Australian incontinence data analysis and development

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AIHW
March 2006

Australian Institute of Health and Welfare
Canberra

AIHW cat. no. DIS 44

This publication is part of the Australian Institute of Health and Welfare's Health Services Series. A complete list of the Institute's publications is available from the Business Promotion and Media Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's website < www.aihw.gov.au>.

ISBN 1 74024 546 6

Suggested citation

Australian Institute of Health and Welfare (AIHW) 2006. Australian incontinence data analysis and development. AIHW cat. no. DIS 44. Canberra: AIHW.

Australian Institute of Health and Welfare

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Published by the Australian Institute of Health and Welfare

Printed by

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Acknowledgments

The authors of this report were Samantha Bricknell, John Goss and Nick Mann. Ros Madden and Dr Diane Gibson advised and assisted in the development of this report.

Special thanks to the Continence Advisory Group who provided expert advice and valued comments on various drafts of the report—Dr Pauline Chiarelli, Glenice Wilson, Jan Sansoni, Barry Cahill and Sean McCreanor—and to members of the Community Care Branch, Australian Government Department of Health and Ageing who also provided detailed input and comment.

Many thanks also to:

- Cathy Hotstone, for data analysis presented in Chapter 4;
- Lesley Millar, for content and editing advice;
- Dr Graham Hawthorne, for provision of data and content advice; and
- Ainsley Morrissey and Cecilia Burke for coordinating the publication process.

We wish to also acknowledge the Australian Government Department of Health and Ageing which funded the project as part of the National Continence Management Strategy.

Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACCMIS	Aged and Community Care Management Information System
ACCNS	Australian Council of Community Nursing Services
ACFI	Aged Care Funding Instrument
ADHD	attention deficit hyperactivity disorder
AIHW	Australian Institute of Health and Welfare
AQOL	Assessment of Quality of Life
BEACH	Bettering the Evaluation and Care of Health
CAAS	Continence Aids Assistance Scheme
CACP	Community Aged Care Package
CNMDSA	Community Nursing Minimum Data Set Australia
CURF	Confidentialised Unit Record File
DALY	disability adjusted life year
DoHA	Australian Government Department of Health and Ageing
EQ5D	European Quality of Life Measure—5D
FRHOM	Functioning and Related Health Outcomes Module
GP	general practitioner
HACC NMDS	Home and Community Care National Minimum Data Set
HIC	Health Insurance Commission
HRQOL	health related quality of life
HUI3	Health Utilities Index Mark 3
ICD	International Classification of Diseases and Related Health Problems
ICD–10	International Classification of Diseases and Related Health Problems, Tenth Revision
ICD–10–AM	International Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
ICF	International Classification of Functioning, Disability and Health
ICIQ	International Consultation on Incontinence Questionnaire
ICPC–2 PLUS	International Classification of Primary Care Version 2 (PLUS)
INI	Initial Needs Identification (assessment tool)
ISSI	Incontinence Symptom Severity Index
KHQ	King’s Health Questionnaire
MAU	multi-attribute utility (instrument)

MBS	Medicare Benefits Scheme
MDS	minimum data set
METeOR	Metadata Online Registry
NCH	National Continence Helpline
NCMS	National Continence Management Strategy
NCSDD	National Community Services Data Dictionary
nec	not elsewhere classified
nfd	not further defined
NHDD	National Health Data Dictionary
NHMD	National Hospital Morbidity Database
NHS	(ABS) National Health Survey
ONI	Ongoing Needs Identification (assessment tool)
PBS	Pharmaceutical Benefits Scheme
QOL	quality of life
RCS	Resident Classification Scale
RSE	relative standard error
SAHOS	South Australian Health Omnibus Survey
SDAC	(ABS) Survey of Disability, Ageing and Carers
UDI	Urogenital Distress Inventory
WHA	Women’s Health Australia (survey)
WHO	World Health Organization
YLL	years of life lost
YLD	healthy years of life lost

Symbols

n.p.	not published by data source
–	nil or rounded to zero, including null cells
. .	not applicable

Summary

This report investigates the prevalence, experience and burden of incontinence in Australia and the related monetary costs and expenditure associated with the condition (Part A). Part B then focuses on the development and description of data items for inclusion in future continence data collections. The recommended data items provide a complete picture of the experience of incontinence in Australia as well as promoting consistency with alternative methods of collecting information on incontinence, such as continence assessment tools.

The report was commissioned by the Australian Government Department of Health and Ageing as part of the National Continence Management Strategy.

Part A: Incontinence in Australia

Definition of incontinence and measurement of severity

- Most definitions of urinary and faecal (anal) incontinence describe a loss of control of urination or defecation respectively; however a universally accepted definition is yet to be achieved.
- The International Consultation on Incontinence has recommended a definition of urinary incontinence as the 'complaint of any involuntary leakage of urine' and faecal (anal) incontinence as the 'involuntary loss of flatus, liquid or solid stool'.
- Similarly, there is no consensus on the measurement of the severity of incontinence.

Prevalence estimates of incontinence in Australia

A prevalence estimate of 'severe' incontinence

- An estimated 545,000 people, or 2.8% of the Australian adult population, experience severe incontinence. This estimate of severe incontinence is calculated from:
    - the population (128,800) living in cared accommodation who always or sometimes need assistance to manage their bladder or bowel control;
    - the population (240,800) living in households who experience very severe or severe urinary incontinence (i.e. the population who experience urine leakage at least several times a week and leak more than a few drops at a leakage event); and
    - the population (202,100) living in households who experience very frequent or frequent faecal incontinence (i.e. the population who experience faecal leakage at least monthly).

  Some persons experienced both severe urinary and faecal incontinence but are only counted once in the overall estimate of severe incontinence.

  This estimate reflects the conceptualisation of incontinence as both a body function impairment (e.g. leakage events) and an activity limitation (e.g. need for assistance) and characterises an inclusive approach to measuring prevalence.

A prevalence estimate of 'moderate' urinary incontinence

- Around 723,100 Australians experience moderate urinary incontinence, i.e. they experience a urine leakage several times a month or less and/or may leak only a few drops. This group represents the population, or a proportion of the population, who may in time develop more severe incontinence.

A prevalence estimate of 'slight' urinary incontinence

- Another 2,877,500 Australians experience slight urinary incontinence, i.e. they experience urine leakage less than once a month and/or may leak only a few drops.

An alternative prevalence estimate of severe incontinence

- An alternative approach to measuring severe incontinence—based on a need for assistance to manage bladder or bowel control and/or the use of continence aids, i.e. incontinence as an activity limitation—estimates that 284,500 Australians (or 1.4% of the population) experience severe incontinence. This group represents the population who may require formal service intervention now or in the future.

International and other Australian prevalence estimates

- Prevalence estimates of urinary incontinence vary considerably largely due to the variation in applied definitions and measures of severity.
- International prevalence estimates for urinary incontinence among men living in the community range from 1–34% and for women from 3–58%; for faecal incontinence international prevalence estimates for males range from 1–15.6% and for women 1.4–19.8%.
- Published Australian prevalence estimates for men and women living in the community also range considerably. Urinary incontinence amongst Australian men range from 2.2–13.0% and Australian women from 19.3– 37.0%. Faecal incontinence estimates range from 5.5% up to 20% of Australian men and 5.3% to 12.9% of Australian women.
- Prevalence estimates for urinary and faecal incontinence among people living in residential care and institutions are much higher. Depending on the definition applied, between 32–78% of adults living in long-term care facilities are estimated to experience urinary incontinence and 10–72% to experience faecal incontinence. Incontinence is considered a significant predictor for institutionalisation of older persons.

Associated factors and risk factors

- Both urinary and faecal incontinence increase with age in both men and women, but occur much earlier for women.
- Women tend to experience urinary incontinence proportionally more than men, regardless of age. The relationship between faecal incontinence and sex is less clear, with some suggestion it is more prominent among women or equally likely to occur in both sexes.
- An extensive list of risk factors has been proposed for incontinence but only a few have received any rigorous assessment. Risk factors include pregnancy, childbirth and parity, menopause, body mass index and obesity, lower urinary track symptoms, constipation,

mobility and cognitive impairment, and specific surgeries, such as prostatectomies, prolapse repair and hysterectomies.

- A number of health conditions are also associated with incontinence, either directly or indirectly, such as dementia, stroke, diabetes mellitus and various neurological and musculoskeletal conditions.

Experience of incontinence in Australia

- Of the 284,500 Australians who always or sometimes needed assistance with bladder or bowel management and/or use continence aids, 79% were aged over 50 years and 65% were aged over 70 years.
- Females represented two thirds of people likely to experience severe incontinence.
- Forty five percent of people experiencing severe incontinence lived in cared accommodation.
- An estimated 128,200 people always needed assistance with bladder or bowel control, 64% of whom lived in cared accommodation. Another 101,300 people sometimes needed assistance with bladder or bowel control; 60% lived in households.
- Almost a third of people (12,400) living in households who always needed assistance with bladder or bowel control were aged 70–84 years. For people living in cared accommodation and needing such assistance, 89% of residents were aged 70 years and older.
- Females represented 55% of people living in households who always needed assistance with bladder or bowel control and 73% of people living in cared accommodation with the same assistance needs.
- Around 60% of people living in cared accommodation and 19% of people living in households required assistance with managing their bladder or bowel control at least 6 times a day.
- Around 55% of household-living people who needed assistance to manage bladder or bowel control relied on informal assistance only with self-care; 16% reported not receiving any assistance from either formal or informal sources.
- Continence aids were used by 184,500 people over the age of 10 years; 100,700 lived in cared accommodation and 83,800 lived in households. Females represented 64% of continence aid users living in households and 74% of continence aid users living in cared accommodation. Sixty three percent of continence aid users living in households were aged 50–84 years and 90% of continence aid users in cared accommodation were aged over 70 years.
- Arthritis and related disorders were the most common associated health conditions for people with severe incontinence living in households, followed by musculoskeletal conditions.
- Dementia (including Alzheimer's disease) was the most common associated health condition for people living in cared accommodation, followed by stroke and arthritis and related disorders.
- Almost 60% of primary carers who usually assisted a person with managing their incontinence spent 40 hours or more a week actively caring for or supervising that person.

- Around 44% of primary carers who usually assisted with managing another person's incontinence reported a change in their physical or emotional wellbeing since taking on the caring role, compared to 27% of carers who did not usually assist in managing incontinence. A similar percentage of carers frequently felt worried or depressed.

Expenditures for incontinence

- The estimated monetary costs of urinary and faecal incontinence in Australia in the health and residential aged care system in 2003 totalled $1.5 billion. The costs of incontinence are large and the impacts are both monetary and non-monetary, and a wide range of personal costs such as laundry, clothing and time costs are generally not captured.
- The majority of incontinence costs are for residential aged care ($1,268 million) and continence aids ($111.7 million). The former expenditure is in part due to the many people with severe incontinence living in cared accommodation and the time intensive nature of caring for persons with severe incontinence.
- Other costs relate to hospital expenditure (e.g. admitted patient services in hospitals), various medical services and pharmaceuticals.
- The total expenditure for incontinence is projected to increase by 201% by 2030–31, with the greatest projected expenditure increase occurring in residential aged care (220% increase between 2003 and 2030–31).

Burden of incontinence

- An estimated 117,700 healthy life years were lost in 2003 due to incontinence.
- The burden of incontinence is particularly apparent for people aged 75 years and over with an estimated 69,000 healthy life years lost due to incontinence. Incontinence is responsible for around one-fifth of healthy life lost for this age group, similar to dementia and hearing and vision impairments which account for an estimated one-fifth and one-sixth of healthy life lost.
- The burden of incontinence is expected to increase by 110% between 2003 and 2031, with 53% of the increase occurring in the 85 years and older population, 27% in the 70–84 years population and 20% for those under 70 years.

Part B: Developing Australian continence data standards

Australian continence data collections

- A total of sixteen Australian data collections, including population health and disability surveys, administrative data collections and health service-data collections, were identified as containing data items related to continence and incontinence, managing incontinence and toileting.

Comparability of continence data items

- Continence data collected in Australia encompass two main themes—incontinence as an impairment or activity limitation, and the sorts of assistance or measures people use to manage their incontinence. These themes relate to the International Classification of Functioning, Disability and Health (ICF) components of Body Functions, Activities and Participation, and Environmental Factors.

- While there is some overlap between information collected in Australian data collections and continence assessment tools, there is a general absence of information collected in the former on participation (in, for example, education, employment and recreational activities) and environmental factors relevant to or associated with the experience of incontinence. Continence assessment tools do not always collect information on need for assistance but some information on participation and environmental factors.

A recommended menu of data items

- Continence (or incontinence) is a multi-dimensional concept. To provide a complete picture of the experience of incontinence in Australia, data items that captured all aspects of a person's functioning relevant to the experience of incontinence were developed. These were based on the common themes of data collections and assessment tools examined. They were also related to the ICF to promote comparability with other information on human functioning.
- A set of 19 data items are recommended for use in continence data collections, so as to provide consistency among future collections and comparability with continence assessment tools. These data items collect information on:
  - the presence of incontinence and associated symptoms (i.e. urgency of need to urinate and frequent urination or defecation) and the type of incontinence experienced (e.g. urge incontinence, stress incontinence);
  - the severity of the incontinence experienced (e.g. frequency of leakage event, the level of assistance required to manage bladder or bowel control);
  - difficulty and need for assistance to manage incontinence and the frequency of need for assistance;
  - the use and type of continence aids and other interventions to manage or alleviate incontinence;
  - associated body function impairments;
  - any activity limitations or participation restrictions affected by the experience of incontinence; and
  - the effects on carers who usually assist in managing another person's incontinence.
- While any combination of these items may be used in future data collections, three modules of differing complexity are proposed depending on collection purpose:
  - *How many Australians have incontinence*: for an estimate of the Australian population experiencing incontinence.
  - *Population needing assistance – the experience of severe incontinence*: for an estimate of the population experiencing more severe forms of incontinence, the methods employed to manage their incontinence and hence the population who may require formal service intervention now or in the future.
  - *A complete picture: incontinence as a multidimensional concept*: for a detailed picture of prevalence, assistance, aids and other intervention use, associated body function

impairments, impact of incontinence on lifestyle and effect on carers of persons needing assistance with incontinence.

Part A: Incontinence in Australia

1 Introduction

1.1 Purpose

Incontinence is a considerable but still somewhat unrecognised problem in Australia. While the symptoms of incontinence are generally not life threatening, the impact on an individual can be severe—on a person's ability to participate in many life areas, the costs associated with managing the condition, and associated stigma.

In recognition of the prevalence and impact of incontinence amongst the Australian population, the Australian Government provided $31 million to support the National Continence Management Strategy. Through this scheme, the Government aims to 'improve continence treatment and management so that more Australians can live and participate in their communities with dignity and confidence'.

In 2004 the Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare (AIHW) to undertake the present study to provide a profile of the Australian population experiencing incontinence. While there is increasing information on the prevalence of urinary and faecal incontinence in Australia, the severity of incontinence experienced, and to some extent the effect incontinence has on a person's ability to participate in life areas, there is limited information on support measures individuals rely on to manage their incontinence, associated health conditions, and the effects on carers caring for someone with incontinence. This report aims to redress this imbalance by presenting analyses on these topics, as well as additional information on effects on participation. Furthermore, the report will also consider the burden of incontinence and associated costs borne by the individual and the health system.

1.2 Outline of Part A

The structure of Part A of the report is as follows:

- Chapter 2 describes definitions of incontinence used in clinical and epidemiological research settings.
- Chapter 3 reviews the wide range of international and Australian prevalence estimates of urinary and faecal incontinence, with reference to the different definitional approaches taken. The chapter also discusses the recognised risk factors for incontinence, and a brief look at the literature on the impact of incontinence on quality of life.
- Chapter 4 presents original analyses of the 2003 ABS Survey of Disability, Ageing and Carers covering areas of need for assistance, use of incontinence aids, health conditions associated with incontinence, and impact of incontinence on participation in education, the labour force and the social context. The final section of this chapter addresses primary carers who care for someone with incontinence, particularly the impact of that care on their physical and social wellbeing.

- Chapter 5 discusses the costs associated with incontinence, including estimates of medical, pharmaceutical, and aids and equipment costs of incontinence, as well as hospital and aged care home expenditure. Costs are projected to 2030–31.
- Chapter 6 provides burden of disease estimates for incontinence in terms of the impact of urinary and/or faecal incontinence on quality of life.

2 Definition and measurement of incontinence

2.1 Definition(s) of incontinence

Incontinence has long evaded a widely accepted definition. Most definitions of urinary and faecal (or anal) incontinence describe a loss of control of urination or defecation respectively. Various reviews of the literature, however, reveal a range of variant definitions applied in the clinical and, especially, epidemiological research environments (Cheater & Castleden 2000).

In response, the 3rd International Consultation on Incontinence recommended urinary incontinence be defined as the 'complaint of any involuntary leakage of urine' (Abrams et al. 2002a: 168). The original International Continence Society (ICS) definition of incontinence incorporated a reference to quality of life, i.e. 'involuntary loss of urine that is a social or hygienic problem' (Hunskaar et al. 2002:168). The ICS, however, conceded that the latter definition is more easily applied in a clinical rather than community-based research setting, and relies on an 'objective demonstration' of urinary incontinence which is not necessarily achievable outside the clinical context. Furthermore, perceiving incontinence as a social or hygienic problem introduces a subjective dimension to what should be an objective assessment, which may influence estimates of prevalence and severity, and other measurable factors.[1,2]

Epidemiological and clinical definitions of urinary incontinence regularly conceptualise incontinence as an involuntary leakage or loss of urine, usually based on the frequency of that leakage or loss over a specified time period. Those time periods, however, differ from study to study, and range from daily episodes to 'ever' experienced. These and other definitions based on volume of urine lost often employ a threshold of severity to delineate between more severe and more moderate forms of urinary incontinence, and are discussed more fully in Section 2.3.

The International Continence Society has argued that definitions based on frequency and loss, with reference to severity, are more a measure of prevalence than a definition *per se* (Hunskaar et al. 2002), and certainly, these 'definitions' are mostly used with the objective of estimating prevalence. However, the application of varying definitions alluded to earlier has led to the publication of widely ranging prevalence estimates (Chapter 3).

The ICS also recognises other, related symptoms that may or may not necessarily result in urinary incontinence. These are:

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[1] The 3rd International Consultation on Incontinence has also developed a definition of 'social incontinence' which was not available at the time of publication.

[2] Foldspang and Mommsen (1997) noted that two studies using the ICS definition of incontinence produced questionable prevalence rates that may not be appropriate for biomedical research.

- urgency, or 'the complain of a sudden compelling desire to pass urine, which is difficult to defer'
- increased daytime frequency, or '…void(ing) too often by day'
- nocturia, or 'wake(ning) at night one or more times to void' (Abrams et al. 2002a:168).

While these symptoms may or may not occur with urinary leakage, on every occasion or ever, they may impact just as severely on a person's ability to complete their daily activities, and hence quality of life (see, for example, Hampel et al. 1997).

A unifying definition of faecal (or anal) incontinence has also escaped consensus.[3] Faecal incontinence is usually defined as the inability to control defecation, or an involuntary or inappropriate loss of liquid or solid stool. Some experts, however, also include the involuntary passage of flatus, caused by a loss of sphincter control. The 2nd International Consultation on Incontinence has proposed a working definition for anal incontinence, similar to that recommended for urinary incontinence, i.e. 'the involuntary loss of flatus, liquid or solid stool that is a social or hygienic problem', with the caveat that the subjective interpretation of this definition will vary from person to person (Norton et al. 2002:987).

Faecal urgency is an additional symptom often excluded from faecal incontinence assessment tools but, like urinary urgency, can exert an important influence on quality of life. Faecal urgency relates to a sudden urgency to pass solid stools, and is generally related to external anal sphincter dysfunction. While this urgency does not always or necessarily end with an episode of faecal incontinence, it may be a precursor symptom, and if ignored in clinical assessment may underestimate the severity of the condition (Vaizey et al. 1999).

2.2 Types of incontinence

Urinary incontinence is further classified into types of incontinence, based on symptoms and extrinsic factors. The most commonly described types of urinary incontinence are:

- Stress incontinence, or involuntary leakage of urine occurring on effort or exertion (e.g. bending over, walking up stairs), or sneezing or coughing. Stress incontinence is thought to occur due to weakened pelvic floor muscles or sphincter pathology which leads to urine loss when intra-abdominal pressure is increased.
- Urge incontinence, or involuntary leakage of urine accompanied by or immediately preceded by urgency. Associated symptoms may include frequent urination, nocturia and nocturnal enuresis.
- Mixed incontinence, or the complaint of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing.
- Nocturnal enuresis, or involuntary loss of urine occurring during sleep (Abrams et al. 2002a:168).

'Other' or unclassified types of incontinence are occasionally discussed in the literature, such as:

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[3] Faecal or anal incontinence may be used to describe faecal leakage, although some experts tend to term incontinence as anal incontinence when including flatus incontinence. This report will refer to any faecal leakage, excepting flatus incontinence, as faecal incontinence, and faecal leakage combined with flatus incontinence as anal incontinence.

- Overflow or outflow incontinence (voiding dysfunction), or failure of the bladder to empty due to overdistention or a blockage to the bladder.
- Neurogenic or reflex incontinence, or loss of urine control due to nerve damage. This type of incontinence is often associated with conditions such as spinal cord injury, multiple sclerosis, Parkinson's disease, and stroke.
- Dribbling (terminal, postmictural, postvoid), or constant dribbling of urine, occurring after urination.

An additional type of incontinence, frequently but not exclusively used with reference to urinary incontinence, is functional incontinence or 'urinary leakage associated with inability to toilet because of impairment of cognitive and/or physical functioning, psychological unwillingness, or environmental barriers' (Ouslander 1994:151). This type of incontinence generally occurs for people who have bladder control but become incontinent due to other factors, such as mobility impairment.

Classification of faecal incontinence is less definite, and terms are often interchanged. Furthermore, the literature does not commonly refer to 'types' of faecal incontinence as it does for urinary incontinence, normally classifying this form of incontinence as faecal matter or flatus lost. Terms that may be used, however, include 'idiopathic', 'sensory', 'neurogenic' and 'motor' incontinence. Norton et al. (2002) support the use of idiopathic incontinence, which refers to faecal incontinence not due to trauma, congenital defects or neurological disease, and to some extent, sensory incontinence or the absence of urge or feeling of passage of stools. However, they argue against the use of 'neurogenic incontinence', as it is essentially the same as idiopathic incontinence, and 'motor incontinence', which is ill defined and mostly related to diarrhoea and irritable bowel syndrome.

2.3 Measurement of severity

The severity of incontinence is usually measured with reference to the frequency of incontinent episodes, frequency of urination or defecation, and/or the volume or amount of urine or faecal matter lost at each episode, but may include other symptoms associated with incontinence (Cheater & Castleden 2000; Hunskaar et al. 2002). How much individuals are bothered by their incontinence or associated symptoms is an alternative method used by some epidemiologists to estimate severity.

The frequency of incontinent episodes is usually set against a specific timeframe, measured as the experience of involuntary loss in the last week, the last month or 6 months, the last year, or 'ever', or a more subjective focal period, e.g. never, rarely, sometimes or often. Frequency of urination is usually considered over a daily period, and defecation over a weekly period. The degree of loss is measured as the volume (e.g. for urinary incontinence—'a few drops' or 'more than just a few drops'), or as a lack of control leading to wetting or soiling of clothes.

Severity is graded using any one or a combination of these measures. Simple grading systems rely on frequency of incontinent episodes alone, and generally consider severe incontinence as that occurring on a weekly or more frequent basis. More intricate measures rely on an index system to grade responses for each measure of incontinence. For example, the Incontinence Symptom Severity Index (ISSI) developed by Sandvik and colleagues (1993) to measure the severity of urinary incontinence is composed of two questions:

- ‘How often do you experience leakage?’ (never = 0, rarely = 1, sometimes = 2 or often = 3) and
- ‘How much urine do you lose?’ (‘drops or just a little’ = 1 or ‘more than just drops’ = 2).

The index is calculated by multiplying the two responses together. An individual is identified as experiencing slight, moderate, severe or very severe incontinence, depending on the multiplied score.

Other severity indices work on a similar premise, although some determine severity on the ‘bothersomeness’, rather than the frequency or experience, of incontinence episodes and symptoms. One example is the Urogenital Distress Inventory (UDI), the short form of which asks respondents how much they are bothered by the following:

- frequent urination
- urine leakage related to a feeling of urgency
- urine leakage related to physical activity, coughing or sneezing
- small amounts of urine leakage (drops)
- difficulty emptying the bladder
- pain or discomfort in the lower abdomen or genital area.

A 4-point Likert scale is used to grade responses: 0 = ‘not at all’, 1 = ‘slightly’, 2 = ‘moderately’ and 3= ‘greatly’—where a score of 0 indicates no incontinence, 1–3 a slight problem with incontinence, 4–6 a moderate problem, 7–9 a problem, and 10–18 a major problem.

A smaller group of studies and severity indices include environmental and participation measures to determine severity, specifically the use of aids and impact on lifestyle. The Wexner score for measuring the severity of anal incontinence is comprised of the categories of incontinence type experienced, pad use and lifestyle alteration and is scored against a frequency scale of never, rarely, sometimes, usually or always.[4] Potential overall scores range from 0 (continent) to 20 (complete incontinence). (See Table A6.1 in Appendix A).

The measurement of incontinence severity, as for incontinence definitions, differs from study to study and the different approaches are not necessarily comparable. This further complicates the process of understanding not only how prevalent incontinence is amongst a specified population, but also what proportion are experiencing more severe incontinence, and hence the population who are in need of additional support measures.

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[4] The Wexner score frequency scale is defined as follows: ‘rarely’ = less than once a month, ‘sometimes’ = once a month or more but less than once a week, ‘usually’ = once a week or more but less than once a day, and ‘always’ = once a day or more.

3 Prevalence estimates and risk factors—a review of the literature

3.1 Variation in prevalence estimates

Variation in the use of definitions and measures of severity has inevitably led to a wide range of prevalence estimates. A review by Herzog and Fultz (1990) listed definitional, conceptual and measurement issues, along with sampling and non-response issues, as responsible for producing prevalence estimate variability. Nonetheless, Cheater and Castleden (2000) found less marked inter-study variability, and lower incontinence prevalence rates, when prevalence estimates were based on severity thresholds rather than more broader or inclusive definitions.

Another potentially confounding factor for estimating the real extent of incontinence is reliance on self-report data. The nature and stigma associated with incontinence, especially faecal incontinence, can compromise self-report data, as some individuals may feel uncomfortable or not wish to acknowledge they experience the condition. Others may consider incontinence a normal part of ageing, or not a significant problem, and hence not worth reporting.

This chapter presents a review of published prevalence estimates of urinary and faecal/anal incontinence from international and Australian studies. New prevalence estimates derived from original AIHW analysis are presented in Chapters 4 (Section 4.2) and 6 (Table 6.10).

3.2 International prevalence estimates (community-living population)

There have been an extensive number of studies published on the prevalence of incontinence, particularly the prevalence of urinary incontinence amongst women. The results from studies on urinary incontinence are numerous and the discussion of international prevalence estimates presented here relies on reviews by Cheater and Castleden (2000), Herzog and Fultz (1990), Sandvik (2003) and Thom (1998), which provide detailed descriptions of the range of estimates reported in the literature. The discussion on faecal incontinence estimates relies on individual studies and reports.

Urinary incontinence

Many of the prevalence estimates of urinary incontinence come from studies of people living in the community, resident in the United Kingdom, various parts of Europe, Japan, New Zealand and North America. Ranges are presented in Table 3.1.

While prevalence estimates for urinary incontinence vary considerably, those based on higher thresholds of severity tend to be more consistent. This is probably because more severe forms of incontinence are more obvious and less easily denied by the respondent, and

Table 3.1: Range of international prevalence estimates for urinary incontinence amongst community-living adults (per cent)

Source	Definition	Males	Females
Cheater & Castleden 2000	Ever	9–19	9–58
	Major or significant[(a)]	5	7–23
Herzog & Fultz 1990	Various	1–5 (Younger men)	4–31 (Younger women)
		6–25 (Older men)	9–42 (Older women)
Sandvik 2003	Significant[(a)]	n.p.	4–22
Thom 1998	Ever	3–5 (Younger men)	12–42 (Younger women)
		11–34 (Older men)	17–55 (Older women)
	Daily	2–11 (Older men)	3–17 (Older women)

(a) Major or significant incontinence was defined as wetting of clothes or the of use incontinence pads, 'social or hygienic problem—ICS definition', or daily/weekly episodes of incontinence.

Note: International prevalence estimates are derived from prevalence studies conducted in the United Kingdom, Sweden, Denmark, Norway, the Netherlands, Spain, Republic of Ireland, United States of America, Canada, New Zealand and Japan.

responses are less dependent on question wording than milder forms of incontinence, such as those picked up in questions on leakage events ever experienced (Herzog & Fultz 1990).

Older men and women consistently reported higher rates of urinary incontinence than their younger counterparts, as did women over men. Thom (1998) estimated the ratio of urinary incontinence of older men to older women to range from 1.0 to 2.4, whereas for younger men to younger women it ranged from 3.2 to 4.5. The higher prevalence of urinary incontinence amongst older men compared to younger men, according to Thom (1998), is the likeliest explanation for this difference.

The type of urinary incontinence experienced also tends to vary with sex and age. Around a third to a half of all women with urinary incontinence in these studies had stress incontinence, with a smaller proportion reporting mixed incontinence, and a smaller proportion again with urge incontinence. However, younger and middle aged women are more likely to experience stress incontinence and older women either mixed or urge incontinence (Chiarelli et al. 1999; Diokno et al. 1986; Miller et al. 2003; Samuelsson et al. 1997, cited in Hunskaar et al. 2002; Thom 1998). Men, on the other hand, are prone to urge incontinence, with a small but significant proportion reporting other or unclassified types of urinary incontinence, e.g. constant dribbling (7.4%, in Ueda et al. 2000) and frequent terminal dribbling (12%, in Sladden et al. 2000).

Faecal and anal incontinence

International prevalence estimates of faecal incontinence are presented in Table 3.2. Definitions used in the studies listed referred to loss of control or involuntary leakage, with occasional use of questions on staining and soiling of underwear. Overall prevalence rates for faecal incontinence ranged from 3% to 17%, and anal incontinence from 2% to 20%. Macmillan et al. (2004) regard sampling methods, inappropriate data collection methods and poor response rates as primary influences on prevalence variation, as well as the absence of a standard definition. There was some evidence of faecal incontinence rates being higher for women than men, but this was not a universal finding.

