pre-operative cystometry in women undergoing surgery for urinary incontinence
- 10:** rate of 'one-to-one' training in pelvic floor exercises (PFE) among women with stress incontinence
- 11:** percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence without vaginal prolapse.

**3.7** One direct measure of outcome relating to urinary incontinence symptoms which can be used in association with any effective intervention has been specified as well as two proxy measures relating to re-admission and re-operation after surgery as follows:

- 12:** rate of re-operation in a hospital provider unit population within two years following surgical treatment for urinary incontinence
- 13:** rate of emergency re-admission (for a urinary related condition and/or specific post-operative complication) within 30 days of discharge, for a hospital provider unit population which has undergone surgery for urinary incontinence
- 14:** changes in urinary symptoms from before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence.

**3.8** Direct measurements of the **impact of incontinence** were considered, particularly those relating to the function and emotional status of the patient and the satisfaction with outcomes and services. The following candidate indicators were specified:

**15:** use of indwelling urethral catheters in long-term care

**16:** changes in health related quality of life as assessed before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence

**17:** a measure of patient satisfaction at six months, within a hospital provider unit population which has undergone surgery for urinary incontinence

**18:** a measure of the attainment of patient specified outcome goals, within a population receiving treatment for urinary incontinence.

**3.9** Having reviewed the evidence it was decided not to develop any indicators related to:

- rate of cystometry in the general population
- rate of artificial sphincter operations
- methods of organising continence services
- the knowledge or training of professionals providing services
- whether people in specific survey populations have been asked directly about whether they are incontinent
- the awareness of patients about the condition, its management and the services available
- drug treatments for incontinence
- admission rates to long term care because of incontinence.

**3.10** Although carers may play an important role in the care of patients with incontinence, the development of indicators in this area was not considered a major priority. However, detailed work on indicators related to carers has been carried out by the Stroke Health Outcomes Group and these are described in the Report of the Group's work (Working Group on Outcome Indicators for Stroke 1997).

## 4. CANDIDATE INDICATOR SPECIFICATIONS

- 4.1** This section contains the detailed specifications of the candidate indicators chosen by the Group. They have been grouped together by their association with the types of health intervention as shown in Exhibit 2.
- 4.2** Guidance notes which explain the attributes used in these specifications are included in Appendix F.
- 4.3** The detailed work of the specifications was carried out by Moyra Amess, Robert Cleary and James Coles of CASPE Research.

## Candidate indicator 1

### Characteristics

*Specificity:* Generic

*Perspective:* Population

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>Incidence and prevalence of urinary incontinence</b>
<b>Intervention aim</b>	Avoid or reduce risk of urinary incontinence.
<b>Definition</b>	<p>Accurate rates of incidence and prevalence are probably best obtained through large population-based surveys. However, general practice data can supplement such surveys with up-to-date local estimates of incidence and prevalence seen by GPs. Two indicators focusing on a GP population have been specified to reflect incidence and prevalence respectively.</p> <p>i) For a given GP population and year: <i>the number of people who present with urinary incontinence as a new problem within the given year, divided by the size of the practice list at the end of the given year.</i> The resulting fraction should be expressed as a percentage and reported with the numerator both as an overall figure, and by patient age-group and sex.</p> <p>ii) For a given GP population and year: <i>the number of people who consult their GP regarding urinary incontinence on one or more occasions within the given year, divided by the size of the practice list at the end of the given year.</i> The resulting fraction should be expressed as a percentage and reported with the numerator both as an overall figure, and by patient age-group and sex.</p>
<b>Rationale</b>	<p>Prevalence rates of urinary incontinence in the UK vary from between 5% and 20% among women and 3% and 10% among men, particularly affecting those who are aged 65 and over (Royal College of Physicians 1995). Much of the variance in rates is as a result of different definitions of urinary incontinence and the methods of inquiry used in such studies. Such rates demonstrate the burden of incontinence in the population and reflect the outcome of the failure to prevent the condition. Accurate rates of prevalence can only be obtained through structured surveys such as that being undertaken in the large MRC Incontinence Study currently underway in Leicester. Once this study is complete and the tools available for general use, surveys of local populations using this method may also be used to provide a reflection of the burden of incontinence in the population. Currently however, these indicators can provide a useful estimate of the burden of urinary incontinence in a local population.</p>
<b>Potential uses</b>	Local surveillance and monitoring of trends.
<b>Potential users</b>	Clinicians, commissioners.

**Possible confounders**

Risk factors for incontinence in the populations being compared are potentially confounding variables. Some control may be obtained if the results are stratified by age, sex, and recognised risk factors such as pregnancy. To allow identification of particular high risk groups within general practice populations, the number on the practice list living in long term care accommodation should be reported separately. Presentation to the general practitioner with incontinence may be influenced by patient awareness of the condition and services available, thus complicating the interpretation of the indicator.

Comparisons based on this indicator may also be confounded by the rate at which patients self refer to other continence specialist services, whose findings may not be reflected in GP data.

The definition of urinary incontinence may also vary among GPs and influences the extent to which they report the problem in the notes.

**Data sources**

i) Numerator data will be obtained from general practice records with documentation of 'urinary incontinence' as a presenting problem (i.e. new) within the relevant year. It is important to separate initial presentations from subsequent consultations for the problem. In general practices which have computerised patient records, this may be identified through use of Read coding of, for example, urinary incontinence (1A23.), stress incontinence (1A24.), or urge incontinence (1A26.) (NHS Centre for Coding and Classification 1996) and some identification that it is a new or initial presentation with the problem. Onset and history of symptoms can be recorded using Read codes. If separate records are held for practice nurse or other health professional consultations, e.g. continence specialists, these should also be surveyed. Ideally, GPs should be able to collect details from open access incontinence services to obtain the complete picture.

ii) The numerator for the prevalence indicator will be defined by consultations for incontinence in the given year, grouped by patients' unique identifiers.

A convenient standard for estimating the size of the practice population is the number of people registered on the general practice list at the end of the relevant year. This figure will provide the denominator for both indicators.

Computerised practices using Read codes should be readily able to report the number of patients in long term care. Suitable codes exist for the appropriate categories of accommodation e.g. lives in a nursing home (13F61), lives in an old peoples' home (13F72) (NHS Centre for Coding and Classification 1996).

<b>Data quality</b>	The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. To improve the value of currently collected routine data, GP data sets could be augmented to allow identification of resolved or existing incontinence problems/symptoms, thus facilitating the collection of prevalence estimates. This source relies on a correspondence between other related services and the GP, so that patients under the care of, for example, a continence specialist nurse, or attending a continence out-patient clinic would be identified to the GP. Patients who are not registered with a GP would be missed with this approach. Some GPs may also be reluctant to accept that residents from nursing and residential homes are their patients, with the potential for lower rates being reported.
<b>Comments</b>	The results of the MRC Leicester Incontinence study will also provide useful normative data for comparison.
<b>Further work required</b>	Further investigation of the quality of computerised records specifically with respect to records regarding incontinence, for example, the identification of initial presentations with incontinence compared to ongoing problems.
<b>Conclusions &amp; priority</b>	<b>F - To be further developed because further work is needed on the methods of measurement.</b>
<b>References</b>	<p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. Information Management Group, NHS Executive, London.</p> <p>Royal College of Physicians (1995). <i>Incontinence: causes, management and provision of services</i>. The Royal College of Physicians, London.</p>

## Candidate indicator 2

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Population

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>Prevalence of urinary incontinence in long-term care</b>
<b>Intervention aim</b>	Avoid or reduce risk of urinary incontinence.
<b>Definition</b>	For a given long-term care population and point in time: <i>the number of residents with urinary incontinence at the time of survey, divided by the size of the population of interest.</i> The resulting fraction, should be expressed as a percentage, and reported with the numerator as an overall age-standardised figure, and by patient age-group and sex.
<b>Rationale</b>	Among the population of men and women who live in long-term care, i.e. residential homes, nursing homes and NHS hospital long term care, an estimated 50-70% were considered to have urinary incontinence (Royal College of Physicians 1995). Prevalence rates will demonstrate the burden of incontinence among these populations and serve as an indicator of the failure to prevent, or successfully treat, this problem.
<b>Potential uses</b>	Local and regional trends over time.
<b>Potential users</b>	Policy makers, clinicians, commissioners.
<b>Possible confounders</b>	Risk factors for incontinence in the populations being compared are potentially confounding variables. Some control may be obtained if the results are stratified by age, sex, and significant functional and mental morbidities such as stroke or other neurological impairments. Comparisons between homes will be confounded by different admission policies e.g. ability to walk.
<b>Data sources</b>	For both NHS long-stay wards and nursing homes, information regarding problems of incontinence may be recorded in both the medical and nursing records, although it may not be held in a uniform format. Residential homes may not hold such extensive clinical records on their residents, and thus require new data collection. The CARE scheme (Continuous Assessment Review and Evaluation) is a clinical audit tool for the long-term care of elderly people (Research Unit of the Royal College of Physicians 1998) and includes urinary incontinence as one of its nine domains. In addition, an Incontinence Audit tool has been developed recently by the Royal College of Physicians based on the CARE model but focusing specifically on incontinence (Royal College of Physicians 1998). Both of these tools, when used, identify residents who have been incontinent in the last month. Use of either audit tool on a regular basis could provide the relevant data in a standardised format for this indicator. As well as the overall figure for incontinence, both tools also capture some detail on severity. In the CARE tool, section six of the resident summary records the number of residents (without a catheter/sheath) who have been incontinent in the last month- a) Never, b) Occasionally (no more than once a week and c) Frequently (more than once a week). The Incontinence Audit

tool has a similar section. Reporting of the number of residents who have a catheter/sheath alongside these figures would provide a detailed summary of the prevalence and severity of incontinence in this population.

Survey tools such as that being developed for the MRC Incontinence Survey in Leicester may provide an alternative method for gathering these rates on a periodic basis.

**Data quality**

The validity of the indicator will depend on the quality of the records within wards and homes, which may not be uniformly high. The use of a standardised measure such as the RCP audit tools or the MRC Incontinence Survey tool will increase the quality of the data available for this indicator and should be encouraged. The CARE scheme has undergone evaluation in a number of nursing homes and several NHS long-term wards. The results from this piloting suggested it was easy to use, encouraged ownership of the scheme and is feasible for use in such an environment (Dickinson and Brocklehurst 1997).

**Comments**

As an important indicator of quality in long term care, a requirement to make such records and/or rates such as these available should be included within social services inspection of such facilities. Commissioners should also be encouraged to request these data within their contract specifications. The frequency of survey could sensibly be linked in with the frequency of registration of the homes.

**Further work required**

None recommended.

**Conclusions & priority**

**B- To be implemented generally by periodic survey.  
This would be every two years on a sample basis to report prevalence.**

**References**

Dickinson, E., and Brocklehurst, J. (1997). Improving the quality of long-term care for older people: lessons from the CARE scheme. *Quality in Health Care*, **6**, 160-164.

Research Unit of the Royal College of Physicians (1998). *The CARE scheme*. The Royal College of Physicians, London.

Royal College of Physicians (1995). *Incontinence: causes, management and provision of services*. The Royal College of Physicians, London.

Royal College of Physicians (1998). *Clinical audit scheme for urinary and faecal incontinence*. The Royal College of Physicians, London.

## Candidate indicator 3

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Population

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>Incidence of urinary incontinence among women following pregnancy</b>
<b>Intervention aim</b>	Avoid or reduce risk of urinary incontinence.
<b>Definition</b>	For a given GP population and year: <i>the number of women who having had a baby in the given year, present with urinary incontinence within a year of the birth, divided by the total number of women who have had a baby in the given year.</i> The resulting fraction should be expressed as a percentage, and reported with the numerator as an overall figure, and by age-group and parity.
<b>Rationale</b>	Pregnancy and delivery are risk factors for urinary incontinence. Studies suggest that the aetiology of post-partum urinary incontinence is multifactorial including pre-pregnancy, pregnancy and delivery factors (Beck and Hsu 1965). Urinary incontinence is a distressing and common problem affecting between 5% and 15% of women under 65 (Royal College of Physicians 1995). This indicator will identify those women with persistent incontinence following pregnancy. If incidence is unexpectedly high this may reflect 'failure to prevent' in this at risk group.
<b>Potential uses</b>	Local comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	Risk factors for incontinence in the populations being compared are potentially confounding variables. Some control may be obtained if the results are stratified by age, and by additional risk factors such as parity.
<b>Data sources</b>	Numerator data should be obtained from general practice records of women who have had a baby in the relevant year, and who then, within a year of the birth, consulted their GP with urinary incontinence as a new problem. In general practices which have computerised patient records, these data may be identified through use of Read coding of childbirth (birth details (63..), and urinary incontinence (1A23.), stress incontinence (1A24.), or urge incontinence (1A26.) as a new problem (NHS Centre for Coding and Classification 1996). Access to information from health visitor records may be a valuable source of data to support this indicator. The health visitor, who is contracted to visit the mother and baby regularly in this period, is in an ideal position to collect this information. Currently there is no standard document to record this information nationally, and so local data collection systems would be required.
	The denominator is the total number of women in the practice who have had a baby in the given year.

**Data quality**

The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. The source relies on a correspondence between other related services and the GP, so that women under the care of, for example a continence specialist or attending a continence out-patient clinic, would be identified to the GP, and therefore documented within the general practice. A health care team approach would most likely ensure all women with incontinence are communicated to the GP and recorded in their casenotes. Women who are not registered with a GP would be missed with this approach.

The data source must be able to identify reliably women with no previous record of incontinence. The ability to do this may vary among GP systems. Equally GPs will have different definitions of incontinence, which will consequently effect the extent to which a problem is recorded as part of the notes.

**Comments**

A better source of data would be health visitor records. Health visitors must visit mother and baby at three months so such data collection could easily be incorporated. While this indicator is recommended for implementation now, if the rates were found to be non-variable, its use should be re-assessed.

**Further work required**

Study into the feasibility of health visitors collecting information on incontinence following pregnancy.

**Conclusion & priority**

**D - To be implemented where local circumstances allow by periodic survey. Routine recording of this indicator may be possible if health visitor data collection was established.**

**References**

Beck, R.P. and Hsu, N. (1965). Pregnancy, childbirth and the menopause related to the development of stress incontinence. *American Journal of Obstetrics and Gynaecology*, **91**, 820-903.

NHS Centre for Coding and Classification (1996). *The Read Codes October 1996 Demonstrators*. Information Management Group, NHS Executive, London.

Royal College of Physicians (1995). *Incontinence: causes, management and provision of services*. The Royal College of Physicians, London.

## Candidate indicator 4

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Rate of pelvic floor exercise training among pregnant women</b>
<b>Intervention aim</b>	Avoid or reduce risk of urinary incontinence.
<b>Definition</b>	<p>For a given GP population and year: <i>the number of pregnant women who report receiving training in pelvic floor exercises (PFE), divided by the number of pregnant women in the given population and year.</i> The resulting fraction, expressed as a percentage, should be reported with an overall figure and by age-group.</p> <p>In this definition, the number of <i>pregnant women</i> refers to those who are greater than 24 weeks pregnant, and who presented to their GP ante-natally in the given year.</p>
<b>Rationale</b>	<p>Childbearing is believed to be a pre-disposing factor for incontinence. Studies suggest that the aetiology of post-partum urinary incontinence is multifactorial including pre-pregnancy, pregnancy and delivery factors (Beck and Hsu 1965). Recent studies showed that daily antenatal PFE were associated with a reduction in the prevalence of incontinence (Wilson et al. 1996). This indicator would provide some insight as to the extent to which education and training in PFE is provided ante-natally on a routine basis. As the provision of such education is fragmented, and unlikely to be either exclusively provided or uniformly recorded within general practice records, the patient is suggested as the preferred source of data for this indicator. The indicator is specified to count only those women who are greater than 24 weeks pregnant to avoid counting pregnancies which are terminated.</p>
<b>Potential uses</b>	Clinical audit.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	The proportion of pregnant women who present late in pregnancy may vary between different practices and reduce the opportunity for this form of ante-natal care. For comparisons, practices may wish to identify such cases to assist the interpretation of this indicator.
<b>Data sources</b>	The numerator information may be obtained by asking each woman whether they had received any form of 'one-to-one' or class training in pelvic floor exercises during their ante-natal period. Further questions should include i) who taught them ii) whether they received an instruction leaflet; iii) when they started doing the exercises? and iv) how many pelvic floor contractions they did each day. Such a set of questions may form part of an audit of ante-natal care and be posed during a post-natal check appointment or by postal survey following pregnancy. A local decision is required as to what should be considered a minimum standard to

qualify as having received such education. The denominator may be obtained from general practice records as the number of women with pregnancies beyond 24 weeks gestation in the relevant year.

