

Australian incontinence data analysis and development

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Australian incontinence data analysis and development

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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.