Table 3.2: International prevalence estimates for faecal and anal incontinence amongst community-living adults (per cent)

Source and population	Definition	Males	Females	Persons
Goode et al. 2005 USA, 65 years+	Loss of control of bowels over the past year	12.4	11.6	12.4
Perry et al. 2002 United Kingdom, 40 years+	Soiling or staining of underwear at least several times a month	2.2	4.0	3.1
Thompson et al. 2002 Canada, 18 years+	Any leakage of liquid or solid stool without anatomic or neurologic abnormality	5.4	8.4	6.9
Edwards & Jones 2001 United Kingdom, 65 years+	Difficulty in controlling bowels	1.0	4.0	3.0
Roberts et al. 1999 USA, 50 years+	Leakage of liquid or solid stool in past year	11.3	14.7	13.2
Johanson & Lafferty 1996 USA, 18–92 years	Any involuntary leakage of stool or soiling of undergarments	8.5	13.5	11.0
Lynch et al. 2001 New Zealand, 18 years+	Score of 3 or more on scale including any incontinence of gas, liquid or stool	14.3	19.8	17.0
De Miguel et al. 1999, cited in Macmillan et al. 2004 Spain, 'adult population'	Any leakage of gas, liquid or solid stool	n.p.	n.p.	8.8
Giebel et al. 1998 Germany, 18 years+	Any loss of control of solid or liquid stool, any loss of control of 'wind' or frequent faecal soiling	15.6	22.4	19.6
Nelson et al. 1995 USA, 18 years+	Unwanted, unexpected or embarrassing loss of control of bowels or gas in the last year	0.8	1.4	2.2

3.3 Australian prevalence estimates (community-living population)

Urinary incontinence

Australian prevalence estimates of incontinence are similarly variable. Table 3.3 presents published estimates of urinary incontinence amongst community-living Australian men and women, most of which are derived from reasonably broad interpretations of incontinence.

Prevalence estimates of urinary incontinence amongst men of all age groups ranged from 2.2% to 13%, and for women, 19.3% to 37%. All estimates listed in Table 3.3 were calculated based on reported experience of urinary incontinence episodes and related symptoms, but definitions differed in terms of time frame and, to some extent, the incontinence items covered in survey questions.

The simplest approach to measuring the prevalence of incontinence was adopted by the Millard (1998), Women's Health Australia survey (Chiarelli et al. 1999) and South Australian

Table 3.3: Australian prevalence estimates for urinary incontinence (per cent)

Source and population	Definition of urinary incontinence	Males	Females	Persons
Avery et al. 2004b				
SAHOS 1998	Ever experienced loss of urine (a) 'when they did not mean to', when they coughed, sneezed or laughed, or (b) associated with a sense of urgency and did not reach the toilet in time(a)	4.4	35.3	20.3
15 years+		2.5 (Stress) 2.9 (Urge)	32.4 (Stress) 14.5 (Urge)	
SAHOS 2001		n.p.	n.p.	21.4
15 years+				
Hawthorne & Sansoni 2004				
SAHOS 2004 15 years+	Urogenital Distress Inventory (UDI) severity score: Level of bothersomeness of 6 symptoms experienced in the last month(b)	0 = Major 1 = Problem 4 = Moderate	3 = Major 4 = Problem 16 = Moderate	2 = Major 4 = Problem 10 = Moderate
Chiarelli et al. 1999 WHA	Experienced leaking urine in the last 12 months			
18–23 years		. .	12.8	. .
45–50 years		. .	36.1	. .
70–75 years		. .	35.0	. .
Chiarelli et al. 2005	No universal definition (see note)	2.2	19.3	10.8
45 years+ (♂) 35 years+ (♀)				
<40 years		—	16.5	n.p.
40–49 years		3.0	20.9	n.p.
50–59 years		4.0	25.7	n.p.
60–69 years		6.8	20.3	n.p.
70–79 years		11.3	23.5	n.p.
80 years+		15.1	28.4	n.p.
Lam et al. 1999	Leaking urine on coughing or sneezing or leaking if unable to reach a toilet in time	3.5 (Stress)	31.5 (Stress)	19.7 (Stress)
18 years+(c)		12.0 (Urge)	25.9 (Urge)	20.1 (Urge)
Gunthorpe 1998, cited in Chiarelli et al. 1999	Incontinence screening question, using 5 items about leaking urine	. .	37.0	. .
18 years+				
Millard 1998	Frequency of urinary loss in last 3 months	13.0	34.0	n.p.
10 years+				

(a) Definition of urinary continence given in Avery et al. 2004b.

(b) Symptoms are: frequent urination; urine leakage related to a feeling of urgency; urine leakage related to physical activity, coughing or sneezing; small amounts of urine leakage (drops); difficulty emptying the bladder; and pain or discomfort in the lower abdomen or genital area. Respondents record level of bothersomeness according to the scale 0 = Not at all, 1 = Slightly, 2 = Moderately, 3 = Greatly. Overall severity score is the total of scores recorded: 0 = No incontinence; 1–3 = Slight problem; 4–6 = Moderate problem; 7–9 = Problem; 10–18 = Major problem.

(c) Mean age for male respondents was 55.3 years and for female respondents 55.7 years.

Note: Estimates published in Chiarelli et al. (2005) were pooled age-stratified prevalence estimates based on 5 and 12 international age-stratified estimates published for men and women respectively.

Health Omnibus Survey (Avery et al. 2004a, 2004b). These three studies asked respondents respectively about their experience of urine leakage in the last 3 months, last 12 months or 'ever'. The 1998, 2001 and 2004 SAHOS differed to the WHA and Millard studies by using questions relating to the experience of stress incontinence (i.e. a loss of urine occurring when the respondent coughed, sneezed or laughed) and urge incontinence (i.e. accidental wetting associated with an urgency to go, but failing to get to a toilet in time). Interestingly, these three approaches produced similar estimates for women, i.e. just over a third of women were affected by some degree of incontinence, except women aged 18–23 years where an estimated 13% experienced incontinence. However, results were different for men—4.4% from the 1998 SAHOS and 13% from the Millard study. It is possible the more general definition given in the Millard study led to a greater reporting of urinary continence by men. Lower estimates were published by Chiarelli et al. (2005) and Hawthorne and Sansoni (2004), which were calculated from more restricted definitions of incontinence. Chiarelli et al. (2005) estimated that 19.3% of Australian women and 2.2% of Australian men, and 10.8% of the overall population, experienced urinary incontinence. These estimates were based on a selection of international prevalence estimates,[5] and applied to age-stratified Australian population estimates.

Hawthorne and Sansoni (2004) present the only Australian estimates that refer to severity scores. Using the Urogenital Distress Inventory (UDI) in concert with data collected in the 2004 SAHOS (see notes in Table 3.3 for method), it was estimated that 2% of the population aged 15 years and over experience incontinence as a 'major problem', 4% as a 'problem', and 10% as a 'moderate problem'. The sex breakdown for these levels of severity is given in Table 3.3—5% of men and 23% of women experienced urinary incontinence as at least a 'moderate problem'. Further discussion of the association between incontinence and sex and age is presented in Section 3.5.

Estimates of urinary incontinence among Australians living in the community derived for this study finds a total of 240,800 Australians who experience severe urinary incontinence, 723,100 Australians who experience moderate urinary incontinence and 2,877,500 Australians who experience slight urinary incontinence (see Table 6.10).

Faecal and anal incontinence

Prevalence estimates for faecal and anal incontinence tend not to vary as widely as those for urinary incontinence. Table 3.4 presents published estimates of faecal and anal incontinence for community-living Australian men and women.

As for urinary incontinence prevalence estimates, the simplest approach to measuring prevalence was to ask respondents of their experience of this form of incontinence with reference to a specific timeframe. Again, the timeframe given, and the wording of questions, differed between studies. Kalantar et al. (2002) estimated a prevalence of 11.3% for the Australian population aged 18 years and over, based on a positive response to any leakage of bowel movements 'at an inappropriate time or place' in the last 12 months. Women were slightly more likely to experience faecal incontinence than men, 11.6% compared to 10.8%. The Avery et al. (2004b) analysis of 1998 SAHOS data used a similar question, i.e. loss of control of bowel movements, but no timeframe was given. These estimates, however, were much lower—2.9% for the overall population aged 18 years and over, and 2.2% for men and 3.5% for women. Estimates for flatus incontinence were also calculated and were generally higher than for faecal incontinence.

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[5] International estimates were included in the analysis if they came from community-based studies, had a response rate of over 65%, included a minimum of 125 participants for each sex, published results by age and sex, and used a validated instrument to measure incontinence.

The highest prevalence estimates were published by Lam et al. (1999), which defined anal incontinence as positive responses to two of three questions on problems with stool leakage, wearing a pad for faecal soiling, or frequent incontinence of flatus. This study estimated the prevalence of anal incontinence as 15% and in contrast to other Australian studies, men experienced anal incontinence (20%) much more than women (11%). The higher prevalence estimates may be explained in part by measuring the prevalence of anal incontinence, i.e. the inclusion of flatus incontinence within the definition of incontinence.

Some consideration of severity was included in the Lam et al. analysis: around 1.8% of respondents experienced stool leakage more than once per week and 0.8% used pads. Hawthorne and Sansoni (2004) also measured severity of faecal incontinence, using the Wexner score, which recorded the number of faecal incontinent episodes in the last month, for solid and liquid stools, or flatus. Daily episodes of anal incontinence, estimated at 2% of the Australian population, were a little higher compared with Lam et al.'s estimate but again, also included flatus incontinence.

Chiarelli et al. (2005) published the lowest estimates of faecal incontinence (solid and liquid stool only) at 5.4% but indicated that their estimates be treated with some caution due to heterogeneity at the study level.

An estimate of faecal incontinence among Australians living in the community derived for this study finds a total of 202,100 Australians who experience very frequent or frequent faecal incontinence (see Table 6.10).

Table 3.4: Australian prevalence estimates for faecal incontinence (per cent)

Source and population	Definition of faecal incontinence	Males	Females	Persons
Avery et al. 2004b				
SAHOS 1998 18 years+	Positive response to either or both problems: loss of control of bowel motions or loss of control of wind	8.1 2.2 (Faecal) 6.8 (Flatus)	12.8 3.5 (Faecal) 10.9 (Flatus)	10.5 2.9 (Faecal) 8.9 (Flatus)
Hawthorne & Sansoni 2004				
SAHOS 2004 18 years+	Reported episodes of leakage of solid or liquid stools, or flatus, in last month	2 = Daily 3 = Weekly 8 = Sometimes	3 = Daily 4 = Weekly 10 = Sometimes	2 = Daily 3 = Weekly 9 = Sometimes
Chiarelli et al. 2005 25 years+	Pooled age-stratified prevalence estimates based on 3 Australian and 1 US age-stratified estimates published for men and women respectively	5.5	5.3	5.4
Kalantar et al. 2002 18 years+	Leakage of bowel movements (excluding flatus) at an inappropriate time or place in last 12 months	10.8	11.6	11.3
MacLennan et al. 2000 15 years+	Faecal incontinence including any loss of control of bowel motions in last year	10.6	12.9	11.8
Lam et al. 1999 18 years+	Positive response to one or more problems: stool leaking, wearing a pad for faecal soiling and/or frequent incontinence of flatus	20.0	11.0	15.0

3.4 Prevalence estimates from institutionalised populations (International and Australian)

The prevalence of urinary and faecal incontinence is much higher amongst people living in residential care and institutions. Table 3.5 lists prevalence estimates for urinary and faecal incontinence amongst people aged over 60 years living in nursing homes, residential care, hospitals or other long-term care facilities. The prevalence of urinary incontinence ranged from 23% and 32% for persons experiencing incontinence episodes once or more times a week to between 40% and 78% for people experiencing any leakage. For faecal incontinence, it ranged from 11% and 18% to 46%. Estimates derived from Pearson (2003) are particularly high.

Table 3.5: Prevalence estimates of urinary and faecal incontinence amongst adults living in long-term care facilities (per cent)

Source	Definition	Urinary incontinence	Faecal incontinence	Doubly incontinent
Pearson 2003 Residents of aged care homes, Australia	Requiring at least some support for bladder and bowel management	66.0	72.0	n.p.
Chassagne et al. 1999 Residents of non-medical nursing homes and geriatric care facilities, France	At least one involuntary loss of faeces	n.p.	46.0	n.p.
Peet et al. 1995 Residents of residential or nursing homes, and hospitals, UK	At least one incontinent episode per week	22.7	17.7	17.7
Borrie & Davidson 1992 Residents of long-term care hospitals, Canada	Not defined	62.0	46.0	44.0
Fonda 1990 Residents in nursing homes, Australia	Ever wet during past 4 weeks, not able to void independently or used drainage devices	78.0	42.0	n.p.
Resnick et al. 1989 Residents of long-term care facilities, USA	Not defined	40.0	n.p.	n.p.
Tobin & Brockelhurst 1986 Residents of local authority residential homes for the elderly, USA	Urinary leakage or faecal soiling more than once per week	32.0	10.3	n.p.
Ouslander & Fowler 1985 Residents of nursing homes, USA	Any leakage	41.0	n.p.	n.p.
Ouslander et al. 1982 Residents of nursing homes, USA	Not defined	n.p.	32.0	n.p.

Of the few studies that estimated double incontinence, around 18% of residents in long-term care facilities in the UK had experienced at least one episode of both urinary and faecal leakage per week (Peet et al. 1995) as did 44% of residents in long-term care hospitals in Canada (Borrie & Davidson 1992).

Dementia and other degenerative neurological conditions, impaired mobility and, in some cases, severe psychiatric conditions typified the residential care population found to experience incontinence (see references in Section 3.4). Other risk factors include age, length of stay at the facility, and, for faecal and anal incontinence, the presence of urinary incontinence.

Incontinence is considered a significant predictor for institutionalisation of older people (see, for example, Nuotio et al. 2003). A recent Australian study by Pearson (2003) reported that 87% of Aged Care Assessment Team (ACAT) respondents identified incontinence as a significant or very significant factor in determining whether an individual be recommended for residential aged care. An overall ranking of critical factors in long-term care decisions placed incontinence, and the ability to manage incontinence, third, after dementia/cognitive function and mobility. This is a trend observed in other countries, such as the US, where it is the second most common reason for requesting nursing home placements (Edwards & Jones 2001).

An estimate of urinary and faecal incontinence among Australians living in cared accommodation derived for this study finds a total of 128,800 Australians who always or sometimes need assistance to manage their bladder or bowel control, i.e. they experience severe urinary and/or faecal incontinence (see Table 6.10).

3.5 Associations with age and sex

Age

Age is the most often cited factor associated with incontinence. Urinary incontinence increases with age in both men and women, but that increase occurs much earlier for women (Table 3.3). Men experience relatively low prevalence of urinary incontinence before the age of 60–70 years (e.g. 3–5%, Thom 1998), after which prevalence rises dramatically (e.g. 11–34%, Thom 1998). This is particularly apparent for urge incontinence.

Women start experiencing incontinence much younger, often in their 30s and associated with pregnancy and childbirth (see Section 3.6). Women then seem to experience two prevalence peaks, the first between the ages of 50–60 years, and again after 70–80 years (Chiarelli et al. 2005; Hannestad et al. 2000; Hawthorne & Sansoni 2004; Lam et al. 1999; Millard 1998); between these two periods the prevalence of incontinence stabilises or, in some studies, is shown to fall. Chiarelli et al. (2005) suggest that this prevalence pattern may be explained by the use of hormone replacement therapy after menopause (which eases milder forms of incontinence),[6] lifestyle changes where activities promoting incontinence are undertaken less often or not at all, and selective mortality of middle-aged women with poorer health, associated with incontinence. However, it is important to note that this pattern is not

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[6] Recent research by Hendrix et al. (2005) contradicts this proposal by reporting the use of menopausal hormone therapy to actually increase the incidence of stress, urge and mixed incontinence amongst women who were continent at the start of the study, and to worsen the frequency of incontinence events and the amount leaked at these events amongst women who already experienced urinary incontinence.

replicated in every study (see, for example, Avery et al. 2004a, 2004b) and may reflect the prevalence pattern for stress incontinence but not urge incontinence.

Faecal and anal incontinence also increases with age. Amongst community-dwelling persons, faecal and anal incontinence may rise with age from around 2–3% to over 10% (Nelson 2004).

Sex

Women generally experience urinary incontinence proportionally more than men, for all age groups. Thom (1998) estimated the prevalence of urinary incontinence in older women (65 years and over) to be 1.3 to 2.0 times greater than for older men. For younger women and men, it is higher, with the ratio of prevalence ranging from 4.1 to 4.5. Chiarelli et al. (2005) found the difference between Australian women and men aged between 20 and 40 years to be even higher—approximately a 7 to 1 ratio. However, in older persons, the sex ratio for urinary incontinence falls to 2:1, probably because of prostate problems, and associated urinary incontinence, men increasingly experience at older ages (see Section 3.6).

Sex differences for faecal incontinence are not so clear cut. Women are traditionally considered to experience faecal incontinence more than men, possibly due to the increased risk of sustaining damage to the pudendal nerve or sphincter muscle during childbirth (Madoff et al. 1992). While some studies show a higher prevalence amongst women (e.g. Kalantar et al. 2002; MacLennan et al. 2000; Nelson et al. 1995; Roberts et al. 1999), others find prevalence amongst men to be similar or higher (Campbell et al. 1985; Lam et al. 1999; Nelson 2004; Thomas et al. 1984).

3.6 Other risk factors

An extensive list of risk factors is proposed for incontinence but only a small number of these have received any rigorous assessment. The majority of research attention has focused on risk factors for urinary incontinence, particularly for women. Only the more prominently studied risk factors for urinary and faecal incontinence are briefly discussed below.

(a) Pregnancy, childbirth and parity: Both urinary and faecal incontinence are commonly associated with pregnancy and childbirth and may predispose women to more chronic episodes of incontinence later in life. Parous women are more likely to experience urinary incontinence compared with nulliparous women (Chiarelli et al. 1999; Thomas et al. 1980 but see Foldspang et al. 1992) and there is some, but still conflicting evidence, that women who have multiple pregnancies (four or more babies) are also more prone. There is conjecture as to whether it is the pregnancy, and the associated weight bearing on the pelvis, or vaginal delivery, which predisposes women to incontinence. For faecal incontinence, childbirth is considered the likelier cause but the mode of delivery does not necessarily differentiate risk. MacLennan et al. (2000) found no significant difference in the prevalence of faecal incontinence in women who had undergone caesarean sections and women who vaginally delivered their child. However, forceps delivery was found to be associated with elevated risks for faecal incontinence.

(b) Menopause: Research on the association between menopause and urinary incontinence has also produced conflicting results. It is suggested that the loss of oestrogen plays a role in urinary incontinence, since the atrophy of urinary tract and bladder tissues, which can lead to infections and storage problems and occurs with menopause, can be reversed with oestrogen replacement.

(c) Body mass index and obesity: The literature suggests a strong but not unchallenged role for obesity and higher BMI (body mass index) in the development of urinary incontinence (see, for example, Brown et al. 1999; Chiarelli et al. 1999; MacLennan et al. 2000). Similar to pregnancy, the added weight carried by obese persons may put too much pressure on the pelvic floor, and cause significant strain, stretching and weakening of the muscles, nerves and other structures.

(d) Lower urinary tract symptoms (LUTS): Lower urinary tract infections and symptoms such as blood in the urine or cloudy urine, burning, and trouble initiating or shutting off flow substantially have been found to increase risk in both men and women in the development and experience of incontinence (Brown et al. 1999; Chiarelli et al. 1999; Diokno et al. 1986; Ueda et al. 2000).

(e) Constipation: Constipation may be associated with both urinary incontinence (Chiarelli & Brown 1999; Paillard & Resnick 1984) and faecal incontinence (Diokno et al. 1990), particularly in older women. The straining associated with constipation possibly weakens pelvic floor muscles and ligaments, resulting in the dysfunction of pelvic floor muscles (Lubowski et al. 1988). Treatment of constipation may significantly reduce the severity of incontinence (Chassagne et al. 2000).

(f) Surgery: The impact of surgery as a precursor to urinary incontinence is more commonly observed in men than women. Men who undergo prostatectomies are particularly susceptible to urinary incontinence; older men are especially vulnerable with a calculated doubling of risk for every 10 years of age (Catalona et al. 1999). Hysterectomies and surgeries such as prolapse repair may increase the risk of urinary incontinence in women (Chiarelli et al. 1999; Milsom et al. 1993) but results so far are inconsistent. The risk of faecal incontinence from anal surgery is relatively low but sphincterotomies and fistulotomies are reported to be riskier surgical procedures and reported to increase the risk of anal incontinence by 8% and 18–52% respectively (Pernikoff et al. 1984 and del Pino et al. 1996, cited in Nelson et al. 2002).

(g) Mobility impairment: Men and women with mobility impairments have been found to be more prone to incontinence compared with their more mobile counterparts. Research proposing this link mostly stems from studies of older people but whether this incontinence is due to the problems people have with getting to the toilet (and, in some cases, removing their clothes) or urinary incontinence being a precursor to frailty is not yet understood.

(h) Cognitive impairment: Dementia, again amongst older people, is a recognised correlate with incontinence, and men and women are equally affected. People with more severe dementia are reported to be considerably more prone to becoming incontinent; a Canadian study of older demented women calculated odds ratios of 1.2, 4.0 and 12.6 for mild, moderate and severe dementia (Hunskaar et al. 1998, cited in Hunskaar et al. 2002). Both dementia and incontinence are predictors for older people to be admitted to aged care homes (Nuotio et al. 2003; Pearson 2003).

(i) Other health conditions and diseases: Diabetes mellitus and neurological conditions such as Parkinson's disease, spinal cord injury and multiple sclerosis are all associated with higher prevalence of urinary and anal incontinence (Brown et al. 1999; Chiarelli & Brown 1999; MacLennan et al. 2000; Nygaard & Lemke 1996; Thom et al. 1997).

Neuropathy, or nerve damage, is a common complication of diabetes (AIHW 2002a). Autonomic neuropathy affects the nerves controlling involuntary body functions, such as bladder function, and hence can lead to incontinence. Neurological conditions affect a person's mobility and ability to undertake self-care tasks such as toileting, as well as causing diarrhoea and faecal impaction.

3.7 Effect on lifestyle

Many studies of urinary and faecal incontinence describe the negative impact of incontinence on lifestyle and wellbeing but for those studies that attempt to quantify this impact, empirical findings tend to be mixed. For some individuals, incontinence exerts an enormous effect on lifestyle, participation and emotional status; for others, the effects are much milder. Fultz and Herzog's (2001) review of these studies argued that such varying conclusions resulted in part from different analytical designs, the absence of a comparative group (i.e. what do the results mean), and non-validated self-assessment of incontinence symptoms. Furthermore, they found that certain groups of respondents were more prone to reporting negative effects, such as younger adults and males.

Emotional wellbeing is possibly the biggest effect for people experiencing severe incontinence. Depression, frustration, embarrassment and sadness are terms often used in the literature. Up to 20% of people with incontinence have indicated feeling such emotions. For example, Fultz and Herzog's (2001) review estimated that around 10% of people with urinary incontinence felt their incontinence had affected feelings about themselves. Edwards and Jones (2001) reported an even greater impact on emotional wellbeing amongst people with faecal incontinence—20% suffered anxiety, and 15% experienced depression.

Incontinence may also affect ability to maintain lifestyle or participation in particular life areas. For example, 52% of people aged 40 years and over who have 'major' faecal incontinence reported 'a lot' of impact on their life (Perry et al. 2002). Around 16% with minor faecal incontinence reported the same. People with urinary incontinence reported somewhat less impact on their lifestyle—1.4% felt their urinary incontinence affected their ability to carry out daily activities, and 1.6% reported their social life had been affected (Perry et al. 2002). Analysis of the 1998 SAHOS by Avery et al. (2004b) found that 2% of people with incontinence aged 15 years and over did not leave the house because of their incontinence, 2.5% could not work as much as they used to, and 26% did not socialise as much as they used to.

Quality of life

The Continence Outcomes Management Suite project recently reviewed incontinence measures (or tools) for recommended use by primary care practitioners, specialist practitioners and researchers (Thomas et al. 2005). Included within this review was discussion of various studies using multi-attribute utility instruments (or MAU instruments) to measure the effect of incontinence on health-related quality of life.

The decline in utility index values for persons with incontinence compared with those not experiencing incontinence indicates that incontinence does impact to some extent on quality of life (Table 3.6). In fact, a number of studies comparing the effect on quality of life of various chronic conditions suggested that the experience of (urinary) incontinence is a very influential factor in overall estimation of an individual's quality of life. For example, Schultz and Kopec (2003), who investigated quality of life using the HUI3 with reference to 21 chronic conditions, found that urinary incontinence was third, after Alzheimer's disease and stroke, in its impact on quality of life. This result occurred for both persons with no other co-morbid conditions and those with at least one other chronic condition. A similar finding was found by Mittmann et al. (1999), also using the HUI3. Avery et al. (2004b), using the SF-36 (Medical Outcomes Study Short Form) assessed health-related quality of life of respondents to the 1998 SAHOS and found that people with incontinence were inclined to report significantly lower self-assessed health than people who did not have incontinence. Respondents with faecal incontinence scored lower than respondents with urinary incontinence as did those with more severe forms of incontinence.

The utility scores listed in Table 3.6, however, demonstrate the inconsistencies in utility scores generated for continence and the varying incontinence severities or incontinence types, depending on the type of utility instrument used. For example, Schultz and Kopec (2003), using the HUI3, reported a utility value for 'incontinence' (0.82) higher than the utility value for 'no incontinence' reported by O'Brien et al. (2001) (0.74). Hawthorne, in Thomas et al. (2005), cautioned against comparing results from these studies since they used varying definitions of incontinence and different population samples, and relied on different descriptive systems, assigned weights and scoring mechanisms. The authors also expressed their concern that the range of utility scores implies that scores may be more dependent on the utility instrument employed, and hence introduce flawed interpretation of results in particular studies, such as those considering the benefits of specific treatment strategies.

Table 3.6: Summary of utility scores reported for different continence status

Source	MAU instrument	Continence status	Utility score	Number
SAHOS 2002 (unpublished)	AQoL	No incontinence	0.84	2,729
		Urinary incontinence	0.71	194
		Faecal incontinence	0.58	87
Hawthorne & Harmer 1999 (unpublished)	AQoL	No incontinence	0.78	29
		Incontinence	0.67	16
O'Brien et al. 2001	EQ5D	No incontinence	0.74	6
		Mild	0.72	209
		Moderate	0.69	182
		Severe	0.61	154
Mittmann et al. 1999	HUI3	No incontinence	0.93	7,509
		Incontinence	0.82	22
Schultz & Kopec 2003	HUI3	No incontinence	0.95	71,773
		Incontinence	0.82	195
SAHOS 2002 (unpublished)	SF-36	No incontinence	0.76	2,729
		Urinary incontinence	0.71	194
		Faecal incontinence	0.63	87
Hawthorne & Harmer 1999	SF-6D	No incontinence	0.70	29
(unpublished)		Incontinence	0.67	16

Note: Partial table replicated from Table 29, Thomas et al. 2005, with kind permission from Graeme Hawthorne (July 2005).

4 Experience of incontinence: need for assistance, associated health conditions and participation

While there is considerable information on the prevalence and severity of urinary and faecal incontinence, there is less detail on the broader effects on people's lives, and on their families and carers. There is also limited information on the health conditions associated with incontinence. The analysis presented in this chapter attempts to answer some of these questions, by presenting data on:

- the need for assistance;
- use of continence aids;
- living arrangements;
- most common associated health conditions;
- participation in education, the labour force and the social setting; and
- the personal effect on primary carers.

4.1 ABS Survey of Disability, Ageing and Carers

The 2003 ABS Survey of Disability, Ageing and Carers (SDAC) is the primary data source used in this chapter, and is an important source of national population data on disability, covering both rural and urban areas in all states and territories. Data are gathered from both households and cared accommodation (hospitals, residential aged care). The ABS conducted previous surveys in 1981, 1988, 1993 and 1998.

The 2003 SDAC defines 'disability' as the presence of one or more of 17 limitations, restrictions or impairments which restrict everyday activities and has lasted or was likely to last for six months or more (Box 4.1). When a survey respondent states that they experience one or more of the 17 listed items, they are 'screened' into the full survey.

Population for analysis

Incontinence is not included as a long-term health condition in the 2003 SDAC Confidentialised Unit Record File (CURF), and so people who experience incontinence are identified from questions on need for assistance with managing bladder or bowel control and the use of continence aids. For the purposes of this chapter, a person with severe incontinence is defined here as someone who always or sometimes needs assistance with managing their bladder or bowel control and/or uses continence aids; this group is used in the majority of analyses presented below. However, there is some consideration of people who experience difficulty with bladder or bowel control but do not need assistance, for comparative purposes. Due to the structure of the relevant questions, incontinence can not be broken down into urinary or faecal incontinence.

The population defined in this chapter as experiencing severe incontinence or experiencing difficulty with bladder or bowel control are those also defined as having a disability, based on a positive response to one or more screening questions listed in Box 4.1. This group is, therefore, a subset of the overall population experiencing incontinence. Incontinence is not always or necessarily an isolated problem and is often associated with or related to other long-term health conditions. The population included in the following analyses represents such a group, and probably those experiencing more severe or chronic forms of incontinence.

Box 4.1: Areas of limitation, restriction or impairment identified by the ABS

Affirmative responses to any of the following categories, where the limitation, restriction or impairment has lasted or was likely to last for six months or more 'screen' the person into the ABS survey:

- *loss of sight, not corrected by glasses or contact lenses;*
- *loss of hearing, with difficulty communicating or use of aids;*
- *loss of speech;*
- *chronic or recurring pain that restricts everyday activities;*
- *shortness of breath or breathing difficulties that restrict everyday activities;*
- *blackouts, fits, or loss of consciousness;*
- *difficulty learning or understanding;*
- *incomplete use of arms or fingers;*
- *difficulty gripping or holding things;*
- *incomplete use of feet or legs;*
- *a nervous or emotional condition that restricts everyday activities;*
- *restriction in physical activities or physical work;*
- *disfigurement or deformity;*
- *head injury, stroke or any other brain damage with long-term effects that restrict everyday activities;*
- *needing help or supervision because of a mental illness or condition;*
- *treatment or medication for any other long-term condition or ailment and still restricted;*
- *any other long-term condition that restricts everyday activities.*

This list thus creates the implicit definition of disability for the ABS 1998 Survey of Disability, Ageing and Carers (ABS 2004a).

This chapter first provides an estimate of the Australian population with a disability experiencing 'severe' incontinence before describing the level and frequency of assistance people need to manage their bladder and bowel control, and the proportion relying on continence aids. The chapter also includes discussion on the living arrangements, associated health conditions and participation of those with severe incontinence (i.e. people with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids), and the effects on carers caring for a person experiencing incontinence.

4.2 Population with ‘severe’ incontinence

In 2003, an estimated 284,500 people with a disability (1.4% of all Australians) experienced severe incontinence, i.e. they always or sometimes needed assistance with bladder or bowel control and/or used continence aids. Within this population group, 128,300 (0.6% of all Australians) always needed assistance with bladder or bowel control, and another 101,300 (0.5% of all Australians) sometimes needed assistance. Around 320,400 people with a disability (1.6%) reported having difficulty with managing their bladder or bowel control but did not need assistance.