**Data quality**

The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. As there are many models of childbirth, there is possibly no one reliable point following pregnancy at which one could pose this question. The best method for obtaining a response from this group may be to send a postal questionnaire either directly to these women or via health visitors. It is acknowledged that response rates can be poor using this method. An alternative time of collection may be at delivery.

Patients who are not registered with a GP would be missed with this approach.

**Comments**

No specific points.

**Further work required**

Development of a questionnaire suitable for a post-natal survey to elicit information on ante-natal education.

**Conclusion & priority**

**F - To be further developed because link with effectiveness is not yet clear.**

**References**

Beck, R.P. and Hsu, N. (1965). Pregnancy, childbirth and the menopause related to the development of stress incontinence. *American Journal of Obstetrics and Gynaecology*, **91**, 820-903.

Wilson, P.D., Herbison, R.M., and Herbison, G.P.(1996). Obstetric practice and the prevalence of urinary incontinence three months after delivery. *British Journal of Obstetrics and Gynaecology*, **103**, 154-161.

## Candidate indicator 5

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Delay to presentation with urinary incontinence</b>
<b>Intervention aim</b>	Avoid or reduce adverse effects of delayed diagnosis and treatment.
<b>Definition</b>	<p>For a given GP population, year and specified time-period (see below): <i>the number of patients for whom the delay between onset of bothersome incontinence and initial presentation to the GP regarding the incontinence falls in to a specified time-period, divided by the number of initial presentations with incontinence within the given year.</i> The resulting fractions should be expressed as percentages, and the numerators and denominator reported both as overall figures and by sex and age-specific group rates.</p> <p>The time periods are:</p> <ul style="list-style-type: none"> <li>- <i>less than six months</i></li> <li>- <i>six months to a year</i></li> <li>- <i>one to five years</i></li> <li>- <i>more than five years.</i></li> </ul>
<b>Rationale</b>	<p>Despite the advances in the diagnosis and treatment of incontinence, the embarrassing nature of this condition delays many sufferers from seeking help (Brocklehurst 1993). Early treatment for urinary incontinence should reduce the time spent suffering distress, and patients should feel able to approach and elicit such help from their doctor or other relevant health clinicians. This indicator, by identifying changes in the numbers who delay seeking help or the scale of that delay, will reflect to some extent the success of local campaigns which aim to reduce the stigma attached to the condition and increase the awareness and use of local services.</p> <p>The categories selected (above) are those used in two studies which asked patients about the time between onset and seeking help (Brocklehurst 1993; Norton et al. 1988). However, alternative categories may be regarded as more appropriate (see Further work).</p>
<b>Potential uses</b>	Clinical audit and provider based comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	No specific ones identified.

<b>Data sources</b>	<p>Clinical assessment during a consultation will address the history of the complaint, and therefore this information should be obtainable, if documented, through a retrospective audit of patient notes. The definition of urinary incontinence developed by the Royal College of Physicians (1995) is 'involuntary or inappropriate loss of urine which may be demonstrated objectively'. The level at which a patient or carer considers incontinence a sufficient problem to warrant seeking help or as 'bothersome' is very subjective and variable (Norton 1995). Ideally, a definition of bothersome incontinence is required to facilitate comparisons across practices. However, the extent to which notes allow discrimination of degrees of incontinence at the onset of the problem is unknown.</p> <p>In general practices which have computerised patient records, data may be identified through use of Read coding of, for example, urinary incontinence (1A23.), date of onset (Xa6pO), and date of patient appointment (9NA1). However, there are no codes for severity or bothersomeness. Ideally this indicator should use data collected prospectively, using a urinary incontinence register to monitor patients with this problem.</p>
<b>Data quality</b>	<p>The quality of the data yielded with this indicator would rely not only on the quality of the notes, which may not be uniformly high, but also on the quality of the information provided by the patient. As this relies on a memory of when the problem became bothersome, the accuracy of the data may be variable.</p>
<b>Comments</b>	<p>No specific points.</p>
<b>Further work required</b>	<p>Further studies are required to assess the effect on outcomes of delay in presentation. Subsequent piloting would then be required both in terms of abstracting items from history taking and the relevant categories to be used.</p>
<b>Conclusion &amp; priority</b>	<p><b>F - To be further developed because the link with effectiveness is not clear and because further work is needed on the methods of measurement.</b></p>
<b>References</b>	<p>Brocklehurst, J.C. (1993). Urinary incontinence in the community: analysis of a MORI poll. <i>British Medical Journal</i>, <b>306</b>, 832-834.</p> <p>Norton, P.A., MacDonald, L.D., Sedwick, P.M., and Stanton, S.L. (1988). Distress and delay associated with urinary incontinence, frequency, and urgency in women. <i>British Medical Journal</i>, <b>297</b>, 1187-1189.</p> <p>Norton, C. (1995). <i>Commissioning comprehensive continence services</i>. The Continence Foundation, London.</p> <p>Royal College of Physicians (1995). <i>Incontinence: causes, management and provision of services</i>. The Royal College of Physicians, London.</p>

## Candidate indicator 6

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Clinical assessment rates following presentation with urinary incontinence within a GP population</b>
<b>Intervention aim</b>	Avoid or reduce adverse effects of delayed diagnosis and treatment.
<b>Definition</b>	<p>For a given GP population and year: <i>the number of patients whose initial presentation with incontinence led to both follow-up actions (listed below) within 30 days of the initial presentation, divided by the number of initial presentations with incontinence.</i> The resulting fraction should be expressed as a percentage, and the numerator and denominator reported both as overall figures, and as sex and age-specific rates.</p> <p>The specified follow-up actions are:</p> <ul style="list-style-type: none"> <li>- <i>abdominal and vaginal or rectal examination carried out</i></li> <li>- <i>urine sample taken.</i></li> </ul>
<b>Rationale</b>	<p>Urinary incontinence is a symptom with many causes and an essential step in its management is to make a diagnosis as to its cause (Royal College of Physicians 1995). A study of people with incontinence revealed that although more people are now consulting their general practitioners about incontinence than shown in previous studies, the actions carried out by general practitioners still appear to be sub-optimal, and show considerable geographic variation (Brocklehurst 1993). Undertaking the appropriate follow-up actions identified above suggests that a good history was taken. This indicator will therefore reflect, to some extent, the failure to assess appropriately.</p>
<b>Potential uses</b>	Clinical audit and local comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	<p>Numerator data may be obtained from patient notes which record consultations for urinary incontinence, plus evidence of a suitable abdominal and pelvic examination, and request for urine sample within 30 days of that initial appointment date. In general practices which have computerised patient records, these data may be identified through use of Read coding of (for example) collection of urine sample (Ua1J4), abdominal (Ua1EP), vaginal (X7A17) and rectal (XM1Dd) examinations, in patients who have consulted their GPs with incontinence (NHS Centre for Coding and Classification 1996). Where such systems are not in place, a retrospective survey of GP notes would be required. The denominator will be obtained from the same source and include all patients who presented to their GP with incontinence as a new problem within the relevant year (see Indicator 1i.).</p>

<b>Data quality</b>	The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. Patients who are not registered with a GP would be missed with this approach.
<b>Comments</b>	A parallel indicator may focus on the diagnosis and action taken for the sub-group of women who present with incontinence following childbirth. As well as general practice records, district nurse, or health visitor notes may be complementary sources of information.
<b>Further work required</b>	None recommended.
<b>Conclusion &amp; priority</b>	<b>D - To be implemented where local circumstances allow by periodic survey.</b>
<b>References</b>	<p>Brocklehurst, J.C. (1993). Urinary incontinence in the community: analysis of a MORI poll. <i>British Medical Journal</i>, <b>306</b>, 832-834.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. Information Management Group, NHS Executive, London.</p> <p>Royal College of Physicians (1995). <i>Incontinence: causes, management and provision of services</i>. The Royal College of Physicians, London.</p>

## Candidate indicator 7

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Rate of referral following presentation with urinary incontinence within a GP population</b>
<b>Intervention aim</b>	Avoid or reduce adverse effects of delayed diagnosis and treatment.
<b>Definition</b>	For a given GP population and year: <i>the number of patients whose initial presentation with incontinence led to a referral to a relevant continence specialist (medical, nursing or therapy) within one month of presentation, divided by the number of initial presentations with incontinence.</i> The resulting fraction should be expressed as a percentage, and the numerator and denominator reported both as overall figures, and as sex and age-specific rates.
<b>Rationale</b>	Urinary incontinence is a symptom with many causes and an essential step in its management is to make a diagnosis as to its cause (Royal College of Physicians 1995). A study of people with incontinence revealed that, although more people are now consulting their general practitioners about incontinence than shown in previous studies, the actions carried out by general practitioners still appear to be sub-optimal, and show considerable geographic variation (Brocklehurst 1993). This indicator will reflect, to some extent, the failure to assess appropriately.
<b>Potential uses</b>	Clinical audit and geographical comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	Numerator data may be obtained from patient notes which record consultations for urinary incontinence, followed by a referral request within 30 days of that initial appointment date. In general practices which have computerised patient records, these data may be identified through use of Read coding of, for example, 'letter sent to consultant - 9NC1' or 'referring the client - Ua049' with accompanying diagnosis codes of incontinence, in patients who presented to their GPs with incontinence (NHS Centre for Coding and Classification 1996). Where such systems are not in place, a retrospective survey of GP notes would be required. The denominator will be obtained from the same source and include all patients who have consulted their GP with incontinence as a new problem within the relevant year (see Indicator 1i.).
<b>Data quality</b>	The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. Patients who are not registered with a GP would be missed with this approach.

<b>Comments</b>	A parallel indicator may focus on the diagnosis and action taken for the sub-group of women who present with incontinence following childbirth. As well as general practice records, district nurse and health visitor notes may be complementary sources of information.
<b>Further work required</b>	None recommended.
<b>Conclusion &amp; priority</b>	<b>D - To be implemented where local circumstances allow by periodic survey.</b>
<b>References</b>	<p>Brocklehurst, J.C. (1993). Urinary incontinence in the community: analysis of a MORI poll. <i>British Medical Journal</i>, <b>306</b>, 832-834.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. Information Management Group, NHS Executive, London.</p> <p>Royal College of Physicians (1995). <i>Incontinence: causes, management and provision of services</i>. The Royal College of Physicians, London.</p>

## Candidate indicator 8

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Clinical assessment rates for those with urinary incontinence in long-term care</b>
<b>Intervention aim</b>	Avoid or reduce adverse effects of delayed diagnosis and treatment.
<b>Definition</b>	<p>For a given long-term care population and point in time: <i>the number of residents with incontinence, who meet the criteria for assessment of their incontinence (see below), divided by the number of residents with urinary incontinence</i>. The resulting fraction should be expressed as a percentage, and the numerator and denominator reported both as overall figures, and as sex and age-specific rates.</p> <p><i>Criteria for assessment:</i></p> <p>Evidence of a full assessment (i.e. the presence of the following information in the patient's records or as recorded within the Royal College of Physicians Incontinence Audit Tool) within four weeks of either a) 'the onset of the problem' - if incontinence started since admission to the home <i>or</i> b) 'admission' - if the patient was admitted with incontinence:</p> <ul style="list-style-type: none"> <li>- relevant history</li> <li>- relevant examinations</li> <li>- team assessment</li> <li>- the cause of this person's urinary incontinence</li> <li>- details of a treatment and management plan</li> <li>- whether this treatment and management plan has been carried out</li> <li>- the effectiveness of this management plan.</li> </ul> <p>This has been adapted from the incontinence audit tool of the Royal College of Physicians (1998) and is also part of the CARE scheme (Research Unit of the Royal College of Physicians 1998) which is a more general clinical audit tool of long-term care of elderly people.</p>
<b>Rationale</b>	<p>Urinary incontinence is a symptom with many causes and an essential step in its management is to make a diagnosis as to its cause (Royal College of Physicians 1995). When a resident in long-term care becomes incontinent of urine, or urinary incontinence worsens, a reason for this change should be sought (Royal College of Physicians and British Geriatric Society 1992). Incontinence may be due to confusion and immobility, related to constipation, or be precipitated by intermittent acute illness such as pneumonia or faecal impaction; or by drugs or inadequate management. Such diagnoses should be made within a short period of time (four weeks) so treatment can be commenced as soon as possible and incontinence resolved or appropriately managed. The timescale of four weeks is specified to</p>

represent a compromise between a more ideal shorter period and a realisation that acceptable delays often occur. The RCP tools also use one month as their period of assessment. This indicator will therefore reflect, to some extent, the failure to investigate, diagnose or treat appropriately.

<b>Potential uses</b>	Clinical audit and provider based comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	The preferred data source for this indicator is through use of the Royal College of Physician's CARE scheme (1998). The tool is intended for audits as part of a regular quality assurance programme in residential, nursing homes and long-term hospital wards caring for older people, on an annual basis. The assessment is also part of the clinical audit scheme for urinary and faecal incontinence (Royal College of Physicians (1998). For this indicator, the numerator is provided by the number of patients who have had an assessment (as listed above) within four weeks of onset of their urinary incontinence or of admission with urinary incontinence. Use of the audit tool requires a survey of the notes to establish whether an assessment has been undertaken as well as recording the resident's current continence status. Surveys of nursing notes may be required to identify specific dates of onset and admission to supplement the audit for the indicator. The denominator is the number of residents recorded as having urinary incontinence at the time of survey.
<b>Data quality</b>	The quality of the data will rely on the use of the RCP tools and the general quality of records in these environments. The use of a standardised measure such as one of the RCP audit tools will increase the quality of the data available for this indicator and should be encouraged. The CARE scheme has undergone evaluation in a number of nursing homes and several NHS long-term wards (Royal College of Physicians 1997). The results from the initial piloting suggested it was easy to use, encouraged ownership of the scheme and feasible to use in such an environment (Dickinson and Brocklehurst 1997).
<b>Comments</b>	No specific points.
<b>Further work required</b>	None recommended.
<b>Conclusion &amp; priority</b>	<b>B - To be implemented generally by periodic survey.</b>

**References**

Dickinson, E., and Brocklehurst, J. (1997). Improving the quality of long-term care for older people: lessons from the CARE scheme. *Quality in Health Care*, **6**, 160-164.

Research Unit of the Royal College of Physicians (1998). *The CARE scheme*. The Royal College of Physicians, London.

Royal College of Physicians and the British Geriatric Society (1992). *High quality long-term care for elderly people*. The Royal College of Physicians, London.

Royal College of Physicians (1995). *Incontinence: causes, management and provision of services*. The Royal College of Physicians, London.

Royal College of Physicians (1998). *Clinical audit scheme for urinary and faecal incontinence*. The Royal College of Physicians, London.

## Candidate indicator 9

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Rate of pre-operative cystometry in women undergoing surgery for urinary incontinence</b>
<b>Intervention aim</b>	Treat underlying mechanisms and causes and avoid adverse consequences.
<b>Definition</b>	For a given year and provider unit population of women who had surgery for incontinence: <i>the number of women who underwent pre-operative cystometry tests within two years of their operation, divided by the total number of patients who received surgery for incontinence in the given year.</i> The resulting fraction should be expressed as a percentage, and the numerator and denominator reported both as overall figures, and as age-specific rates.
<b>Rationale</b>	Cystometry measures the pressure/volume relationship of the bladder (Royal College of Physicians 1995) and is considered to be the single most useful investigation for distinguishing between different causes of incontinence and whether there are single or multiple factors involved (Jarvis et al. 1980). Multichannel cystometry testing is considered the gold standard for diagnosis of bladder dysfunction although simpler tests are considered efficient and effective (Fonda et al. 1993). The indicator is intended to provide an indication of the proportion of patients receiving appropriate investigations prior to surgery.
<b>Potential uses</b>	Clinical audit and provider based comparisons.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	Some patients who have changed providers during management for their incontinence may have undergone cystometry in a different unit to that where they received their surgery. These cases are probably infrequent, but could be excluded from analysis in the assessment of a particular provider unit's care.
<b>Data sources</b>	Patients may undergo cystometry tests as in-patients, day cases, out-patients, or as ward attenders. For contract minimum data, the existing procedure code within OPCS-4 used to identify urodynamics or cystometry is M478 - 'Other specified urethral catheterisation of bladder'. This would only be recorded if the procedure was done as an in-patient. The out-patient/ward attenders minimum data set is currently only optional and as yet, its use is not widespread. Routine data are therefore unlikely to provide the full picture. This limitation means that this indicator must currently rely on a review of the notes for those patients who received surgery for their incontinence. Ideally, all providers would code their out-patient procedures so enabling detection of cystometry in any unit. Read coding (e.g. cystometry - 7B2C6 and urodynamics - X7714) is now also optional for recording ward attender activity.