4.3 Assistance and the use of aids

Need for personal assistance

Of those people with a disability who always need assistance with bladder or bowel control, 45,600 (36%) lived in households and 82,600 (64%) lived in cared accommodation (Tables 4.1 and 4.2). Of people with a disability who sometimes need assistance with bladder or bowel control, 60,800 (60%) lived in households and 40,500 (40%) in cared accommodation. Almost all persons who reported experiencing difficulty with bladder or bowel control but did not need assistance lived in households (97%).

Of those people with a disability who always need assistance with their bladder or bowel control, the majority living in households were aged 0–19 years (40%) or 70–84 years (27%) (Table 4.1). The high prevalence of incontinence amongst the 0–19 year age group may in part be explained by nocturnal enuresis, or bedwetting, but it should be noted that 78% of children and youth in this age group who always needed assistance with bladder or bowel control were aged over 10 years.

Among people with a disability living in households and sometimes needing assistance with bladder or bowel control, almost a third (31% or 18,500 people) were aged 70–84 years (Table 4.1).

Among people living in cared accommodation and who always need assistance with bladder or bowel control, 50% were aged 85 years or older, and another 39% 70–84 years (Table 4.2). While the preponderance of people over 70 years in cared accommodation facilities influences this finding a comparison of need for assistance within these age groups suggests that the majority of people with disabilities who lived in cared accommodation in 2003 did experience severe incontinence. For example, 62,100 cared accommodation residents with a disability and aged 85 years and over needed some level of assistance with bladder and bowel control, compared with 18,400 who did not experience difficulty or need assistance (Table 4.2). In contrast, 10,600 people aged 85 years and over and living in households needed assistance with bladder or bowel control compared with 111,400 who did not.

Females represented 55% of people living in households who always needed assistance with bladder or bowel control, 52% of people who sometimes needed assistance and 63% of those experiencing difficulty with bladder or bowel control but did not need assistance. Excluding the 0–19 year age group, females’ need for assistance to manage bladder or bowel control was higher for age groups 50 years and older, whereas males tended to report needing assistance after the age of 70 years. Females in cared accommodation represented 73% of residents who always need assistance and 71% of residents who sometimes need assistance.

Table 4.1: People with a disability living in households, by age and level of assistance needed with bladder or bowel control, 2003

	Level of assistance needed								
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control		
	’000	%	’000	%	’000	%	’000	%	Total with a disability
Males									
0–19	10.9	53.2	9.1	31.3	*4.2	*3.7	229.1	13.4	253.3
20–49	**1.8	**8.8	*5.1	*17.5	16.1	14.0	558.0	32.7	580.9
50–69	0	0.0	*4.0	*13.8	38.8	34.0	570.0	33.4	612.8
70–84	*6.3	*30.7	9.8	33.8	50.0	43.7	303.0	17.8	369.1
85+	**1.6	**7.8	**1.0	**3.6	*5.3	*4.7	44.2	2.6	52.1
All males	*20.5*	*44.9*	*29.1*	*47.9*	*114.3*	*36.7*	*1,704.3*	*51.6*	*1,868.2*
Females									
0–19	*7.2	*28.4	*4.2	*13.3	*2.9	*1.5	157.0	9.8	171.2
20–49	**2.2	**8.7	*6.1	*19.3	39.0	19.8	487.2	30.5	534.5
50–69	*5.9	*23.6	*8.5	*27.1	69.5	35.3	533.8	33.4	617.7
70–84	*6.2	*24.5	*8.7	*27.4	64.8	32.9	354.5	22.2	434.2
85+	*3.7	*14.8	*4.3	*13.4	20.9	10.6	67.2	4.2	96.1
All females	*25.2*	*55.1*	*31.7*	*52.1*	*197.0*	*63.3*	*1,599.8*	*48.4*	*1,853.7*
Persons									
0–19	18.0	39.5	13.3	21.8	*7.1	*2.3	386.1	11.7	424.5
20–49	*3.9	*8.7	11.2	18.4	55.0	17.7	1,045.2	31.6	1,115.3
50–69	*5.9	*13.0	12.5	20.5	108.3	34.8	1,103.8	33.4	1,230.5
70–84	12.4	27.2	18.5	30.5	114.7	36.8	657.6	19.9	803.2
85+	*5.3	*11.6	*5.3	*8.7	26.2	8.4	111.4	3.4	148.2
All persons	**45.6**	**100.0**	**60.8**	**100.0**	**311.3**	**100.0**	**3,304.1**	**100.0**	**3,721.7**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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Table 4.2: People with a disability living in cared accommodation, by age and level of assistance needed with bladder or bowel control, 2003

	Level of assistance needed								
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control		
	’000	%	’000	%	’000	%	’000	%	Total with a disability
Males									
0–49	**1.8	**8.0	**1.0	**8.4	**0.4	**12.5	*2.9	*16.9	*6.1
50–69	*2.7	*11.9	**1.3	**10.9	**0.4	**12.5	*3.2	*18.6	*7.6
70–84	10.0	44.2	*5.2	*43.7	**1.4	**43.8	*5.7	*33.1	22.3
85+	*8.1	*35.8	*4.4	*37.0	**1.0	**31.3	*5.4	*31.4	18.9
All males	*22.6*	*27.4*	*11.9*	*29.5*	**3.2*	**35.6*	*17.2*	*37.6*	*54.9*
Females									
0–49	**1.2	**2.0	**0.5	**1.8	**0.2	**3.4	**1.8	**6.3	*3.7
50–69	*3.7	*6.2	**1.6	**5.6	**0.1	**1.7	**1.7	**6.0	*7.1
70–84	22.0	36.7	9.9	34.7	**1.9	**32.2	12.0	42.1	45.8
85+	33.1	55.2	16.5	57.9	*3.7	*62.7	13.0	45.6	66.3
All females	*60.0*	*72.6*	*28.5*	*70.5*	**5.9*	**65.6*	*28.5*	*62.4*	*122.9*
Persons									
0–49	*3.0	*3.6	**1.5	**3.7	**0.6	**6.7	*4.7	*10.3	9.8
50–69	*6.4	*7.7	*2.9	*7.2	**0.5	**5.6	*4.9	*10.7	14.7
70–84	32.0	38.7	15.1	37.4	*3.3	*36.7	17.7	38.7	68.1
85+	41.2	50.0	20.9	51.7	*4.7	*52.2	18.4	40.3	85.2
All persons	**82.6**	**100.0**	**40.5**	**100.0**	**9.1**	**100.0**	**45.7**	**100.0**	**177.8**

Notes

1. Younger age groups have been combined due to very small cell sizes.
2. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Frequency of need for assistance

Table 4.3 assesses the frequency of need for assistance with self-care for persons who always or sometimes need assistance with their incontinence. Due to the structure of the SDAC it was not possible to assess the need for assistance specifically with the management of bladder or bowel control.

For people with a disability who always or sometimes need assistance to manage bladder or bowel control, 60% living in cared accommodation and 19% living in households required assistance six or more times a day. Overall, 96% of people living in cared accommodation needed assistance at least one to two times a day; 52% living in households reported a similar frequency of need for assistance.

Table 4.3: People with a disability who need assistance to manage their bladder or bowel control, by frequency of need for assistance with self-care and residential status, 2003

	Cared accommodation		Households		Total	
Frequency of need for assistance	**’000**	**%**	**’000**	**%**	**’000**	**%**
6+ times a day	75.9	59.9	29.4	18.6	105.3	42.4
3–5 times a day	30.7	24.2	29.0	18.4	59.7	24.1
1–2 times a day	15.1	11.9	24.1	15.3	39.2	15.8
1–6 times a week	**2.3	**1.8	13.7	8.7	16.0	6.4
Less than once a week	**1.2	**0.9	25.4	16.1	9.3	3.7
Not known	**1.3	**1.0	—	—	**1.3	**0.5
Total[(a)]	**126.7**		**157.7**		**284.4**	

(a) Total includes respondents who have no difficulty with self-care and respondents who have difficulty with self-care but do not need assistance. Percentages therefore do not add up to 100%.

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Informal versus formal assistance

Around 55% of people with a disability who need assistance to manage bladder or bowel control and live in households relied on informal self-care assistance, and another 22% used a mixture of informal and formal self-care assistance (Table 4.4). Only 7% of people who needed assistance with managing bladder or bowel control received formal assistance only for self-care activities. Of note is the 16% of people who needed assistance with bladder or bowel control who reported not receiving any self-care assistance from either formal or informal sources.

This picture is somewhat different to that reported by persons with a profound or severe core activity limitation[7] living in households. Almost 80% of this group reported that their self-care needs were met by formal assistance and 8% by a combination of informal and formal sources (AIHW 2005a). No self-care assistance was received by 10% of persons with a profound or severe core activity restriction.

Table 4.4: People with a disability who need assistance to manage their bladder or bowel control, by type of assistance received with self-care, 2003

	Type of assistance received				
	Receives formal assistance only	**Receives informal assistance only**	**Receives formal and informal assistance**	**Receives no assistance**	**Total[(a)]**
’000	*8.7	66.8	26.7	19.3	**121.6**
Per cent	*7.2	55.0	22.0	15.9	**100.0**

(a) Total does not include people who have no difficulty with self-care or people who have difficulty with self-care but do not need assistance.

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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[7] A person with a profound or severe core activity limitation requires assistance in at least one of three core activities—self-care, mobility or communication.

Need for assistance with toileting

The association between assistance with toileting[8] and assistance with managing bladder and bowel control is presented in Table 4.5. For people with a disability living in households and who always need assistance with toileting, 57% always needed assistance with managing their bladder and bowel control and 8% sometimes needed assistance with bladder or bowel control. However, 33% of this group reported not having any difficulty with bladder or bowel control, suggesting a need for assistance with toileting is not necessarily associated with a need for assistance with bladder or bowel control. A similar pattern is found for people with a disability living in households who sometimes need assistance with toileting— 25% reported sometimes needing assistance with bladder or bowel control and 57% reported not having any difficulty at all.

Table 4.5: People with a disability and need for assistance with toileting, by need for assistance with bladder or bowel control and residential status, 2003

	Assistance with toileting									
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty		Does not use a toilet(a)	
	’000	%	’000	%	’000	%	’000	%	’000	%
Assistance with managing bladder and bowel control										
					Households					
Always needs assistance	31.1	57.1	**2.1	**3.8	**1.7	**1.9	10.7	0.3	—	—
Sometimes needs assistance	*4.6	*8.3	13.4	24.9	*6.4	*7.1	36.4	1.0	—	—
Does not need assistance but has difficulty	**0.8	**1.4	*7.8	*14.6	22.7	25.0	279.4	7.9	**0.6	**11.3
Has no difficulty	18.1	33.2	30.5	56.7	60.2	66.1	3,190.4	90.7	*4.8	*88.7
Total	**54.6**	**100.0**	**53.8**	**100.0**	**91.1**	**100.0**	**3,516.9**	**100.0**	**5.4**	**100.0**
					Cared accommodation					
Always needs assistance	71.4	81.7	*5.9	*17.3	**1.2	**10.1	**1.6	**4.1	*2.5	*42.5
Sometimes needs assistance	11.9	13.6	19.9	58.2	*3.5	*30.3	*5.0	*13.0	**0.1	**1.7
Has difficulty but does not need assistance	**1.3	**1.5	*2.5	*7.2	*2.5	*21.5	*2.7	*7.0	**0.1	**1.9
Has no difficulty	*2.8	*3.2	*5.9	*17.3	*4.4	*38.1	29.3	75.9	*3.2	*53.9
Total	**87.5**	**100.0**	**34.2**	**100.0**	**11.7**	**100.0**	**38.6**	**100.0**	***5.9**	***100.0**

(a) Does not use a toilet includes people using attached aids such as colostomy bags, catheters, etc. and who have no control over their bladder or bowel (i.e. rely totally on continence aids).

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

An association between assistance and toileting is much more pronounced for people living in cared accommodation, especially for those who always need assistance with toileting, where 82% of these people also indicated always needing assistance with bladder or bowel

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[8] A need for assistance with toileting refers to any difficulty associated with using a toilet.

control. For those in cared accommodation who sometimes need assistance with toileting, 58% reported sometimes needing assistance with bladder or bowel control, 17% always needing assistance and 17% not having any difficulty with bladder or bowel control.

Use of aids

A total of 83,800 people with a disability aged 10 years and over and living in households reported using continence aids; 64% were female (Table 4.6). Around 100,700 people with a disability living in cared accommodation also used continence aids (Table 4.7). Again, females were the more common users of continence aids, representing 74% of all continence aid users living in cared accommodation.

Table 4.6: People aged 10 years and over with a disability living in households, by sex, age and use of continence aids, 2003

	Uses continence aids		Does not use continence aids but uses other aids		Does not use aids		Total	
	’000	**%**	**’000**	**%**	**’000**	**%**	**’000**	**%**
Males								
10–19	*3.0	*2.0	44.8	30.1	101.0	67.9	148.8	100.0
20–49	*4.6	*0.8	196.6	33.8	379.7	65.4	580.9	100.0
50–69	*3.2	*0.5	251.5	41.0	358.1	58.4	612.8	100.0
70–84	15.6	4.2	224.6	60.9	128.8	34.9	369.0	100.0
85+	*3.5	*6.7	41.2	79.1	*7.4	*14.2	52.1	100.0
Females								
10–19	**2.0	**1.8	34.9	13.7	72.8	66.4	109.7	100.0
20–49	*6.9	*1.3	191.8	57.1	335.8	62.8	534.5	100.0
50–69	14.7	2.4	277.6	44.9	325.4	52.7	617.7	100.0
70–84	19.1	4.4	252.8	58.2	162.2	37.4	434.1	100.0
85+	11.2	11.7	72.9	75.9	12.0	12.5	96.1	100.0
Persons								
10–19	*5.0	*1.9	79.7	30.8	173.8	67.2	258.5	100.0
20–49	11.5	0.1	388.4	34.8	715.5	64.1	1,115.4	100.0
50–69	17.9	1.5	529.1	43.0	683.5	55.5	1,230.5	100.0
70–84	34.7	4.3	477.4	59.4	291.0	36.2	803.1	100.0
85+	14.7	9.9	114.1	77.0	19.4	13.1	148.2	100.0
Males	*29.9*	*35.7*	*758.7*	*47.8*	*975.0*	*51.8*	. .	. .
Females	*53.9*	*64.3*	*830.0*	*53.2*	*908.2*	*48.2*	. .	. .
Persons	**83.8**	**100.0**	**1,588.7**	**100.0**	**1,883.2**	**100.0**	. .	. .

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Around 10% of people with a disability aged 85 years and older living in households used continence aids, as did 4% of people aged 70–84 years (Table 4.6). The proportion of similarly aged persons living in cared accommodation using continence aids was considerably higher—58% of persons aged 85 years and older and 55% of persons aged 70–84 years (Table 4.7). This marked difference in continence aid use between household and cared accommodation living persons also occurred for younger persons. The predominance of continence aid use amongst persons living in cared accommodation compared with those living in households may relate to a number of factors, including severity of the incontinence experience and accessibility of aids.

Table 4.7: People aged 10 years and over with a disability living in cared accommodation, by sex, age and use of continence aids, 2003

	Uses continence aids		Does not use continence aids but uses other aids		Does not use aids		Total	
	'000	%	'000	%	'000	%	'000	%
Males								
10–49	**1.8	**28.3	**1.8	**28.7	*2.7	*43.0	*6.2	100.0
50–69	*3.2	*41.4	*2.7	*34.3	**1.9	**24.3	*7.8	100.0
70–84	11.5	50.5	*9.1	*39.7	**2.2	**9.8	22.8	100.0
85+	10.2	52.8	*7.9	*40.8	**1.2	**6.3	19.4	100.0
Females								
10–49	**1.3	**33.2	**1.2	**31.5	**1.4	**35.2	*3.9	100.0
50–69	*4.2	*57.4	**1.9	**26.1	**1.2	**16.5	*7.3	100.0
70–84	26.8	56.8	15.8	33.5	*4.6	*9.7	47.1	100.0
85+	41.7	61.5	22.9	33.8	*3.2	*4.8	67.8	100.0
Persons								
10–49	*3.1	*30.2	*3.0	*29.8	*4.0	*40.0	10.1	100.0
50–69	*7.4	*49.2	*4.6	*30.3	*3.1	*20.5	15.1	100.0
70–84	38.3	54.8	24.8	35.5	*6.8	*9.7	69.9	100.0
85+	51.9	58.1	30.8	34.5	*4.5	*5.0	89.3	100.0
Males	*26.7*	*26.5*	*21.5*	*34.0*	*8.1*	*43.8*	. .	. .
Females	*74.0*	*73.5*	*41.8*	*66.0*	*10.4*	*56.2*	. .	. .
Persons	**100.7**	**100.0**	**63.3**	**100.0**	**18.5**	**100.0**	. .	. .

Notes

1. Younger age groups have been combined due to very small cell sizes.
2. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The need for assistance combined with aid use may denote more severe incontinence. Table 4.8 shows the level of assistance needed by people who use continence aids.

Half of all persons with a disability and using continence aids always needed assistance with managing bladder or bowel control and around a fifth (21%) sometimes needed assistance. An estimated 22% of continence aid users did not need any assistance but experienced

Table 4.8: People aged 10 years and over with a disability and using continence aids, by level of assistance needed to manage bladder and bowel control, by sex, 2003

	Level of assistance needed with bladder and bowel control								
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control		Total using continence aids
	’000	%	’000	%	’000	%	’000	%	’000
Males	29.6	51.1	14.9	25.8	*8.1	*13.9	*5.3	*9.1	57.9
Females	64.0	49.6	23.4	18.2	32.5	25.2	*9.0	*7.0	129.0
Persons	**93.6**	**50.2**	**38.4**	**20.5**	**40.6**	**21.7**	**14.3**	**7.7**	**186.8**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

difficulty. Males who used aids were much more likely to report sometimes needing assistance with managing bladder or bowel control (26%) compared to 18% of females who used aids, while females who used aids were much more likely to report having difficulty but not needing assistance with managing bladder or bowel control (25%) compared to males (14%).

4.4 Living arrangements

The living arrangements of people with severe incontinence are presented in Table 4.9.

In 2003, an estimated 126,800 people with severe incontinence lived in cared accommodation, and 157,700 lived in households. For people aged under 70 years, the majority with severe incontinence lived in households, and for those aged 85 years and over, the majority lived in cared accommodation. There were slightly more people with severe incontinence aged 70–84 years living in households than cared accommodation (51,200 compared to 48,700).

Males aged 85 years and over with severe incontinence were much more likely to live in cared accommodation (12,800 males) than households (5,000). There were more females with severe incontinence living in cared accommodation at younger ages, with 33,400 females living in cared accommodation and 28,300 living in households. The difference for females with severe incontinence and aged 85 years and over is even greater—51,000 lived in cared accommodation in 2003 and 15,500 lived in households.

The data presented in Table 4.9 confirm the age and sex association with incontinence discussed in Chapter 3. Seventy-nine per cent (226,000) of Australians in 2003 who reported having a disability and severe incontinence were aged over 50 years; 65% or 184,200 were aged 70 years or older. People with a disability reporting severe incontinence were also much more likely to be female (187,000 or 66%) than male (97,500 or 33%). This sex difference was apparent for all age groups presented in Table 4.9, except the youngest (0–19 years), which might be influenced by the higher prevalence of intellectual and similar disabilities amongst boys in this age group (AIHW 2004a), and its association with need for assistance with bladder or bowel control and/or use of continence aids (unpublished analysis of 2003 SDAC CURF).

Table 4.9: People with severe incontinence[(a)]: age and sex by residential status, 2003 ('000)

	Cared accommodation	Households[(b)]	Total
Males			
0–19	**0.2	20.6	20.8
20–49	*2.8	*8.4	11.2
50–69	*4.0	*5.5	9.5
70–84	15.3	22.9	38.2
85+	12.8	*5.0	17.8
All males	*35.1*	*62.4*	*97.5*
Females			
0–19	**0.1	11.3	11.4
20–49	**1.8	13.3	15.1
50–69	*5.4	26.9	32.3
70–84	33.4	28.3	61.7
85+	51.0	15.5	66.5
All females	*91.7*	*95.3*	*187.0*
Persons			
0–19	**0.3	31.9	32.2
20–49	*4.6	21.7	26.3
50–69	9.4	32.4	41.8
70–84	48.7	51.2	99.9
85+	63.8	20.5	84.3
All persons	**126.8**	**157.7**	**284.5**

(a) Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

(b) Households include private and non-private dwellings, where non-private dwellings include hostels, hotels, motels, educational and religious institutions, guest houses, caravan parks, and self-care units in retirement villages which may have cared accommodation on-site.

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.5 Associated health conditions

Tables 4.10 and 4.11 list the most common health conditions, reported as 'main disabling condition', associated with severe incontinence, for people living in households and cared accommodation respectively. Due to small cell sizes, health conditions have been clustered in most instances into health condition groupings based on ICD–10 chapter headings. Arthritis and related disorders and stroke are identified separately in Table 4.10, and dementia (including Alzheimer's disease), stroke and arthritis and related disorders are identified separately in Table 4.11.

For people living in households, arthritis and related disorders was the most common associated health condition—22,300 or 14% of people with a disability and severe incontinence also reported having arthritis and related disorders (Table 4.10). The next most common group of conditions were musculoskeletal conditions, in particular back problems (20,400 people or 13%), followed by neurological conditions (16,200 people or 10.2%) and mental and behavioural disorders (psychiatric) (15,900 people or 10.2%) (see notes in Table 4.10 for related health conditions). These four health condition groups were also most commonly associated with severe incontinence amongst females, although mental and behavioural disorders (psychiatric) were slightly more common (11%) than neurological conditions (9%). The pattern, however, for males was quite different—mental and behavioural disorders (other) was the most commonly associated group of health conditions (13%), followed by neurological conditions (13%). The relatively high proportion of young males (i.e. under 15 years) with severe incontinence reporting intellectual and developmental disorders, autism or ADHD as their main disabling condition has likely influenced the association between severe incontinence and mental and behavioural disorders (other).

A somewhat different picture emerges when considering people living in cared accommodation (Table 4.11). Dementia (including Alzheimer's disease) was by far the most common condition associated with severe incontinence—46,000 or 36% of people living in cared accommodation had either dementia or Alzheimer's disease and incontinence. Stroke (11%) and arthritis and related disorders (9%) were also commonly associated health conditions.

The two most common health conditions associated with incontinence amongst males with a disability in cared accommodation were dementia (including Alzheimer's disease) (30%) and stroke (16%). Around 39% of women in cared accommodation who experienced incontinence also had dementia (including Alzheimer's disease), 10% experienced arthritis and related disorders, and 9% had had a stroke.

Table 4.10: People with a disability living in households with severe incontinence[(a)]: ten most common associated health conditions, by sex, 2003

	Males		Females		Persons	
Health condition	**’000**	**%**	**’000**	**%**	**’000**	**%**
Arthritis and related disorders	*2.9	*4.7	19.4	20.4	22.3	14.2
Musculoskeletal	*7.6	*12.2	12.8	13.4	20.4	12.9
Neurological	*8.0	*12.8	*8.2	*8.6	16.2	10.2
Mental and behavioural disorders (psychiatric)	*7.4	*11.9	10.8	11.3	15.9	10.2
Mental and behavioural disorders (intellectual/learning)	*8.2	*13.3	*3.2	*3.3	11.5	7.3
Stroke	*4.4	*7.1	*4.2	*4.4	*8.6	*5.5
Respiratory	**2.4	**3.9	*5.0	*5.2	*7.4	*4.7
Injury	*3.0	*4.8	*4.3	*4.5	*7.3	*4.6
Neoplasms	*3.5	*5.7	*3.5	*3.7	*7.1	*4.5
Circulatory (excluding stroke)	**2.3	**3.7	*4.1	*4.3	*6.4	*4.1
All other conditions	12.5	20.0	19.9	20.9	32.4	20.5
Total	**62.4**	**100.0**	**95.3**	**100.0**	**157.7**	**100.0**

(a) Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

Notes

1. ‘Musculoskeletal’ includes back problems (dorsopathies), osteoporosis, other soft tissue/muscle disorders (including rheumatism), repetitive strain injury/occupational overuse syndrome and other diseases of the musculoskeletal system and connective tissue (ICD Chapter 10).
2. ‘Neurological’ includes Parkinson’s disease, epilepsy, multiple sclerosis, cerebral palsy, migraine, paralysis, chronic/postviral fatigue syndrome and other diseases of the nervous system (ICD Chapter 6).
3. ‘Mental and behavioural disorders (psychiatric)’ includes depression/mood affective disorders, nervous tension/stress, schizophrenia, phobic and anxiety disorders, mental and behavioural disorders nfd and other mental and behavioural disorders (ICD Chapter 5).
4. ‘Mental and behavioural disorders (intellectual/learning)’ includes intellectual and developmental disorders, mental retardation/intellectual disability, autism, and attention deficit disorder/hyperactivity (ICD Chapter 5).
5. ‘Respiratory’ includes asthma, emphysema, and other diseases of the respiratory system (ICD Chapter 10).
6. ‘Injury’ includes head injury/acquired brain damage, leg/knee/foot/hip damage from injury/accident, complications/consequences of surgery and medical care nec, and other injury and poisoning and certain other consequences of external causes (ICD Chapter 19).
7. ‘Neoplasms’ includes prostate cancer and other neoplasms (tumours/cancers) (ICD Chapter 2).
8. ‘Circulatory (excluding stroke)’ includes heart disease, angina, hypertension, other diseases of the circulatory system and other heart diseases (ICD Chapter 9).
9. ‘All other conditions’ includes dementia, Alzheimer’s disease, diabetes, diseases of the genitourinary system (kidney and urinary system (bladder) disorders (except incontinence), other diseases of the genitourinary system), diseases of the digestive system (enteritis and colitis, other diseases of the intestine, abdominal hernia, and diseases of the digestive system), sensory/speech (glaucoma, sight loss, other diseases of the eye and adnexa, diseases of the inner ear, deafness/hearing loss, and speech impediment), certain infectious and parasitic diseases, diseases of the blood and blood-forming organs and certain disorders involving the immune system, other endocrine/nutritional and metabolic disorders, congenital malformations, deformations and chromosomal abnormalities, breathing difficulties/shortness of breath, other symptoms/signs and abnormal clinical and laboratory findings nec, restriction in physical activity or physical work, and other 2003 codes which have no ICD-10 equivalent (all other ICD chapters).
10. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 4.11: People with a disability living in cared accommodation with severe incontinence[(a)]: ten most common associated health conditions, by sex, 2003

	Males		Females		Persons	
Health condition	**’000**	**%**	**’000**	**%**	**’000**	**%**
Dementia (including Alzheimer’s disease)	10.5	30.0	35.5	38.8	46.0	36.3
Stroke	*5.6	*15.9	*8.5	*9.3	14.1	11.1
Arthritis and related disorders	**1.5	**4.3	9.5	10.4	11.1	8.7
Neurological	*4.9	*14.0	*5.8	*6.3	10.7	8.5
Mental and behavioural disorders (psychiatric)	*2.9	*8.3	*7.6	*8.4	*10.6	*8.3
Circulatory (excluding stroke)	**1.5	**4.2	*4.4	*4.8	*5.8	*4.6
Musculoskeletal	**0.1	**1.6	*3.6	*3.9	*4.1	*3.2
Sensory/speech	**0.1	**2.6	*2.8	*3.1	*3.7	*3.0
Respiratory	**1.2	**3.3	**2.2	**2.4	*3.4	*2.7
Injury	**1.1	**2.9	**1.5	**1.6	*2.5	*2.0
All other conditions	*3.3	*9.4	*8.0	*8.7	11.3	8.9
Total	**35.1**	**100.0**	**91.7**	**100.0**	**126.7**	**100.0**

(a) Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

Notes

1. ‘Neurological’ includes Parkinson’s disease, epilepsy, multiple sclerosis, cerebral palsy, migraine, paralysis, and other diseases of the nervous system (ICD Chapter 6).
2. ‘Mental and behavioural disorders (psychiatric)’ includes depression/mood affective disorders, schizophrenia, phobic and anxiety disorders, nervous tension/stress, mental and behavioural disorders nfd, and other mental and behavioural disorders (ICD Chapter 5).
3. ‘Circulatory (excluding stroke)’ includes heart disease, angina, hypertension, other diseases of the circulatory system and other heart diseases (ICD Chapter 9).
4. ‘Musculoskeletal’ includes back problems (dorsopathies), osteoporosis, other soft tissue/muscle disorders (including rheumatism), and other diseases of the musculoskeletal system and connective tissue (ICD Chapter 13).
5. ‘Sensory/speech’ includes glaucoma, sight loss, other diseases of the eye and adnexa, diseases of the inner ear, deafness/hearing loss, tinnitus, other diseases of the ear and mastoid process and unspecified speech difficulties (ICD Chapters 5, 7 and 8).
6. ‘Respiratory’ includes asthma, emphysema, respiratory allergies, bronchitis/bronchiolitis and other diseases of the respiratory system.
7. ‘Injury’ includes head injury/acquired brain damage, leg/knee/foot/hip damage from injury/accident, arm/hand/shoulder damage from injury/accident, complications/consequences of surgery and medical care nec, and other injury and poisoning and certain other consequences of external causes (ICD Chapter 19).
8. ‘All other conditions’ includes diabetes, neoplasms (prostate cancer and other neoplasms (tumours/cancers)), diseases of the genitourinary system (kidney and urinary system (bladder) disorders (except incontinence), other diseases of the genitourinary system), diseases of the digestive system (enteritis and colitis, other diseases of the intestine, and diseases of the digestive system), certain infectious and parasitic diseases, diseases of the blood and blood-forming organs and certain disorders involving the immune system, other endocrine/nutritional and metabolic disorders, congenital malformations, deformations and chromosomal abnormalities, restriction in physical activity or physical work, breathing difficulties/shortness of breath, pain nfd, skin allergies (dermatitis and eczema), other diseases of the skin and subcutaneous tissue, other symptoms/signs and abnormal clinical and laboratory findings nec, and other 2003 codes which have no ICD-10 equivalent (all other ICD chapters).
9. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.6 Participation

The effect of incontinence on a person’s lifestyle varies from individual to individual, depending to some extent on the severity of the incontinence, the type of incontinence experienced, the support received to manage incontinence, and how people feel about their symptoms.

Participation is discussed here within three participatory spheres—education, the labour force, and the social setting.

Education

In 2003, 24,400 children and youth aged 5–20 years with severe incontinence attended school, representing 93% of such children (Table 4.12) and 17% of all children with a disability at school. While their participation was proportionally higher than other children with a disability (87%), this result may be somewhat misleading given the number of continent children who did not attend school either because they were too young or who had already completed their schooling.