<b>Data quality</b>	The quality of the data would rely on the quality of the patient notes which is unlikely to be uniformly high. Mandatory coding of out-patient/ward attenders activity and an extension of the current OPCS codes to include common procedures such as cystometry, would facilitate routine use of this indicator. Full use of the new NHS number would also facilitate tracking of patients who receive their cystometry and operation in different hospital units.
<b>Comments</b>	No specific points.
<b>Further work required</b>	Pilot of abstraction of relevant procedures from patient notes.
<b>Conclusion &amp; priority</b>	<b>E - To be implemented following IT development on a routine basis.</b>
<b>References</b>	<p>Fonda, D., Brimage, P.J., and D'Astoli, M. (1993). Simple screening for urinary incontinence in the elderly: comparison of simple and multichannel cystometry. <i>Urology</i>, <b>42</b>, 536- 540.</p> <p>Jarvis, G. J. , Hall, S., Stamp, S., Miller, D.R., and Johnson, A. (1980). An assessment of urodynamic examination in incontinent women. <i>British Journal of Obstetrics and Gynaecology</i>, <b>87</b>, 893-896.</p> <p>Royal College of Physicians (1995). <i>Incontinence: causes, management and provision of services</i>. The Royal College of Physicians, London.</p>

## Candidate indicator 10

### Characteristics

*Specificity:* Condition-specific  
*Perspective:* Clinical  
*Timeframe:* Cross-sectional  
*Outcome relationship:* Indirect

<b>Title</b>	<b>Rate of ‘one-to-one training’ in pelvic floor exercises (PFE) among women with stress incontinence</b>
<b>Intervention aim</b>	Treat underlying mechanisms and causes and avoid adverse consequences.
<b>Definition</b>	For a given year and general practice population: <i>the number of women presenting with symptoms of stress incontinence in a given year, who report having received one-to-one training in pelvic floor exercises (as specified) within three months of presenting with incontinence, divided by the number of women who presented with stress incontinence in the given population and year.</i> The resulting fraction, expressed as a percentage should be reported with its numerator and denominator as overall figures, and by age-group.
<b>Rationale</b>	<p>Pelvic floor exercises (PFE) are strongly recommended for women with stress incontinence who do not have concurrent pathology requiring surgery (Agency for Health Care Policy and Research 1992). The aim of PFE is to ‘teach the patient to (re)gain control over the peri-vaginal musculature, by learning to contract the pelvic-floor muscles, while inhibiting contraction of abdominal musculature’ (quoted in de Kruif and van Wegan 1996). To increase women’s awareness of correct muscle use, a device to measure pressure changes is used as a form of biofeedback. Electrical stimulation is also often used for stress incontinence. The umbrella term ‘pelvic floor re-education’ may be used to refer to these methods in combination. A literature review commissioned for this project and provided as Appendix C to this report concluded that the research evidence supports the use of PFE for the treatment of stress incontinence. However, there is insufficient evidence to identify the precise way in which exercises should be taught, and attention needs to be focused on ensuring that women are performing the exercises correctly. This indicator by measuring the number of women who receive ‘one-to-one’ training in pelvic floor exercises with a professional, should to some extent reflect whether appropriate care is being provided for the treatment of stress incontinence.</p> <p>‘One-to-one training’ in pelvic floor exercises is defined here as including, as a minimum, the following:</p> <ul style="list-style-type: none"> <li>- Vaginal examination to determine correct muscle action (Bump et al. 1991; Bo et al. 1988);</li> <li>- Training for 3 months with increasing exercises during that three month period (Morkved and Bo 1996);</li> <li>- Taught by specialist physiotherapists or nurses (continence advisers), GP or other professional with specialist knowledge.</li> </ul> <p>As the provision of such education is fragmented, and unlikely to be either exclusively provided or uniformly recorded within general practice records, the patient is suggested as the preferred source of data for this indicator.</p>

<b>Potential uses</b>	Clinical audit.
<b>Potential users</b>	Clinicians, commissioners.
<b>Possible confounders</b>	To control for those for whom PFE are inappropriate, the number who have concurrent pathology and thus require surgery should be reported separately.
<b>Data sources</b>	The numerator information may be obtained through a postal survey to women with a new diagnosis of stress incontinence without contraindicated pathology, made in the relevant year. Such a survey would ask each woman (i) whether they had received one-to-one training with a physiotherapist or continence nurse, (ii) the length of the training programme and (iii) whether it involved vaginal examination and feedback regarding correct muscle action. A positive response to all three of these would count as receiving one-to-one pelvic floor re-education and be included in the numerator of this indicator. The denominator may be obtained from the number of presentations for stress incontinence among women in the relevant year. In general practices which have computerised records, the denominator may be obtained through use of Read coding e.g. stress incontinence (1A24). Read coding also facilitates detailed coding of pelvic floor re-education and in practices where relevant computerised records are held, appropriate cases could be readily identified.
<b>Data quality</b>	The validity of the indicator will depend on the quality of responses and response rate from the postal survey. Some form of validation exercise may be possible by auditing notes held by physiotherapists, continence advisers or within the general practice notes themselves, where relevant.
<b>Comments</b>	The use of this indicator may be valuable in the evaluation of a new post such as a continence adviser or other continence service.
<b>Further work required</b>	Testing of a postal questionnaire designed for this purpose.
<b>Conclusion &amp; priority</b>	<b>F - To be further developed because further work is needed on the methods of measurement.</b>
<b>References</b>	<p>Agency for Health Care Policy and Research (1992). <i>Urinary incontinence in adults: Publication No. 92-0038</i>. AHCPR, Rochville, USA.</p> <p>Bo, K., Larsen, S., Oscid, S., Kvarstein, B., Hagen, R., and Jorgensen, J. (1988). Knowledge about and ability to correct pelvic floor muscle exercises in women with urinary incontinence. <i>Neurourology and Urodynamics</i>, <b>7</b>, 261-262.</p> <p>Bump, R.C., Hurt, W.G., Fantl, J.A., and Wyman, J.F. (1991). Assessment of Kegel pelvic floor muscle performance after brief verbal instruction. <i>American Journal of Obstetrics and Gynaecology</i>, <b>165</b>, 322-329.</p>

de Kruif, Y.P. and van Wegan, E.E.H. (1996). Pelvic floor muscle exercise therapy with biofeedback for women with stress urinary incontinence: a meta-analysis, *Physiotherapy*, **82**, 107-113.

Morkved, S. and Bo, K.(1996). The effect of post-natal exercises to strengthen the pelvic floor muscles. *Acta Obstetrics Gynaecology Scandanavica*, **75**, 382-385.

## Candidate indicator 11

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence without vaginal prolapse</b>
<b>Intervention aim</b>	Treat underlying mechanisms and causes and avoid adverse consequences.
<b>Definition</b>	For a given year and provider unit population of women (without vaginal prolapse) undergoing initial surgical treatment for stress incontinence: <i>the number of surgical anterior repairs, divided by the total number of initial surgical procedures for stress incontinence in the given provider unit and year.</i> The resulting fraction should be expressed as a percentage, and the numerator and denominator reported both as overall figures, and as age-specific rates.
<b>Rationale</b>	This indicator is intended to identify provider units who have comparatively high rates of anterior repair for the treatment of female stress incontinence. Literature reviews support the view that retropubic (including Burch colposuspension) and needle suspension procedures produce a superior result to that of the anterior repair in terms of curing urinary incontinence and are therefore the preferred techniques for the surgical treatment of urethral hypermobility (Agency for Health Care Policy and Research 1992). About 85% of women are reported as being continent one year after colposuspension compared with 50-70% after anterior colporrhaphy or needle suspension (Downs and Black 1996). In addition, the benefit of colposuspension is maintained for at least five years whereas the benefits of anterior colporrhaphy and needle suspension diminish more rapidly (Downs and Black 1996).
<b>Potential uses</b>	Provider based comparisons.
<b>Potential users</b>	Policy makers and commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	The data for the provider unit population may be obtained from the contract minimum data set of the provider for the specified year. The relevant number of anterior repairs would be given by the number of finished consultant episodes recording an ICD-10 diagnosis code of 'stress incontinence' (N39.3), together with an OPCS-4 procedure code of 'anterior colporrhaphy nec' (P23.2), 'anterior & posterior colporrhaphy (P23.1), 'anterior & posterior colporrhaphy and amputation of cervix uteri' (P22.1) or 'anterior colporrhaphy and amputation of cervix nec' (P22.2) . The denominator will be the number of finished consultant episodes within the provider's CMDS for the relevant year with an ICD-10 primary diagnosis code of 'stress incontinence' (N39.3) plus any relevant OPCS-4 surgical procedure code (see Exhibit 3 on page 45).

<b>Data quality</b>	The validity of comparisons based on the contract minimum data set depends on the accuracy and completeness of clinical coding, which may not be uniformly high.
<b>Comments</b>	No specific points.
<b>Further work required</b>	None recommended.
<b>Conclusion &amp; priority</b>	<b>A - To be implemented generally on a routine basis.</b>
<b>References</b>	<p>Agency for Health Care Policy and Research (1992). <i>Urinary incontinence in adults</i> : <i>Publication No. 92-0038</i>. AHCPR, Rockville, USA.</p> <p>Downs, S. and Black, N. (1996). <i>Systematic review of the literature on the effectiveness of surgery for stress incontinence in women</i>. Health Services Research Unit, Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, London.</p>

## Candidate indicator 12

**Characteristics**

*Specificity:* Generic

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>Rate of re-operation in a hospital provider unit population within two years following surgical treatment for urinary incontinence</b>
<b>Intervention aim</b>	Treat underlying mechanisms and causes and avoid adverse consequences.
<b>Definition</b>	<p>Two re-operation indicators were specified by the Group: i) the number of re-operations as a percentage of all operations and ii) the number of re-operations as a percentage of all <u>first</u> operations.</p> <p>i) For a given provider unit, and year: <i>the number of patients who underwent surgery for urinary incontinence in a given year and unit, who subsequently, not more than two years later, underwent further surgery for urinary incontinence in any unit, divided by the total number of operations for urinary incontinence, in the given unit and year.</i> The resulting fraction should be expressed as a percentage, and its numerator and denominator reported both as overall figures, and by patient age-group, sex and type of operation.</p> <p>ii) For a given provider unit, and year: <i>the number of patients who underwent surgery for urinary incontinence <u>for the first time</u> in a given year and unit who subsequently, not more than two years later, underwent further surgery for urinary incontinence in any unit, divided by the total number of patients undergoing surgery for urinary incontinence <u>for the first time</u>, in the given unit and year.</i> The resulting fraction should be expressed as a percentage, and its numerator and denominator reported both as overall figures and by patient age-group, sex, and type of operation.</p> <p>Similar indicators may also be defined to measure re-operation rates within a five year period.</p>
<b>Rationale</b>	The first indicator gives the rate of re-operation at a provider unit level. This will provide clinicians with a simple measure of the two-year success rate of various surgical procedures for urinary incontinence. The second definition can be considered an enhancement of the first indicator. It identifies the success rate at an individual patient level, by counting the number of initial procedures per patient which need re-operation within two years. As this requires additional surveying of the notes to identify whether the patient has had any previous operations for incontinence, it is unlikely that this indicator could be used on a routine basis.
<b>Potential uses</b>	Clinical audit, and provider based comparisons.
<b>Potential users</b>	Clinicians, provider management, commissioners.

**Possible confounders**

Casemix factors such as severity, and co-morbidities should be taken into account when making comparisons between units. In addition, patients who are unfit for a second operation and losses to follow-up resulting from geographical moves or death will also need consideration when interpreting this indicator. The indicator, as specified, will not include independent sector activities.

**Data sources**

To calculate these indicators, three years of the contract minimum data set are required.

i) For the first definition the data are completely available from the CMDS. The indicator requires the same calculation as for indicator ii) (see below) but without excluding re-operations from either the numerator or denominator. Linkage of first and second procedures undertaken at different hospitals would only be obtained with reference to the new NHS number.

(ii) For this indicator the denominator will be available from the given unit's CMDS for the year of interest (year one of the three available years of data), as the number of consultant episodes recording an ICD10 diagnosis code for incontinence (e.g. Stress incontinence- N39.3; Other specified urinary incontinence (overflow, reflex, urge) - N39.4; Unspecified urinary incontinence- R32), together with a relevant OPCS4 procedure code (see Exhibit 3). As the CMDS does not record whether the operation is a re-operation, further information will need to be gathered from a survey of the notes to identify any re-operations in this group. The numerator will be the subgroup of patients from the denominator group whose records, when followed up for two years from their initial operation date, include another consultant episode recording an ICD10 diagnosis code for incontinence (e.g. N39.3; N39.4, R32), together with a relevant OPCS4 procedure code (see Exhibit 3) at any unit. Linkage of primary and re-operation episodes across hospitals would most easily be achieved using the new NHS number once its use is widespread.

**Data quality**

The validity of comparisons based on the contract minimum data set depends on the accuracy and completeness of clinical coding, which may not be uniformly high. The value of the indicator in identifying all re-operations within two years, relies on full use of the new NHS number, or an alternative patient identifier. Losses to follow-up and any deaths will effect the validity of this indicator. Attempts should be made to exclude from the denominator any deaths which occurred during the two year period. This would require patient record linkage with mortality data. Re-operations undertaken within independent hospitals would not be identified.

**EXHIBIT 3 : RELEVANT SURGICAL PROCEDURES FOR URINARY INCONTINENCE**

<b>Description</b>	<b>Code</b>
Endoscopic suspension of neck of bladder	M51.2
Suprapubic sling	M52.1
Retropubic suspension of neck of bladder	M52.2
Colposuspension of neck of bladder	M52.3
Implantation of artificial urinary sphincter into outlet of male bladder	M64.2
Insertion of prosthesis for compression of bulb of male urethra	M75.2
Other open operations on urethra	M75
Anterior colporrhaphy	P23.1/P23.2

**Comments**

Re-operation rates could be low due to a lack of availability rather than the absence of need.

Ideally this indicator would be reported on a person-years at risk basis thus discounting for death.

**Further work required**

None recommended.

**Conclusion & priority**

**C - To be implemented where local circumstances allow on a routine basis.**

**References**

None.