Almost half (49%) of the children with severe incontinence were educated in special schools, compared with 14% of other children with a disability. Children with a disability who did not need assistance or use aids for their incontinence were much more likely to attend an ordinary school (48% compared to 24%).

Table 4.12: Participation of people with a disability aged 5–20 years in education, by incontinence status, 2003

	Needs assistance with bladder or bowel control and/or uses continence aids		**Does not need assistance with bladder or bowel control and does not use continence aids**	
Type of school	**’000**	**%**	**’000**	**%**
Ordinary school	*6.1	*23.5	68.2	48.0
Special class	*5.5	*21.1	35.1	24.7
Special school	12.7	48.8	19.7	13.9
Total attending school	**24.4**	**93.4**	**123.1**	**86.5**
Not attending school (because of disability)	**1.2	**4.5	*4.1	*2.9
Not attending school (too young)			**2.5	**1.7
Not attending school (finished school)	**0.5	**2.1	12.6	8.8
Total not attending school	***1.7*	***6.6*	*19.2*	*13.5*
Persons	26.1	100.0	142.3	100.0

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Labour force participation

Labour force participation is presented in Table 4.13 for people who always need assistance with bladder or bowel control, who sometimes need assistance, and those who experience difficulty with bladder or bowel control but do not need assistance.

The labour force participation of people aged 15–64 years, with a disability and with more severe incontinence (i.e. always needing assistance) was very low in 2003, with a participation rate of 5.2% (Table 4.13). The participation rate of people who sometimes need assistance with managing their incontinence and/or used continence aids was much higher (37%), and comparable with persons who had difficulty managing their incontinence but did not need assistance (40%).

Table 4.13: Labour force participation of people aged 15–64 and 65+ years with a disability, by need for assistance or use of continence aids to manage bladder or bowel control, 2003 ('000)

	Always needs assistance and/or uses continence aids		Sometimes needs assistance and/or uses continence aids		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control	
	15–64	**65+**	**15–64**	**65+**	**15–64**	**65+**	**15–64**	**65+**
Employed	—	—	*7.8	**0.8	50.8	*7.7	997.9	54.3
Unemployed	**0.6	—	**0.8	—	*5.0	—	92.2	—
Not in labour force	10.9	19.1	14.6	*8.6	84.5	158.2	922.7	961.0
Total in labour force	**0.6**	**—**	**8.6**	****0.8**	**55.7**	***7.7**	**1,090.1**	**54.3**
Total	*11.5*	*19.1*	*23.2*	*25.8*	*140.0*	*165.9*	*2,012.8*	*1,015.3*
Unemployment rate	100.0	—	9.2	—	8.9	—	8.5	—
Participation rate	5.2	0.0	37.1	3.1	39.7	4.6	54.2	5.3

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Unemployment rates were the same (9%) for people sometimes needing assistance or not needing assistance but experiencing difficulty.[9]

Labour force participation rates were highest (54%) for people with a disability who had no difficulty with bladder or bowel control, but their unemployment rate was the same at 9%.

The labour force participation of people aged 65 years and over with a disability and either sometimes needing assistance with bladder or bowel control or having difficulty with bladder or bowel control were similar, at 3.1 and 4.6 respectively. For people in the same age group and reporting not having a difficulty with bladder or bowel control, the labour force participation rate was only slightly higher, at 5.3.

Social participation

Table 4.14 compares how often people aged 15 years and over with a disability, and who always or sometimes needs assistance with bladder or bowel control, are able to go out. Male and female differences were quite marked.

Males who felt they could go out as often as they liked were less likely to be using aids (44%) than were females (61%). Whether this indicates differential availability of assistance (as an alternative), differential take-up of aids, or convenience of aids for males can only be speculated about. Males and females who reported not being able to go out as often as they would like were equally likely to use continence aids (66% and 65% respectively).

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[9] The participation rate for people with a disability in 2003 was 53%, and 15% and 36% respectively for people with a profound and severe disability respectively (AIHW 2005a), and the unemployment rate was 9% (AIHW 2005a).

Table 4.14: Social participation of people aged 15 years and over, with a disability and who need assistance with bladder or bowel control, by use of continence aids, 2003

	Can go out as often as would like		Cannot go out as often as would like		Does not leave home at all		Total
	'000	**%**	**'000**	**%**	**'000**	**%**	**'000**
Males							
Uses aids	11.9	43.7	12.8	66.0	*2.5	*100.0	27.3
Doesn't use aids	10.9	62.4	6.7	34.0	0	0.0	17.5
All males	*22.9*	*100.0*	*19.4*	*100.0*	**2.5*	**100.0*	*44.8*
Females							
Uses aids	24.2	60.5	27.9	64.9	**0.5	**22.2	52.6
Doesn't use aids	15.8	39.5	15.1	35.1	**1.9	**77.8	32.8
All females	*40.0*	*100.0*	*42.9*	*100.0*	***2.4*	***100.0*	*85.3*
Persons							
Uses aids	36.1	57.5	40.7	65.2	*3.1	*61.9	79.8
Doesn't use aids	26.7	42.5	21.7	34.8	**1.9	**38.1	50.3
All persons	**62.8**	**100.0**	**62.3**	**100.0**	***5.0**	**100.0**	**130.1**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.7 Carers

In 2003, there were 56,354 primary carers, or 12% of all primary carers, who usually assisted with managing another person's incontinence (Table 4.15). Of these carers, 32% were a spouse or partner, 31% a father or mother and 30% a son or daughter.

Table 4.15: Relationship of primary carer to person requiring assistance with incontinence, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	'000	**%**	**'000**	**%**
Spouse/partner	18.3	32.4	177.3	42.6
Father or mother	17.6	31.2	92.9	22.3
Son or daughter	16.7	29.7	105.1	25.3
Other relative, friend or neighbour	*3.8	*6.7	40.8	9.8
Total	**56.4**	**100.0**	**416.1**	**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Primary carers who usually assist with managing incontinence reported spending a considerable number of hours per week in their caring role—59% spent 40 hours or more a week actively caring or supervising and another 22% spent between 20 and 40 hours a week (Table 4.16). Among primary carers who did not usually assist with managing incontinence, 41% spent less than 20 hours a week actively caring and 34% 40 hours or more.

Table 4.16: Number of hours per week primary carer spends actively caring or supervising, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	’000	**%**	**’000**	**%**
Less than 20 hours	*6.9	*11.9	170.7	41.0
20 to less than 40 hours	12.1	21.5	74.5	17.9
40 hours or more	33.1	58.8	141.1	33.9
Not stated	*4.3	*7.6	29.9	7.2
Total	**56.4**	**100.0**	**416.1**	**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

For primary carers who assist people with more severe forms of incontinence, the effect of this type of care on the carer can be especially demanding. Table 4.17 compares the general wellbeing of primary carers who usually assist with managing another's incontinence, and primary carers who do not, and finds evidence for a negative effect on wellbeing in the former group. For example, 44% of carers who usually assist with managing another person’s incontinence reported a change in their physical or emotional wellbeing since taking on the caring role, compared to 27% of carers who do not assist in managing another’s incontinence.

Table 4.17: Physical and emotional wellbeing of primary carers who usually and do not usually assist with managing incontinence, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	’000	**%**	**’000**	**%**
Physical or emotional wellbeing				
Has changed due to caring role	24.9	44.3	111.6	26.8
Has not changed due to caring role	27.0	47.8	275.4	66.2
Not stated	*4.5	*7.9	29.1	7.0
Weariness and lack of energy				
Feels weary or lacks energy due to caring role	24.6	43.7	134.6	32.3
Does not feel weary or lack energy due to caring role	27.3	48.4	252.5	60.7
Not stated	*4.5	*7.9	29.1	7.0
Worry and depression				
Frequently feels worried or depressed due to caring role	25.2	44.7	112.6	27.1
Does not frequently feel worried or depressed due to caring role	26.7	47.4	274.4	65.9
Not stated	*4.5	*7.9	29.1	7.0
Total	**56.4**	**100.0**		**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Around 44% of primary carers who usually assisted with managing another’s incontinence also reported feeling weary or lacked energy due to their caring role, and 45% frequently felt worried or depressed (Table 4.17). A lower percentage of primary carers who did not usually assist with managing incontinence reported similar feelings, 32% and 27% respectively. It is important to note that this pattern may be an indication of the co-morbidities experienced by the person being cared for, rather than just the incontinence itself.

5 Expenditures for incontinence

5.1 An estimate of incontinence expenditure

The costs of incontinence are large and the impacts are both monetary and non-monetary. This chapter focuses on health system and residential aged care expenditures and expenditures on continence aids. There are a wide range of other personal costs such as laundry, clothing and time costs which have not been captured.

There have been limited studies of the costs of incontinence in Australia. One study estimated the costs of urinary incontinence for women in the community to be $710 million in 1998—$339 million on treatment costs and $372 million on personal costs (Doran et al. 2001). Moore et al. (2005) present much useful data on the costs of incontinence in various settings, but do not attempt to make an overall estimate of the costs of incontinence.

The present study estimates that the monetary costs of urinary and faecal incontinence in Australia in 2003 totalled $1.5 billion. The costs in various areas of the health and residential aged care sector are detailed in Table 5.1.

Table 5.1: Health and residential aged care expenditures for incontinence, 2003

Area of expenditure	Expenditure
Residential aged care	$1,268 million (assistance with bladder/bowel control and toileting)
Admitted patient services in hospitals	$89.8 million
Non admitted patient services in hospitals	Unknown
Unreferred (GP) services	$5.9 million
Pathology & imaging	$4.3 million
Specialist medical services	$3.8 million
Pharmaceuticals requiring a prescription	$12.2 million
Over-the-counter medication	Unknown(a)
Other health professionals	Unknown(a)
Other health services	$4.2 million
Continence aids	$111.7 million (urinary incontinence only)
Total	**$1,500 million**

(a) Future analysis of the SAHOS may enable an estimation of these costs.

Note: Expenditures listed above are total expenditures whether funded by government or by individuals, except for residential aged care where only government subsidies are included, as contributions by residents are considered to be covering non-health and welfare costs such as food and accommodation and so government subsidies are considered to be covering all of the health and welfare costs of incontinence.

5.2 Residential aged care

The vast majority of monetary costs imposed by incontinence are for residential aged care. It is a large proportion of expenditure because many of the people with severe incontinence are in residential aged care, and because caring for people with severe incontinence is very time intensive. In residential aged care this time must be paid for, whereas at home there is no payment from the health and aged care budget for the time carers must spend in assisting people with incontinence. (Some carers receive Carer Payments which can be considered to be part-compensation for the care they provide, but there is no valid method for estimating what portion of Carer Payments could be considered to be for incontinence care).

The estimates of expenditure on incontinence in residential aged care are derived from the aged care database using the answers to questions 5, 6 and 7 on the resident classification scale (RCS) questionnaire. The population used for this work are residents who had valid RCS assessments for a period including 30 June 2003. This population was assumed to be representative of the population in residential aged care for the whole 12 months of 2003.

The cost of incontinence in residential aged care has been calculated by first calculating the current level of basic subsidy funding for residential aged care. This includes the current cost of assisting residents with incontinence. Second, the level of basic subsidy funding for residential aged care that would be paid if the residents did not have incontinence is calculated. The difference between the two numbers is the cost due to incontinence.

The level of funding for each client is determined by the RCS. Each resident is classified according to the answers given to the RCS questionnaire. Each answer has a different weight applied and the sum of these weights gives an overall score for the resident. In order to calculate the impact of incontinence the answers recorded on the questionnaire for the toileting, bladder management and bowel management questions have been recoded to give a weight of 0 to these questions. This has the effect of reducing the RCS score for the patient. A new RCS classification was then calculated for each resident and the difference in the level of funding between the new RCS classification and the old was calculated. This difference is the estimate of the cost of incontinence in the residential aged care sector.

This estimated cost (see Table 5.2) is the cost to the Australian Government of incontinence and toileting problems in residential aged care, because the $1.3 billion is the amount by which Australian Government subsidies to aged care homes would be reduced if none of the residents had incontinence or toileting problems. But it is not necessarily the actual cost to aged care homes of incontinence and toileting problems. Whether this is so depends on whether the funding formulas on which the payments are based accurately represent the costs incurred by aged care homes. The funding formulas were based on costing studies done some years ago, and it is possible that the funding formulas now over or perhaps under represent actual costs. There is some evidence, for example, that for bowel management, the current formulas overestimate the actual costs to aged care homes of that problem.

This subsidy of $1.3 billion is 32% of the total basic residential aged care subsidy of $4.0 billion and about 30% of total Australian Government subsidies for residential aged care facilities.

A significant proportion of the costs above are due to assistance with toileting. Is this need for toileting assistance due to incontinence? There is a very large association between the two variables. In residential aged care almost all of those who need major or extensive support with bladder and/or bowel control also need assistance with toileting. The patterns of expenditure for bowel and bladder management and assistance with toileting are very similar, with just under three-quarters of all expenditure attributed to females and one-quarter to males.

Table 5.2: Basic subsidy funding to residential aged care facilities that can be attributed to toileting, bladder management and bowel management, 2003 ($ million)

Type of assistance	Cost
Bladder management only	$184.971
Bowel management only	$351.504
Both bladder and bowel management[(a)]	$528..480
Assistance with toileting	$598.695
Assistance with toileting without bowel or bladder management[(b)]	$0.147
All bladder and bowel management and assistance with toileting[(a)]	$1,268.191

(a) The cost associated with 'Both bladder and bowel management' and 'All bladder and bowel management and assistance with toileting' is not that associated with the sum of the costs of the individual parts. The removal of bladder management may cause a drop in the RCS classification from RCS1 to RCS2; however while bowel management may have a similar effect, the combination of bowel and bladder management may not be sufficient to reduce the classification any further and thus incur a change in the applicable subsidy. In addition the change in the level of funding between each classification is not the same. Therefore a change from RCS1 to RCS2 will incur a different level of subsidy than a change between RCS2 and RCS3.

(b) Expenditure due to assistance with toileting when the resident did not have bowel or bladder management problems.

Source: AIHW analysis of DoHA ACCMIS database.

The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) sheds light on this issue. As will be discussed in Part B of this report, urinary continence is the function of control over urination (ICF b6202) and urinary incontinence is an impairment of this function. Toileting is not a body function like urinary continence, but is an activity. It is the planning and carrying out of the elimination of human wastes and cleaning oneself afterwards (ICF d530). Many people have activity limitations, and require assistance to carry out those activities. Those who have toileting limitations may have these limitations because of intrinsic bladder dysfunction and so have lost the function of control over urination. Or they may have toileting limitations because their dementia leads to a cognitive impairment which leads to lack of awareness and in turn a toileting limitation.

Most people who need assistance with toileting need that assistance because of a lack of control of urination (or defecation). Even those who need assistance with toileting because of, for example, mobility problems have, in one sense, a urination problem. It is not a problem with bladder functioning, but it is a problem with getting to the toilet which if not attended to results in inappropriate urination (see discussion of functional incontinence in Chapter 2.2, Part A, where functional incontinence is defined as 'urinary leakage associated with inability to toilet because of impairment of cognitive and/or physical functioning, psychological unwillingness, or environmental barriers').

Thus, needing assistance with toileting and lack of control of urination or defecation are so tightly linked that one can say that toileting limitation is the other face of continence impairment. It is therefore appropriate to consider that the costs of assisting with toileting in aged care homes are part of incontinence management costs.

Estimates for expenditures on assistance with bladder and bowel control and toileting in residential aged care are presented in Table 5.3; they do not include the costs of dealing with catheters and stoma aids as these costs cannot be separately estimated from the residential aged care data base.

Table 5.3: The amount of residential aged care basic subsidy funding that can be attributed to assistance with toileting, and bladder and bowel management, by age and sex, 2003

	Bladder and bowel management		Assistance with toileting		All bladder and bowel management and assistance with toileting	
Age group	cost ($ million)	per cent	cost ($ million)	per cent	cost ($ million)	per cent
Male						
0–49	1.8	0.3	2.4	0.4	4.7	0.4
50–69	16.0	3.0	19.7	3.3	40.3	3.2
70–84	70.5	13.3	83.4	13.9	174.0	13.7
85+	51.6	9.8	57.7	9.6	123.0	9.7
Total	**139.9**	**26.5**	**163.2**	**27.3**	**342.1**	**27.0**
Female						
0–49	1.9	0.4	2.4	0.4	4.9	0.4
50–69	17.1	3.2	20.4	3.4	42.5	3.4
70–84	146.6	27.7	165.5	27.6	352.7	27.8
85+	223.1	42.2	247.2	41.3	526.0	41.5
Total	**388.6**	**73.5**	**435.5**	**72.7**	**926.1**	**73.0**
All persons	**528.5**	**100.0**	**598.7**	**100.0**	**1,268.2**	**100.0**

Source: AIHW analysis of DoHA ACCMIS database.

5.3 Hospital expenditure

Expenditure in hospital for patients with incontinence is hard to measure. The Economic Framework Report (Moore et al. 2005) showed that the coding for incontinence as a principal diagnosis on hospital morbidity records is inadequate. And even if it were adequate, most of the expenditure in hospital that is due to incontinence is for patients whose principal diagnosis is not incontinence.

One source of data that provides us with information about the continence status of long stay patients in hospital is the ABS Survey of Disability, Ageing and Carers. The 2003 survey showed that at any one time 45% of long stay hospital patients always needed help with bladder or bowel control and 23% sometimes needed help. The Hospital Morbidity Database records 6,001 people with a length of stay greater than 3 months. The patient's incontinence is estimated to impose the same burden on hospital staff as incontinence in residential aged care facilities imposes but at a higher cost to allow for higher cost structures in hospitals, i.e. $36 per day in hospitals compared with $24 per day in residential aged care facilities (Moore et al. 2005). The annual incontinence cost then for these long stay hospital patients who always or sometimes need help with bladder/bowel control is $35.3 million.

Analysis of the Hospital Morbidity Database provided an estimate for the number of patients in hospital for less than 3 months for whom an additional diagnosis of incontinence was recorded. The cost of incontinence for these patients was also determined by applying a cost of $36 per day to their length of stay. The estimate of expenditure due to incontinence amongst hospital patients with a length of stay shorter than 3 months is $29.5 million. This is expected to be an underestimate because incontinence as an additional diagnosis is often not recorded in the hospital morbidity database, in circumstances when it should be. In addition there is expenditure in hospitals for patients where the principal diagnosis is incontinence—this expenditure is $25 million. Total hospital expenditure for incontinence in 2003 was therefore estimated to be $90 million (Table 5.4).

5.4 Medical and other health system expenditures

Medical services

Of the 20.3% of the 1998 South Australian community population who had urinary incontinence, only 29% said they had consulted a health professional about it, i.e. 5.9% of the South Australian community population (Avery et al. 2004b:59). The time frame in which they had seen a health professional was not ascertained. Of those who had consulted a health professional, 70% said they had seen a GP and 41% said they had seen a specialist.

The Bettering the Evaluation and Care of Health (BEACH) survey collects information about the number of people who have seen their GP about incontinence and who are referred to specialists because of their incontinence. It is estimated, using this data, that there were 94,000 GP attendances and 30,000 out-of-hospital specialist attendances for urinary incontinence nationally in 2000–01. If there were two GP attendances per person this is 0.3% of the adult population. This BEACH data are compatible with the 1998 SAHOS if the time frame the SAHOS respondents answered regarding their consultation with a health professional for incontinence was in regard to the last 1 or 2 decades. This is possible given that the duration of the condition is frequently decades and many people do not often seek their doctor's advice on their incontinence.

In addition, Dowell et al. (1999) found that of the 97 women who came to a Sydney clinic for treatment of stress, urge or mixed incontinence by nurse continence advisors, 52 had seen a GP in the last year, and 51 had seen a specialist.

Both the Sydney clinic data and the 1998 SAHOS indicate a greater use of specialist services relative to GP services as compared to the BEACH data. The BEACH estimates of specialist referrals are subject to high uncertainty, therefore the estimate of use of specialists has been increased, so the number of specialist attendances is assumed to be 41/70 of the GP attendances. The 41/70 is derived from the SAHOS results where 70% said they had seen a GP and 41% said they had seen a specialist. Estimated costs are increased proportionally.

Medical services costing (see Table 5.4) uses the BEACH data for its GP expenditure estimates because it is the only survey which indicates the actual provision of GP services for urinary incontinence in a particular year. The numbers are much lower than the numbers estimated by Doran et al. (2001), based on Dowell et al. (1999), but that is not surprising, because their estimate of use of services is based on a group of women who are actively seeking treatment, whereas most people with incontinence are not actively seeking treatment in any one year.

Pharmaceuticals

It is estimated using the BEACH data that in 2000–01, 260,000 pharmaceuticals were prescribed and used for incontinence. This is an average of 2.8 pharmaceuticals used per GP attendance. The total expenditure on pharmaceuticals was estimated to be $12 million (Table 5.4).

The pharmaceuticals prescribed for incontinence fall into two main areas—urinary incontinence and faecal incontinence. The main pharmaceuticals prescribed were antidiarrheals (24.9%), antibacterials (15.2%), urologicals (10.2%), psychoanaleptics (10.1%), drugs for functional gastrointestinal disorders (7.4%), pituitary and hypothalamic hormones (5.8%), sex hormones (5.5%), mineral supplements (5.1%) and analgesics (3.4%). These 9 groups of drugs make up 88% of prescriptions written for urinary or faecal incontinence by GPs. Most of the antidiarrheal drugs (99%) were prescribed for faecal incontinence, the antibacterials were prescribed more often for urinary incontinence (62%), the urologicals were only prescribed for urinary incontinence and the psycholanaleptics were prescribed more often for urinary incontinence (63%) than for faecal incontinence.

Drugs prescribed for constipation are not included in the costs of incontinence. There were 45% more prescriptions for constipation than for both urinary and faecal incontinence combined, accounting for approximately $18 million. Around 93% of these prescribed drugs were laxatives.

Other health services

It has not been possible to estimate expenditures for incontinence in the areas of non-admitted patient services, other health professional services and over-the-counter medicaments. It is known that people with incontinence do quite often see physiotherapists, and the use of non-admitted patient services in hospitals is considerable. However, some of the expenditure for non-admitted patient services is included in the specialist service expenditure calculated above.

The Australian Government provided $31 million from 1999 to 2006 to support the National Continence Management Strategy (NCMS). In 2003–04, $4.2 million was spent. This expenditure funds specific projects aimed at continence issues such as the Continence Helpline and a communications strategy. This expenditure is included in 'other health services' in Table 5.4.

5.5 Continence aids

The 1998 SAHOS asked people the average amount of money they spent each month on aids or products to help with their urinary incontinence (Avery et al. 2004b). The average expenditure for those using aids was $18.48 per month. This number was increased by the rate of inflation between 1998 and 2003 and the percentage of the 1998 population using aids was applied to the 2003 community-living population. The resulting estimated expenditure for 2003 was $101 million.

Continence Aids Assistance Scheme (CAAS) expenditure was $10.6 million in 2003–04 (Intouch 2005). This included $8.19 million on continence items, $14 million on administration and $1.09 million on freight.

Table 5.4: Expenditure by governments and individuals for incontinence, excluding residential aged-care, 2003 ($ million)

	Admitted patients including private medical expenditure	Un-referred (GP) medical services	Imaging and pathology	Specialist medical services	Total out-of-hospital medical expenditure	Pharmaceuticals requiring a prescription	Continence aids	Other	Total expenditure excluding residential aged care
Males									
0–19	1.7	0.67	0.31	1.98	2.96	1.66	4.9	0.02	11.2
20–49	6.4	0.15	0.11	0.00	0.26	0.51	31.3	0.29	38.8
50–69	6.2	0.21	0.24	0.17	0.62	0.66	14.6	0.31	22.4
70–84	12.4	0.32	0.25	0.00	0.57	0.64	4.4	0.19	18.2
85+	5.2	0.08	0.02	0.12	0.22	0.29	0.5	0.03	6.2
Females									
0–19	1.4	0.76	0.85	0.36	1.97	1.11	4.8	0.08	9.3
20–49	12.0	1.14	0.52	0.40	2.06	1.57	30.9	1.68	48.2
50–69	16.9	1.28	0.76	0.55	2.59	2.75	14.5	1.11	37.8
70–84	17.9	0.98	1.07	0.25	2.30	1.98	5.2	0.40	27.8
85+	9.7	0.35	0.19	0.00	0.53	1.03	0.8	0.06	12.1
Persons									
0–19	3.1	1.43	1.16	2.33	4.92	2.77	9.7	0.10	20.5
20–49	18.4	1.28	0.63	0.40	2.31	2.08	62.2	1.97	86.9
50–69	23.1	1.49	1.00	0.72	3.21	3.41	29.0	1.42	60.2
70–84	30.3	1.30	1.32	0.26	2.88	2.62	9.6	0.59	46.0
85+	14.9	0.43	0.20	0.12	0.75	1.31	1.3	0.09	18.3
Total	**89.8**	**5.93**	**4.31**	**3.83**	**14.08**	**12.20**	**111.7**	**4.2**	**232.0**

Note: Unreferred (GP) medical services, imaging and pathology and specialist medical services together add up to 'Total out-of-hospital medical expenditure'.

Source: AIHW disease expenditure database.

Industry sources indicate that the wholesale expenditure for continence aids for the community and supermarkets was about $45 million. Of this, $8 million was through the CAAS, leaving $37 million. This wholesale cost of $37 million is not inconsistent with the retail costs of aids estimated from the SAHOS of $101 million.

5.6 Projection of expenditure due to incontinence to 2031

The total expenditure for incontinence is projected to increase by 201% from $1.5 billion in 2003–04 to $4.5 billion in 2030–31 (Table 5.5). The sector with the greatest projected increase is residential aged care (220% increase between 2003 and 2030–31). Admitted patient expenditure is expected to increase 141% and other expenditures show an increase of 91%. Expenditure for continence aids is projected to increase by 61% over the 27-year period.

Table 5.5: Expenditure for incontinence 2003 to 2030–31 ($ million)

	2003	2010–11		2020–21		2030–31		
	Expen-diture	Expen-diture	Change since 2003 (per cent)	Expen-diture	Change since 2010–11 (per cent)	Expen-diture	Change since 2020–21 (per cent)	Change since 2003 (per cent)
Residential aged care	1,268	1,668	32	2,495	50	4,065	63	220
All out-of-hospital, pharmaceutical, medical and other	30	36	17	45	27	58	28	91
Continence aids	112	129	15	154	20	179	17	61
Admitted patients	90	110	23	153	38	216	42	141
Total expenditure	**1,500**	**1,942**	**29**	**2,847**	**47**	**4,518**	**59**	**201**

The factors driving the projected increase in expenditure for incontinence are population growth, demographic ageing and excess health price inflation (increases in health prices above the overall inflation rate). Figure 5.1 shows the impact of these factors on health system expenditure for incontinence.

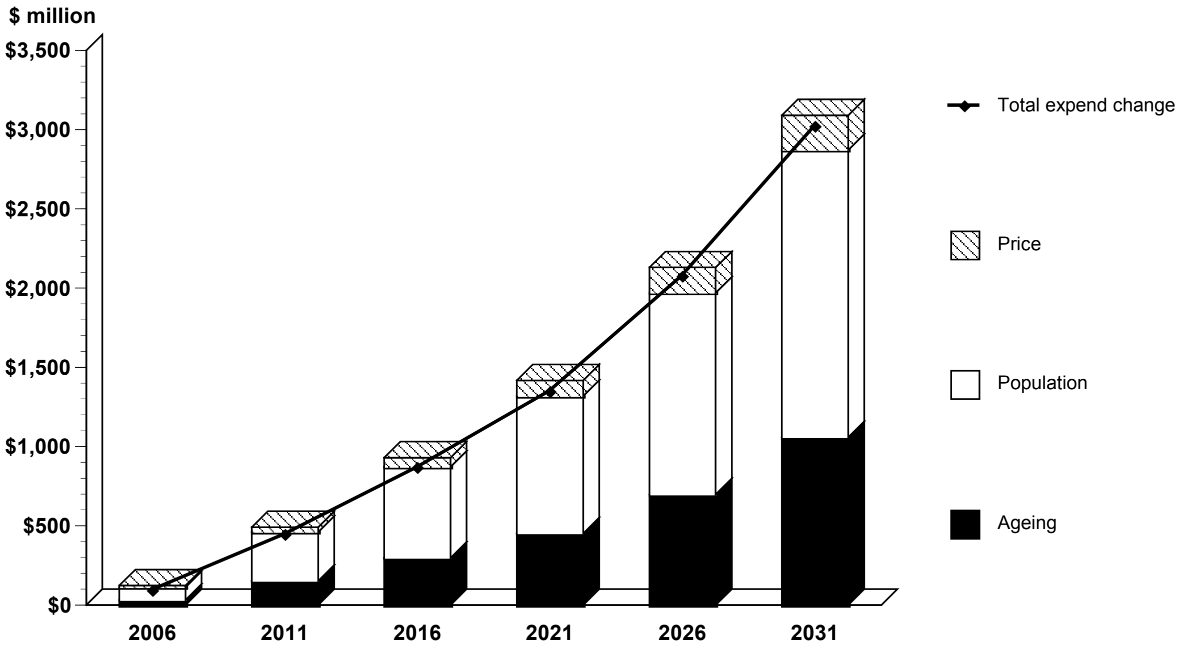

Figure 5.1: Decomposition of projected change in health and aged care expenditure for incontinence, 2003 to 2030–31

5.7 Sensitivity analysis

The projected growth in expenditure for incontinence is driven in part by an assumption of the future rate of excess health price inflation. The base assumption is for annual growth in excess health price inflation of 0.7%. Table 5.6 shows the effect of changing this base assumption by ±0.2%. The low excess health price inflation (0.05%) results in an expenditure of $4.4 billion for incontinence in 2030–31 compared to $4.9 billion with the higher excess health price inflation of 0.9% per year. The percentage increase in expenditure for incontinence ranges from 185% to 217% for the different assumptions. This is a difference of 0.03% as a percentage of GDP in 2030–31 (Table 5.6).

Table 5.6: Expenditure for incontinence with different health price growth assumptions, 2003 to 2030–31

	$ million			Percentage of GDP	
Annual growth in excess health price inflation (per cent)	2003	2030–31	Per cent change	2003	2030–31
0.5	1,500	4,278	185%	0.22%	0.31%
0.7	1,500	4,518	201%	0.22%	0.33%
0.9	1,500	4,772	218%	0.22%	0.34%

6 Burden of incontinence

6.1 Burden of disease analysis

Burden of disease analysis is a method for analysing the mortality and morbidity impact of health conditions and impairments. Too often analyses focus on the impact of a health condition on mortality, and ignore its impact on quality of life. The burden of disease approach combines the impact of morbidity and premature mortality in one measure called the disability adjusted life year (DALY). The premature mortality component is measured in terms of years of life lost (YLL) and the morbidity component in terms of years of life spent living in states of less than full health (YLD) (Salmon et al. 2002). The YLD is a measure of the impact of a health condition or impairment in restricting activity and participation.

The burden of disease for Australia for all health conditions has been estimated (AIHW: Mathers et al. 1999). These 1996 results are currently being updated to 2003 and will be published in 2006 by the Australian Institute of Health and Welfare and the University of Queensland.

In this chapter, the burden of incontinence is estimated by analysing the number of people with incontinence and then estimating the severity of the condition or the degree to which quality of life is reduced.

Sections 6.2 to 6.4 discuss the measurement of the prevalence and severity of incontinence (in terms of its effect on 'quality of life') for the purpose of burden of disease analysis. Section 6.5 discusses measuring severity in such a way that different levels of severity can be added up, and Sections 6.6 to 6.8 estimates the burden due to incontinence in terms of healthy life years lost.

6.2 Prevalence and severity of faecal incontinence in households (SAHOS)

The most common way to measure the prevalence of faecal incontinence is with the Wexner instrument. This measure was recommended in the Continence Outcomes Measurement Suite Report (Thomas et al. 2005).

The Wexner is scored from five questions in the 2004 SAHOS, which describe the frequency of problems with solid stool (Question X4), liquid stool (X5) or gas (flatus or wind) (X6), the need to wear a pad to protect underwear (X8) and the impact on lifestyle of bowel or stool leakage (X1) (see Table A6.1, Appendix A for Wexner scoring system and Appendix B for the full text of questions).

There are many people in the 2004 SAHOS who only have problems with flatus incontinence (802 out of 1,099 in the survey showing any problem with faecal incontinence on the five Wexner questions). The Assessment of Quality of Life (AQOL) for 'flatus incontinence only' is shown below (Table 6.1)—not many with only flatus incontinence have a decreased AQOL.

Table 6.1: AQOL scores for different severities of flatus incontinence only by age and sex, 2004

	AQOL score for different frequencies of flatus incontinence only				
	None	Rarely	Sometimes	Often	More than daily
Males					
15–19	0.90	0.87	0.90	1.00	0.91
20–24	0.91	0.91	0.94	—	0.84
25–29	0.90	0.82	0.83	0.85	0.86
30–34	0.86	0.78	0.73	0.63	0.00
35–39	0.84	0.79	0.85	0.76	0.63
40–44	0.85	0.82	0.92	0.66	0.61
45–49	0.81	0.79	0.90	0.97	—
50–54	0.83	0.73	0.72	0.73	—
55–59	0.77	0.85	0.74	0.74	0.37
60–64	0.81	0.75	0.50	0.66	0.69
65–69	0.81	0.76	0.82	0.91	0.36
70–74	0.80	0.86	0.82	—	—
75+	0.75	0.76	0.80	—	0.50
All males	**0.84**	**0.81**	**0.81**	**0.84**	**0.65**
Females					
15–19	0.83	0.76	0.54	—	—
20–24	0.85	0.82	0.99	—	—
25–29	0.84	0.79	0.91	0.73	0.76
30–34	0.87	0.84	0.80	0.77	0.52
35–39	0.88	0.81	0.82	0.65	0.72
40–44	0.87	0.83	0.74	0.94	0.93
45–49	0.82	0.80	0.74	0.54	0.61
50–54	0.80	0.75	0.72	0.81	0.59
55–59	0.80	0.84	0.73	0.67	0.79
60–64	0.80	0.80	0.79	0.72	0.50
65–69	0.84	0.81	0.59	0.65	0.71
70–74	0.78	0.75	0.66	0.55	0.61
75+	0.70	0.64	0.70	0.58	0.69
All females	**0.82**	**0.79**	**0.76**	**0.70**	**0.68**

Note: The ‘Flatus incontinence only’ group has flatus problems as indicated by question X6 but indicate no problems on X4, X5, X8 and/or X10.

Source: AIHW analysis of 2004 SAHOS.

This is particularly so for men who ‘rarely’, ‘sometimes’ and ‘often’ have flatus incontinence. They have similar AQOL scores to those men who report no flatus incontinence. For women the ‘sometimes’, ‘often’ and ‘more than daily’ groups have lower AQOL than women who report no flatus incontinence. However, for those who do have a decreased AQOL score, it may be due to conditions other than flatus incontinence.

Table 6.2 shows the relationship between flatus incontinence only and the elimination question (Question Y8) in the SAHOS. This question asked whether there were slight, marked or serious problems or no control with bladder and bowel functions. Of the 802 people with 'flatus incontinence only', 675 (84%) considered their bladder and bowel worked normally and without problems. Of the remaining 127, 109 considered they had slight problems with bladder and/or bowel functions, 16 considered they had marked problems, and 3 considered they had serious problems.

Table 6.2: Flatus incontinence and bladder and/or bowel problems for SAHOS respondents, 2004

	Problems with bladder and/or bowel (Y8)					
Flatus incontinence only (X6)[(a)]	**No problems**	**Slight**	**Marked**	**Serious**	**No control**	**All persons**
Never	1,819	134	10	4	0	1,966
Rarely	417	51	6	2	0	476
Sometimes	168	37	5	0	0	210
Often	55	15	5	1	0	75
More than daily	35	6	1	0	0	41
Flatus rarely or more often	*675*	*109*	*16*	*3*	*0*	*802*
All persons	**2,493**	**242**	**26**	**6**	**0**	**2,768**

(a) Group with no problems on X4, X5, X8 and/or X10.

Note: There were 3,015 respondents in the SA Health Omnibus Survey (SAHOS).

Source: AIHW analysis of 2004 SAHOS.

In light of this data, we consider that it is unhelpful to analyse the flatus incontinence only group in company with those suffering solid and liquid faecal incontinence. Those who have flatus incontinence only do not seem to have significant quality of life problems and almost all consider they do not have a bladder and/or bowel function problem. Thus the analysis below includes 'flatus incontinence only' as a separate category and applies a zero severity weight. This means it makes no contribution to the overall burden of incontinence. However, the estimate of 660,000 people with flatus incontinence only is included in Table 6.10.

The four remaining Wexner questions have some significant overlap. The people who use pads or have their lifestyle affected by bowel or stool leakage are largely a subset of the people who report problems with leaking or losing control of solid and/or liquid stool.

The question arises as to how much extra information is obtained from including the pad and lifestyle questions as compared to using just the liquid and solid stool questions. An index was calculated just using the liquid and stool questions, and this was compared with an index based on the four questions—liquid, stool, pads and lifestyle. The correlation between the two indexes was 0.94. Thus the ranking of people on these incontinence scores does not change very much by adding in the pads and lifestyle questions, i.e. there is little additional information value in adding in the pads and lifestyle questions. Thus the analysis below uses information from the solid and/or liquid stool questions only.

Table 6.3 shows the impact on prevalence estimates of using just these two Wexner questions rather than the four Wexner questions. Occasional solid and/or liquid problems occur for 5.8% of the community dwelling population, and frequent or very frequent problems occur for 1.3% of the population.

Table 6.3: Prevalence of faecal incontinence by different sub-scales of the Wexner scale, 2004

Category	Score	Solid & liquid (per cent)	Score	Solid & liquid plus pads and lifestyle; occasional & higher (per cent)
None	0	92.9	0	92.1
Occasional	1–2	5.8	1–3	6.4
Frequent	3–4	1.1	4–8	1.3
Very frequent	5–8	0.2	9–12	0.2
Occasional and higher	1–8	7.1	1–12	7.9
Frequent and very frequent	3–8	1.3	4–12	1.6

Note: The scoring system is described in Table A6.1 in Appendix A.

Source: AIHW analysis of 2004 SAHOS.

Adding in those who have an occasional + score on the pads and lifestyle questions, but who are not already in the solid and liquid group adds 0.6 percentage points to the occasional group, and 0.2 percentage points to the frequent group, i.e. 0.8 percentage points added overall. The group who are added in have some rather inconsistent answers, e.g. there are 8 people who say they frequently need to wear pads to protect underwear from stool and/or have their lifestyle altered by bowel or stool leakage, but who also say they never leak, have accidents or lose control with solid or liquid stool.

For the burden of disease analysis the 'frequent' and 'very frequent' prevalence of 1.3% is used for the prevalence of faecal incontinence. This is 202,000 people living in the community who at least sometimes, i.e. more than once a month, have solid or liquid stool leakage or accidents.

Of this group the 'very frequent' group (32,000 people) should have a high severity weight in the burden of disease analysis. The SAHOS analysis of AQOL, EQ5D, HUI3 and SF6D by Hawthorne and Sansoni (2004), indicates the severity weight for daily faecal incontinence relative to no faecal incontinence is between 0.35 and 0.11. (15D is excluded as it seems not to be valid in measuring incontinence). A simple average of the relative scores on these four instruments gives 0.24. Allowing for the impact of comorbidity, a severity weight of 0.2 was assumed for 'very frequent' faecal incontinence. For the 'frequent' group, a severity weight of 0.06 is applied. The international literature indicates that very frequent faecal incontinence deserves a high severity weight, but is unhelpful as to the exact level. The SAHOS data seems to be the best data available. It is odd that the very frequent faecal incontinence weights are lower than the very severe urinary incontinence weights (see Table 6.9), but this is in line with the SAHOS results. Sensitivity analysis was done on the severity weights for very frequent faecal incontinence. Using a severity weight of 0.3 instead of 0.2 increased healthy life years lost by 1,863 years (see Table 6.11). This results in an overall increase of 1.6% in healthy life years lost due to incontinence.

6.3 Prevalence and severity of urinary incontinence in households (SAHOS)

The Incontinence Symptom Severity Index (ISSI) is made up of two questions (W7 and W8 in the 2004 SAHOS; see Appendix B). People are asked how often they experience urine leakage and how much urine leakage occurs. There are five response levels for the question of how often urine leakage is experienced (never, less than once a month, several times a month, several times a week and every day or night) and they are scored as 0, 1, 2, 3 or 4.

There are four response levels for the question related to quantity of urine leakage—none, a few drops, a little, and more and they are scored respectively as 0, 1, 2 or 3. In this analysis, the severity of urinary incontinence has been allocated according to the ISSI score as shown in Table A6.2 (Appendix A).

Some level of urinary incontinence was reported by 24.4% of the population (10.2% of males and 38.1% of females) (Table 6.4). Severe or very severe urinary incontinence was reported by 1.5% of the population (0.3% of males and 2.6% of females). For males the level of severity increases with age to 85+ years where 40% of men report some level of urinary incontinence. For females the proportion reporting some level of urinary incontinence is 34% for ages 20–49 years and peaks at 52% for those aged 50–69 years.

Table 6.4: Proportion of urinary incontinence at each severity level, by age group and sex, 2003 (per cent)

	Severity of urinary incontinence as measured by ISSI					
	None	**Slight**	**Moderate**	**Severe**	**Very severe**	**Total**
Males						
20–49	95.0	4.6	**0.4	—	—	100.0
50–69	84.5	12.0	*3.0	**0.4	—	100.0
70–84	73.4	20.8	*4.9	**0.5	**0.3	100.0
85+	*59.6	40.4				*100.0
All males	*89.8*	*8.2*	*1.6*	**0.3*	***0.0*	*100.0*
Females						
20–49	65.6	27.5	5.7	*0.8	**0.4	100.0
50–69	47.6	36.3	12.2	*2.6	*1.2	100.0
70–84	59.7	24.5	10.4	*4.8	**0.5	100.0
85+	60.4	29.6				100.0
All females	*61.9*	*27.9*	*7.6*	*1.9*	**0.7*	*100.0*
Persons						
20–49	80.4	16.0	3.0	*0.4	**0.2	100.0
50–69	65.8	24.4	7.7	*1.5	*0.6	100.0
70–84	65.7	22.9	8.0	*3.0	**0.4	100.0
85+	60.2	29.8				100.0
All persons	**75.6**	**18.2**	**4.7**	**1.1**	***0.4**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

Stress and urge incontinence

The two principal types of urinary incontinence—stress incontinence and urge incontinence—are identified from the 2004 SAHOS using questions W2 and W3 (urine leakage related to a feeling of urgency and urine leakage related to physical activity, coughing or sneezing; see Appendix B). There are four response levels on each question—not at all, slightly, moderately, and greatly.

For males, the prevalence of some stress incontinence is fairly constant and small until the age of 65 and then the prevalence increases with age (Table 6.5). For females the picture is different with prevalence increasing with age up to the age of 69 years when the prevalence drops and then remains fairly constant as a proportion of the population. The peak prevalence for females is for 65–69 years when it reaches 58% of the population.

Table 6.5: Proportion of the population suffering from stress incontinence by severity, sex and age, 2003 (per cent)

	Not incontinent	Slightly incontinent	Moderately incontinent	Greatly incontinent	Refused to answer	Total
Males						
20–49	98.2	*1.4	—	**0.1	**0.3	100.0
50–69	95.4	*3.8	**0.3	—	**0.4	100.0
70–84	89.5	*7.5	**1.9	**0.5	**0.6	100.0
85+	*81.7	18.3				*100.0
All males	*96.5*	*2.7*	**0.3*	***0.2*	**0.3*	*100.0*
Females						
20–49	64.2	29.7	3.6	2.5	—	100.0
50–69	43.8	45.1	7.9	*3.2	—	100.0
70–84	58.2	27.3	11.1	*3.2	**0.3	100.0
85+	63.2	36.8				100.0
All females	*60.6*	*31.3*	*5.5*	*2.6*	***0.0*	*100.0*
Persons						
20–49	81.3	15.4	1.8	1.3	**0.1	100.0
50–69	69.3	24.7	4.1	*1.6	**0.2	100.0
70–84	71.8	18.7	7.1	*2.0	**0.4	100.0
85+	68.4	31.6				100.0
All persons	**78.2**	**17.3**	**2.9**	**1.4**	***0.2**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

For males, the prevalence of some urge incontinence is fairly low in younger ages and increases to 30% for those aged 70–84 years and 50% for those 85 years and over (Table 6.6). For women the prevalence is 34% for those aged 50–69 years, 38% for those aged 70–84 years and 37% for those aged 85 years and over.

Table 6.6: Proportion of the population suffering from urge incontinence by severity, sex and age, 2003 (per cent)

	Not incontinent	Slightly incontinent	Moderately incontinent	Greatly incontinent	Refused to answer	Total
Males						
20–49	95.7	3.5	**0.4	**0.1	**0.3	100.0
50–69	85.8	9.6	*3.2	**1.0	**0.4	100.0
70–84	69.2	22.5	*5.1	*2.6	**0.6	100.0
85+	*49.8	50.2				*100.0
All males	*89.9*	*7.3*	*1.7*	**0.7*	**0.3*	*100.0*
Females						
20–49	79.5	16.2	2.3	*2.0	—	100.0
50–69	65.8	24.3	6.6	*3.4	—	100.0
70–84	61.9	24.4	10.0	*3.4	**0.3	100.0
85+	63.2	36.8				100.0
All females	*74.5*	*18.4*	*4.6*	*2.4*	***0.0*	*100.0*
Persons						
20–49	87.7	9.8	1.3	1.1	**0.1	100.0
50–69	75.7	17.0	4.9	2.2	**0.2	100.0
70–84	65.1	23.5	7.9	*3.1	**0.4	100.0
85+	59.4	40.6				100.0
All persons	**82.1**	**13.0**	**3.2**	**1.6**	***0.2**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

6.4 Prevalence and severity of incontinence in residential aged care (RCS)

The data for incontinence in residential aged care facilities are derived from the aged care database using the answers to questions 5, 6 and 7 on the RCS questionnaire. The population used for this work are residents who had valid RCS assessments for a period including the 30 of June 2003. This population was assumed to be representative of the population in residential aged care for the whole year. Prevalence estimates are presented in Table 6.7.

Table 6.7: Permanent residents of residential aged care who are reported as requiring support with bladder or bowel management or assistance with toileting, by age and sex, 30 June 2003

Age group	Total permanent residents as at 30/6/2003	Needs assistance with toileting		Needs support with bladder management		Needs support with bowel management	
		Permanent residents (no.)	Per cent of total residents	Permanent residents (no.)	Per cent of total residents	Permanent residents (no.)	Per cent of total residents
Males							
0–49	538	419	83.3	357	70.9	455	90.5
50–69	5,037	3,450	68.5	2,919	58.0	3,896	77.3
70–84	19,962	14,099	70.6	12,769	64.0	16,535	82.8
85+	14,985	9,677	64.6	8,962	59.8	12,261	81.8
Total	**40,522**	**27,645**	**68.2**	**25,007**	**61.7**	**33,147**	**81.8**
Females							
0–49	503	420	83.5	363	72.2	447	88.9
50–69	4,749	3,465	73.0	3,259	68.6	3,932	82.8
70–84	40,566	27,597	68.0	28,204	69.5	33,558	82.7
85+	60,299	40,808	67.7	42,873	71.1	50,443	83.7
Total	**106,117**	**72,290**	**68.1**	**74,699**	**70.4**	**88,380**	**83.3**
All persons	**146,639**	**99,935**	**68.2**	**99,706**	**68.0**	**121,527**	**82.9**

Source: AIHW analysis of 2003 ABS Survey of Disability, Ageing and Carers confidentialised unit record file (CURF) and the Residential Aged Care System.

6.5 Severity of incontinence

Severity of incontinence has been described in general terms in the sections above. However in order to measure the overall severity of incontinence a common metric for describing the impact of incontinence must be used. This is done by weighting each level and type of incontinence with a severity weight so that the different levels and types can be added together. The severity weight must be derived from a multi-attribute utility measure in order for such addition to be valid. These severity weights are often called utility weights or disability weights.

Review of literature on severity weights for incontinence

A household survey of 32,781 people across ten countries asked people to characterize urinary incontinence in terms of six key dimensions of health (Salmon et al. 2002). Urinary incontinence was defined as 'loss of control over urination'. Respondents varied significantly in their responses but the median respondent considered that such urinary incontinence would cause mild difficulty for mobility, no difficulty with self-care activities of washing and dressing, mild difficulty with usual activities, moderate difficulty with pain, moderate difficulty with affect, and mild difficulty with cognition. Consistent with these ratings on the six domains, respondents considered urinary incontinence to be quite a severe state, giving an overall rating on the visual analog scale of 0.415 (where 0 good and 1 is worst possible health state).

A Canadian survey asked people to evaluate the severity of their own health conditions using the HUI3 instrument (Shultz & Kopec 2003). Those with urinary incontinence showed quite high severities compared to other conditions, and this was also the case when only those with urinary incontinence were compared with others who only had one condition. Urinary incontinence was the third most severe condition with a deviation from normal health of 13% after Alzheimer's disease (34% deviation from normal health) and the effects of stroke (17%). Urinary incontinence was considered a bigger problem than epilepsy (8% deviation from normal health), heart disease (6%), arthritis/rheumatism (9%) and cataracts (8%). The severity levels for many of the conditions in this survey were surprisingly low. This may be partly due to the fact that respondents were those with the conditions; most other utility surveys ask experts or the general population. These groups are asked the theoretical question as to what they consider the impact of the disease would be if they or someone else had it. These views are different to those with a health condition as this group tend to adapt to the condition in such a way that the impact of that condition on their wellbeing is moderated (Cummins 2003). Thus they consider the utility decrement due to the condition to be less than the assessment of experts or the general population.

The 2004 SAHOS measured the HUI3, the EQ5D, the AQOL, the 15D, and the SF6D. On all multi-attribute utility instruments there were reductions in utility as the severity of urinary incontinence increased. The 15D showed higher levels of utility than the other instruments which were quite consistent. For the other four instruments the utility score if there was no urinary incontinence was 0.86, for slight urinary incontinence (as defined by the UDI) 0.8, for moderate urinary incontinence 0.72 and for problem or major incontinence a mean of 0.63 (Hawthorne & Sansoni 2004).

These studies show that, though there is great variability in attitudes towards the severity of the impact of urinary incontinence, on average urinary incontinence is considered a severe condition which has impact on a number of key domains of health.

The SAHOS results do not allow for comorbidity. The Canadian survey showed that comorbidity makes a large impact on the HUI3 scores (Shultz & Kopec 2003). Those with urinary incontinence alone had HUI3 scores of 0.82 (1 perfect health, - 0.36 worst possible state), but those who had urinary incontinence with other chronic conditions had an HUI3 score of 0.61, and the score for all people who had urinary incontinence was 0.64, i.e. the overall score is significantly affected by the other conditions that a person has in addition to urinary incontinence. Utility scores for people in the SAHOS with different severities of incontinence are listed below.

Utility scores are presented in Table 6.8 but do not allow for comorbidities, so much of the low utility level that people with severe incontinence record is due to other conditions, i.e. only part of the reduced utility is due to the incontinence. To properly adjust the utility scores for comorbidities a detailed analysis of the full 2004 SAHOS is needed. This analysis requires obtaining permission from all contributors to the 2004 SAHOS to use their data, and then doing a multivariate analysis of the full data set. It is recommended this analysis be done.

Table 6.8: Utility scores for people with different levels of urinary incontinence, 2004

ISSI	Average of AQOL	Average of EQ5D	AQOL relative to group without urinary incontinence	EQ5D relative to group without urinary incontinence	Average of AQOL & EQ5D
0	0.823	0.835	1.00	1.00	1.00
1 (Slight)	0.750	0.760	0.91	0.91	0.91
2 (Moderate)	0.661	0.688	0.80	0.82	0.81
3 (Severe)	0.449	0.499	0.55	0.60	0.57
4 (Very severe)	0.435	0.456	0.53	0.55	0.54
All persons	**0.792**	**0.805**	**0.96**	**0.96**	**0.96**

Source: AIHW analysis of 2004 SAHOS.

In the meantime, for this report, an interim comorbidity adjustment was made based on the Canadian study, i.e. the AQOL and EQ5D utility scores derived from the SAHOS are increased by the ratio 0.82/0.64 =1.28. So, for example, the 0.53 AQOL score for very severe urinary incontinence relative to those without incontinence is increased by 1.28 to give a score of 0.68, and similarly for the EQ5D the 0.55 is increased by 1.28 to give a score of 0.70. The average is 0.69, which, converted to the burden of disease severity weights used here, comes to 0.31. The severity weights used in this preliminary analysis are listed in Table 6.9.

Table 6.9: Provisional severity weights for different types of incontinence

Residential aged care	Severity weight
Profound problems with bladder/bowel control in residential aged care	0.35
Severe problems with bladder/bowel control in residential aged care	0.25
Difficulty with bladder/bowel control in residential aged care	0.15
Urinary incontinence in the community	
Very severe incontinence	0.31
Severe incontinence	0.24
Moderate incontinence	0.02
Slight incontinence	0
Faecal incontinence in the community	
Very frequent faecal incontinence	0.2
Frequent faecal incontinence	0.06
Flatus incontinence only	0

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2). Severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

6.6 Healthy life lost due to incontinence

The overall healthy life lost due to incontinence is calculated by multiplying the number of people with incontinence by the severity weights for this condition (see Table 6.10 for prevalence of type of incontinence and severity).

Table 6.10: Prevalence of incontinence by type of incontinence, severity and sex, 2003

	Males	Females	All persons
Profound problems with bladder/bowel control in residential aged care	19,245	56,066	75,311
Severe problems with bladder/bowel control in residential aged care	14,093	33,908	48,001
Difficulty with bladder/bowel control in residential aged care	1,340	4,174	5,514
Total in residential aged care	**34,678**	**94,148**	**128,826**
Very severe incontinence	2,064	62,400	64,464
Severe incontinence	29,417	146,963	176,380
Moderate incontinence	123,196	599,923	723,120
Slight incontinence	621,872	2,255,690	2,877,562
Total urinary incontinence in households	**776,549**	**3,064,976**	**3,841,526**
Very frequent faecal incontinence	13,918	18,042	31,960
Frequent faecal incontinence	32,786	137,384	170,170
Total faecal incontinence in households	**46,704**	**155,426**	**202,130**
Flatus incontinence only	312,065	345,097	656,939
Total very severe, severe, moderate and frequent incontinence in households	**201,381**	**964,712**	**1,166,104**
Total very severe, severe and frequent incontinence in households(a)	**74,687**	**341,526**	**416,213**
Total very severe, severe, moderate and frequent incontinence	**205,882**	**939,755**	**1,145,637**
Total very severe, severe and frequent incontinence(a)	**109,365**	**435,674**	**545,039**

(a) 'Total very severe, severe and frequent incontinence in households' and 'Total very severe, severe and frequent incontinence' excludes those with 'flatus incontinence only'. It also counts only once the overlap group, i.e. 3,498 men and 23,263 women, who have both very frequent or frequent faecal incontinence and severe or very severe urinary incontinence.

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

Source: AIHW analysis of 2004 SAHOS and 2003 ABS Survey of Disability, Ageing and Carers confidentialised unit record file (CURF). Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

Overall it is estimated that about 117,700 healthy life years were lost in 2003 due to incontinence (Table 6.11). In the 75 years and over age group, 69,000 healthy life years were lost due to incontinence (Table 6.12). This compares to about 300,000 healthy life years lost due to all health conditions in 2003 in the 75 years and over age group (AIHW unpublished).

Incontinence is therefore responsible for about one-fifth of the healthy life years lost for those 75 years and over. In comparison, dementia is responsible for about one-fifth of healthy life years lost for this age group and hearing and vision disorders are responsible for about one-sixth of healthy life years lost (AIHW unpublished).

The estimates of the burden of disease due to incontinence in this study are made on a somewhat different basis to the estimates in the national burden of disease report (AIHW: Mathers et al. 1999). In that report, the burden of disease due to urinary incontinence included only urinary incontinence due to parity, overweight and obesity, constipation and surgery. Urinary incontinence due to bowel problems, urinary tract

Table 6.11: Healthy life years lost in 2003 due to different types of incontinence by sex

	Males	Females	All persons
Profound problems with bladder/bowel control in residential aged care	6,736	19,623	26,359
Severe problems with bladder/bowel control in residential aged care	3,523	8,477	12,000
Difficulty with bladder/bowel control in residential aged care	201	626	827
Total in residential aged care	**10,460**	**28,726**	**39,186**
Very severe incontinence	640	19,344	19,984
Severe incontinence	12,543	79,524	92,067
Moderate incontinence	2,464	11,998	14,462
Slight incontinence	0	0	0
Total urinary incontinence in households	**8,105**	**56,326**	**64,431**
Very frequent faecal incontinence	1,039	2,661	3,727
Frequent faecal incontinence	2,281	8,034	10,349
Total faecal incontinence in households	**3,320**	**10,695**	**14,076**
Flatus incontinence only	0	0	0
Total in households	**11,425**	**67,021**	**78,507**
Total	**21,885**	**95,747**	**117,693**

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

infection and other conditions is estimated as part of those other conditions, not as part of urinary incontinence. Faecal incontinence is not included as a separate condition, but as part of other conditions. Also the burden of disease study reports estimates on the burden due to the *incidence* of incontinence in 1996, whereas this study estimate is calculated from the *prevalence* of incontinence in 2003. These differences mean that the burden of disease estimates in this report for incontinence are not comparable with the 1996 study or the 2003 burden of disease estimates for urinary incontinence that will be published in 2006 as part of the national burden of disease study.

It should also be noted that part of the dementia burden of disease that is mentioned above is due to the incontinence burden borne by people with dementia, and part of the incontinence burden is due to dementia, especially for residents in aged care homes, where the comorbidity of dementia and incontinence is very common.

Table 6.12: Healthy life years lost in 2003 due to different types of incontinence by age group

	20–49	50–69	70–84	85+	65–74	75+	All
Profound problems with bladder/bowel control in residential aged care	224	1,686	10,945	13,504	2,420	22,796	26,359
Severe problems with bladder/bowel control in residential aged care	66	777	4,886	6,271	1,093	10,436	12,000
Difficulty with bladder/bowel control in residential aged care	5	51	330	442	77	720	827
Total in residential aged care	**294**	**2,514**	**16,161**	**20,217**	**3,590**	**33,951**	**39,186**
Very severe incontinence	5,109	7,643	2,051	5,181	2,704	6,627	19,984
Severe incontinence	17,752	42,457	21,986	9,872	18,523	24,239	92,067
Moderate incontinence	5,310	6,284	2,457	411	1,414	1,117	14,462
Slight incontinence	0	0	0	0	0	0	0
Total urinary incontinence in households	**27,405**	**54,005**	**25,430**	**15,193**	**22,641**	**31,983**	**122,034**
Very frequent faecal incontinence	2,378	4,894	1,920	1,156	1,471	2,196	10,349
Frequent faecal incontinence	688	2,205	0	833	1,201	833	3,727
Total faecal incontinence in households	**3,066**	**7,100**	**1,920**	**1,990**	**2,672**	**3,029**	**14,076**
Flatus incontinence only	0	0	0	0	0	0	0
Total in households	**30,471**	**61,105**	**27,350**	**17,183**	**25,313**	**35,012**	**136,110**
Total	**30,765**	**63,619**	**43,511**	**37,400**	**28,903**	**68,963**	**175,296**

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix A).

6.7 Different health conditions and other factors associated with incontinence

What proportion of the prevalence and burden of incontinence can be associated with other health conditions and other factors? The factors associated with incontinence are covered in detail in Section 3.6. The 1996 burden of disease study estimated that, based on Chiarelli et al. (1999), about 60 to 70% of urinary incontinence was attributable to parity, overweight and obesity, constipation and surgery. Around 30–40% of the incontinence in middle-aged women is attributable to parity, whereas only 8% in older women is.

6.8 Projection of burden due to incontinence to 2031

As the population grows and ages there will be an increasing number of people living with incontinence and so the burden will grow. There is no reason to believe however, that, on average, the prevalence of incontinence in each age group will increase, as most of the factors that are associated with incontinence are expected to stabilise or decline. Birth rates are likely to be stable or fall rather than increase. Rates of prostate operations are not expected to increase. Overweight and obesity are expected to increase and if this does occur will lead to an increase in incontinence rates. But this may well be balanced by a decline in other factors. So the estimates below assume stability in the rates of incontinence in each age group. The projected increases, then, in the burden of disease are due to population growth, and to ageing.

Healthy life years lost due to incontinence in people under 50 is expected to increase by 17% between 2003 and 2031 (Tables 6.13 and 6.14). In contrast for those aged 70–84 years, the increase will be 119%, and for those 85 years and over the increase will be 263%. The highest growth of the burden due to incontinence will occur in the period 2026 to 2031 where the growth is 15%, and the lowest growth will be 13% in the period 2021 to 2026. The higher growths occur in the periods when the population aged 85 years and over is growing the most.

Overall it is expected that the burden of incontinence will increase by 110% between 2003 and 2031, with 53% of the increase occurring in the 85+ population, 27% in the 70–84 years population, and 20% in those aged under 70 years.