## Candidate indicator 13

### Characteristics

*Specificity:* Generic

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>Rate of emergency re-admission (for a urinary related condition and/or specific post-operative complications) within 30 days of discharge, for a hospital provider unit population which has undergone surgery for urinary incontinence</b>
<b>Intervention aim</b>	Treat underlying mechanisms and causes and avoid adverse consequences.
<b>Definition</b>	For a given provider unit population and year: <i>the number of emergency admissions (to any unit) for a urinary related condition or specific post-operative complication, occurring not more than 30 days after discharge from an in-patient stay at the given unit which ended in the given year and included surgical treatment for incontinence, divided by the number of in-patient stays involving surgical treatment for incontinence which occurred at the given unit and ended in the given year.</i> The resulting fraction should be expressed as a percentage, and the numerator and denominator reported separately both as overall figures, and as age and sex-specific rates.
<b>Rationale</b>	Unplanned re-admission may reflect an adverse outcome of antecedent health care and/or the development of complications following surgery for incontinence. With appropriate consideration of patient risk factors re-admission rates may draw attention to aspects of the planning, organisation and delivery of care that may require review. A 30 day period is selected for follow-up firstly, as it is the period commonly adopted when observing relevant re-admissions, and secondly due to the problem of ‘noise’ occurring over periods longer than 30 days.
<b>Potential uses</b>	Clinical audit, provider based comparisons.
<b>Potential users</b>	Clinicians, provider management, commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	<p>The denominator is defined, within the contract minimum data set for a given provider, by the number of consultant episodes recording an ICD-10 diagnosis code of incontinence (e.g. Stress incontinence- N39.3; Other specified urinary incontinence (overflow, reflex, urge) - N39.4; Unspecified urinary incontinence- R32), together with a relevant OPCS-4 procedure code (with a discharge date within the specified year) (see Exhibit 3 on page 45).</p> <p>Records relevant to the numerator will be included among consultant episodes (from any provider unit) for a urinary related complaint (i.e. recording an ICD-10 primary or secondary diagnosis code of incontinence e.g. N39.3, N39.4, R32) or a specific post-operative complication (as recorded in Exhibit 4), with an emergency admission method, and an episode start date that is equal to the admission date.</p>

The subset of these records that relate to re-admissions within 30 days of an appropriate earlier discharge, may be identified by means of the NHS number and the difference between the original date and the new episode start date. Re-admissions to other hospitals would rely on the use of the NHS number.

<b>EXHIBIT 4 : RELEVANT POST-OPERATIVE COMPLICATIONS</b>	
<b>Description</b>	<b>Code</b>
Pulmonary embolism	I26.0/I26.9
Deep vein thrombosis	I80.1-I80.3
Retention of urine	R33.X
Complications of procedures, not elsewhere classified (incl.haemorrhage and vascular complications)	T81
Septicaemia	A40/A41

**Data quality**

The validity of the data will depend on the quality of the CMDS diagnoses which is unlikely to be uniformly high. Attempts should be made to exclude from the denominator any deaths which occurred during the initial hospital admission spell or the 30 day period. This would require patient record linkage with mortality data. Interpretation of the results of this indicator should be undertaken with some consideration of the potential perverse incentives to score well on this indicator (Milne and Clarke 1990). Key methodological issues relating to re-admission rates are discussed in Henderson et al. (1989).

**Comments**

Although 30 days is commonly used, data sets may allow analysis at a number of different time intervals.

**Further work required**

The potential utility of this indicator needs further study.

**Conclusion & priority**

**C - To be implemented where local circumstances allow on a routine basis.**

**References**

Henderson, J., Goldacre, M.J., Graveney, M., and Simmons, H.M. (1989). Use of medical record linkage to study re-admission rates. *British Medical Journal*, **299**, 709-713.

Milne, R., and Clarke, A. (1990). Can re-admission rates be used as an outcome indicator? *British Medical Journal*, **301**, 1139-1140.

## Candidate indicator 14

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Longitudinal

*Outcome relationship:* Direct

<b>Title</b>	<b>Change in urinary symptoms from before treatment to six months afterwards, within a provider unit population receiving treatment for incontinence</b>
<b>Intervention aim</b>	Treat underlying mechanisms causes and avoid adverse consequences.
<b>Definition</b>	<p>For a given population of patients receiving treatment for incontinence, at a given provider unit, in a given year: <i>a summary of the changes observed in individual patients, from pre-treatment baseline (recorded within the given year), to a follow-up at six months after treatment, with respect to a measure of urinary symptoms (to be specified), as administered six months after treatment is completed.</i> The statistics, which have not been specified, will describe the distribution of observed changes for each dimension of the instrument, broken down by patient age-group and sex.</p> <p>This indicator may also be used to identify changes at five year follow-up, as a measure of longer term outcomes following treatment.</p>
<b>Rationale</b>	<p>The most important outcome of treatment for incontinence is whether symptoms have improved as a result, and the degree of that improvement. Historically, the evaluation of treatment has relied upon the physician's opinion, the use of scales that do not examine lower urinary tract symptoms in detail, and objective diagnostic testing (Jackson et al. 1996). These, however, are time consuming and expensive and take no account of the patient's perception of the problem. The use of a subjective assessment tool is attractive to complement objective clinical measures and it can be inexpensive, non-invasive and potentially self-administered (Jackson et al. 1996).</p> <p>Several questionnaires have been developed to assess incontinence symptoms within research studies, for example, the symptom questionnaire from the MRC North Thames Stress Incontinence Study (Black et al. 1996) and the Bristol Female Lower Urinary Tract Symptoms questionnaire (Jackson et al. 1996). As a consequence, they tend to be long and detailed, which for routine use may cause administrative problems. Equally, their role in research has meant that few are developed to measure across a range of symptoms which result from different causes. The Bristol questionnaire does however include all female lower tract urinary symptoms.</p> <p>As it stands this indicator requires an assessment tool which will assess urinary symptoms in general. The selection of a single standard instrument for the indicator should ideally await completion of the MRC Incontinence Study in Leicester, where the researchers are developing a severity measure, validated against pad tests and three day diaries, to use within their study.</p>

<b>Potential uses</b>	Clinical audit, provider based comparisons.
<b>Potential users</b>	Clinicians, provider management, commissioners.
<b>Possible confounders</b>	No specific ones identified.
<b>Data sources</b>	<p>Although symptoms are likely to be the subject of clinical assessment both pre- and post- treatment, such assessments are not made in a standard form. The specification of a standard form of symptom assessment would allow data on the severity of the incontinence to be aggregated and compared between provider units.</p> <p>A symptom questionnaire of the kind described above may, in general, be administered face to face, over the telephone or by postal survey. The MRC study in North Thames relied on postal surveys and the Bristol study asked patients to self-complete the questionnaire when attending a clinic appointment.</p>
<b>Data quality</b>	If not self-completed, inter-administrator reliability for the instrument used will depend on appropriate instruction of interviewers and their use of interview scripts. The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities. The exclusion from formal assessment of patients with hearing or cognitive disabilities, or who are not English speaking, may also have a systematic effect on aggregate health status data.
<b>Comments</b>	No specific points.
<b>Further work required</b>	An instrument in the research field should be shortened and validated. Definition of appropriate summary statistics.
<b>Conclusion &amp; priority</b>	<b>D - To be implemented where local circumstances allow by periodic survey.</b>
<b>References</b>	<p>Black, N., Griffiths, J., and Pope, C. (1996). Development of a symptom severity index and a symptom impact index for stress incontinence in women. <i>Neurourology and Urodynamics</i>, <b>15</b>, 630-640.</p> <p>Jackson, S., Donovan, J., Brookes, S., Eckford, S., Swithinbank, L., and Abrams, P. (1996). The Bristol Female Lower Urinary Tract Symptoms Questionnaire: development and psychometric testing. <i>British Journal of Urology</i>, <b>77</b>, 805-812.</p>

## Candidate indicator 15

### Characteristics

*Specificity:* Condition-specific

*Perspective:* Clinical

*Timeframe:* Cross-sectional

*Outcome relationship:* Indirect

<b>Title</b>	<b>Use of indwelling urethral catheters in long-term care</b>
<b>Intervention aim</b>	Reduce impact of incontinence on general well-being.
<b>Definition</b>	For a given long stay care population and point in time: <i>the number of residents with urethral catheters which have been indwelling for longer than four weeks, divided by the number of residents with incontinence in the given long stay care population.</i> This fraction, expressed as a percentage, should be reported with both the numerator and denominator as an overall age-standardised figure and by patient age-group and sex.
<b>Rationale</b>	<p>Most of those who are incontinent and in long-term care will have an unstable neurogenic bladder (Malone-Lee 1990), which by its very nature is very difficult to manage. Urinary catheters are likely to have a limited role in the management of incontinence in this group because with unstable bladders leakage alongside the catheter commonly occurs (Barnes and Malone-Lee 1986). In an American review, it was suggested that approximately 50% of nursing home patients are incontinent and that approximately 2-4% will require urinary catheterisation (Agency for Health Care Policy and Research 1992). In other studies a figure of up to 28% is cited as the proportion of patients with long-term urinary catheters in residential chronic care (Getliffe 1995).</p> <p>In this population, catheterisation as a long-term solution to incontinence should be limited to patients who are terminally ill, or for whom bed and clothing changes are painful and disruptive (Agency for Health Care Policy and Research 1992). Over-use of catheters to manage incontinence, other than for short term periods, is a potential sign of sub-optimal care and an indication that further assessment and alternative treatment could be offered. Long-term care may include residential and nursing homes as well as NHS long stay wards.</p>
<b>Potential uses</b>	Provider comparisons between homes/GPs or at a health authority level and within clinical audit programmes within homes or wards.
<b>Potential users</b>	Clinicians, commissioners and providers.
<b>Possible confounders</b>	As the indicator is aiming to identify those patients where there is no known urological abnormality, patients with known urological pathology or a neurological basis for their incontinence should be controlled for or excluded from analysis. Some account should also be taken of the characteristics of populations being compared e.g. the percentage which are extremely frail, terminally ill, or disabled.

<b>Data sources</b>	The CARE scheme (Continuous Assessment Review and Evaluation) is a clinical audit tool for the long-term care of elderly people (Research Unit of the Royal College of Physicians 1998). One of nine areas covered by the tool is urinary incontinence. Information collected by this tool includes individual details of urinary incontinence from the use of catheters to a history of the problem and treatment. The instrument asks 'Does the resident have a urinary catheter?' and 'How often is it changed?' (i.e. number of weeks between changes). The audit tool does not ask how long indwelling urinary catheters have been used to manage the incontinence so the indicator relies on snap shot information as to the use of catheters, which may be misleading. The second edition of the CARE scheme refers to indwelling catheters as a method of management and by implication a long-term procedure. If computerised information systems were in place, Read codes could be used i.e. urinary incontinence (1A23.) and indwelling catheter (8D74). The denominator data may be collected as for Indicator 8.
<b>Data quality</b>	The validity of the indicator will depend on the quality of the records within wards and homes which may not be uniformly high. The use of standardised measure such as the RCP audit tools will increase the quality of the data available for this indicator and should be encouraged. The CARE scheme has undergone evaluation in a number of nursing homes and several NHS long-term wards. The results from the initial piloting suggested it was easy to use, encouraged ownership of the scheme and is feasible for use in such an environment (Dickinson and Brocklehurst 1997).
<b>Comments</b>	The value of this indicator may rely on whether an agreement of an appropriate level of catheterisation for a certain age group can be determined. The use of this indicator within the community, such as within a GP population, may be considered as an alternative.
<b>Further work required</b>	More assessment on the quality of data yielded using the RCP CARE and incontinence audit tools.
<b>Conclusion &amp; priority</b>	<b>B - To be implemented generally by periodic survey.</b>
<b>References</b>	<p>Agency for Health Care Policy Research (1992). <i>Urinary incontinence in adults</i> : Publication No. 92-0038. AHCP, Rockville, USA.</p> <p>Barnes, K.E., and Malone - Lee, J.G. (1986). Long-term catheter management: minimising the problems of premature replacement due to balloon deflations. <i>Journal of Advanced Nursing</i>, <b>11</b>, 303-307.</p> <p>Dickinson, E., and Brocklehurst, J. (1997). Improving the quality of long-term care for older people: lessons from the CARE scheme. <i>Quality in Health Care</i>, <b>6</b>, 160-164.</p>

Getliffe, K. (1995). Long-term catheter use in the community. *Elderly Care*, **7**, 19-22.

Malone-Lee, J.G. (1990). New data on urodynamics in the symptomatic elderly. *Neurology and Urodynamics*, **9**, 409-410.

Research Unit of the Royal College of Physicians (1998). *The CARE scheme*. The Royal College of Physicians, London.

## Candidate indicator 16

### Characteristics

*Specificity:* Generic

*Perspective:* Patient

*Timeframe:* Longitudinal

*Outcome relationship:* Direct

<b>Title</b>	<b>Changes in health related quality of life as assessed before treatment to six months afterwards within a provider population receiving treatment for urinary incontinence</b>
<b>Intervention aim</b>	Reduce impact of urinary incontinence on general well-being.
<b>Definition</b>	For a given population of patients undergoing treatment for incontinence, at a given provider unit, in a given year: <i>a summary of the changes observed in individual patients, from pre-treatment baseline (recorded within the given year), to a follow-up at six months after treatment, with respect to a multi-dimensional measure of general health related quality of life (to be specified).</i> The summary statistics, which have not been specified, will describe the distribution of observed changes for each dimension of the instrument, broken down by patient age-group and sex.
<b>Rationale</b>	<p>The case for employing general health status (alternatively, 'health related quality of life') measures in assessments of the effectiveness of clinical interventions has been argued both in general (e.g. Bowling 1991) and for urinary incontinence in particular (Kelleher 1996).</p> <p>For present purposes, the required health status instrument should meet a number of criteria. Firstly, the measure should be broadly based in terms of the components of health status it measures - to reduce the chances that aspects of the outcome that are of importance to patients are not excluded from consideration. Furthermore, the results relating to these different dimensions of health status should be reported separately - so that important aspects of the outcome are not obscured by aggregation. Secondly, the metrical properties of the instrument (in terms of validity, reliability, and sensitivity to clinical intervention) should have been demonstrated in the population of interest. Thirdly, the design of the instrument should meet practical considerations relating to its administration.</p> <p>Studies in the literature have used various generic health status measures. The Norwegian language version of the Sickness Impact Profile (SIP) has been used among women with incontinence in two age-groups - 40-60 years and 70 years and over (Kelleher 1996). The study concluded that the impact on quality of life was both age- and symptom-related. Grimby et al. (1993) used the Nottingham Health Profile (NHP) and compared scores in those 'with incontinence' with those 'without'. The results showed a significantly higher level of both emotional impairment and social isolation among the incontinent women. The Short Form-36 has also been used in a randomised controlled trial comparing the effectiveness of an active pelvic floor stimulator versus a sham device. However, no significant improvements were seen in the SF 36 score, which may reflect its relative insensitivity to the impact of urinary symptoms (Kelleher 1996).</p>

Incontinence-specific quality of life questionnaires have also been developed. The Incontinence Impact questionnaire (Wyman et al. 1987) is one example which consists of 26 questions on the impact of incontinence across three dimensions: activities of daily living; social isolation and self perception. A more recently developed instrument is the King's Health Questionnaire, which as well as questions on the impact of urinary incontinence, includes an assessment of urinary symptoms, incontinence coping strategies and subjective severity measures. The scoring is similar to the Short Form-36 and can be presented in the 'form of a quality of life profile with scores out of 100 presented for each domain, or the scores can be summated to produce a total score for each patient' (Kelleher 1996).

The selection of a single standard instrument for the indicator should ideally await completion of the MRC Incontinence Study in Leicester. In this study, as well as using some existing measures i.e. three dimensions from the SF 36 - General Health Perceptions, Bodily Pain and Vitality; and components of the Hospital Anxiety and Depression scale, other tools are being developed to measure life satisfaction, and the psychosocial impact of urinary incontinence and dysfunction.

Pre-treatment assessments can act as a baseline for longitudinal measures of the change in health status, and as case mix descriptors for inter-unit comparisons.

Assessments of general health status provide a measure of the level of health related quality of life enjoyed by patients following treatment. This indicator restricts follow-up data collection to a single point six months after completion of that treatment. This is in recognition of the difficulty of interpreting general health status data from longer term follow-ups - which will necessarily be influenced by a range of health issues unrelated to previous incontinence.

<b>Potential uses</b>	Clinical audit, provider based comparisons.
<b>Potential users</b>	Clinicians, provider management, commissioners.
<b>Possible confounders</b>	Co-morbidity, and life events affecting health will influence both pre- and post-treatment levels of general health status.
<b>Data sources</b>	Although aspects of general health status are likely to be the subject of informal clinical assessment both before and after treatment, such assessments are not made in a standard form. The specification of a standard form of general health status assessment would allow data on health related quality of life to be aggregated and compared between provider units.

The health status questionnaires described above may, in general, be administered by post, face to face, or over the telephone. Linkage between pre- and post-treatment data can be established on the basis of the NHS number.