Table 6.13: Healthy years of life lost due to incontinence by age group, persons, projected to 2031

Age group	2003	2006	2011	2016	2021	2026	2031
<49	30,765	31,526	32,989	33,989	34,851	35,444	35,856
50–69	63,619	68,596	78,457	86,682	94,005	97,765	101,744
70–84	43,511	45,515	49,881	58,661	69,948	83,514	95,250
85+	37,400	42,566	56,241	70,317	82,677	103,273	135,597
Total	**175,296**	**188,203**	**217,568**	**249,649**	**281,481**	**319,996**	**368,447**

Table 6.14: Percent change in healthy years of life lost due to incontinence by age group, persons, 2003–2031

	Per cent change						
Age group	2003–06	2006–11	2011–16	2016–21	2021–26	2026–31	2003–31
<49	2	5	3	3	2	1	17
50–69	8	14	10	8	4	4	60
70–84	5	10	18	19	19	14	119
85+	14	32	25	18	25	31	263
Total	**7**	**16**	**15**	**13**	**14**	**15**	**110**

Appendix A

Table A6.1: Scoring of solid stool/liquid stool of the Wexner sub scale, 2004

	Do you leak, have accidents or lose control with solid stool?				
Do you leak, have accidents or lose control with liquid stool?	Never/ Refused	Rarely, i.e. less than once in the past four weeks	Sometimes i.e. less than once a week, but more than once in the past four weeks	Often or usually, i.e. less than once a day but more than once a week	Always, i.e. more than once a day, or whenever you have a bowel movement
Never/refused	0	1	2	3	4
Rarely, i.e. less than once in the past four weeks	1	2	3	4	5
Sometimes i.e. less than once a week, but more than once in the past four weeks	2	3	4	5	6
Often or usually, i.e. less than once a day but more than once a week	3	4	5	6	7
Always, i.e. more than once a day, or whenever you have a bowel movement	4	5	6	7	8

Note: 'Occasional' faecal incontinence is a score of 1 or 2 on the solid and liquid sub-scale. 'Frequent' is a score of 3 or 4. 'Very frequent' is a score of 5 to 8.

Table A6.2: Scoring of incontinence symptom severity index (ISSI) measure

ISSI score		**How much urine is lost each time?**			
		None (0)	A few drops (1)	A little (2)	More (3)
How often is urine leakage experienced?	Never (0)	0	0	0	0
	Less than once a month (1)	0	1	2	3
	Several times a month (2)	0	2	4	6
	Several times a week (3)	0	3	6	9
	Every day or night (4)	0	4	8	12

Note: 'Slight' urinary incontinence is defined as a score of 1–2, 'moderate' as 3–6, 'severe' as 7–9 and 'very severe' as 10–12.

Appendix B

Questions from the SA 1994 Omnibus health survey

Many people are inconvenienced by urinary problems.

Could you please tell me if you experience these problems and, if so, how much you are bothered by them?

W1. Frequent urination?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused……………………..

W2. Urine leakage related to feeling of urgency (a sudden desire to urinate)?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused………………………

W3. Urine leakage related to physical activity, coughing or sneezing?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused………………………

W4. Small amount of urine leakage (drops)?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused………………………

W5. Difficulty emptying your bladder?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused………………………

W6. Pain or discomfort in the abdominal or genital area?

Not at all…………………….
Slightly………………………
Moderately………………….
Greatly………………………
Refused………………………

W7. How often is urine leakage experienced?

Never…………………………………….
Less then once a month…………………
Several times a month…………………..
Several times a week……………………
Every day or night………………………
Refused…………………………………...

W8. How much urine is lost each time?

None………………………….
A few drops………………….
A little………………………...
More………………………….
Refused……………………....

X4. Do you leak, have accidents or lose control with solid stool?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks………………………
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement……………..
Refused………………………………………………….

X5. Do you leak, have accidents or lose control with liquid stool?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week……………………………..
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………..

X6. Do you leak, have accidents or lose control with gas (flatus or wind)?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………….

X7. Do you leak stool if you don't get to a toilet in time?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………….

X8. Do you need to wear a pad to protect your underwear from stool?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………….

X9. Does stool leak so that you have to change your underwear?

Never……………………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………….

X10. Does bowel or stool leakage cause you to alter your lifestyle?

Never…………………………………………………

Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..

Often or usually, i.e. less than once a day
but more than once a week…………………………….

Always, i.e. more than once a day, or
whenever you have a bowel movement………………

Refused………………………………………………….

Part B: Developing Australian continence data standards

1 Introduction

1.1 Purpose

In 2001–02 the AIHW was commissioned to undertake a review of existing health and community care data sets, to identify data items that could contribute to the monitoring of incontinence and its treatment and management (AIHW 2002b). This review concluded that variation in the definition of incontinence, and the range and definitional variation of incontinence-relevant data items included in Australian data collections, limit the useability of incontinence data for benchmarking or monitoring prevalence and treatment of incontinence.

In 2004 the Australian Government Department of Health and Ageing again commissioned the AIHW to undertake the present study (Part B of this report) including another review of continence-relevant data collections, this time with the aim to inform and make recommendations for harmonising established and future continence program data. This work is being conducted alongside other established incontinence projects, and other work on dementia, to ensure cross-fertilisation and comparable outcomes. It was proposed that recommendations be presented as areas of information and options for potential data item sets considered vital to collecting informative and comparable data on incontinence prevalence estimates, management and outcomes.

1.2 Data standards and data dictionaries

The international and national standards used to inform this report are the International Classification of Functioning, Disability and Health (ICF) (see Section 1.3) and the national data dictionaries. Adherence to data standards ensures there is mutual understanding of the meaning of underlying concepts between different parties, and promotes consistency and comparability of data for analysis and interpretation.

To facilitate the development of data for reporting purposes, the relevant policy agencies of the Commonwealth, states and territories and the two statistical agencies (the ABS and the AIHW) have signed four national information agreements for the fields of health, community services, housing and Indigenous housing. Two of the main products resulting from the national information agreements relevant to this report are the *National Community Services Data Dictionary* (NCSDD Version 3, AIHW 2003a) and the *National Health Data Dictionary* (NHDD Version 12, AIHW 2004b). These data dictionaries are compiled by the respective information management groups established under the information agreements and are published by the AIHW. The dictionaries are major pieces of Australian national information infrastructure. They contain national information models, and associated data elements, specified in accordance with International Organization for Standardization (ISO) standards. The dictionaries provide a menu of standard data elements, from which national minimum data sets can be specified, for the major national collections in the fields of health, community services, housing and Indigenous housing. Minimum data sets established under the community services, health and housing agreements are obligatory for all to report on, and all signatories are obliged to use the relevant national data dictionaries. The dictionaries are also intended to assist a much broader audience, e.g. service providers developing their own information systems, and researchers.

The data dictionaries provide information necessary to understand the meaning of the data elements and ensure consistency in application of the definitions and classifications.

In addition, METeOR, or the Metadata Online Registry, has been developed by the AIHW as the Institute's online registry of nationally endorsed metadata standards. This has involved restructuring of national metadata presented in the NCSDD and NHDD in line with the latest version of the international standard for metadata identification and recording. These metadata standards allow information to be consistently defined, so that information can be compared across different service delivery settings and sectors. METeOR is available at <http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>.

1.3 International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) was endorsed by the World Health Assembly in May 2001 (WHO 2001). The ICF has been widely accepted as a framework for conceptualising disability and has been used in a range of applications (AIHW 2003b). For example, the ABS has used the ICF framework and its main concepts in Australian disability surveys (e.g. ABS 1999).

The ICF is an international and national standard for classifying functioning and disability and is part of the Australian Family of Health and Related Classifications endorsed by the Australian Health Ministers Advisory Council. The ICF has proven to be a useful framework for comparing data collections and measurement tools, e.g. a recent study comparing dependency information across aged and community care programs (see AIHW 2004c).

Disability is a multidimensional concept, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences (WHO 2001). The conceptual framework of the ICF consists of three components: body functions and structures, activities and participation, and environmental factors (Figure 1.1). These components are defined 'in the context of health' to distinguish disability from other circumstances, such as poverty, that may contribute to restricting a person's participation in society. Within each component a classification structure is provided, which can be used to organise information on various domains[1] of the disability experience. For example, the activities and participation component consists of nine broad areas of life, such as self-care, mobility and communication. The first two components—body functions and structures, activities and participation—can be expressed in two ways. They can indicate neutral or positive aspects of health states summarised under the umbrella term 'functioning' or they can be used to indicate problems (impairment, activity limitation or participation restriction); these are summarised under the umbrella term 'disability' (AIHW 2003b). Impairments are 'problems in body function or structure such as significant deviation or loss' in, for example, hearing or vision. Activity limitations are 'difficulties an individual may have in executing activities' such as eating or drinking.

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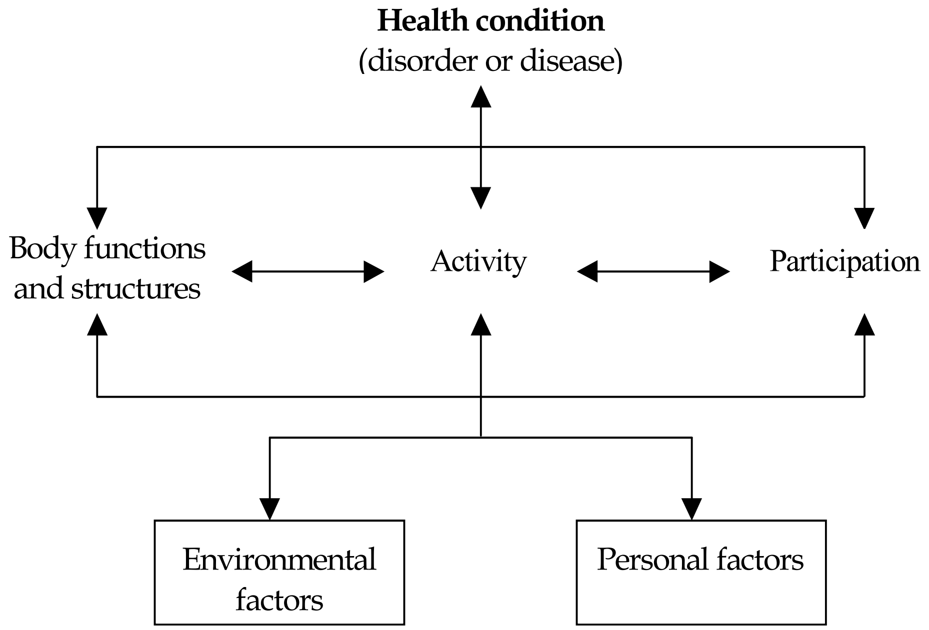
[1] A domain is a practical and meaningful set of related physiological functions, anatomical structures, actions, tasks, or areas of life (WHO 2001:3).

Participation restrictions are 'problems an individual may experience in involvement in life situations' such as participation in education and employment (WHO 2001:7–10).

Environmental factors and personal factors represent an important new component of the ICF in recognition of their effects on functioning and disability. Personal factors are not part of the classification because of the large social and cultural variance associated with them. Environmental factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives'. Personal factors are 'the particular background of an individual's life and living' (WHO 2001:16–17).

All the ICF components are distinct but interrelated. On the one hand, an individual's negative experience relating to any one domain of a component may be considered to constitute disability. On the other hand, the experience of disability is often complex and multidimensional. In the ICF framework, a person's functioning in a specific domain of a component is considered as a dynamic interaction between the health condition and environmental and personal factors (WHO 2001:18–19).

It should be noted that ICF does not cover situations that are not health related, such as participation restrictions due solely to socioeconomic factors (WHO 2001). This therefore distinguishes disability from disadvantage or exclusion unrelated to health.



Source: WHO 2001.

Figure 1.1: Interactions between components of the ICF

1.4 Method

A search was first undertaken for Australian data collections currently collecting information on incontinence. Once assembled, these collections were investigated for all data items pertaining to (in)continence, managing incontinence and toileting. Chapter 2 provides a description of these data collections, their scope and all incontinence-relevant data items.

Data items were grouped and mapped with reference to the International Classification of Functioning, Disability and Health (ICF). These items were compared, to determine the underlying themes in Australian incontinence data, and the sorts of data items consistently included in these collections.

A review of incontinence assessment or outcome tools was also undertaken with reference to the Continence Outcomes Measurement Suite project (Thomas et al. 2005), so to compare the type of information collected using these tools with that found in Australian data collections. Again, these items were grouped and mapped with reference to the ICF, and compared with data collection items for conceptual comparability and consistency.

The results of these mapping exercises, and reference to the content of incontinence assessment tools, were used to construct a menu of recommended data item options for use in the redevelopment of future data collections.

1.5 Outline of Part B

The rest of Part B of the report comprises three chapters:

- Chapter 2 summarises the scope, purpose and content of identified Australian data collections and a brief description of data items related to (in)continence, managing incontinence and toileting.
- Chapter 3 describes, with reference to the ICF, the sorts of (in)continence-related data items currently collected in Australian data collections, and discusses key themes and the comparability of data items. Information collected using continence outcome assessment and utility index tools is also investigated, primarily to compare continence information collected in clinical and epidemiological research contexts against Australian data collection items.
- Chapter 4 recommends a composite of data themes and items for inclusion in administrative data collections, based on the results presented in Chapter 3.

2 Australian continence data collections

2.1 Population health and disability surveys

Survey of Disability, Ageing and Carers (SDAC)

The ABS Survey of Disability, Ageing and Carers is Australia's primary source of national population data on disability. Data are gathered from both households and cared accommodation and cover both rural and urban areas in all states and territories. Information is collected on three population groups—people with a disability, older people (i.e. those aged 60 years and over), and carers or persons who provide assistance to older people and those with disabilities. Five surveys have been conducted, in 1981, 1988, 1993, 1998 and 2003.

A person is defined by the survey screening questions, as having a disability if they have any limitation, restriction or impairment which has lasted, or is likely to last, for at least 6 months and restricts everyday activities (ABS 2004b). A person with a disability may have a specific limitation or restriction, either a restriction in one or more core activities (self-care, mobility and communication) or a schooling or employment restriction. The severity of disability experienced is measured by the need for assistance with one or more activities. Therefore:

- Profound—a profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity task.
- Severe—a severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication.
- Moderate—a moderate core activity restriction refers to a person who has difficulty performing a core activity but does not need assistance.
- Mild—a mild core activity restriction refers to a person who has no difficulty performing a core activity but uses aids or equipment because of their disability.

Self-care, as defined as a core activity in the SDAC, includes showering or bathing, dressing, eating, toileting, and bladder or bowel control (ABS 2004b). Incontinence-related data items collected in the SDAC include:

- impairment or restriction as a result of head injury, stroke or other brain damage (Table 3.1a) (collected in 1998 but not in 2003);
- impairment or restriction which causes the most problems (not collected in 2003 SDAC) (Table 3.1a) (collected in 1998 but not in 2003);
- condition producing most restriction impairment (not collected in 2003 SDAC) (Table 3.1a) (collected in 1998 but not in 2003);
- self-care: level of assistance needed with bladder or bowel control (Table 3.1b);

- uses aids for incontinence (Table 3.1c)
- type of assistance primary carers usually provides: managing incontinence (Table 3.1c) (ABS 2004a).

National Health Survey (NHS)

The National Health Survey is a population survey designed to obtain national benchmark information on a range of health-related issues, and to enable changes in health to be monitored over time. Surveys so far completed were conducted in 1989–90, 1995, 2001 and 2004; the 2001 and 2004 surveys are the first two surveys in a new series of triennial ABS health surveys. The broad topics covered in the 2001 and 2004 surveys are similar to those included in the 1995 survey.

The content of the surveys in the NHS series has differed between surveys, around a common (or core) data set. The 2001 survey covered five main areas:

- Indicators of health status and injuries (e.g. self-assessed health status, health transition, quality of life scale, K10 scale to indicate psychological distress, long-term conditions focusing in particular on asthma, diabetes, cardiovascular and cancer).
- Health-related actions taken (visits to hospitals and day clinics, consultations with doctors, dentists and other health professionals, use of medications (for national health priority area conditions only), days away from work and other days of reduced activity).
- Health risk factors (e.g. smoking, alcohol consumption, diet, exercise, body mass, sun protection, breastfeeding, immunisation).
- Supplementary women's health items (e.g. breast and cervical cancer screening practices, contraceptive/protective behaviours, hormone replacement therapy, breastfeeding history).
- Demographic and socioeconomic characteristics (ABS 2002).

The NHS collects information on urinary incontinence as a long-term health condition; faecal incontinence is collapsed into the category 'Diseases of the digestive system', and the sub-category 'Symptoms and signs involving the digestive system (ABS 2002, 2003).

Women's Health Australia (WHA)

The Australian Longitudinal Study on Women's Health, or Women's Health Australia, is a large, longitudinal population-based survey of 40,000 Australian women over a 20-year period, which commenced in 1995. Researchers based at the University of Newcastle and University of Queensland are responsible for the management of the survey and dissemination of project results (see www. newcastle.edu.au/centre/wha/index.html for further information). The study was commenced in response to initiatives arising from the National Women's Health Policy and aims to collect women's health information relevant to the development of policy and best practice by Australian and State Government Departments of Health.

Three base year survey cohorts representing young (18–23 years), middle-aged (45–50 years) and older (70–75 years) women are surveyed every three years. Information is collected on five main themes—use of and satisfaction with health care services, life stages and key events, time use, weight and exercise, and violence. The study also links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database.

Continence information is collected using the following question (Table 3.1a):

> In the last 12 months have you had any of the following problems?
>
> Leaking urine: Never/Rarely/Sometimes/Often

Data on the efficacy of health service intervention for treating incontinence are also collected, based on the respondent's self-rated satisfaction with health services available to help the problem (Table 3.1c).

South Australian Health Omnibus Survey (SAHOS)

The South Australian Health Omnibus Survey was first conducted in 1990 and has run yearly since, primarily to assess health planning, delivery and evaluation. The survey is demand driven, where health organisations can purchase questions for inclusion in respective surveys (Wilson et al. 1992). General results stemming from each survey are provided to all clients, but responses to survey questions owned by different clients are not provided unless permission has been granted.

The population in scope are South Australians aged 15 years and over living in private dwellings (Wilson et al. 1992). Information is collected on health conditions, risk factors and demographics. Also included are a series of questions derived from utility measures such as the EuroQOL, AQOL and HUI–III, such as items on ease or limitation associated with executing activities (e.g. mobility, communication) and feelings of community connectedness.

The SAHOS incontinence module comprises questions on experience of frequent urination and urine leakage, and leakage or loss of control of stools and gas (Table 3.1a). Data on the need to wear continence pads for faecal incontinence are also collected (Table 3.1c).

2.2 Administrative data collections

Home and Community Care National Minimum Data Set (HACC NMDS)

The Home and Community Care Program, which is jointly funded by the Australian, state and territory governments, provides community care services to frail older people and their carers (around 80% of the HACC client population) and people of all ages with a disability, and their carers. The aim of the program is to enhance the independence of these people and avoid their premature admission to long-term residential care.

The HACC NMDS is client-based and collected nationally by HACC agencies every 3 months. Data are forwarded to the HACC National Data Repository at the Australian Government Department of Health and Ageing. HACC agencies include those organisations or organisational sub-units responsible for the direct provision of HACC-funded assistance to clients. Data collected per collection period are only on those clients who have received HACC-funded services from an agency within the 3-month reporting period. Therefore, not all clients may necessarily be included in each collection period nor the type(s) of assistance received from HACC-funded agencies (AIHW 2002b).

Incontinence is not separately identifiable in the HACC NMDS (V2.0) but it is subsumed within data items on assistance for personal care and self-care aids received respectively:

- primary type of assistance received: personal care (includes toileting);
- assistance with goods and equipment received: self-care aids (includes aids that assist with urinary incontinence, e.g. bag, incontinence pad, and faecal incontinence, e.g. colostomy bag, bowel pad) (Table 3.1c).

A new data item 'Functional status—additional items' includes a code for toileting, i.e. whether the person can manage the toilet, but no code for incontinence (Table 3.1b).

Ongoing Needs Identification (ONI) and Initial Needs Identification (INI)

The ONI and INI are two assessment tools developed by the Centre for Health Service Development at the University of Wollongong for use in various states and territories within HACC programs (see www.uow.edu.au/commerce/chsd/screening.html and www.health.qld.gov.au/hacc/ONInteractive.asp).

The ONI, developed for use in New South Wales and Queensland, includes items on continence and incontinence in the Health Conditions Profile. The ONI uses three incontinence items: experience of urine leakage, whether leakage events are related to coughing or sneezing, and experience of faecal soiling or change of bowel habit, which are documented in the Core ONI if identified as an issue for the client (Table 3.1a). The Queensland version of the ONI also uses a comment box to record any health conditions that may be associated with incontinence, and require further investigation.

A recent review of the ONI suggested use of alternative items on incontinence based on a review of relevant literature and current practice (CHSD 2005). These items record the frequency of urine leakage and faecal leakage or loss, the amount of urine loss, and a severity index for urinary incontinence derived from questions based on leakage and amount.

The INI, developed for Victoria and South Australia, does not include specific questions on continence although incontinence may be recorded within a section on (other) health conditions, where the client is asked to relate any relevant health problems experienced in the past that may relate to present problems or current conditions that are longstanding, persistent or recurrent. These health condition issues may be recorded as requiring action.

Aged Care Assessment Program Minimum Data Set (ACAP MDS)

The Aged Care Assessment Program (ACAP) is an Australian, state and territory government funded program to assess the needs of frail, older Australians and recommend and facilitate care services appropriate to a person's needs. ACATs, or Aged Care Assessment Teams, assess persons for recommended admission to residential care or residential respite, or the receipt of Community Aged Care Packages (AIHW 2002b).

The ACAP MDS specifies a collection of information on individual assessments. Between 1991 and 2001, the MDS underwent a review and then redevelopment, resulting in Version 2.0 of the data collection designed to report on the core work of ACATs (AIHW 2004c). The information collected by ACATs relates to client characteristics and circumstances, such as socio-demographic information, health status, functional abilities, current assistance from services, documentation of the assessment process, and components of the ACAT's care plan for the client, e.g. recommended long-term care setting.

Version 2.0 of the data collection includes data on incontinence, defined as a health condition and body function impairment:

- health condition, using ICD–10–AM codes: stress/urinary incontinence, bowel/faecal incontinence and unspecified urinary incontinence;
- body function impairment (based on ICF): defecation functions, urination functions (Table 3.1a);

and as an activity limitation, although management of incontinence is not separately identifiable and categorised within self-care (Table 3.1b).

Community Aged Care Packages (CACP)

The Community Aged Care Package (CACP) program was established in 1992 by the Australian Government to provide assistance to enable frail or disabled older people with complex care needs to continue living in the community (AIHW 2004c). Younger people with disabilities may also access a care package where there are no appropriate care options available in the area.

A CACP data dictionary was developed but has not been implemented as a national minimum data set. Information recorded regarding provision of CACPs is stored on ACCMIS, held by the Australian Government Department of Health and Ageing (AIHW 2004c).

A data item on core activity limitation, which collects information on the core activit(ies) in which an individual requires the help or supervision of another, includes codes for toileting and managing incontinence (Table 3.1b). Assistance received with personal care is captured in the data item 'Types of assistance received' but neither toileting nor managing incontinence can be identified separately (Table 3.1c).

Resident Classification Scale (RCS)

The Resident Classification Scale (RCS) data are collected on the care needs of clients residing in residential aged care facilities. Through information collected on the RCS form, all residents are categorised into a care category, which determines the level of subsidy an agency will receive in respect of that person (AIHW 2002b). RCS data are also stored on ACCMIS.

The appraisal used for the RCS does not consider all of a resident's care needs, just those that have been identified as contributing the most to differences in the total cost of residential care. New clients are assessed within 30 days of entering a residential aged care facility, and undergo reassessment every 12 months unless a significant change in care needs occurs.

The RCS uses two incontinence data items—bladder management and bowel management of the resident being assessed (Table 3.1b). These items record whether the resident is continent of urine or faeces, and if not, the level of support needed, in terms of use of continence aids and/or an individualised continence program.

A review of the RCS was commenced in 2002 with recommendations for the refinement of a reduced RCS question set, and development of complementary assessment tools. The Aged Care Funding Instrument (ACFI) is one product that has emerged from this process and is undergoing a national trial in 2005; it will be used to provide information on the care needs of residents in residential aged care facilities to determine government subsidy levels for each resident (see www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-rcspage-rcsreview.htm). The ACFI consists of 13 domains, of which domains 4 and 5 relate to toileting and continence respectively. The continence item consists of a checklist of 11 questions from which a person is rated as being continent (rating A), occasionally incontinent (rating B), frequently incontinent (rating C) or always incontinent (rating D) (Table 3.1b). The toileting item refers to use of a toilet and associated toilet hygiene; a person is rated as being independent, in need of supervision, or in need of physical assistance for each toileting care need.

National Continence Helpline (NCH)

The National Continence Helpline is a national telephone information, referral and counselling service, established under the National Continence Management Strategy and managed by the Continence Foundation of Australia. The helpline is staffed by continence nurse advisers and offers advice, information and clinic referrals to persons experiencing or caring for someone with urinary and/or faecal incontinence.

Information collected during each call is entered into the helpline database. Depending on the nature of the call, data may be collected on the:

- nature of the call (e.g. type of incontinence, aids and equipment);
- reason for call (e.g. product and surgical procedure information, financial assistance, educational literature, preventative measures);
- caller type (professional, carer or client);
- response to call (e.g. referral, literature sent);
- caller characteristics (e.g. age, gender, ethnicity) (Continence Foundation of Australia 2004, personal communication).

The Continence Foundation collates quarterly results for analysis and reporting to the Australian Government Department of Health and Ageing.

The NCH includes two relevant data items—continence issue, whereby the type of incontinence is recorded (Table 3.1a) and reason for call, where clients may be ringing for information on aids and equipment (e.g. their use, access) (Table 3.1c).

Continence Aids Assistance Scheme (CAAS)

The Continence Aids Assistance Scheme is an Australian Government program introduced in 1993 which aims to assist people of working age with permanent or ongoing incontinence resulting from a neurological condition or severe intellectual impairment to defray the cost of continence management. Clients receive a subsidy of $470 per annum on continence aids ordered through Intouch.

Information collected by the contractor relates to client orders, client expenditure against their subsidy allocation, complaints and financial information. One data item on incontinence is included in the CAAS collection, i.e. type of incontinence experienced by the client. Incontinence is recorded as urinary, bowel or urinary and bowel (Table 3.1a). The aids received by a CAAS client are also recorded as a separate data item (Table 3.1c).

2.3 Health service data collections

Bettering the Evaluation and Care of Health (BEACH)

The BEACH project is a continuous collection of morbidity and treatment data from a random sample of 1,000 GPs across Australia, who provide information on approximately 100 GP–patient encounters. Approximately 20 GPs participate each week, 50 weeks a year (see www.fmrc.org.au/beach.htm).

The aim of BEACH is to provide a quality database of GP–patient encounter information from which general practice data can be used by government bodies, GP organisations, consumers, researchers, and the pharmaceutical industry, amongst others. BEACH uses three interrelated data collections: encounter data (e.g. reasons for encounter, problems managed, medications prescribed and other treatments); GP characteristics (e.g. age, sex, years in practice, practice size); and patient characteristics (e.g. age, sex, Aboriginal and Torres Strait Islander status).

Potential data items on incontinence from the BEACH collection include reasons for encounter and problems managed, coded using ICPC–2 PLUS (Table 3.1a). Medical interventions prescribed to alleviate incontinence are recorded in the data items clinical treatment, imaging and pathology tests ordered, and medications/vaccinations prescribed for diagnosis/problem (Table 3.1c).

Community Nursing Minimum Data Set Australia (CNMDSA)

The CNMDSA was developed by the Australian Council of Community Nursing Services (ACCNS) in 1994 and is based on domiciliary nursing services (through membership of the ACCNS) (AIHW 2002b). The purpose of the data set is to produce useable data for policy makers and to standardise data items on nursing for use in planning and monitoring at the clinical and management levels. Data have been collected by some domiciliary care services but collection is not mandatory and no national data set of all relevant agencies exists.

The CNMDSA collects data on both nursing diagnosis (based on the North American Nursing Diagnosis Association codes) and medical diagnosis (ICD–10–AM codes) for recipients of care, from which incontinence can be identified. An additional item on dependency in activities of daily living measures the severity of the incontinence as the frequency of incontinent episodes over a daily period.

National Hospital Morbidity Database

The National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals. Data related to admitted patients in almost all hospitals are included: public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities (AIHW 2005b).

The database records information on 'hospital separations' and not patients, where a separation refers to the episode of care, which can be a total hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in type of care (AIHW 2005b). Diagnoses, procedures and external causes are recorded.

Incontinence may be recorded, using ICD–10–AM codes, as a principal or additional diagnosis responsible for a patient's episode of care in hospital. Data items on surgical and non-surgical procedures that are relevant to incontinence are also included, again based on ICD–10–AM codes. A list of procedure codes are given in AIHW (2002b).

Medicare Benefits Scheme (MBS)

The Medicare Benefits Scheme provides free or subsidised treatment by practitioners such as general practitioners, specialists, participating optometrists and dentists. These subsidies mostly cover out-of-hospital medical services but also apply to medical services delivered in hospitals to private patients. The Health Insurance Commission (HIC) is responsible for administering payments and information for the Medicare program.

MBS data collected by HIC cover only those services eligible for Medicare benefits, as listed in the Medicare Benefits Schedule. The MBS data include Medicare item number, Medicare benefit, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. Eight Medicare item numbers refer to procedures and operations used specifically for urinary or faecal incontinence (Table 3.1c).

Pharmaceutical Benefits Scheme (PBS)

The Pharmaceutical Benefits Scheme (PBS) is also administered by the HIC and was set up to reimburse pharmacists who have dispensed eligible prescription pharmaceuticals at a cost greater than the patient's contribution. The PBS data collection includes information on prescriptions dispensed to general patients where a pharmacist is eligible for a reimbursement, prescriptions dispensed to persons who have been issued a health care card, or those who have reached the safety net threshold.

The HIC website contains aggregate statistics, based on PBS items and group categories, for each state and territory (see www.hic.gov.au/providers/health_statistics/statistical_reporting/pbs.htm). Data comprises drug codes as classified in the Pharmaceutical Benefits Schedule (Table 3.1c).

3 Mapping and comparability of continence data items

3.1 Definitions of incontinence

Definitions of incontinence used in the clinical and research fields vary; while all define incontinence as the loss of, or inability, to control urination or defecation, they differ as to what degree of loss constitutes incontinence *per se*. The 3rd International Continence Society defined urinary incontinence as the 'complaint of any involuntary leakage of urine' (Abrams et al. 2002a:168), whereas many clinical and research definitions focus on frequency or amount of loss over a given time period. This variation has produced a wide range of prevalence estimates, especially for urinary incontinence (see discussion in Part A, Chapter 3).

The ICF classifies continence either or both as a body function or a self-care activity. As a body function, it is classified as a urination function (urinary continence) or defecation function (faecal continence and flatulence), where incontinence is an impairment of that function. Continence as a component of self-care is classified as a toileting activity involving the regulation of urination or defecation. Regulating is defined in the ICF as 'coordinating or managing'. A problem with regulating continence, or incontinence, is hence classified as an activity limitation.

3.2 Key themes

Continence data collected in Australia encompass two key themes—incontinence as an impairment or activity limitation, and the sorts of assistance or measures people experiencing incontinence need, rely on or have used to manage or alleviate their incontinence. Within these themes, four primary types of data items are routinely collected in Australian data collections—incontinence as an impairment, incontinence as an activity limitation, assistance needed to manage incontinence, and medical interventions to relieve incontinence, such as medications and surgical procedures.

Tables 3.1a, 3.1b and 3.1c maps these data items to the ICF. The first primary data item, incontinence as an impairment, maps broadly to the ICF component of Body functions, and more specifically to Urinary continence (ICF code b6202) and Faecal continence (ICF code b5253). The second primary data item, of incontinence as an activity limitation, maps to the ICF component of Activities and Participation, and the area of Toileting (ICF code d530), or Regulating urination and defecation (ICF codes d5300 and 5301 respectively).

The theme of assistance and intervention relates to Environmental factors, i.e. factors which make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO 2001). The more general forms of assistance—personal assistance and aids and equipment used—map to the chapter headings of support and relationships (ICF code 3340 Personal care providers and personal assistants) and products and technology (ICF code 1151 Assistive products and technology for personal use in daily living) respectively.

Medical treatment and intervention map to both Products and technology (primarily, for medication prescription and use—ICF code e1101 Drugs) and services, systems and policies, or more specifically, health services (ICF code e5800 Health services).

Results from the mapping exercise presented in Tables 3.1a, 3.1b and 3.1c and are discussed below in Section 3.3.

3.3 Data item comparability

The scope and purpose of the data collections described in Chapter 2 determine the sorts of incontinence-related data items included in each collection, and hence the detail of incontinence information collected. This section compares the use and mix of primary incontinence data items in Australian data collections as tabulated in Tables 3.1a–c, and describes how comparable primary data items are between collections.

With few exceptions, most of the collections reviewed do not include data items corresponding to the ICF component of Body structures or other sub-components of Activities and Participation. The latter omission stands in contrast to the focus of many incontinence symptom and quality of life assessment tools (see Section 3.4 for further discussion).

Body function items

Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)

Continence data items included in most data collections characterise incontinence as an impairment of urinary or faecal continence (Table 3.1a).

The SDAC includes data items which describe incontinence as an impairment (and as a self-care activity limitation—see below) associated with a health condition. That impairment may be identified as the main restricting impairment associated with a health condition, the impairment causing the most problems, or a long-term impairment/restriction resulting from head injury, stroke or other brain damage.[2]

The population health surveys WHA and SAHOS use impairment-related data items derived from a series of questions on typical problems associated with incontinence, e.g. urine and faecal leakage and, in SAHOS, the bothersomeness and severity of that leakage. In SAHOS, up to 8 and 7 urinary and faecal continence questions respectively can be used to determine the experience and severity of incontinence.

Impairment data items from the population health and disability surveys are often used to estimate the prevalence of incontinence in Australia. However, the different definitional approaches used in these collections potentially produce varying estimates, and could make comparison between estimates difficult. This is further confounded by some data collections, such as the NHS and ACAP MDS, and the ONI and INI assessment tools using data items in

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[2] The 1998 SDAC includes data items as described; the 2003 SDAC only includes incontinence in the data items on long-term impairment/restriction resulting from head injury, stroke or other brain damage.

Table 3.1a: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Body functions)

Body functions: Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)									
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS[a]**		**HACC (QLD ONI)**	**ACAP MDS**	**CACP**	**RCS/ACFI**
Data item	Restriction or impairment causing the most problems Condition producing main restricting impairment Long-term restriction as a result of head injury, stroke or other brain damage		Experienced 'leaking urine' in the last 12 months?	Experienced following problems and how much bothered by them: (a) frequent urination (b) urine leakage (c) small amount of urine leakage Small amount of leakage (drops)?	Experienced urgent need to have a bowel movement that makes you rush to the toilet Experienced leakage, accidents or loss of control with (a) solid stool (b) liquid stool or (c) gas or (d) if you don't get to a toilet in time	2004: (i) Leaking urine? (ii) Is this related to coughing or sneezing? (iii) Faecal soiling/change of bowel habit? 2005: (i) Frequency of urine leakage (ii) Amount of urine lost (ii) Frequency of faecal leakage	Body function impairment		
Data domain or codes	17 Incontinence (bladder or bowel)		1 Never 2 Rarely 3 Sometimes 4 Often	1 Not at all 2 Slightly 3 Moderately 4 Greatly 5 Refused	1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refuse	See (b) in table notes	Four-digit code based on ICF: 6003: Defecation functions 7002: Urination functions		
Collection	**NCH**	**CAAS**	**BEACH**	**CNMDSA**		**NHMD**	**MBS**	**PBS**	
Data item	Continence issue	Continence type	Reasons for encounter Problems managed	Nursing diagnosis	Medical diagnosis	Principal diagnosis Additional diagnosis			
Data domain or codes	Faecal Urinary Faecal and urinary	1 Urinary 2 Bowel 3 Urinary and bowel	ICPC-2 PLUS codes	North American Nursing Diagnosis Association codes	ICD-10-AM codes	ICD-10-AM codes			

(a) Questions from 2004 SAHOS.

(b) Domain for 2004 QLD ONI: Leaking urine or faecal soiling: 1 Never 2 Sometimes 3 Often; Domain for 2005 QLD ONI (suggested): Frequency of urine leakage: 0 Never 1 Less than once a month 2 One to several times a month 3 One to several times a week 4 Every day and/or night; Amount of urine lost each time: 1 A few drops 2 A little 3 More; Frequency of faecal leakage or loss: 0 Never 1 Rarely (less than once in past 4 weeks) 2 Sometimes (less than once a week, but more than once in past 4 weeks) 3 Often or usually (less than once a day but more than once a week) 4 Always (more than once a day).

Note: Collection abbreviations can be found in Chapter 2 description of data collections.

Table 3.1b: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Activities and Participation)

Activities and Participation: Self-care (Toileting) (ICF codes d5300 Regulating urination and d5301 Regulating defecation)								
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS**	**HACC NMDS**	**ACAP MDS**	**CACP**	**RCS/ACFI**
Data item	Level of assistance needed with bladder/bowel control				Functional status: ability to manage the toilet with or without help	Activity limitation: activity in which help or supervision of another individual is needed	Core activity in which the help or supervision of another individual is needed	RCS: Bladder management [(a)]; Bowel management[(b)] ACFI: Incontinence management
Data domain or codes	1 Always needs help or supervision 2 Sometimes needs help or supervision 3 Does not need help or supervision but has some difficulty 4 Has no difficulty with bladder or bowel control				Only toileting	Self-care Managing incontinence is not separately identifiable	4: Toileting 5: Managing incontinence	RCS: A Not applicable — continent B Some support C Major support D Extensive support ACFI:[(c)] A: Continent B: Occasionally incontinent C: Frequently incontinent D: Always incontinent
Collection	**NCH**	**CAAS**	**BEACH**	**CNMDSA**	**NHMD**	**MBS**	**PBS**	
Data item				Dependency in activities of daily living: a person's ability to carry out activities				
Data domain or codes				1 Continent 2 Incontinent less than daily 3 Incontinent once/24 h 4 Incontinent 2–6 times/24 h 5 Incontinent more than 6 times/24 h 6 Incontinent more than once a night only				

(a) RCS Bladder management data domain: Not applicable—person is continent of urine; Some support—person would be occasionally incontinent but continence supported by prompting only or wears external continence aids occasionally; Major support—person wears continence aids at all times related to frequent incontinence that cannot be improved by a continence program but, for behavioural or other reasons, cannot use continence aids; Extensive support—person would be frequently incontinent but has individualised continence program in place to optimise continence level.

(b) RCS Bowel management data domain: Not applicable—person is continent of faces; Some support—person wears continence aids at all times related to frequent incontinence that cannot be improved by a continence program; Major support—person's constipation is prevented or continence level maintained by a bowel management program; Extensive support—person would usually be incontinent but has an individualised continence management program in place to optimise continence level.

(c) Continent—continent of urine or faeces or self manages continence devices; Occasionally incontinent—incontinent of urine less than or equal to once per day, or incontinent of faeces less than or equal to once per week, or continent with regular prompting to manage occasional urinary and/or bowel incontinence or disorder; Frequently incontinent—incontinent of urine 2 to 3 times per day; or incontinent of faeces 2 to 3 times per week, or continent with a continence management program to manage frequent urinary and/or bowel incontinence or disorder; Always incontinent—incontinent of urine more than 3 times per day; incontinent of faeces more than 3 times per week, or continent with a continence management program to manage a person who is always incontinent of urine and/or faeces.

Table 3.1c: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental factors)

Environmental factors: Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)									
Collection	**SDAC**		**NHS**	**WHA**	**SAHOS**	**HACC NMDS**	**ACAP MDS**	**CACP**	**RCS/ACFI**
Data item	Uses aids for incontinence	Type of assistance primary carer usually provides to main recipient of care			Need to wear continence pad (bowel incontinence)	(i) Primary type of assistance received (ii) Assistance with goods and equipment received	Recommended formal assistance with activities	Type of assistance received	
Data domain or codes	1 Uses incontinence aid(s) 2 Does not use incontinence aid(s) but uses other aids(s) 3 Does not use aid(s)	1 Usually assists with managing incontinence 2 Does not usually assist with managing incontinence			1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refused	(i) 5: Personal care Toileting, not incontinence (i) Self-care aids Continence aids identified by the code (04) and (05) but are recorded as self-care aids	Self-care Incontinence is not separately identifiable	1: Personal care Personal care includes assistance with daily self-care tasks such as toileting and managing incontinence. Incontinence is not separately identifiable	
Collection	**NCH**		**CAAS**	**BEACH**	**CNMDSA**	**NHMD**	**MBS**	**PBS**	
Data item	Continence issue Reason for call	Product currently used(a)	Type of CAAS aids received						
Data domain or codes	Aids and appliances		List of Service Administrator's catalogue codes						

(a) NCH product codes include CISC, Commode, pan or urinal, Cones, Deodorant, Chair pad, Feminine hygiene pad, IDC or SP Catheter, Incontinence garments, Penile pad, Personal alarm, Plastic sheet, Anal or urethra plug, Anal/urethral or stoma pouches, Reused bed sheets or chair pads, Skin-care products, Towels/handkerchief/tissues, Urodome and Nil.

Table 3.1c (continued): Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental factors)

Environmental factors: Medical interventions (ICF codes e1101 Drugs and e5800 Health services)								
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS**	**HACC NMDS**	**ACAP MDS**	**CACP**	**RCS/ACFI**
Data item		Medications used	Satisfaction with health services available to help with problem					
Data domain or codes		0037: Other genitourinary	1 Yes 2 No 3 Not applicable					
Collection	**NCH**	**CAAS**	**BEACH**	**CNMDSA**	**NHMD**	**MBS**	**PBS**	
Data item			Drugs prescribed Imaging and pathology tests Clinical treatment	Procedure (surgical)	Procedures (surgical and non-surgical)	Procedures qualifying for Medicare Benefits	PBS drug items	
Data domain or codes			ICPC-2 codes	ICD-10-AM codes	ICD-10-AM codes	MBS item codes	PBS drug item codes	

which incontinence is described as a health condition. The ICF defines health conditions as a 'disease or disorder', and the context in which an impairment of a body function (or an activity limitation or participation restriction) exists and is affected. Further discussion on definition and prevalence estimates can be found in Part A of the report.

In the NHMD and CNMDSA collections, incontinence as an impairment is identified by 'principal' and 'additional diagnosis' (NHMD) and 'medical diagnosis' (CNMDSA) and coded using ICD–10–AM. CNMDSA also employs North American Nursing Diagnosis Association codes to code the data item 'nursing diagnosis'. Depending on the level and interpretation of the diagnosis, this data item can map to health condition or an impairment of urinary/faecal continence function. BEACH uses two data items to indicate impairment (or health condition)—reason for encounter and problem managed—coded using ICPC–2 PLUS.

All collections allow differentiation between the two forms of incontinence, except SDAC which groups bladder and bowel incontinence under incontinence.

Activities and Participation items

Toileting (ICF codes d5300 Regulating urination and d5301 Regulating defecation)

Incontinence associated with the activity of toileting, and the management of that activity, is a concept almost exclusively used in administrative data collections measuring the need for support in activities of daily living. Toileting and continence map to the ICF codes d5300 Regulating urination and d5301 Regulating defecation, where regulating is defined as 'coordinating and managing, such as by indicating need, getting into the proper position, choosing and getting to an appropriate place…, manipulating clothing before and after…, and cleaning oneself after…'. An individual who experiences difficulty in completing any aspect of this activity is considered to have an activity limitation, which may be relieved through reliance on some form of assistance.

Data items used in the ACAP MDS, CACP, RCS (and ACFI) and CNMDSA collections effectively define incontinence as an activity limitation, where the help or supervision of another individual is needed (Table 3.1b). The SDAC also includes a data item on activity limitation related to incontinence. How information on this limitation is collected differs between collections and data items do not map exclusively to Activities and Participation. This is particularly apparent for the incontinence items used in the SDAC, RCS and CNMDSA collections. While both the SDAC and RCS (and ACFI) items record limitation or difficulty managing incontinence, their data domains enlist assistance, support or equipment, i.e. environmental factors, as a means to measure that limitation or difficulty. For example, the SDAC data item refers to always, sometimes or not needing help or supervision with managing bladder and bowel control and the RCS items of bladder and bowel management support are defined by frequency of aid use and effect of a continence program (see Table 3.1b).

The CNMDSA data item focuses on 'dependency' in activities of daily living, in which remaining continent is defined as an activity. Unlike the SDAC and RCS collections, the data domain for this item does not reference environmental factors of assistance or support but assesses how often an individual experiences episodes of incontinence over a 24-hour period i.e. a problem or impairment with the function of continence.

Environmental factors items

Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)

The concepts of assistance and equipment relate to the ICF component Environmental factors, and more specifically to the areas of Products and technology (for aid and equipment use) and Support and relationships (for personal assistance).

Information on the use of aids and equipment is collected in the NCH, CAAS, SDAC, SAHOS and HACC NMDS collections. The NCH and CAAS collections provide a more comprehensive picture of aid use, i.e. the sorts of aids used (and needed). Aid use and need are identified more simply in the SDAC and HACC NMDS collections—whether an individual uses aids for incontinence and the primary type of assistance received—although continence aids in the HACC NMDS are grouped with self-care aids and not separately identifiable. The SAHOS includes a data item on need to wear continence pads for faecal incontinence, and the frequency of the need to use pads. This data item complements the suite of data items used in SAHOS to measure severity of incontinence experienced.

While data items on personal assistance are collected in the administrative data collections HACC NMDS, ACAP MDS and CACP, data are collected about self-care, with no specific detail on continence-related activities. The SDAC, however, does include a data item on personal assistance for managing incontinence but, unlike the data item on aid use, this data item is collected from the perspective of the caregiver, not the individual experiencing incontinence.

Medical treatment and procedures (ICF codes e5800 Health Services and e1101 Drugs)

Data items on medical intervention are almost the sole focus in the health service collections BEACH, CNMDSA, NHMD, MBS and PBS. Medical treatment and procedures for alleviating incontinence map (roughly) to the area of Health services, systems and policies (ICF code e5800), and more specifically to Health services, or 'services and programmes at a local, community, regional, state or national level, aimed at delivering interventions to individuals for their physical, psychological and social wellbeing…' (WHO 2001:203). Procedures, however, more closely map to other classification systems, namely the Australian Classification of Health Interventions and ICPC–2. The range of procedures potentially used to alleviate incontinence are too numerous to repeat here.

BEACH includes data items on clinical treatment prescribed and any tests (e.g. pathology) requested by the general practitioner, which may be linked through analysis to problem treated (i.e. incontinence). Information on surgical and non-surgical procedures relevant to incontinence is collected in the CNMDSA and NHMD (using ICD–10–AM codes) and MBS (MBS item codes for procedures qualifying for Medicare Benefits) collections.

Drugs are another environmental factor that can alleviate an impairment or activity limitation such as incontinence. Three collections include data items on drugs prescribed or used to treat incontinence or related symptoms—BEACH (drug labels prescribed), PBS (drug items prescribed under the PBS), and NHS (medications used for genitourinary conditions). However, identification of drugs used specifically to manage incontinence is complex.

3.4 Comparability with continence assessment tools

With few exceptions, most of the collections reviewed do not include data items corresponding to the ICF component of Body structures or other sub-components of Activities and Participation. The latter omission stands in contrast to the focus of many incontinence symptoms and quality of life assessment tools, discussed in this section.

The consequences of incontinence for general wellbeing are not only affected by the type and severity of incontinence but also by an individual's environment and psychosocial adjustment to the condition. Abrams et al. (2002b) have recommended that any assessment of an individual with incontinence should include:

- a history and general assessment, including questions on nature and duration of symptoms, previous surgical procedures, environment, mobility, cognitive status, and bowel function;
- assessment of symptoms, such as frequency of incontinence, perceived quantity of leakage, and perceived impact of leakage;
- measurement of symptoms (e.g. urodynamics), using bladder and bowel charts etc.;

and when appropriate symptom indications are present:

- further symptom and quality of life assessment, using functional outcome validated questionnaires.

Standard clinical tests, such as urodynamics assessments, tend to associate poorly with symptoms and functional outcomes, and so a broad range of continence assessment tools have been developed to measure both symptoms and effects on wellbeing. These assessment tools comprise two main types—the assessment of symptoms of incontinence and the assessment of functional outcomes, or the effects of incontinence on quality of life. The latter group of tools are generally classified as either condition-specific or a more generic measure (Naughton et al. 2004).

Such tools are often used in concert to measure the effect of incontinence and the outcome of treatment methods, the latter through objective measures of reduction in the severity of incontinence (e.g. frequency of, and amount, leaked or voided) and subsequent assessment of improvement in quality of life.

Functional outcome assessment tool and utility index items

The number of functional outcome assessment tools (and utility indexes) in use is extensive. The Continence Outcomes Measurement Suite Project recently investigated this range of continence outcome measurement tools to recommend specific tools for use in Australia by (a) primary care practitioners involved in the delivery of health services to people with incontinence, (b) specialist incontinence practitioners and (c) incontinence researchers (Thomas et al. 2005). The recommended assessment tools followed a review of the research literature, consultations with practitioners and discussion with measurement experts. An extension of this project was the inclusion of five health-related quality of life instruments utility indexes in the 2004 SAHOS, for their evaluation of the effect of incontinence and intervention on quality of life. The results indicated that while four of the five instruments produced similar scores and score variation, there were differences in sensitivity, and two instruments—AQOL and HU13—proved to be better measures in terms of validity and reliability (Hawthorne & Sansoni 2004; Thomas et al. 2005).

Given the wide range of tools a select, but representative, group has been chosen for the present study, to assess comparability. The selection was based on recommendations made by Thomas et al. (2005) and an earlier evaluation conducted by the 2nd International Consultation on Urinary Incontinence (reviewed in Naughton et al. 2004).

Outcome assessment tool and utility index items are mapped to the ICF in Table 3.2. Continence assessment tools focus on symptoms and the effects of these symptoms. Items map mainly to the ICF components of Body functions and Activities and Participation respectively, and to a lesser extent Environmental factors.

Tools to assess the symptoms of urinary incontinence listed in Table 3.2 are the Urogenital Distress Inventory (UDI), including the UDI 6 short form, King's Health Questionnaire (KHQ), Incontinence Symptom Severity Index (ISSI), and ICS Male, and the Wexner Faecal Incontinence Score, for faecal incontinence. The urinary incontinence symptom tools focus specifically on frequency (KHQ and ISSI), amount of leakage (UDI and ISSI), type of incontinence (all except ISSI), voiding problems (UDI, KHQ and ICS*male*) and pain (UDI and KHQ). The Wexner scores frequency of different forms of faecal incontinence (solid, liquid and gas), use of pads, and impact on lifestyle.

Condition-specific quality of life tools mostly focus on the impact incontinence has on a person's participation in various life areas. The most common life areas covered in the tools and mapped to the ICF are:

- domestic life (shopping, maintenance work, housework)
- interpersonal interactions and relationships (intimate and family relationships, and friendships)
- major life areas (employment)
- community, social and civic life (social life, recreational and religious activities).

These life areas relate to the more broadly defined participation groupings used in generic quality of life measures, e.g. 'social limitations', 'role limitations'.

Generic health-related quality of life (HRQOL) measures also, unlike most condition-specific HRQOL tools, measure the impact on activities, such as mobility and self-care (e.g. hygiene, eating and drinking) and a range of body functions such as cognition, vision, hearing and pain.

Emotional response to incontinence is another important item included in condition-specific and generic QOL measures, such as the experience of depression, anxiety, embarrassment and frustration. These responses are in part a result of the attitude of others towards incontinence (another environmental factor) but also the individual's feelings towards the manageability of the condition, especially for those with more severe forms.

With the exception of ICIQ and the Wexner, which include an item on protection use, there is little consideration of equipment and products used to manage incontinence or the sorts of environmental factors that could improve manageability of the condition. AQOL scores the frequency of use of medical aids and visits to health professionals.

Table 3.2: Mapping of items from continence assessment tools to the ICF

Body functions

Chapter heading (ICF)	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
Mental functions	b130 Energy and drive functions	Energy	KHQ		SF-36
	b134 Sleep functions		KHQ	MUSIQ	AQOL, SIP
	b152 Emotional functions		KHQ	IIQ, U-IIQ, MUSIQ, LIS	SIP, AQOL, HU13, EQ5D, SF-36
	b164 Higher-level cognitive functions	Cognition			HU13
Sensory functions and pain	b210 Seeing functions				AQOL, HU13
	b230 Hearing functions				AQOL, HU13
	b280 Sensation of pain	Discomfort and pain	UDI, KHQ		AQOL, HU13, EQ5D, SF-36
Functions of the digestive, metabolic and endocrine systems			WEX		
Genitourinary and reproductive functions	b610 Urinary excretory functions b620 Urination functions b630 Sensations associated with urination functions	Incontinence symptoms	KHQ, UDI, ICIQ, ISSI, ICS*male*, MUDI		

Activities and Participation

Chapter heading	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
Communication	d310 Communicating with—receiving—spoken messages and d330 Speaking				AQOL
Mobility	d440 Fine hand use	Dexterity			HU13
	d450–d469 Walking and moving	Ambulation			SIP, HU13, EQ5D
	d470–d489 Moving around using transportation	Travelling by car or bus		IIQ	AQOL
Self-care		Personal care and hygiene		LIS	SIP, EQ5D

Table 3.2 (continued): Mapping of items from continence assessment tools to the ICF

Activities and Participation (continued)					
Chapter heading	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Condition-specific	Generic/utility index
	d550 Eating and d560 Drinking	Eating/drinking			SIP
Domestic life	d6200 Shopping	Shopping		IIQ, U-IIQ, MUSIQ, LIS	
	d640 Doing housework	Housework		IIQ, LIS	SIP, AQOL
	d650 Caring for household objects	Maintenance work		IIQ, U-IIQ	AQOL, SIP
Interpersonal interactions and relationships	d750 Informal social relationships	Relationships	KHQ	IIQ, U-IIQ, MUSIQ	
	d7500 Informal relationships with friends	Visiting friends		IIQ, U-IIQ	AQOL
	d760 Family relationships	Family life		LIS	AQOL
	d7702 Sexual relationships	Sexual activities	ICIQ	IIQ, MUSIQ, LIS	
Major life areas	d480–d859 Work and employment	Employment		IIQ, LIS	SIP
Community, social and civic life	d910 Community life	Voluntary work		IIQ	
	d920 Recreation and leisure	Recreational activities		IIQ, U-IIQ	SIP, AQOL
	d9200 Sports	Exercise		U-IIQ, MUSIQ	
	d9204 Hobbies	Hobbies		IIQ, MUSIQ, LIS	
	d930 Religion and spirituality	Religious activities		IIQ, U-IIQ	
	d9205 Socialising	Social life	KHQ, ICIQ	IIQ, U-IIQ, LIS	SIP

Table 3.2 (continued): Mapping of items from continence assessment tools to the ICF

Environmental factors					
Chapter heading	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Condition-specific	Generic/utility index
Products and technology	e1101 Drugs	Use of prescribed medicine			AQOL
	e1151 Assistive products and technology for personal use in daily living	Protection use and type	ICIQ, WEX		AQOL
Support and relationships	e310 Immediate family	Stability of support		MUSIQ	
	e355 Health professionals	Medical treatment from doctor or health professional			AQOL

Notes

1. AQOL = Assessment of Quality of Life, EQ5D = EuroQOL 5D, HU13 = Health Utilities Index Mark 3, ICIQ = International Consultation on Incontinence Questionnaire, ICSmale = International Continence Society male questionnaire; IIQ = Incontinence Impact Questionnaire, ISSI = Incontinence Symptom Severity Index, KHQ = King's Health Questionnaire, LIS = Leicester Impact Scale, MUDI = Male Urogenital Distress Inventory, MUSIQ = Male Urinary Symptom Impact Questionnaire, SIP = Sickness Impact Profile, UDI = Urogenital Distress Inventory, U-IIQ = Urge-Incontinence Impact Questionnaire, WEX = Wexner Faecal Incontinence Score.
2. A small proportion of assessment tools assess impact on 'everyday life', 'lifestyle' or 'usual activities' etc. rather than defining specific activities, and these items therefore can not be mapped to the ICF. These include the Wexner Faecal Incontinence Score, ICIQ and EQ5D.

Sources: Avery et al. 2004c; Bergner et al. 1981; Donovan et al. 1996; Handa & Massof 2004; Hawthorne et al. 2000; Health Utilities Incorporated 2004; Kelleher et al. 1997; Lubeck et al. 1999; Naughton et al. 2004; Robinson & Shea 2002; Shaw et al. 2004; Thomas et al. 2005; van der Vaart et al. 2003

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Comparability with Australian incontinence data items

Overall, there is some overlap between information collected in Australian data collection and incontinence assessment tools, after comparison of Tables 3.1a–c and 3.2. This overlap is largely at the Body function component with only minimal overlap at other components. Body function items used in assessment tools tend to be more detailed than those collected in data collections, reflecting the use of such tools to describe the symptoms of incontinence.

The most consistent difference between assessment tools and incontinence data collections is the coverage of participation, and to some extent activities, and environmental factors respectively. All the quality of life assessment tools, and some symptom-based tools, include activity and participation items and, while the breadth of these items varies between tools, most have items where respondents rate how incontinence has affected their domestic life, relationships, employment and community and social life. None of the data collections include data items on participation as affected by incontinence specifically, although generic participation items in collections such as the SDAC do allow analytical investigation of participation restrictions associated with incontinence.

In contrast, continence assessment tools tend not to look at the sorts of environmental factors that may affect a person's experience of incontinence, whereas many of the data collections do. The omission of equipment and assistance are conspicuous examples; ICIQ and the Wexner are the only assessment tools reviewed here which include an assistance item, in this case protection use and type. Assistance is not consistently covered in Australian data collections but some sort of relevant 'assistance' data item(s) are included in the four administrative data collections, and the national disability collection (SDAC).

4 Promoting consistency in continence data collections

4.1 A menu of data items

The differences in purpose and operational context of the data collections reviewed have produced varying 'interpretations' of incontinence (for example, incontinence as an impairment versus incontinence as an activity limitation). Hence the assemblage of data items used to collect information on incontinence also varies. An important finding of the review was that none of the collections contained a definition of incontinence. Some collections contained an implicit definition but most essentially offered items relevant to incontinence from which a user could create their own definition and estimate related prevalence numbers.

The purpose of this report is not to define incontinence but to outline key themes and options for potential data item sets useable in a wide range of collections and/or assessment tools. If these items are used as a standard 'menu', and if context and purpose is taken into account, this would promote greater consistency and comparability across the field, and greater quality in many collections and tools.

The recommendations listed below were developed with reference to both the general themes currently collected in Australian data collections and those in continence symptom and quality of life assessment tools.

In the process of developing these recommendations, it was essential that proposed data items were:

- independently valid yet retained a level of inter-relation and complementarity for more detailed analysis, and
- appropriate to the general context and scope of an administrative data collection.

A multidimensional concept

Australian data collections generally collect information about incontinence as an impairment of body function and/or as an activity limitation, and about the assistance and measures people experiencing incontinence use or need to manage or relieve their incontinence. The results from the review indicate that 'continence' and 'incontinence' are an multidimensional concept that may draw on different components of the ICF model.

A person's functioning is an amalgam of body functions, the activities they engage in, and their participation in life areas, influenced by environmental factors and their personal characteristics (WHO 2001). To collect concise information on functional status, a composite of data items capturing these components is essential. For information on the functional status of a person with incontinence, this composite of items may be categorised as:

- identification/'diagnostic'
- measure of severity

- assistance and aid use
- participation.

Such data items enable description of the prevalence and severity of incontinence amongst the collection’s population, the support available or needed to manage the condition, and how participation in life areas may be affected by incontinence, and potentially improved when support is received.

This composite or menu of data items, however, needs to be flexible enough for inclusion in data collections with different focuses and purposes.

Functioning and Related Health Outcomes Module (FRHOM)

The AIHW is currently developing a Functioning and Related Health Outcomes Module, or FRHOM, which can be used to collect data on functioning, and to relate to other sources of functioning information gathered in assessment and other measurement tools. The FRHOM will provide summary level information on functioning with reference to body function impairments, activities and participation, and the influence of the environment (AIHW forthcoming). The information derived from the module can be used to describe a person’s health status, outcomes of health interventions, and the need for assistance in areas of human functioning.

The FRHOM is to undergo pilot testing focusing on specific health conditions (e.g. acquired brain injury, cardiovascular disease). The final product may be used as an additional template for future refinement of the third incontinence module presented in Section 4.4.

4.2 Proposed data items

The proposed data items presented below are described with reference to the ICF components of Body functions, Activities and Participation, and Environmental Factors, and the concept of severity. Other demographic items relating to age, sex, Indigenous status of the respondent, and carer availability are available on METeOR (see Chapter 1 for URL).

Health condition (‘Diagnosing’ incontinence)

Incontinence as a health condition will not be discussed here, chiefly because incontinence does not appear to be an ‘identifiable’ health condition. Although ICD codes are used in health services collections, such as BEACH and the National Hospital MDS (see AIHW 2002b) to denote incontinence (Table 3.1a), this method may only be appropriate for the purposes of these sorts of collections. The very complexity of incontinence, incorporating the dimensions of body function, activity limitation and participation restriction, necessitates a method of identification that is broader than one based solely on body-related information.

Body functions

The ICF body function codes can be used in two ways, depending on the level of information required, and when using various data collections. First, directly relevant body function codes can assist in the ‘identification’ of continence impairments. Second, a list of body function codes can be used to record the range of other body functions that may be affected by, or the related impairments that may coexist with, incontinence. These two approaches are discussed below.