<b>Data quality</b>	<p>Recent use of general health status questionnaires in the UK, as a postal survey, face to face, and by telephone, has demonstrated that pre-operative and short term post-operative response rates are acceptable (Bardsley and Coles 1992). Response rates of 70-80% have been recorded for self-completion of the SF 36 in older patients with better response and completion from those in an ambulatory setting than in-patient care (Parker et al. 1998). Use of the telephone for post-operative follow-up may have a systematic effect on health status data, as those without phones are excluded from the assessments. The exclusion from formal assessment of patients with hearing or cognitive disabilities, or who are not English speaking, may also have a systematic effect on aggregate health status data.</p> <p>Inter-administrator reliability for the health status instrument will depend on appropriate instruction of interviewers and their use of an interview script.</p> <p>Longitudinal indicators can encounter difficulty in achieving complete follow-up. Presentation of the longitudinal indicator should take this into account by giving a count of those lost to follow-up; and details of the distributions of their baseline scores, in a format that allows comparison with the corresponding distributions for those, where follow up was possible.</p>
<b>Comments</b>	No specific points.
<b>Further work required</b>	Selection of a general health status measure and possibly further pilot testing in the population of sufferers of incontinence. Definition of appropriate summary statistics.
<b>Conclusion &amp; priority</b>	<b>F - To be further developed because further work is needed on the methods of measurement.</b>
<b>References</b>	<p>Bardsley, M.J. and Coles, J.M. (1992). Practical experiences in auditing patient outcomes. <i>Quality in Health Care</i>, <b>1</b>,124-130.</p> <p>Bowling, A. (1991). <i>Measuring health: a review of quality of life measurement scales</i>. Open University Press, Buckingham.</p> <p>Grimby, A., Milstom, I., Molander, U., Wiklund, I., and Ekelund, P. (1993). The influence of urinary incontinence on the quality of life of women. <i>Age and Ageing</i>, <b>22</b>, 82-89.</p> <p>Kelleher, C. (1996). Quality of life. In <i>Urogynaecology</i>. (ed. L. Cardozo) pp 677-690. Churchill Livingstone.</p>

Parker, S.G., Peet, S.M., Jagger, C., Farhan, M., and Castleden, C.M. (1998). Measuring health status in older patients. The SF 36 in practice. *Age and Ageing*, **27**, 13-18.

Wyman, J.F., Harkins, S., Choi, S., Taylor, J., and Fantl, J.A. (1987). Psychosocial impact of urinary incontinence in women. *Obstetrics and Gynaecology*, **70**, 378-380.

## Candidate indicator 17

### Characteristics

*Specificity:* Surgery-specific

*Perspective:* Patient

*Timeframe:* Cross-sectional

*Outcome relationship:* Direct

<b>Title</b>	<b>A measure of patient satisfaction at six months, within a hospital provider unit population which has undergone surgery for urinary incontinence</b>
<b>Intervention aim</b>	Reduce impact of urinary incontinence on general well-being.
<b>Definition</b>	For a population of patients which, six months previously underwent surgery for incontinence at a given provider unit: <i>a summary of patients' responses to a questionnaire measuring satisfaction with in-patient care and out-patient follow-up (to be specified).</i>
<b>Rationale</b>	While patient satisfaction is itself a desirable outcome, there is also evidence that care which is less than satisfactory is also less effective (Kaplan et al. 1989). It has been shown that patients' reported levels of satisfaction can reflect doctor's technical competence as judged by independent, professional assessors (Dimatteo and Hays 1980).
<b>Potential uses</b>	Clinical audit, provider based comparisons.
<b>Potential users</b>	Clinicians, provider management, commissioners.
<b>Possible confounders</b>	A range of social and demographic variables have been shown to influence patient satisfaction (Fitzpatrick 1990). As a minimum, comparative analyses of satisfaction should be informed by knowledge of the age/sex mix of patients at different units.
<b>Data sources</b>	The Royal College of Surgeons (RCS) comparative audit service provides an extensive and standard survey of patient satisfaction among surgical patients (Meredith and Wood 1994). The comprehensive nature of this measure, with respect to surgical interventions may make it an appropriate benchmark against which alternative generic measures (e.g. Wilkin et al. 1992; Smith 1992; Thompson 1988) may be judged, and a basis for developing an incontinence surgery specific version.
<b>Data quality</b>	Pilot testing of the RCS instrument has reported acceptable response rates.
<b>Comments</b>	It is recognised that there is need for the development of further measures which assess satisfaction with treatments for urinary incontinence other than surgery.
<b>Further work required</b>	Selection of a generic measure, or development of a condition-specific questionnaire, on the basis of pilot data collection experience among patients who have undergone surgery for incontinence.
<b>Conclusion &amp; priority</b>	<b>F - To be further developed because further work is needed on the methods of measurement.</b>

## References

- Dimatteo, M.R., and Hays, R. (1980). The significance of patients' perceptions of physician conduct: a study of patient satisfaction in a family practice centre. *Journal of Community Health*, **6**, 18-34.
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## Candidate indicator 18

### Characteristics

*Specificity:* Generic

*Perspective:* Patient

*Timeframe:* Longitudinal

*Outcome relationship:* Direct

<b>Title</b>	<b>A measure of the attainment of patient specified outcome goals, within a population receiving treatment for urinary incontinence</b>
<b>Intervention aim</b>	Reduce impact of urinary incontinence on general well-being.
<b>Definition</b>	For a given population of patients with urinary incontinence, and year: <i>a summary of patient's scores with respect to a measure of attainment of patient specified goals.</i> It is intended that a maximum of five goals are specified at the outset of a programme of care, with a binary assessment of their attainment at a review at a specified time. A range of summary statistics may be useful including distribution of goal attainment across patients, both in terms of absolute number of goals attained (e.g. X% achieved three goals), and/or in terms of the proportion of the number of goals set (e.g. Y% achieved at least half or all of their set goals).
<b>Rationale</b>	<p>One desirable goal of treatment for urinary incontinence should include a return to a good 'quality of life' which, ideally, should be defined in terms individual to each patient (Ruta and Garratt 1994). An attempt to measure the degree to which such an outcome has been achieved requires some form of individual statement of a patient's goals in undergoing treatment (perhaps weighted by their relative importance), and an assessment of whether such goals have been attained. The outcomes assessed by standard measures (e.g. SF-36) are 'pre-selected' and therefore may exclude what is important for the individual, and thus not be sensitive to the changes which show an individual's progress.</p> <p>Individualised outcomes measurement tools either in use or currently under evaluation include: Goal Attainment Scaling (Stolee 1992); Treatment Evaluation by le Roux's Method (TELER; le Roux 1993); Canadian Occupational Performance Measure (COPM; Law et al. 1994); Patient Orientated Evaluation Method (POEM; Bassetlaw Physiotherapy Research Group 1992), Schedule for the Evaluation of Individual Quality of Life (SEIQoL; O'Boyle et al. 1992); Measure Yourself Medical Outcomes Profile (MYMOP; Paterson 1996) and the Binary Individualised Outcome Measure (Spreadbury and Cook 1995). These measures cover a range of sophistication in the methods used in individual goal setting and assessment. The assessment may include a simple binary yes/no measure as to the attainment of the goal, or involve scales rating the level of performance achieved towards the goal. Goal setting may categorise and weight the goals as to the level of importance assigned by the individual and the COPM includes an assessment of satisfaction with performance as well as an attainment rating. A maximum of five goals with a three month review period is suggested to enhance comparability across provider units, which is as specified in the Binary Individualised Outcome Measure (Spreadbury and Cook 1995).</p>

The key advantage of the method is the potential to derive the required information through the formalisation of the care planning review process that will already be in place. So, in the first instance a simple system - that most closely resembles existing practice- is recommended whereby a binary assessment is made for a limited number of goals previously agreed between patient and professional. A tested version of a binary approach is the Binary Individualised Outcome Measure, developed by occupational therapists in Nottingham (Spreadbury and Cook 1995). Any of the other similar tools described record this minimal information and therefore no specific approach or tool is recommended.

**Potential uses**

It may be a valuable tool to audit outcomes locally and to use as a structured basis for useful discussions regarding the aims and achievements of care.

**Potential users**

Clinicians, commissioners.

**Possible confounders**

Because increased levels of achievement may be obtained both by increased effectiveness and reduced ambition, any comparisons between populations or providers using this indicator need to be sensitive to the nature of the goals set. This may involve a detailed discussion of the goals themselves and is unlikely to be something which could be done mechanistically.

**Data sources**

Performance measures of this type are a central component of the treatment programme provided by therapists and professionals allied to medicine. The data for this indicator should therefore be generally available but are likely to involve additional formal data collection to allow their use in this indicator. Although the Binary Individualised Outcome Measure is designed for use by occupational therapists, any member of the team involved in rehabilitation of patients could be involved in goal setting.

**Data quality**

Both the Binary Individualised Outcome Measure and the Canadian Outcome Performance Measure are popular and used extensively in England. The COPM has been demonstrated as reliable and responsive among clients receiving rehabilitation services for stroke, Parkinson's Disease, hip fracture and arthritis, using a three month review period (Law et al. 1991).

Although it is in the professional interest of the staff to address real problems and/or achieve meaningful goals, there may be a perverse incentive to set low, easily achievable goals, in order to score highly on this indicator. The client-centred nature of the goal setting may discourage this to some extent. However, patient expectations will of course be partly determined through the attitudes and recommendations of the professionals providing care. Indeed, one desirable outcome of rehabilitation will be the acceptance of realistic goals on the part of the client. Sufficient training to enable staff to learn and adopt the required techniques will increase data quality. Such training would ensure that goals are clearly defined and measurable as well as realistic and achievable through the planned programme of therapy.

<b>Comments</b>	No specific points.
<b>Further work required</b>	Pilot testing of one or more of these tools in a population of patients receiving treatment for urinary incontinence. The consumer group InContact are currently seeking funds possibly to test this type of assessment.
<b>Conclusion &amp; priority</b>	<b>F - To be further developed because further work is needed on the methods of measurement.</b>
<b>References</b>	<p>Bassetlaw Physiotherapy Research Group (1992). <i>The POEM Catalogue</i>. Bassetlaw Hospital and Community Services NHS Trust.</p> <p>Law, M., Baptiste, S., Carswell, A., McColl, M.A., Polatajko, H., and Pollock, N. (1991). <i>Canadian Occupational Performance Measure</i>. Canadian Association of Occupational Therapists, Canada.</p> <p>Le Roux, A. (1993). TELER: the concept. <i>Physiotherapy</i>, <b>79</b>, 755-758.</p> <p>O'Boyle, C., McGee, A., Hickey, K., Joyce, C., and O'Malley, K. (1993). <i>The schedule for the evaluation of individual quality of life (SEIQoL): administration manual</i>. Department of Psychology, Medical School, Royal College of Surgeons in Ireland, Dublin.</p> <p>Paterson, C. (1996). Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. <i>British Medical Journal</i>, <b>312</b>,1016-1020.</p> <p>Ruta, D., and Garratt, A. (1994). Health status to quality of life measurement. In <i>Measuring health and medical outcomes</i> (ed. C.Jenkinson). UCL Press, London.</p> <p>Spreadbury, P. and Cook, S. (1995). <i>Measuring the outcomes of individualised care: The Binary Individualised Outcome Measure</i>. Nottingham City Hospital NHS Trust.</p> <p>Stolee, P. (1992). The use of goal attainment scaling in a geriatric care setting. <i>Journal of the American Geriatric Society</i>, <b>40</b>, 574-578.</p>

## 5. RECOMMENDATIONS

### To be implemented generally

- 5.1** It is **recommended** that the following indicators be implemented generally (the numbers refer to the indicator specifications in Section 4):
- 11: percentage of anterior repair procedures undertaken in a population of women undergoing surgery for stress incontinence without vaginal prolapse**
  - 2: prevalence of urinary incontinence in long-term care**
  - 8: clinical assessment rates for those with urinary incontinence in long-term care**
  - 15: use of indwelling urethral catheters in long-term care.**
- 5.2** **Anterior repair** in women undergoing surgery for stress incontinence has been shown to be the least effective procedure and this indicator will allow the monitoring of its use. In units where the percentage is high the procedures used for stress incontinence should be reviewed. The data to compile the indicator are routinely available from the contract minimum data set and the indicator should be available **routinely**.
- 5.3** The **prevalence of urinary incontinence in long-term care** is not generally known. Urinary incontinence may adversely affect the quality of life of elderly people and yet may be prevented or treated. This indicator will allow the prevalence to be monitored and action could be taken where the prevalence is shown to be inappropriately high.
- 5.4** The **clinical assessment rates for those with urinary incontinence in long-term care** complements the information on the prevalence of urinary incontinence in long-term care as it will demonstrate that appropriate action has been taken to manage the problem.
- 5.5** Use of **indwelling catheters in long-term care** should be limited but there is some evidence that they may be overused. This indicator will allow this to be monitored and will add to the information gained from the two indicators above.
- 5.6** It is recommended that the indicators 2, 8, and 15 are compiled by **periodic surveys**. These could form part of the annual registration of long-term care accommodation. A number of audit and evaluation tools are being developed which may be used to collect the data. These include the Continuous Assessment Review and Evaluation Scheme, and the Incontinence Audit tool, both developed by the Royal College of Physicians, or the tool from the MRC Incontinence Survey in Leicester.

**To be implemented where local circumstances allow on a routine basis**

**5.7** It is **recommended** that the following indicators be implemented where local circumstances allow on a routine basis:

**12: rate of re-operation in a hospital provider unit population within two years following surgical treatment for urinary incontinence**

**13: rate of emergency re-admission (for a urinary related condition and/or specific post-operative complication) within 30 days of discharge, for a hospital provider unit population which has undergone surgery for urinary incontinence.**

**5.8** The **re-operation rate** provides an indication of failure of the initial procedure. Units with high rates compared with others, or with increasing rates, may benefit from reviewing their procedures. Care must be taken in comparing the figures between units as higher rates may reflect more diligent follow-up.

**5.9** The **rate of emergency re-admission within 30 days of discharge** is an indicator of the quality of care in the initial admission, although it is also influenced by other factors outside the hospital's control, such as patients' social circumstances.

**To be implemented where local circumstances allow by periodic survey**

**5.10** It is **recommended** that the following indicators be implemented where local circumstances allow by periodic survey:

**3: incidence of urinary incontinence among women following pregnancy**

**6: clinical assessment rates following presentation with urinary incontinence within a GP population**

**7: rate of referral following presentation with urinary incontinence within a GP population**

**14: changes in urinary symptoms from before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence.**

**5.11 Urinary incontinence following pregnancy** may reflect the care provided both pre- and post-natally. Little information is currently available. This indicator would allow this problem to be quantified in a more systematic way. In order to obtain adequate numbers for most purposes, such as comparison of trends over time, individual GP practices will have to be aggregated.

- 5.12** At present there is no way of evaluating whether patients presenting in primary care with urinary incontinence are **clinically assessed** appropriately. This indicator will allow those in primary care who have an interest in this area to audit their practice.
- 5.13** The **rate of referral following presentation with urinary incontinence** will add to the information gained from the above indicator for those in primary care auditing their practice.
- 5.14** The indicator reflecting **changes in the urinary symptoms before and after treatment** allows the assessment of an important aspect of care from the patient's perspective. This should be of interest to all involved in treating urinary incontinence.

**To be implemented following IT development on a routine basis**

- 5.15** It is **recommended** that the following indicator be implemented on a routine basis following IT development:

**9: rate of pre-operative cystometry in women undergoing surgery for urinary incontinence.**

- 5.16** The **rate of pre-operative cystometry** will demonstrate if women are being appropriately investigated prior to surgery for incontinence. This is an important aspect of care prior to any surgical procedure and yet data on this are not readily available. Coding of out-patient and ward attenders would enable these data to be captured and this information would be valuable to those monitoring services.

**To be further developed**

- 5.17** It is **recommended** that the following indicators require further development before implementation is considered either because the link with outcomes is not clear, or because further work is needed on methods of measurement:

- 1: incidence and prevalence of urinary incontinence**
- 4: rate of pelvic floor exercise training among pregnant women**
- 5: delay to presentation with urinary incontinence**
- 10: rate of 'one-to-one' training in pelvic floor exercises (PFE) among women with stress incontinence**
- 16: changes in health-related quality of life as assessed before treatment to six months afterwards, within a provider unit population receiving treatment for urinary incontinence**

**17: a measure of patient satisfaction at six months, within a hospital provider unit population which has undergone surgery for urinary incontinence**

**18: a measure of the attainment of patient specified outcome goals, within a population receiving treatment for urinary incontinence.**

**5.18** If a satisfactory way of measuring **incidence** and **prevalence of urinary incontinence** (indicator 1) in the general population can be developed it will provide a useful baseline for much of the work on urinary incontinence. It will allow changes in incidence and prevalence to be monitored over time, which may reflect outcomes such as the avoidance of post-partum incontinence.

**5.19** If further work shows that the **rate of pelvic floor exercise training among pregnant women** (indicator 4) and the **delay to presentation with urinary incontinence** (indicator 5) lead to improved outcomes, we recommend that these indicators should be collected by periodic survey where local circumstances allow.

**5.20** If suitable measures can be developed for collection of the **rate of 'one-to-one' training in pelvic floor exercises** (indicator 10), and those covering **changes in quality of life, patient satisfaction and attainment of patient specified goals**, (indicators 16, 17 and 18) we recommend that they should be collected by periodic survey where local circumstances allow. Indicators 16 to 18 are potentially important as they are the main indicators that reflect the patient's perspective on the results of treatment.

## **Conclusions**

**5.21** As described in the indicator specifications, indicators collected routinely may be used to highlight differences:

- over time
- between providers
- between groups of patients.

**5.22** The main use of such indicators is to make broad comparisons to identify potentially important differences or anomalies that require further detailed examination. Small differences in routine indicators may be caused by a wide range of factors, many of which will probably not reflect differences in health outcomes attributable to the provision of care.

**5.23** Some indicators may best be used in combination to gain additional information. For example:

- For those in long-term care, the prevalence of urinary incontinence (indicator 2) together with the clinical assessment rates (indicator 8) and the use of indwelling catheters (indicator 15) would provide more interpretable information on how incontinence is being managed than any one indicator alone.
- To assess how a provider unit manages urinary incontinence, the following indicators could be reviewed together: the rate of preoperative cystometry (indicator 9), the percentage of anterior repair procedure undertaken (indicator 11), the rate of re-operation within two years (indicator 12), the rate of emergency re-admission within 30 days (indicator 13), and changes in urinary symptoms before treatment and six months afterwards (indicator 14).
- Within general practice, clinic assessment rates following presentation with urinary incontinence (indicator 6) and rate of referral following presentation with urinary incontinence (indicator 7) would demonstrate how urinary incontinence is being managed in an area.

# APPENDIX A: BACKGROUND TO THE WORK

## Summary

**A.1** Over the last few years a major component of the Department of Health's and NHS Executive's strategy has been to promote the development and use of measures of health outcome. In July 1993 the Central Health Outcome Unit (CHOU) was set up within the Department of Health (DoH). Commissioned by the DoH, in 1993 a feasibility study of potential outcome indicators was published by the Faculty of Public Health Medicine and a package of indicators was published by the University of Surrey for consultation. Following these two phases of development, a third phase of work was initiated by the CHOU. Its remit is to report on 'ideal' health outcome indicators.

## Central Health Outcome Unit

**A.2** The CHOU is an internal DoH unit whose goal is 'to help secure continuing improvement in the health of the people of England through cost-effective and efficient use of resources' (Lakhani 1994). The objectives of the Unit are to:

- encourage and co-ordinate the development of health outcome assessment, particularly in respect of the development of appropriate methods, appropriate data collection systems, expertise, analytical skills, and interpretation
- encourage and support the use of health outcome assessment and information in making policy about health interventions and in the planning, delivery and monitoring of services.

**A.3** Several national committees have a special interest in outcomes and have been kept informed of progress:

- Clinical Outcomes Group
- Public Health Network
- CMO Working Group on Information Management and Technology.

## **Phases 1 and 2**

**A.4** The Faculty of Public Health Medicine was commissioned to undertake a feasibility study of potential indicators which reflect health end-points for health services and which cover topics in which health care has an important contribution to make. This work, (McColl and Gulliford 1993) was constrained in that the set of indicators were to:

- be based on reliable routinely collected data
- reflect health service interventions rather than the wider influence on health.

**A.5** The University of Surrey was commissioned to produce a package of comparative statistics based on the outcome measures recommended in the feasibility study. Forty indicators were chosen, 18 for maternal and child health, three for mental health and the rest for other topics in adult health. The publication (Department of Health 1993) contained indicator definitions, maps and scatter plots showing geographical variations, and tables presenting the rates, with corresponding observed numbers and confidence intervals when appropriate.

## **The Phase 3 work ideal indicators of health outcome**

**A.6** In the third and current phase of the work on health outcomes a number of research institutions were commissioned to assist in developing a structured approach to identify indicators to cover a number of clinical topics. The prime contractor is the Unit of Health-Care Epidemiology, Department of Public Health and Primary Care, University of Oxford.

**A.7** The respective roles of the supporting organisations are as follows:

- Unit of Health-Care Epidemiology, University of Oxford, to provide epidemiological and managerial support to the Group and co-ordinate the input of the other agencies.
- CASPE Research, in London, to provide technical advice with regard to the indicators and their data sources, and prepare the detailed indicator specifications.
- NHS Centre for Reviews and Dissemination, University of York, to produce reviews of the literature on the effectiveness and cost-effectiveness of relevant interventions.
- UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds, to provide support in identifying measures and instruments to be used for assessing outcomes.
- Royal College of Physicians' Research Unit, in London, to co-ordinate the clinical input.

- A.8** In the previous work a key criterion for selection of indicators was the requirement for the work to be based on routinely available data. This practical constraint has meant that the recommended indicators were selected and opportunistic rather than an ideal set. This inevitably led, as the DoH acknowledged, to a bias towards outcomes which may be measurable now but which may not necessarily be those which are most appropriate and most needed. The aim of the third phase is to advise on and develop 'ideal' outcome indicators without confining recommendations to data which have been routinely available in the past.
- A.9** The initial task of the third phase of the work was to select clinical topics for detailed study. In order to ensure that the work would be manageable, and that the NHS would have the capacity to absorb the output, the CHOU decided to limit the activity to five clinical topics a year.
- A.10** A workshop to initiate the work which was attended by over 70 individuals representing a wide range of interests was held in January 1995. A report of the proceedings has been published (Goldacre and Ferguson 1995). The main aims of the workshop were:
- to identify the criteria which should be used to choose clinical topics for the Phase 3 work
  - to suggest a list of potential clinical topics which workshop participants would like to be included in the Phase 3 work.
- A.11** Following further consultation within and outside the DoH, the CHOU decided in June 1995 to include the following topics in the first two years of Phase 3 work:
- Asthma
  - Breast cancer
  - Cataract
  - Diabetes mellitus
  - Fracture of neck of femur
  - Incontinence
  - Myocardial infarction
  - Pregnancy and childbirth
  - Severe mental illness
  - Stroke.

### **Health outcome information**

**A.12** In this work the potential uses of outcome information have been identified as follows:

- for clinical decision-making and audit of clinical work, including:
  - management of individual patients
  - audit and management of health professionals' practice
  - research
- for informing decisions about the strategic and operational development of services
- for comparisons of organisations in the delivery of services which may be:
  - provider based
  - population based
- for assessing progress towards agreed standards or targets for health outcomes, agreed nationally or locally, which may be:
  - identified from the research literature
  - set by clinical and managerial decisions.

**A.13** Current managerial interests which are relevant to the use of health outcome information include:

- The NHS goal 'to secure, through the resources available, the greatest improvement in the physical and mental health of people in England'
- clinical audit
- evidence-based commissioning.

**A.14** An important purpose of the work has been to recommend indicators which, if possible, would allow 'health gain' to be assessed alongside information used to measure health service input. The particular focus has been to make recommendations about aggregated statistical information about people with particular conditions which can be used to:

- enable providers of care to review outcomes of the care of their patients
- make comparisons, where appropriate, of health outcomes against locally agreed targets and/or between different places and/or over time.

**A.15** The information may be obtained from continuous data collection systems but, when having continuously collected information is unnecessary, or when the cost or complexity of this is high, use should be made of sample survey techniques or periodic surveys.

**A.16** Health indicators are more likely to be successful if they fit naturally into the everyday work of health care professionals than when they have to be collected as a separate activity. The aim is to have indicators that are:

- *Relevant* because professionals use them everyday in treating their patients and will record them accurately.
- *Reliable* because they can be validated or cross checked from other sources.
- *Responsive* because they readily identify changes in the patient's state of health.
- *Research-based* because there is a plausible link between processes of care and outcome.

**A.17** In common with the approach taken to other types of indicators by the NHS, it is recognised that useful outcome indicators should be capable of identifying circumstances worthy of investigation but that, in themselves, they may not necessarily provide answers to whether care has been 'good' or 'bad'. In particular it is acknowledged that there may be difficulties in drawing causal conclusions - say, that a particular aspect of care caused a particular outcome - from indicators derived from non-experimental clinical settings. Nonetheless, the vast majority of clinical care is delivered in routine rather than experimental practice. The assessment of its outcomes entails, by definition, the use of observational rather than experimental data.

**A.18** To be useful, work on 'ideal' outcome aspects needs to incorporate considerations of practicability. It is a time of rapid change in information technology. What may be feasible now in some places may not be feasible everywhere. What may not be practical today may become so in a year or two.

## APPENDIX B: URINARY INCONTINENCE WORKING GROUP

**B1.** The Urinary Incontinence Working Group was formally constituted in February 1996 and met four times, completing its work in February 1997. The Report was completed in March 1998. The terms of reference were:

- To advise on indicators of the prevention, treatment and management of people with urinary incontinence, including the prevention of adverse outcomes of delayed treatment. In doing so to consider not only their physical but also their social and emotional well-being.
- To make recommendations about the practicalities of the compilation and interpretation of the indicators, and to advise if further work is needed to refine the indicators and/or make them more useful.

**B2.** The membership of the Working Group and the staff of the supporting organisations are shown below. The composition of the Group included the major professional and managerial groups and representatives of patient and carers involved with the prevention, treatment and care of urinary incontinence.

### **Chairman and members**

Physicians	John Brocklehurst	Manchester ( <b>Chairman</b> )
	Claire Fowler	London
	Mark Castleden	Leicester
Urologist	Paul Abrams	Bristol
Gynaecologists	Linda Cardozo	London
	Stuart Stanton	London
GPs	Colin Thome	Runcorn
	Jacqueline Jolleys	Leicester
Nurses	Angela Billington	Baldock
	Mandy Wells	London
Physiotherapist	Jo Laycock	Penrith
Researcher	Brenda Roe	Liverpool
CEOs	Jackie Axelby	Northumberland
	Suzanne Cosgrave	Worthing
Voluntary body DoH	Christine Norton	Continence Foundation
	Jeffrey Graham	

### **Academic support and secretariat**

Michael Goldacre, Alastair Mason, Ewan Wilkinson & John Fletcher,  
University of Oxford

James Coles, Robert Cleary & Moyra Amess, CASPE Research

Alison Eastwood, Centre for Reviews and Dissemination, University of York

Andrew Long, UK Clearing House on Health Outcomes, University of Leeds

# APPENDIX C: WORK COMMISSIONED FROM NHS CENTRE FOR REVIEWS AND DISSEMINATION

**Alison Eastwood, October 1996**

## **SCOPE**

- C1.** The Working Group commissioned three short literature reviews relating to specific effectiveness issues:
- interventions associated with pregnancy and childbirth to prevent incontinence
  - surgical techniques to relieve incontinence
  - organisation of continence services.
- C2.** Given the short time period available for the work, it has not been possible to systematically identify and summarise the evidence. Instead, attention has focused on existing reviews, with additional reference to primary studies where relevant.
- C3.** Although there is quite a large volume of literature in the area of urinary incontinence, there has been relatively little rigorous research into the efficacy of treatments for urinary incontinence, and in general randomised controlled trials have been small and few (Pearson et al. 1995). Furthermore, there are problems in the choice of outcome measures for evaluations of interventions to treat urinary incontinence, as there is no agreed 'gold standard', and there is wide variation in both the subjective and objective outcome measures used (AHCPR 1992; Pearson et al. 1995). These points will be returned to below.

## **INTERVENTIONS ASSOCIATED WITH PREGNANCY AND CHILDBIRTH**

### **Introduction**

- C4.** This section assesses the evidence of effectiveness of interventions to prevent or treat urinary incontinence in women associated with pregnancy and childbirth. Stress incontinence as a result of damage to the pelvic floor muscles is a risk for women after delivery, and problems may start during pregnancy (Wells 1990a). The aim of relevant interventions is to strengthen the pelvic floor muscles, this can be done in a number of ways including; pelvic floor exercises, weighted cones, perineometer, pelvic exercisers, clinical biofeedback and electrical stimulation (Pearson et al. 1995).

### **Quality of available evidence**

- C5.** Although the majority of evidence for interventions for stress incontinence is based on women, the average age of patients reported in studies is often relatively high. This may mean that patients with incontinence due to factors other than pregnancy and childbirth are included in the trial, which might restrict the generalisability of the findings.
- C6.** The Agency for Health Care Policy and Research guidelines (AHCPR 1992) identify a number of limitations in determining the effectiveness of behavioural interventions in general:
- use of different outcome criteria
  - variability in number and frequency of treatment sessions
  - variability of comprehensiveness in training procedures
  - absence or variability in follow-up data
  - concurrent application of multiple interventions which confound outcomes
  - unspecified criteria for group assignment
  - use of heterogeneous samples
  - uncontrolled inclusion of subjects who had failed previous incontinence treatments
  - lack of standardised terminology for the various behavioural techniques.
- C7.** The AHCPR (1996) rate the strength of evidence supporting each recommendation on the following criteria:
- A.** The recommendation is supported by scientific evidence from properly designed and implemented controlled trials providing statistical results that consistently support the guideline statement.
- B.** The recommendation is supported by scientific evidence from properly designed and implemented clinical series that support the guideline statement.
- C.** The recommendation is supported by expert opinion.
- C8.** Pearson et al. (1995) identified 11 randomised controlled trials of pelvic floor exercises (PFEs), the regimes for which varied in all of the studies, and only three studies compared PFEs with no treatment. Others who have reviewed work in this area highlight the lack of rigorous research (Williams et al. 1995; Wells 1990b).

## **Results**

**C9.** Although the use of **pelvic floor exercises** is the main non-surgical treatment for women with mild to moderate genuine stress incontinence, there has been little research into how PFE 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 (Wells 1990a).

**C10.** Wells (1990b) undertook a review of the literature to identify English language studies, excluding case studies or clinical papers, assessing the effectiveness of PFE. She identified 22 studies of varying quality, with wide variation in the study design, sample size, and details of treatment and commented:

‘Patients were reported as cured in eight papers, with ranges from 31% to 73% efficacy. Five papers described outcome as successful with ranges of efficacy from 38% to 93%. Other papers reported outcomes as improved (86%); a paper combined cured and improved (74%); good (one study 78%, another 43%); marked alleviation (96%); or overall reduction in incontinence. No studies reported complications with treatment, but two papers did note that 5% to 11% of subjects had increased leakage after treatment.’

She highlights the lack of good quality research, and identifies the need to answer research question about technique, intensity, adjunct treatments, long-term outcome and prevention.

**C11.** The AHCPR (1996) guideline update states the following recommendations of relevance to PFE, although no specific detail is given for women during pregnancy or childbirth:

- Pelvic muscle exercises are strongly recommended for women with stress urinary incontinence (Strength of evidence = A).
- Teaching women pelvic muscle exercise may prevent urinary incontinence (Strength of evidence = C).
- Teaching exercises to strengthen pelvic muscles may decrease the incidence of urinary incontinence (Strength of evidence = C).

**C12.** The AHCPR (1992) guidelines emphasise the need for health care providers to ‘teach patients the correct method of contracting and discriminating the muscle with palpation and verbal feedback to assure accurate performance’. The benefit of home training and monitoring devices has not been demonstrated in well-designed clinical trials.