‘Identifying’ incontinence

Incontinence can be identified using the ICF body functions codes for:

- Functions of ‘control’—b6202 Urinary continence (functions of control over urination) and b5253 Faecal continence (functions involved in voluntary control over the elimination function);
- Functions of ‘frequency’—b6201 Frequency of urination (functions involved in the number of times urination occurs) and b5252 Frequency of defecation (functions involved in the frequency of defecation).

The ICF also codes for Faecal consistency (b5251—consistency of faeces such as hard, firm, soft or watery) and Flatulence (b5254—functions involved in the expulsion of excessive amounts of air or gases from the intestines), which are more commonly collected in epidemiological and clinical studies, although the SAHOS does include related questions.

Since items on functions of control and frequency are collected in only a few Australian data collections reviewed, we need to look to the continence symptom assessment tools for guidance.

Many assessment tools record incontinence in terms of presence and severity.[3]The actual ‘presence’ of incontinence is normally identified as the experience of leakage. The simplest method, as used, for example, in the U-UDI (Urogenital Distress Inventory for Urge Incontinence), is to ask respondents whether they have experienced, in this case during the last 4 weeks, any episodes of urine leakage. A similar approach has been adopted by the WHA, where respondents were asked if urine leakage had been experienced in the last 12 months. A comparable data item based on this approach is given in Box 4.1 (data item 1a) and relates to the ICF codes ‘functions of control’. An item based on experience of leakage may be a better identifier of incontinence in scenarios where information is collected solely or partly on a self-reporting basis—not all respondents who experience leakage may consider themselves incontinent, and may not identify as having either form of incontinence if simply asked whether they experience incontinence.

The data collected from data item 1a would provide a crude estimate of the population who experience some degree of incontinence, i.e. anyone who has had at least one episode of leakage over a given time period, and the type of incontinence they experience.

Data item 1b captures the population who experience ‘urgency’, defined by Abrams et al. (2002a:168), with reference to urinating, as ‘…a sudden compelling desire to pass urine, which is difficult to defer’. Urgency may or may not result in an incontinent event and does not necessarily occur periodically, but is related to functions of control and can require considerable management strategies to prevent an incontinence event occurring. Inclusion of urgency as a data item, alongside data on incontinence as a function of control, allows identification of persons experiencing incontinence, urgency or both.

The type of urinary incontinence experienced is detailed in data item 1c. Stress, urge and, to a lesser extent, mixed incontinence are the primary types of urinary incontinence

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[3] ‘Bothersomeness’ is a more recently introduced concept in the measurement of incontinence severity but will not be discussed here.

information collected in clinical and epidemiological surveys. Two additional categories are included—nocturnal enuresis, for urine leakage occurring during sleep, and 'other', which incorporates less common types of incontinence experienced. These categories may or may not be included in the completed data item depending on the level of detail required.

Faecal incontinence can manifest itself as incontinence of solid and/or liquid stool. Because the type of faecal incontinence does not impact on incontinence management, a data item is not suggested here.

Box 4.1: Identifying incontinence

Data item 1a: Incontinent of urine or faeces (control)

Definition: *Whether a person has experienced an episode or episodes of urine leakage or faecal soiling/loss over a defined time period.*[4]

Example value domain:

1 Urine leakage

2 Faecal leakage

3 Both urine and faecal leakage

4 Neither urine nor faecal leakage or a sense of urgency to urinate or defecate

Data item 1b: Urgency with urination or defecation

Definition: *Whether a person experiences a strong sense of urgency to urinate or defecate.*

Example value domain:

1 Sense of urgency to urinate

2 Sense of urgency to defecate

3 Sense of urgency to urinate and defecate

4 Neither a sense of urgency to urinate nor defecate

Data item 1c: Type of urinary incontinence

Definition: *The primary type of urinary incontinence a person experiences.*

Example value domain:

1 Stress urinary incontinence (urine leakage occurring on effort or exertion, or on sneezing or coughing)

2 Urge urinary incontinence (urine leakage accompanied by or immediately preceded by urgency)

3 Mixed urinary incontinence (urinary leakage associated with urgency and also with exertion, effort, sneezing or coughing)

4 Nocturnal enuresis (urinary leakage occurring during sleep)

5 Other (may include overflow incontinence, neurogenic or reflex incontinence and dribbling)

See Abrams et al. (2002a) for terminology of types of urinary incontinence.

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[4] Because differing time periods are used in various studies and assessment tools a specific time period is not given here.

Severity and body function impairment: interweaving presence and severity

Many assessment tools, and population health surveys such as the SAHOS, rarely use data items measuring general presence of incontinence but rely on items that incorporate severity scales to identify presence of leakage. The frequency of urination or defecation, often collected alongside, or sometimes instead of, leakage information, is also commonly structured against a point scale, which may be used to measure severity levels. This incorporation of a measure of severity within identifier items allows estimation of the overall population with incontinence, and the population experiencing more severe incontinence.

Severity of incontinence in clinical and epidemiological settings is often measured with a range of items but the frequency of (a) urination and (b) incontinence events (leakage), and the volume lost at each episode, are most commonly used. These are measures of severity related to body function impairments. Frequency of urination items, which relate to the ICF code 'functions of frequency', records how often an individual needs to urinate or defecate over a set time period—over 24 hours for urination, and usually a week for defecation. Incontinence events or frequency of leakage, which combines ICF codes 'functions of frequency' and 'functions of control', is regularly scored against a 4- or 5-point scale, whereby a respondent indicates how often they experience leakage over a given time period.

While these items are not mutually exclusive, they do provide different measures of incontinence. All indicate an impairment with control and/or frequency of need to urinate or defecate. An item on frequency of urination and defecation also allows an assessment of the regularity of incontinence events against actual frequency of urination or defecation, and may be an indicator of a body function (or structure) impairment associated with the overproduction of urine and faecal matter. Furthermore, frequent urination is a possible sign of future incontinence problems for those not yet reporting incontinence events. Box 4.2 details data items (data items 2a and 2b) to measure the severity of incontinence in terms of frequency of urine leakage and faecal leakage respectively, Box 4.3 includes an item on amount of urine lost during an incontinence event, and Box 4.4 presents data items on frequency of urination during the day and during the night, and frequency of defecation over the week (data items 4a, 4b and 5 respectively).

Box 4.2: Severity of incontinence—body function impairment (I)

Data item 2a: Incontinence—frequency of urine leakage

Definition: *How often a person experiences urine leakage.*

Example value domain:

0 Never
1 Less than once a month
2 Once or more times a month
3 Once or more times a week
4 More than once a day

Data item 2b: Incontinence—frequency of faecal leakage

Definition: *How often a person experiences faecal leakage.*

Example value domain:

0 Never
1 Less than once a month
2 Once or more times a month
3 Once or more times a week
4 More than once a day

Box 4.3: Severity of incontinence—body function impairment (II)

Data item 3: Incontinence—amount of urine lost

Definition: *The amount of urine lost when a person experiences urine leakage.*

Example value domain:

0 Does not experience urine leakage
1 A few drops
2 More than a few drops

Box 4.4: Severity of incontinence—body function impairment (III)

Data item 4a: Incontinence severity—frequency of urination (day)

Definition: *The frequency with which a person urinates during the day, or while awake.*

Example value domain:

1 1–3 times a day
2 4–6 times a day
3 7–10 times a day
4 10 or more times a day

Data item 4b: Incontinence severity—frequency of urination (night)

Definition: *The frequency with which a person urinates during the night, i.e. when sleeping.*

Example value domain:

1 1–2 times a night
2 3–4 times a night
3 5 or more times a night

Data item 5: Incontinence severity—frequency of bowel movements

Definition: *The frequency with which a person defecates on a weekly basis.*

Example value domain:

1 Once or less
2 Twice
3 3–4 times
4 5–12 times
5 13–21 times
6 22–26 times
7 27 or more times

Related body function impairments

Incontinence may occur with, or contribute to, other body function impairments. Examples of impairments that coexist with incontinence, as regularly collected in assessment tools, include impairments of mental functions, such as energy, sleep and emotional functions (e.g. depression, frustration, anxiety), mobility, and sensory functions, such as pain (see Table 3.2). Revealing other body function impairments associated with incontinence provides a broader understanding of a person's functional status, including the additional health or other forms of care a person may need, or the possible combined effect on participation.

The ICF provides an extensive list of body functions, which can be used at various levels. The chapter headings listed in Box 4.5 represent the highest level of body functions domains in data item 6; more specific body functions fall within these chapters. Depending on the purpose of the item, and the collection itself, value domains for a data item on body function impairment will differ depending on level of detail needed. It is recommended that the user refer to the *National Community Services Data Dictionary* (Version 3.0) or METeOR for further guidance on value domain development.

Box 4.5: Identifying body function impairments associated with incontinence

Data item 6: Incontinence—co-existent body function impairments

Definition: *Other body function impairments reported by a person experiencing incontinence. Impairments of body functions are problems in body functions such as a loss or significant departure from population standards or averages.*

Example value domain (categories 1–8 are based on ICF chapter headings):

1 Mental functions
2 Sensory functions and pain
3 Voice and speech functions
4 Functions of the cardiovascular, haematological, immunological and respiratory systems
5 Functions of the digestive, metabolic and endocrine systems
6 Genitourinary and reproductive functions
7 Neuromusculoskeletal and movement-related functions
8 Functions of the skin and related structures
9 Cognitive functions*

* Dementia is generally not included within mental function categories in Australian administrative data collections, and therefore an additional domain 'Cognitive functions' has been added.

Activities and participation

Incontinence as an activity limitation

Continence, or the management of bladder and bowel control, can also be conceptualised as an activity of self-care, and incontinence then as an activity limitation. An activity limitation is defined as 'difficulties an individual may have in executing activities'. The ICF codes management of bladder and bowel control under 'Toileting' (d530) or the activity of 'planning and carrying out the elimination of human waste…, and cleaning oneself afterwards'. The relevant codes for urinary and faecal continence are:

- d5300 Regulating urination
- d5301 Regulating defecation

Data on the difficulties associated with executing an activity such as regulating urination or defecation are often collected in Australian population and administrative data collections with reference to the need for assistance or supervision. In this context the presence of incontinence is not the activity limitation (difficulty) itself, it is the inability to manage the incontinence without some sort of external assistance that is limiting. A data item solely focused on need for assistance, however, does not capture the whole population experiencing difficulty managing their incontinence, and hence an item must distinguish between, and collect information on, persons who experience difficulty but can still manage on their own, and those who require assistance. The SDAC includes such an item. Data item

7, presented in Box 4.6, is based on this SDAC item and incorporates the concepts of difficulty and need for assistance so to differentiate between three population groups: persons who experience difficulty and need assistance at least sometimes to manage their incontinence, persons who do have some difficulty but do not currently need assistance, and those who generally do not experience problems with incontinence. The first group targets the population who use or may need formal interventions to manage their incontinence; the latter group a proportion of individuals who may, with age or a worsening of their incontinence, require assistance in the future.

The level of assistance needed to manage incontinence complements this data item, and is addressed in the following section on severity and activity limitation.

Box 4.6: Incontinence as an activity limitation (severity of incontinence—activity limitation I)

Data item 7: Incontinence—difficulty and need for assistance

Definition: *Whether an individual experiences difficulty and the level of assistance needed to manage their urinary or faecal incontinence (i.e. bladder or bowel control).*

Example value domain:

1 Always needs assistance to manage incontinence
2 Sometimes needs assistance to manage incontinence
3 Does not need assistance but has some difficulty managing incontinence
4 Has no difficulty with bladder or bowel control

Severity and activity limitation

Severity can also be measured through assessing a person's management of their incontinence with relation to need for assistance. This severity data item considers incontinence as an activity limitation. Some of the data collections reviewed already employ variations on this measure, ranging from whether any support is needed to the amount of support needed. The former method is partly captured in data item 7 if a person reports they experience difficulty managing their incontinence and need assistance to manage the incontinence. To measure severity more precisely, measuring the level of assistance needed is clearly the preferred option.

The 'activity limitation' question used in the SDAC is a template from which such an item may be developed. The level of assistance needed relates, in the SDAC, to the impact of a disabling condition—'always needing' assistance is defined as profound, 'sometimes needing' assistance as severe, and 'does not need' assistance but 'has difficulty' as moderate. It is generally information on the more severe end of the spectrum (i.e. always and sometimes needing assistance) where support and service-based administrative data collections are focused, and hence data on this group are pertinent to policy development and distribution of monies.

How much assistance a person needs is another measure of severity. The SDAC also uses an item whereby the respondent indicates the frequency of assistance needed over a defined time period. This data item (data item 8) can be collected alongside the data item on need for assistance to create a broader picture of the personal assistance needs a person uses to manage their incontinence.

Box 4.7: Severity of incontinence—activity limitation (II)

Data item 8: Incontinence—frequency of need for assistance

Definition: *The frequency of assistance needed to manage incontinence (bladder or bowel control).*

Example value domain:

0 Does not need assistance
1 Less than once a month
2 1–3 times a month
3 1–6 times a week
4 1–2 times a day
5 3–5 times a day
6 6 or more times a day

Incontinence and participation restrictions/other activity limitations

The absence in most data collections reviewed of measures of participation restriction contrasts to its standard inclusion in continence assessment tools. Data items regarding impact on lifestyle add a further dimension to the assessment of severity and need for assistance (see below), and contribute to the understanding of a person's functional status.

The ability to participate in various life areas, or undertake activities, is the most frequently used measure in condition-specific assessment tools but the SAHOS and SDAC are the only population surveys that collect information on the impact of incontinence on a person's life. Depending on the level of detail required, participation may focus on the effect incontinence has on lifestyle generally (as asked in SAHOS: *Does bowel or stool leakage cause you to alter your lifestyle?*) or on a specified list of activities and life areas pertinent to the population in scope. The ICF component of activities and participation lists the following broad activity and participation domains;[5] domains commonly used in continence-specific assessment tools are bolded (see Table 3.2).

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility (moving around using transportation)
- Self-care
- **Domestic life**
- **Interpersonal interactions and relationships**
- **Major life areas**
- **Community, social and civic life** (WHO 2001).

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[5] There is as yet no consensus amongst ICF developers and users how to best split this list into specified activities and participation domains, and one option suggested is to retain it as a single list (AIHW 2003b).

The ICF provides an extensive list of activities and life areas within these chapter headings which can be used to guide selection of relevant life areas. As for impairments of body function, it is recommended that the user refer to the 'Activities and participation domains' data item in the *National Community Services Data Dictionary* (Version 3.0).

Box 4.8 presents an example data item, based on the sorts of activities and life areas included in continence assessment tools. This item may be used to identify the effect that the presence (and severity) of incontinence has on a person's ability to participate and to assess improvements in a person's participation related to current assistance or interventions.

Box 4.8: Incontinence and activity limitations/participation restrictions

Data item 9: Incontinence—associated activity limitations/participation restrictions

Definition: *The activities and life situations in which a person experiences limitations or restrictions associated with or affected by their incontinence.*

Example value domains:

1 Self-care
  1.1 Washing oneself
  1.2 Caring for body parts
  1.3 Dressing
  1.4 Eating
  1.5 Drinking
  1.6 Looking after one's health
2 Mobility
  2.1 Walking and moving around
  2.2 Moving around using transportation
3 Domestic life
  3.1 Shopping
  3.2 Housework
  3.3 Maintenance work
4 Interpersonal interactions and relationships
  4.1 Informal social relationships, including with friends
  4.2 Family relationships
  4.3 Sexual relationships
5 Major life areas
  5.1 Education
  5.2 Work and employment
6 Community, social and civic life
  6.1 Community life, such as volunteering
  6.2 Recreation and leisure
  6.3 Sports
  6.4 Hobbies
  6.5 Religion and spirituality
  6.6 Socialising

Environmental factors

Environmental factors are often neglected in data collections despite their sometimes profound effect on a person's experience or management of a health condition, disability or impairment, and hence their functioning. The management of incontinence often relies on personal assistance, the use of aids, or a combination of the two. Aids are a critical means for managing incontinence, particularly for those persons still living and interacting with the community. A number of Australian data collections include, to some extent, items on environmental factors, often incorporated within questions on support or assistance needed. Personal assistance is the primary or only form of support normally considered in these collections. Therefore, a more complete approach would include reference to aids.

The key purpose of many health and community service data collections is to determine what assistance is needed and can be accessed by a person. This requires clear delineation of actual use, additional need and the sorts of assistance or support used and needed. A simple template for an item on use of aids to manage incontinence is given in data item 10 (Box 4.9). The type of continence aids that might be used by a person experiencing incontinence are listed in data item 11 (Box 4.10). The aids listed reflect aids and equipment specific to the management of incontinence and exclude more generic items, such as gloves or creams that may be used in conjunction with these aids to manage incontinence.

Box 4.9: Incontinence—use of aids

Data item 10: Incontinence—use of aids

Definition: *Use of aids and equipment to manage incontinence (bladder or bowel control).*

Example value domain:

1 Uses aids or equipment to manage incontinence
2 Does not use aids to manage incontinence

Medical interventions and prevention

A record of interventions provides an indication of the extent of potentially more severe forms of incontinence in Australia, by virtue of the need for medical intervention. Some information on additional interventions is available from collections such as the Medicare Benefits Schedule and BEACH collections, but data are difficult to reconcile because of the differences between populations in scope. Data item 12 provides a method by which information on these alternative forms of intervention can be collected (Box 4.11).

Box 4.10: Incontinence—type of continence aids

Data item 11: Incontinence—type of aids used

Definition: *Type of aids and equipment used to manage incontinence (bladder or bowel control).*

Example value domain:

1 Continence pads
  1.1 Disposable
  1.2 Reusable
2 Continence pants
  2.1 Disposable
  2.2 Reusable
3 Drainage bags and accessories
4 Bottles and urinals
5 Catheters and catheter accessories
6 Condom drainage systems/protective sheaths/external catheters
7 Urethral plugs/vaginal bows/penis clamps
8 Anal plugs/anal tampons/anus bags
9 Stomal appliances
10 Faecal softeners and suppositories
11 Enemas and suppositories
12 Continence sheets and waterproof seat covers
13 Other

Box 4.11: Incontinence—interventions

Data item 12: Incontinence—other interventions

Definition: *Other forms of support or intervention used or undertaken to manage incontinence.*

Example value domain:

1 Preventative measures, such as pelvic floor exercises
2 Management strategies, such as time voiding, double voiding, bladder retraining
3 Medications
4 Surgical procedures
5 Diagnostic tests
6 Other interventions

Additional support

As stated earlier, items on support should be able to ascertain actual use from additional need for support. Data item 13 (Box 4.12) serves as a basic template for identifying additional need for support or interventions to manage incontinence, from which more detailed items may be developed, such as frequency of need for particular forms of assistance.

Box 4.12: Incontinence—need for intervention or additional support

Data item 13: Incontinence—need for intervention or additional support[6]

Definition: *The need for intervention or additional support to manage incontinence (bladder or bowel control).*

Example value domain:

1 Additional need for personal assistance
2 Additional need for aids and equipment
3 Additional need for other interventions
4 Does not need additional assistance or intervention methods

Additional items

Effect on carer wellbeing

The physical and emotional effects of caring for a person with incontinence, particularly someone with severe incontinence, can be substantial. Analysis presented in Part A, Chapter 4 showed that some carers who assisted another person with their incontinence had felt a negative impact on their physical and emotional wellbeing.

Two data items that may be used to indicate the effect on carer wellbeing are given in Box 4.13. These items are modelled on data items used in the primary carer component of the SDAC. Data item 14 ascertains the time, in hours, a carer spends assisting a person with their incontinence over a weekly period. Two value domains are suggested: one where the carer estimates the total hours spent on a daily or a weekly basis, without reference to value domain prompts, the second based on the value domain used in the SDAC to measure the number of hours a carer assists a person with self-care. The latter option is the least preferable as it is based on the sorts of hours that may be spent assisting on any combination of self-care activities. Further work would be required to estimate the sorts of hours a carer may need to spend assisting a person with their incontinence so as to develop an appropriate value domain.

Data item 15 allows the carer to indicate the physical and emotional consequences, if any, of caring for someone with incontinence. Each of the values in the value domain are drawn from questions directed to primary carers in the SDAC, and refer to the carer's physical and emotional response to the caring role, and the effect of the caring role on their relationship with the person being cared for, other family members and friends. This value domain will require further development, and may need to be split into two items.

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[6] Respondent may indicate need for more than one support type or intervention.

Box 4.13: Incontinence—effect on carer wellbeing

Data item 14: Incontinence—hours of caring

Definition: *Number of hours a carer spends in a week assisting a person in managing their incontinence OR Number of hours a carer spends on a daily basis assisting a person in managing their incontinence.*

Carer to estimate number of hours……….

Example value domain:

1 <20 hours per week
2 20–39 hours per week
3 40+ hours per week

Data item 15: Incontinence—effects on carer physical and emotional wellbeing

Definition: *The effects on a carer's physical and emotional wellbeing associated with assisting a person to manage their incontinence.*

Example value domain:

1 Feels weary or lacks energy due to caring role
2 Sleep frequently interrupted due to caring role
3 Feels worried or depressed due to caring role
4 Feels angry or resentful due to caring role
5 Relationship with person being cared for affected due to caring role
6 Relationships with other family members affected due to caring role
7 Relationships with friends affected due to caring role

Risk factors

A range of risk factors identified for urinary and faecal incontinence are described in Part A, Chapter 3 and include:

- constipation
- lower urinary tract symptoms
- mobility, cognitive and neurological impairments (and related health conditions)
- pregnancy, childbirth and parity
- menopause
- obesity
- surgeries, such as prostatectomies, prolapse repair, hysterectomies.

Including a data item on risk factors provides some indication as to the health conditions, life events or other factors associated with incontinence. However, any recommendation for a data item on risk factors is somewhat premature, particularly given the variable relationship of these factors to the development and experience of incontinence, i.e. some of these factors can be defined as precursors to incontinence, as influencing incontinence and/or associated with incontinence. As such, an item is not proposed here, with the recommendation that any future data item rely on a very clear definition of what constitutes a risk factor *per se*, and, in turn, a risk factor for incontinence.

Toileting and incontinence

Toileting, in its very broadest sense, may be considered as both the ability to perform tasks associated with using the toilet and the ability to manage bladder and bowel control. Australian population surveys and various administrative collections, however, tend to differentiate between the two by including data items on ability to manage toileting (i.e. tasks associated with using the toilet) alongside, or in place of, items on ability to manage incontinence. For example, the SDAC collects information on the need for assistance with toileting, which refers to any difficulty associated with using a toilet, and the need for assistance with bladder and bowel management, or difficulty associated with bladder and bowel control. The CACP dictionary also separates toileting (use of toilet) from managing incontinence as an activity of self-care, although it is coded together under personal care. In contrast, Version 2.0 of the HACC NMDS does not include managing incontinence as an item of functional status, relying solely on the activity of toileting as the ability to 'manage the toilet…without or with some help' or complete inability 'to manage the toilet without help', as an indicator of the population with incontinence. This item is used to identify activities where a person may require assistance and the extent of assistance they may need.

While the ability to use or manage the toilet and the ability to manage incontinence are related, they are not one and the same; thus the use of an item on toileting alone is not necessarily a good indicator of the population who experience incontinence, or who need assistance with their incontinence. Careful question wording clearly defining that toileting includes bladder and bowel control as well as the ability to get to and perform tasks associated with using the toilet may encourage better reporting. However, this approach ultimately masks two very different aspects of toileting, and, hence, the different needs of the individual and the sorts of assistance appropriate to their needs. A suggested method, depending again on purpose of the collection, is to include two items that clearly separate tasks of toileting from the management of bladder and bowel control as activities of self-care. Further investigation is needed to test suitable question wording and sequential placement of items.

4.3 Interrelationship of themes and data items

The data themes and data items described fulfil two purposes, i.e. that each data item stands alone to provide crucial information on an aspect of incontinence, and that the data items together provide a more detailed account of the experience of people with incontinence. Listed in Table 4.1 are the sorts of information that can be derived from individual data items and data item combinations.

These data items may also be used to monitor changes, over successive collection years, regarding improvements in management of incontinence, and effect on participation, in relation to changing environmental factors.

Table 4.1: Incontinence themes and proposed data items

Themes	Proposed data items and related estimates	Status of development
Estimate of prevalence of urinary and faecal incontinence	Item 1a: Broad estimate based on body function impairment.	For further development
	Item 7: Narrower estimate based on activity limitation (difficulty with managing incontinence and need for assistance).	See metadata item 'Activity—level of difficulty' in NCSDD.
	Item 1c: Estimate of population experiencing different types of urinary incontinence.	For further development
Estimate of prevalence of persons experiencing sense of urgency	Item 1b: Broad estimate of population experiencing sense of urgency.	For further development
Estimate of population experiencing more severe forms of incontinence		
Severity, as measured by body function impairment	Item 2a/b: Estimate of population experiencing frequent (as defined by user) episodes of urine or faecal leakage, in combination with:	For further development
	Item 3: Estimate of population experiencing more than a few drops of urine leaked during an incontinence event.	For further development
	Items 4a/b and 5: Estimate of population experiencing overly frequent (as defined by respondent) need to urinate or defecate.	For further development
Severity as measured by activity limitation and need for assistance	Item 7: Estimate of population who need assistance to manage their urinary or faecal incontinence and the level of assistance needed.	See ABS SDAC 'need for assistance' data item
	Item 8: Estimate of how much personal assistance a person needs, over the week, to manage their incontinence.	ABS SDAC 'frequency of need for assistance' data item
The environmental factors persons with incontinence rely on to manage their incontinence	Items 7 and 8 as above for personal assistance.	ABS SDAC 'need for assistance' data item ABS SDAC 'frequency of need for assistance' data item
	Item 10: Estimate of population who use continence aids to help manage their incontinence.	ABS SDAC 'use of continence aids' data item
	Item 11: Types of aids used for incontinence.	For further development
Other interventions used to manage or alleviate incontinence	Item 12: Estimate of population who use alternative interventions, e.g. preventive measures, medications, surgical procedures, to alleviate or manage incontinence.	For further development
The need for additional assistance or interventions	Item 13: Estimate of population who need additional personal assistance or aids, or interventions to manage incontinence.	For further development
The potential effect of incontinence on participation	Item 9: Estimate of population whose lifestyle has been affected by incontinence, and the sorts of life areas impacted upon.	See metadata items 'Activity and participation domains' and 'Participation extent' in the NCSDD
Associated or coexistent body function impairments	Item 6: Types and commonality of body function impairments associated with or related to incontinence.	See metadata item 'Body functions' in the NCSDD
Effect on carer	Items 14 and 15: Total number of hours spent per week assisting someone with their incontinence, and the physical and emotional effects of that caring role.	ABS SDAC various items on effect of the carer role (see ABS 2004a).

4.4 Summary and recommendations

Part B of this report reviewed Australian data collections which included continence relevant data items, alongside continence assessment tools, to determine the sorts of information on incontinence currently collected in Australia and to guide the development of draft items for possible inclusion in future collections.

This chapter provides 19 data items that may be used to collect information on the prevalence and severity of incontinence amongst Australians, and the sorts of assistance and support they need or use to manage their incontinence. If these items are used as a standard 'menu', and if context and purpose are taken into account, this approach would promote greater consistency across the field and greater quality in many incontinence-related collections and tools.

This report recommends three 'incontinence modules', which differ in terms of complexity of item usage and sorts of information collected, and for inclusion depending on the underlying purpose of the collection.

Module 1 How many Australians have incontinence

For collections that simply require an estimate of the population experiencing incontinence, use data item 1a (Incontinent of urine or faeces (control)). Data item 1a captures the broadest possible group, i.e. all persons who may have experienced an episode of incontinence over a defined time period. For a better estimate of the population who experience more severe incontinence, then data items based on data items 2a (Incontinence—frequency of urine leakage) and 3 (Incontinence—amount of urine lost) for urinary incontinence and data item 2b (Incontinence—frequency of faecal leakage) for faecal incontinence are essential.

Module 2 Population needing assistance—the experience of 'severe' incontinence

The second module is appropriate for collections focusing on the population experiencing more severe incontinence—those who may require formal service intervention now or in the future.

Most incontinence-related administrative collections, and some population surveys such as the SDAC, currently collect information on incontinence as an activity limitation. This method of determining severity is recommended here, in part because many administrative collections reviewed use a similar data item to identify incontinence (Table 3.1b). The combination of items to collect such information would therefore include:

- data item 7 (Incontinence—difficulty and need for assistance), to determine prevalence estimates of those who need assistance to manage their incontinence (severe incontinence) and those who do not need assistance but have difficulty managing their incontinence (mild/moderate incontinence). This data item can also be used to estimate the amount of assistance the population with severe incontinence need. This item probably mostly relates to assistance from informal care, and therefore provides information on (a) in which cases formal services are needed and (b) the demands on primary carers.
- data item 8 (Incontinence—frequency of need for assistance), to estimate the frequency of need for assistance (e.g. separating 'profound' from 'severe').

- data item 10 (Incontinence—use of aids), to estimate the population who rely on continence aids. This item, in combination with data item 7, provides estimates of the population relying solely on personal assistance, the population relying solely on continence aids, and the population using both forms of support.
- data item 13 (Incontinence—need for intervention or additional support), to estimate the degree of additional support needed, and the sort(s) of additional support required. This item can be collected not just for people who report needing personal assistance, but also those experiencing difficulty managing their incontinence.

Since most epidemiological studies tend to focus on incontinence as a body function impairment, data items 2a and 2b (Incontinence—frequency of urine leakage and Incontinence—frequency of faecal leakage), 4a and 4b (Incontinence—frequency of urination (day/night)), 5 (Incontinence—frequency of bowel movements) and 1c (Type of urinary incontinence) may also be considered for inclusion, at least for comparative purposes. If data items 2a, 2b, 4a, 4b and 5 are collected alongside data items 7 (Incontinence—difficulty and need for assistance) and 8 (Incontinence—frequency of need for assistance), it is recommended that there be some examination and mapping of responses to these two sets of items, to assess how well the different measures of severity relate to one another.

Module 3 A complete picture: incontinence as a multidimensional concept

For a complete picture of the population experiencing incontinence, it is recommended that the whole suite of items be used, and this may be more appropriate for a collection focusing solely on the incontinent population. Some of the additional information that is collected using this module includes:

- the type of aids needed and use of alternative interventions to manage incontinence;
- a better understanding of the types of body function impairments that may be associated with incontinence generally, and more severe forms of incontinence, and hence the additional support and other intervention measures this population does or may require;
- the impact of incontinence on lifestyle, participation and the pursuit of specific activities;
- the effect on carers caring for persons with incontinence.

The data items in this module ensure comparability with the sorts of information collected using assessment tools and in epidemiological research; the data items relate to national data standards where available. Most importantly, it provides a whole-of-person description of the experience of incontinence, which is generally unavailable from most collections, and many epidemiological studies, and is essential for a whole-of-person approach to assisting people with incontinence.

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