- C13.** From their review of quality assessed randomised controlled trials, Pearson et al. (1995) estimate the odds of improvement in urinary incontinence of pelvic floor exercises compared to no treatment to be 3.4 (95% CI: 1.5, 7.9). They conclude that there is limited evidence that pelvic floor exercises alleviate symptoms, but their efficacy in prevention has not been demonstrated. The need for professional assessment and guidance and follow-up to support pelvic floor exercise regimes is highlighted.
- C14.** Pearson et al.(1995) identified only one large scale randomised controlled trial (Sleep and Grant 1987), which evaluated 1800 women within 24 hours of childbirth. The trial compared intensive PFE with routine PFE advice as a method of preventing post-natal incontinence, but there was no reduction in urinary incontinence in the intensive group compared with the routine group. However, better compliance was found in the intensive exercise group, and significantly fewer women in this group reported feelings of depression.
- C15.** The trial by Sleep and Grant (1987) is the only trial included in a Cochrane Collaboration review of intensive post-natal pelvic floor exercises (Kaufman 1995). Three other trials were identified for this review, but excluded due to lack of clinical outcomes. Kaufman identified methodological weaknesses in the Sleep and Grant trial, namely that no reliability or validity of the instruments used was reported. Furthermore, the experimental group experienced an increase in social support and this may have affected the outcomes rather than the intensive exercise programme. She concludes that: ‘intensive pelvic floor exercises did not appear to decrease incontinence rates when compared to the routine use of these exercises. It is not clear whether the exercises, or the social support, or a combination of the two resulted in the decreased incidence of depression and pain experienced.’
- C16.** Wilson et al. (1996) undertook a postal survey of all women three months post-partum who were resident in the Dunedin area of New Zealand, to examine the relation between obstetric factors and the prevalence of urinary incontinence three months after delivery. When looking at all respondents, they found a protective effect of PFE done daily during pregnancy (odds ratio 0.6 , 95% CI: 0.4-0.9). However, no significant effect was found for less frequent ante-natal PFE (few/week, weekly, few/month), or for any frequency of ante-natal PFE in any of the subgroups of women (all women with no previous incontinence, all primiparae, primiparae with no previous incontinence). The results may be prone to recall bias, as the information was collected three months post-partum. Also, the respondents to the survey (the authors report a 70.5% response rate) were different to the non-responders in a number of measures (age, gestational age, birthweight, analgesia, spontaneous onset of labour). Due to the limitations of the study design and the limited effect found, no clear conclusions can be drawn. As the authors state: ‘a prospective study would be required to see whether daily PFE during pregnancy were really protective.’

- C17.** There is limited evidence about the effectiveness of PFE in the long-term. Cammu and van Nylén (1995) evaluated the outcome of PFE for genuine stress incontinence after five years. They conclude that given compliance and a certain level of continence established after initial treatment, continence can be maintained over five years. However, the study size is small and the average age of the women was relatively old (52.4 years).
- C18.** Bo and Talseth (1996) evaluated the effect of PFE five years after a structured training program. They found a significant increase in incontinence after five years, although 75% of patients showed no leakage during stress test and 70% were satisfied with their condition. However, this study is only based on 23 women, three of whom were excluded as they had had surgery, six of whom had become post-menopausal between the original intervention and five year follow-up.
- C19.** In their review of the incontinence literature, Williams et al. (1995) conclude that: 'there is most certainly a place for pelvic muscle re-education programmes but further research needs to be undertaken in this area to determine who will benefit from the training, how patients can be motivated to undertake the training, and continue it to achieve maximum benefits and determine the long-term effects of this behavioural approach to incontinence'.
- C20.** Initial results from pre-menopausal women suggest that **vaginal cones** may be useful as an adjunct to pelvic muscle training (AHCPR 1992). The recent guideline update (AHCPR 1996) recommends that: 'vaginal weight training is recommended for stress urinary incontinence in pre-menopausal women. (Strength of evidence = B)'. This is based on the results from four studies including 103 pre-menopausal women, which resulted in the subjective 'cure' or greatly improved status of 68-80% after four to six weeks of treatment. There were also improvements in a number of objective outcome measures such as reduction of urine loss on pad test, increased pelvic muscle strength, and minimal or no adverse reactions. It was noted that in several studies PFEs were performed at the same time.
- C21. Biofeedback of performance** has been shown to be useful in reinforcing the patients' ability to discriminate muscle contraction, but the frequency of use and those patients most likely to benefit has not been established. Furthermore 'successful application of biofeedback is highly dependent on the knowledge and skill of the health care provider' (AHCPR 1992). The guideline update (AHCPR 1996) states: 'pelvic muscle rehabilitation and bladder inhibition using biofeedback therapy are recommended for patients with stress urinary incontinence, urge urinary incontinence, and mixed urinary incontinence (Strength of evidence = A).

- C22.** With respect to **electrical stimulation** the AHCPR (1992) guidelines state that: 'research is needed to determine the efficacy of electrical stimulation either when used alone or in combination with other management strategies to treat urinary incontinence. Ideal parameters for electrotherapies have not been established by controlled clinical trials, and research needs to be conducted before this technique becomes a standard treatment for urinary incontinence'.
- C23.** Moore (1994) reviews the literature for electrical stimulation (both continuous and intermittent) for genuine stress incontinence from both non-randomised and randomised controlled trials. She concludes that although this therapy appears promising, there is no good evidence to say that stimulation is better than PFE.
- C24.** Laycock et al. (1995) undertook a randomised controlled trial of acute and chronic electrical stimulation in combination therapy for genuine stress incontinence. Acute stimulation involved several short treatments at maximum intensity, whereas chronic involved low intensity, low frequency for several hours a day over a period of several months. They found that pelvic floor muscle power was significantly improved in the acute treatment group, but that this does not correlate with symptom improvement.

### **Conclusions**

- C25.** From the literature identified, the research evidence supports the use of PFE for the treatment of stress incontinence. However, there is insufficient evidence to identify the precise way in which exercises should be taught. Attention needs to be focused on ensuring that women are performing the exercises correctly.
- C26.** The use of vaginal cones and biofeedback may be useful to reinforce pelvic floor exercises in certain women, but there is insufficient evidence that electrical stimulation is better than pelvic floor exercises, or is effective in combination with them.
- C27.** There is insufficient evidence to evaluate the use of PFE in the prevention of urinary incontinence. One study points towards the possible protective effect of daily ante-natal PFE, but further research is required.

## **SURGICAL TECHNIQUES**

### **Introduction**

**C28.** This section examines the evidence on surgical techniques for the treatment of urinary incontinence. The main reason for assessing this area is to see if there is sufficient evidence to suggest that colposuspension should be undertaken in preference to all other surgical techniques.

### **Quality of available evidence**

**C29.** The AHCPR (1992) guidelines identify a number of caveats to consider in evaluating the literature on surgery for urinary incontinence. These include:

- the non-standard reporting of outcomes (cure, improvement, complications)
- the reporting of total rather than specific complication rates
- the non-standard statistical evaluation of patients who are lost to follow-up
- the impact of operator expertise.
- early reports of new procedures include higher complication rates and lower success rates than later reports
- adequate description of patient selection is often lacking in surgical series.

**C30.** In their recent systematic review, which included randomised controlled trials, non-randomised trials, prospective and retrospective cohort studies, and case-control studies, Downs and Black (1996) highlight the methodological limitations of the literature in assessing the effectiveness of surgical interventions. These include case definition, confounding, details of the precise surgical procedure being undertaken, follow-up, external validity, outcome assessment and statistical power. They gave a quality score to the 76 studies (presented in 79 reports) included in their review; the highest score being 48 (out of a maximum of 100) and the lowest seven. In general, studies were particularly poor with regard to external validity and statistical power.

**C31.** Much of the literature evaluates the results of one form of surgery, few comparisons are available between different types of surgery. Further, where randomised controlled trials of different surgical procedures are identified, surgeons are rarely randomised. As Jarvis (1994) points out: 'only when surgical procedures are compared using the principles of randomisation for both operation and surgeon may the real expectations from each surgical procedure be clarified.'

## **Results**

- C32.** The AHCPR (1992) guidelines identify the three main types of procedure used to treat hypermobility, the most common cause of urinary stress incontinence, to be anterior vaginal repair, retropubic suspension and needle suspension. They conclude that: “review of the available literature shows that the retropubic and needle suspension procedures produce a superior result to that of the anterior repair in ‘curing’ urinary incontinence and, therefore, are the two preferred techniques”. For the retropubic suspension techniques they identified 31 studies incorporating 2,788 patients, ‘cure’ rates averaged 78% with complication rates of 18%. For needle bladder neck suspension techniques, 1,355 patients were reviewed (the number of studies is not given), of which 84% were continent and complication rates ranged from 2 to 60% .
- C33.** In the recent guideline update (AHCPR 1996) the recommendation is: ‘Retropubic or needle suspension is recommended for women with hypermobility when stress urinary incontinence is the primary indication for surgery. On the basis of greater efficacy, these procedures are recommended over anterior vaginal repair for hypermobility (Strength of evidence = B)’.
- C34.** Jarvis (1994) undertook a review of surgery for genuine stress incontinence to see whether any one specific surgical procedure is more effective than the others. He hand-searched 16 journals from 1970, and identified 213 studies, describing 237 groups of patients who had undergone a total of 20,481 surgical operations. Attention was focused on objective outcome measures, cure assessed by urodynamic assessment, and only women with genuine stress incontinence were included. Where possible, results were taken from a minimum follow-up of one year, although comparability between studies was difficult. Jarvis found that only the Marshall-Marchetti-Krantz procedure (mean objective continence rate 89.5%), colposuspension (89.8%), endoscopic bladder neck suspensions (86.7%), and bladder sling operations (93.9%) yielded mean continence rates of over 85%. Further only the colposuspension and bladder sling operations had tight confidence intervals around the continence rates (95% CI: 87.6-92.1% and 89.2-98.6% respectively). He concludes that: ‘despite the apparent large amount of information available in the literature, there is no single genuine stress incontinence operation which should be offered to all women in all situations as a first choice.’ He highlights the need for better quality comparative studies. Of the 213 studies included in the review, only seven were truly randomised trials.

- C35.** Pearson et al. (1995) reviewed the randomised controlled trials of surgical interventions. They identified nine randomised controlled trials evaluating 17 procedures, but only two of the trials randomised surgeons as well as procedures. The authors found that colposuspension was more successful one year after operation than the Pereyra or vaginal repair. However, long-term success rates may be substantially lower than those rates at one year. They conclude that although there is a small amount of evidence to support surgical procedures, it is less clear that benefits last.
- C36.** Williams et al. (1995) note the lack of randomised controlled trials, and in particular long-term evaluations of the effectiveness of surgical methods. They conclude that: 'where objective outcome measures are described in studies there are few long-term follow-ups providing evidence of long-term effect.'
- C37.** Alcalay et al. (1995) report on the long-term follow-up of women undergoing Burch colposuspension 10 to 20 years ago. They undertook a longitudinal retrospective study of 109 women with genuine stress incontinence and found that cure of continence was time dependent, declining for 10 to 12 years before reaching a plateau.
- C38.** Downs and Black (1996) have recently undertaken a systematic review of the literature of the effectiveness of surgery for stress incontinence in women. They identified 11 randomised controlled trials, 20 non-randomised trials or prospective cohort studies and 45 retrospective cohort studies for inclusion, searching the literature from 1966 to the present. The majority of papers compared colposuspension with anterior colporrhaphy, needle suspension or slings. A number of studies compared different ways of performing each of the main procedures. Comparing colposuspension with other techniques, they found that colposuspension appears to be more effective than anterior colporrhaphy or needle suspension in curing and improving stress incontinence. About 85% of women are reported as being continent one year after colposuspension compared with 50-70% after anterior colporrhaphy or needle suspension. The benefit of colposuspension is maintained for at least five years whereas the benefits of anterior colporrhaphy and needle suspension diminish quite rapidly. There is little in the way of accurate information on post-operative complications. There is insufficient evidence that the effectiveness of colposuspension and sling procedures differ.

- C39.** When assessing the effectiveness of different methods of performing procedures, Downs and Black (1996) found that: 'different methods of performing colposuspension have not been shown to be associated with significant difference in outcome. There is evidence that laparoscopic colposuspension may have a higher failure rate than the open procedure.' They conclude that: 'the methodological quality of the studies that have reported the effectiveness of surgery for stress incontinence is poor. The value of surgery and the relative effectiveness of different procedures is therefore unclear.' Further: 'given the methodological shortcomings of most evaluative studies, evidence as to the effectiveness of surgery for stress incontinence is weak. It appears that colposuspension may be more effective and the effect more long-lasting than that for anterior colporrhaphy and needle suspension. There is little information on the value of sling procedures.' They highlight the lack of data on complications and the need for more rigorous research before recommendations of best practice can be made.
- C40.** The Royal College of Physicians (1995) only reference one review of surgery for urinary stress incontinence (Jarvis 1994), which is described above. They state that: 'there is no general agreement as to the surgical procedure of choice for genuine stress incontinence. In general, vaginal surgery is simpler, resulting in less morbidity, fewer complications and a shorter hospital stay. However, retropubic operations, although more complicated, will produce a longer lasting cure in the majority'.
- C41.** A relatively early review of the literature assessed the effectiveness of the Marshall-Marchetti-Krantz procedure, which is a method of colposuspension (Mainprize and Drutz 1988). Details of their search strategy is not given, but they identified 56 articles for inclusion. The overall success rate was 86.1% (2,712 cases), with 92.1% success in primary and 84.5% success in repeat procedures (although the definition of success is not given). Mortality overall was 0.2%, although none of the deaths were directly attributable to the procedure. Morbidity was 21.1%, the most common complications being wound complications (5.5%), urinary tract infections (3.9%), and osteitis pubis occurred in 2.5% of cases. The results of this analysis must be interpreted with caution as the majority of studies included were retrospective case series and little detail of the included studies is given. Also, 11.4% of patients were lost to follow-up. The authors conclude that the initial results of the Marshall-Marchetti-Krantz procedure appear successful, but long-term outcomes remain unclear.

- C42.** Jarvis (1995) undertook a meta-analysis of trials published since 1970, to determine if long-needle bladder neck suspension for genuine stress incontinence is more effective with endoscopy (Stamey procedure) than without (Pereyra procedure). No trials were identified which compared the two procedures and so the results from trials were combined to undertake the analysis. He found that there was no statistically significant difference between the two procedures and concludes that the analysis detected no improvement in the likelihood of continence under endoscopic control to aid suture placement. Unfortunately, no detail of the primary studies included in the analysis is given, and potential bias from differences between the studies cannot be excluded.
- C43.** Korn (1994) looking at the modified Pereyra procedure for stress urinary incontinence concluded that: 'until a randomised controlled trial is done, the available evidence supports the use of permanent suture material whenever the modified Pereyra procedure is performed'

### **Conclusions**

- C44.** From the identified literature, there is insufficient evidence to recommend any specific surgical procedure. In particular, although colposuspension may be more effective and have a larger more long-lasting effect than anterior colporrhaphy or needle suspension, the quality of the available evidence is not sufficient to recommend it as best clinical practice.

## **THE ORGANISATION OF CONTINENCE SERVICES**

### **Introduction**

- C45.** The aim of this section is to assess the evidence which has been used to evaluate the organisation of continence services. Therefore, it is of interest to know whether organised continence services afford better provision of treatment and if so, which model of organisation is the most effective.
- C46.** In 1983 the Incontinence Action Group published a report (Kings Fund 1983) of their consideration of incontinence with the major objective of: 'encouraging sufferers to report it, and their doctors and nurses to become confidently informed in its management'. The Group identified: 'the huge gap which exists between available knowledge of the causes and methods of management and that which is actually known to practising nurses and doctors.' In the report six recommendations were made encompassing education, organisation, evaluation of products and public education.

Included in the organisation of services, the Group recommended: 'that a continence nurse adviser be established in each health district. To facilitate this, we suggest that each district should set up a committee or a working group, including representatives of nursing, supplies and relevant medical specialties, and the continence nurse specialist would be associated with this group.'

- C47.** As Roe et al. (1996) pointed out in a report evaluating health interventions by primary health care teams and continence advisory services: 'the development of continence services has historically been largely ad hoc with no clear evidence of their clinical or economic evaluation in relation to cost effectiveness and outcomes. Despite the fact that there has been a lack of clinical and economic evidence on which to base policy, the debate regarding the structure of continence services is ongoing.'

#### **Quality of available evidence**

- C48.** No reviews were identified which evaluated different methods of organisation of continence services and it would appear that there has been little rigorous primary research. Much of the literature consists of descriptions of how services have been set up, or components which should be included in a continence service, rather than evaluation of different organisational methods. As Roe (1994) has noted: 'no evaluation of patient outcomes related to incontinence has been undertaken for a health authority with an established continence advisory service compared with one without'. Where evaluation exists, it is normally an audit of a given service such as measuring the number of patients seen and access. For example, Swaffield (1995) has reviewed the literature of both retrospective and concurrent audit of delivery of continence care.

- C49.** There has been work to provide guidance for the composition of continence services, for example from The Continence Foundation (1995) and The Royal College of Physicians (1995) but much of the guidance is based on opinions of what constitutes best practice, rather than clear research evidence.

#### **Results**

- C50.** Rhodes and Parker (1993) examined the role of continence advisers in England and Wales, by means of a postal questionnaire to all known continence advisers, interviews with a small sample of advisers, and group discussions with advisers in four regional locations. They found wide variation between advisers, both in terms of the amounts of time spent in different activities and the relative importance attributed to them. They also found that advisers have

a wide range of training needs which are not adequately addressed by the nursing courses currently on offer. They conclude by stating that the changing role of continence advisers challenges the notion of advisers as clinical nurse specialists, and moves more towards an increase in managerial responsibility at the expense of clinical practice. They present three potential models for the provision of continence services:

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

**C51.** Swaffield (1994) has examined the management and development of continence services in the light of the NHS and Community Care Act of 1990. The Act has imposed a statutory requirement on local authorities to co-ordinate arrangements for assessing community care needs on an inter-agency basis. This has implications for the assessment of elderly patients, many of whom may require continence services. Swaffield concludes that: 'there is a need for protocols, systems and evaluation measures across community care team boundaries'.

**C52.** The Continence Foundation (1995) produced guidance for health authorities on the commissioning of continence services. This document emphasised the complex nature of the problem and the need for comprehensive services to meet the needs of patients. Before NHS reorganisation, most district health authorities had continence advisers with district-wide responsibility across hospital, community and often social services. More recently this has become fragmented, with continence advisers frequently being community-based, with no contract for services in the acute sector. Ideally, the management of incontinence is based on a multidisciplinary co-ordinated service, which will include education as well as the provision of clinical services for individual patients. This report highlights 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 continence services need careful co-ordination across trust boundaries and across the primary care/hospital interface.'

**C53.** The Continence Foundation (1995) report that the precise role of the continence adviser is not clear: 'while there is general consensus as to the importance of the role of the continence adviser, there is a lack of research on how a continence adviser can operate most effectively, and little consensus on an appropriate mix of education, prevention, treatment, and support and management functions'.

**C54.** In their report on the causes, management and provision of services for incontinence, the Royal College of Physicians (1995) identify the following components for an ideal continence service:

- a defined method of entry for patients referred by general practitioners, nurses, hospital staff and patients themselves
- access to appropriate diagnostic facilities, including urodynamic and ano-rectal
- access to medical and surgical consultants with a special interest in incontinence
- integration of continence services for children with other paediatric services
- attention to the wishes of patients and carers
- access to nurses and physiotherapists with special training in treatment modalities for incontinence
- a role for one or more specialist continence advisers in the education of the public and professionals in continence maintenance
- a policy concerning the purchasing and supply of containment materials and equipment in the community, in residential and nursing homes and in hospitals
- well defined audit and quality assurance systems.

**C55.** The Royal College of Physicians (1995) also report Department of Health guidelines which identify five key components of an effective continence service:

- active, enthusiastic consultant and general manager involvement
- continence advisers with management and teaching skills and a small caseload to maintain their clinical skills
- a computer to store patient information
- active publicity work and sympathetic, knowledgeable telephone advice
- a separate budget.

**C56.** Oxfordshire have produced guidelines for shared care for continence services (Working Group on Female Incontinence 1995). These provide guidance for the management of female urinary incontinence by the primary health care team. The guidelines give the objectives of community continence clinics, and provide diagrams of how referral to services should take place, but no reference is made to the evidence in producing the guidelines.

### **Evaluation of services**

- C57.** Roe et al. (1996) undertook a survey of two district health authorities, one with a continence advisory service and one without. They concluded that: 'people with incontinence in the health authority with a continence service received more appropriate health interventions based upon good practice for the restoration or promotion of continence and referral than those in the health authority without a service.' Furthermore, those people in the health authority without a service were less likely to receive further information and health education, and less likely to be satisfied with the health care and services they received.
- C58.** An early study (Badger et al. 1983) of the introduction of a continence nurse adviser found no reduction in hospital admissions or in the overall resource use, although half of the subjects experienced an improvement in continence, as well as an increased understanding of the problem and the opportunity to discuss it with someone knowledgeable. The study also discusses the methodological problems encountered trying to evaluate the service.
- C59.** In their work to develop methodologies to identify urinary incontinence, Pearson et al. (1995) undertook surveys of health service users and people reporting urinary incontinence. Their findings included the following:
- people with urinary incontinence are much more likely to seek help from GPs than other health professionals
  - there are substantial opportunities for increasing the detection of urinary incontinence in community nursing services; in some hospital specialties (urology, gynaecology, care of the elderly) and in social services assessments for residential community care
  - little is known about user satisfaction with incontinence services
  - available data on the actual health care costs of urinary incontinence services are inadequate
  - the role of social services in assessing community care and residential care needs provides considerable opportunities for the detection of urinary incontinence
  - review of hospital notes suggests that screening for bladder problems was in theory routine (as part of the case-history), but in practice inconsistent.
- C60.** Walters and Realini (1992) undertook a review of the evaluation and treatment of women with urinary incontinence in the primary care setting. They found that urinary incontinence can be diagnosed accurately by family physicians using basic tests. Many women experience improvement in incontinence with properly employed behavioural and pharmacologic therapy. Other women benefit from referral for specialised evaluation and consideration for surgical therapy.

**C61.** McDowell et al. (1994) undertook a randomised controlled trial to determine the difference in the recognition and intervention/referral rates for urinary incontinence by out-patient geriatric assessment units and private physicians in community based practices in America. They found that the geriatric assessment units were better than physicians in community based practices at identifying patients with both mild and severe urinary incontinence. Intervention/referral rates were low for both groups, and the authors highlight the need for increased emphasis on urinary incontinence in education for preparing physicians and other health providers as well as the need for continuing education for those already in practice.

### **Conclusions**

**C62.** There is little or no evidence available to identify the most effective way of providing continence services. Despite the recent changes in provision, little work has been undertaken to rigorously evaluate services. It seems likely that any method which provides a systematic approach to the management of incontinence may improve outcomes. For example, in one area, before a community continence management programme was introduced, the number and needs of the patients receiving continence products were unknown. Clinic files were congested with 'dead' records as well as active ones. Patients were referred from all sources and products were issued on demand. (Thompson 1990). A systematic approach to providing continence services may improve this situation, but it is not clear precisely what the most effective approach is. As Roe (1993) has noted: 'district-wide continence advisory services have been set up, but to date no study has evaluated their outcomes or effectiveness.'

**C63.** There are a number of different models on which continence services can be based, varying in the level of specialisation, and the role the continence adviser takes (supervisory, educational, co-ordinational or clinical). Each model has its own potential benefits and problems (for example, links between community and acute sector, cost implications, education of health care professionals), which have not been fully evaluated or compared in the literature. There are still large areas of uncertainty and much more rigorous research is needed to address these questions.

## APPENDIX D: GLOSSARY OF MEDICAL TERMS

<i>Detrusor muscle</i>	- A muscle whose contraction results in pushing down or out; in this case the bladder muscle.
<i>Detrusor instability</i>	- A disorder which causes the bladder muscle to contract uncontrollably giving rise to sensations of urgency and frequency and, if severe, urge incontinence. The reason for this behaviour of the bladder is often unknown, ie 'idiopathic detrusor instability'.
<i>Detrusor hyperreflexia</i>	- The same type of disorder of function of the bladder as detrusor instability. But occurring as a complication of a neurological disease.
<i>Enuresis</i>	- The involuntary loss of urine, ie incontinence.
<i>Genuine stress incontinence</i>	- Leakage from the bladder due to weakness of the bladder outlet guarding mechanism; not due to involuntary contraction of the bladder muscle.
<i>Residual urine</i>	- The urine remaining in the bladder after attempts to void.
<i>Sphincter</i>	- A ring-like band of muscle fibres that constricts or closes an orifice.

## APPENDIX E: METHODS FOR CHOOSING INDICATORS

- E1.** Candidate outcome indicators were identified by the Group with the help of the following:
- the health outcome model for urinary incontinence (see Section 2)
  - various classifications of the characteristics of outcome indicators.
- E2.** The Group noted that indicators may be related to:
- i. causal factors in the general population or relating to the individual
  - ii. knowledge, attitudes, behaviour in the general population
  - iii. knowledge, attitudes including satisfaction with service delivery, behaviour of individual patients with urinary incontinence
  - iv. patients' symptoms, function, health status, well-being
  - v. patients' clinical state
  - vi. patients' pathological/physiological state
  - vii. events occurring to patients as endpoints of the earlier occurrence of disease and/or interventions such as contacts with general practitioners, out-patients visits, in-patient admissions, death.
- E3.** The data sources for the indicator entities noted in paragraph E2 will differ. It is likely that:
- indicators for (i) and (ii) would come from population survey
  - indicators for (iii) and (iv) would come from patients either opportunistically or when specifically called
  - indicators for (v) and (vi) would come from doctors and other health professionals
  - indicators for (vii) would come from administrative information systems.
- E4.** The Group recognised the high cost and complexity of obtaining information from continuous data collection systems. Particular consideration was given to obtaining outcome indicator data from a sample such as a periodic survey when it is not essential to have continuously collected information.
- E5.** Four characteristics of an outcome indicator have been identified and each has been classified. They are:
- measurement perspective, relating to whose perspective the indicator is most relevant (see paragraph E6)
  - specificity (see paragraph E7)
  - measurement timeframe (see paragraph E8)
  - outcome relationship, in that the indicator is either a direct or an indirect, proxy measurement of outcome (see paragraph E9).

- E6.** For the Group's purposes measurement perspective was classified as that from the patient's, the clinical, or the population's viewpoint. In the treatment of urinary incontinence, for example, a measurement of quality of life may be most relevant to the patient's perspective while clinical concerns may properly focus on measures of urodynamics. The population perspective has a broader view, best addressed by measures able to assess the burden of the condition as a whole. Of course, these perspectives are not necessarily in opposition and will often be associated with shared goals. Where possible, a set of indicators should be developed which satisfies all three measurement perspectives.
- E7.** The specificity of an indicator relates to whether it is specific or generic in application. For example, urodynamic measurements are specific to urological function. The measurement of general health status is much less specific and would be influenced by a number of conditions. Condition-specific indicators have the advantage that their relative insensitivity to other conditions is likely to increase their sensitivity to changes in the condition of interest. Generic measures provide outcomes relevant to a wide range of conditions. A comprehensive indicator set might contain examples of both generic and specific indicators.
- E8.** The measurement timeframe relates to whether the indicator is:
- cross-sectional and thus an indicator at a single point in time for any one individual
  - a longitudinal measure of progression over time for any one individual.
- E9.** The Group's main task has been to develop direct indicators of health outcome although in many areas it may be difficult to identify or obtain such information. However, it is recognised that some care processes are so closely related to the production of benefits that the successful completion of the intervention might be used as a proxy measure of the actual outcome. In the absence of direct outcomes, proxy indicators have therefore been developed.
- E10.** There is increasing recognition of the importance of outcome measures derived from data generated by patients and carers. For the purposes of our work, three main areas of interest have been identified:
- impact of the condition on the patient and/or carer
  - satisfaction of the patient and/or carer with the care provided
  - awareness of the patient and/or carer of the management of the condition.

**E11.** The condition may impact on the patient in terms of:

- general health
- specific impairments associated with the condition
- disabilities
- handicaps.

**E12.** The condition may impact on carers in terms of their:

- physical health
- psychological health
- social functioning.

**E13.** With the assistance of the check-lists and a knowledge of the condition supplemented by commissioned work, the Group addressed the following key questions:

- What are health professionals trying to achieve for each patient?
- What can each patient realistically expect will be achieved for him/herself?
- What should be achieved for the population as a whole in respect of the prevention, care or cure of the disease?

# APPENDIX F: GUIDANCE NOTES FOR INDICATOR SPECIFICATIONS

<b>Title</b>	<b>A short title to identify the indicator</b>
<b>Intervention aim</b>	<p>Distinguishes the level of intervention for which the indicator is primarily developed. It is assumed that, for a given condition, an ideal set of indicators would be reasonably balanced across the spectrum of health intervention stages. For urinary incontinence these stages are:</p> <ul style="list-style-type: none"><li>- reduce or avoid risk of urinary incontinence</li><li>- reduce or avoid adverse effects of delayed detection and treatment</li><li>- treat underlying mechanisms, causes and avoid adverse consequences</li><li>- reduce impact of incontinence on general wellbeing.</li></ul>
<b>Characteristics</b>	<p>Classifies the indicator on four dimensions:</p> <ul style="list-style-type: none"><li>- Specificity: <i>condition specific or generic</i>.</li><li>- Perspective: <i>population, clinical or patient</i>.</li><li>- Timeframe: <i>cross-sectional measure</i> or <i>longitudinal assessment</i> of change</li><li>- Outcome relationship: whether it is a <i>direct</i> measure of outcome or an <i>indirect</i> measure of structure or process, used as a proxy for outcome.</li></ul>
<b>Indicator definition</b>	<p>In addition to a definition of the variable of interest, the description specifies:</p> <ul style="list-style-type: none"><li>- how the variable is to be aggregated across cases, e.g. definitions of both a numerator and a denominator</li><li>- if a variable is to be reported with respect to a set of denominators, e.g. mortality broken down by age and sex</li><li>- if appropriate, how longitudinal change in the variable is to be represented, e.g. over what time interval and whether absolute difference or proportional change.</li></ul>
<b>Rationale</b>	<p>A brief statement of the reasons and objectives behind the indicator, both in terms of the issues it addresses and it's selection from a range of potential alternatives.</p>
<b>Incontinence definition</b>	<p>A single definition of incontinence will be used as identified in paragraph 2.1. Its application is affected by the rationale, location of incidence and data sources used and these factors are addressed in each indicator definition.</p>

<b>Potential uses</b>	<p>The following classification has been used:</p> <ul style="list-style-type: none"><li>- local management of practice</li><li>- clinical audit</li><li>- provider based comparisons</li><li>- population based comparisons</li><li>- assessment of regional/national trends or progress towards targets.</li></ul> <p>It is recognised that a given indicator may serve several purposes. Indicators that are valuable for the management of individual patients are likely to have practical advantages with respect to data collection in a clinical setting. However, in order for such indicators to be useful for other purposes, a method of aggregation across cases must be specified for the variable of interest.</p>
<b>Potential users</b>	<p>The following classification has been used:</p> <ul style="list-style-type: none"><li>- clinicians</li><li>- provider management</li><li>- commissioners</li><li>- national/regional policy makers</li></ul>
<b>Possible confounders</b>	<p>This section has attempted to identify the population risk factors likely to influence the outcome indicator, and therefore useful in its interpretation. Where such factors are well defined and have a clear or potential association with the outcome of interest, they may be used to specify denominators to be included in the indicator definition itself.</p>
<b>Data sources</b>	<p>Where possible, existing sources of data have been identified for deriving the indicator and the degree to which complete coverage of the population of interest would be obtained has been noted. Where data are not widely available from existing systems, suggestions for new methods of data collection, capable of wide implementation have been made.</p>
<b>Data quality</b>	<p>While the theoretical capabilities of existing and proposed information systems are outlined above, the actual or expected limitations of those systems - in terms of their completeness and accuracy etc. - are noted in this section.</p>
<b>Comments</b>	<p>General comments regarding the indicator's definition, validity, practicality etc.</p>
<b>Further work required</b>	<p>Suggestions about the additional research and development work required to complete the indicator's specification to a level appropriate for large scale piloting.</p>
<b>Conclusion &amp; priority</b>	<p>A statement indicating the Working Group's assessment of the priority for implementation.</p>
<b>References</b>	<p>Appropriate references used in the construction of the indicators.</p>

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