

The background is a complex, abstract composition. It features a blue-toned city skyline with various skyscrapers. Overlaid on this are numerous white line-art icons representing business and technology, such as gears, bar charts, pie charts, a magnifying glass, a handshake, a shield, and a network of nodes. The entire scene is framed by flowing, wavy lines in shades of blue and green, creating a sense of movement and digital connectivity.

Economic Cost of Incontinence in Australia

Continence Foundation of Australia

June 2024

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Glossary

Acronym	Full name
ACFI	Aged-Care Funding Instrument
ACT	Australian Capital Territory
ACTES	Australian Capital Territory Equipment Scheme
AIHW	Australian Institute of Health and Welfare
AR-DRG	Australian Refined Diagnosis Related Groups
AUD	Australian dollar
CAPS	Continence Aids Payment Scheme
CMAS	Continence Management Advice Service WA
CMASS	Continence Management and Support Scheme
DALYs	Disability adjusted life years
FI	Faecal incontinence
GDP	Gross domestic product
GP	General practitioner
ICD	International classification of diseases
ICS	International Continence Society
MASS QLD	Medical Aids Subsidy Scheme Queensland
MBS	Medicare Benefits Schedule
NCP	National Continence Program
NDIS	National Disability Insurance Scheme
NT DEP	Northern Territory Disability Equipment Program
NSW	New South Wales
OAB	Overactive bladder

Acronym	Full name
PBS	Pharmaceutical Benefits Scheme
QLD	Queensland
RACF	Residential aged care facility
SNS	Sacral nerve stimulation
UI	Urinary incontinence
UUI	Urge urinary incontinence
VSLY	Value of a statistical life year
WA	Western Australia
YLD	Years of healthy life lost due to disability
YLL	Years of life lost due to mortality

The background image shows a busy city street at night. A large, semi-transparent circular overlay is centered on the page, containing white text. The text provides statistics on the impact of incontinence in Australia for the year 2023. The background features a multi-story building with lit windows and a crowd of pedestrians crossing the street, creating a sense of urban activity.

In 2023, there were over 7.2 million Australians aged 15 and over affected by incontinence to some degree, costing \$66.6 billion in financial costs and \$33.8 billion in lost wellbeing.

Executive summary

Over 7.2 million Australians aged 15 and over are affected by incontinence to some degree. An estimated **2.4 million men and 4.8 million women** experienced some level of urinary and / or faecal incontinence in 2023. This is a 53% increase in the number of people suffering from incontinence in Australia since the last national study was completed in 2010. The financial cost of incontinence in 2023 was \$66.6 billion, with an additional \$33.8 billion in lost wellbeing for people living with incontinence.

Overview

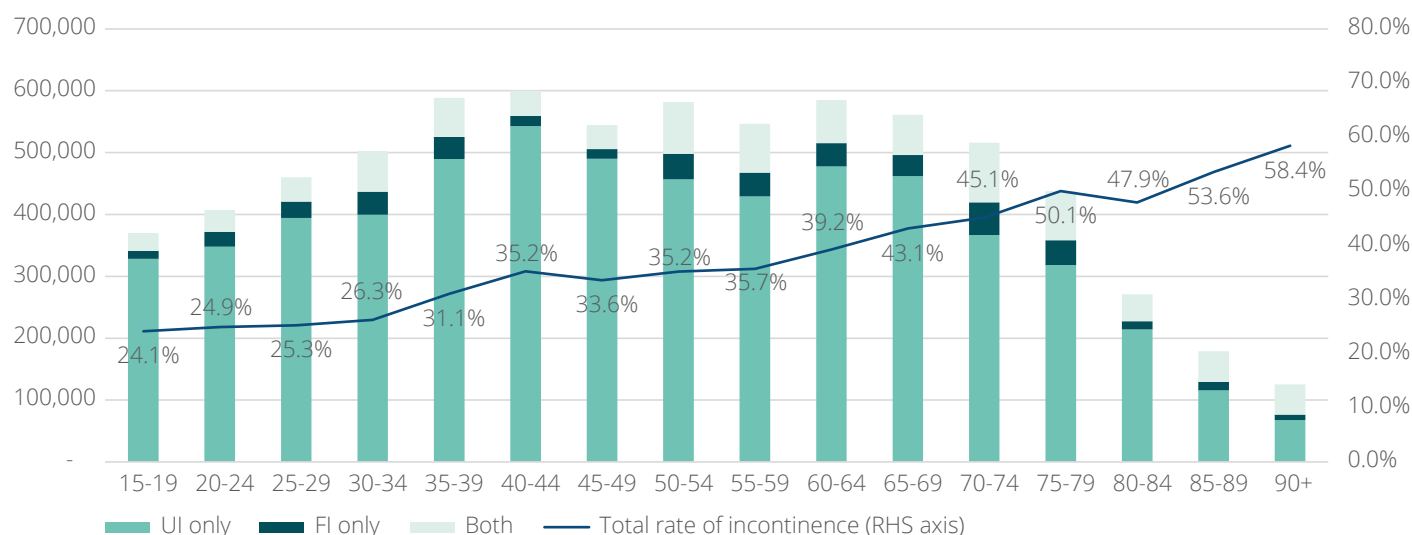
This report, commissioned by the Continence Foundation of Australia (the Foundation), from Deloitte, provides recent modelling data on the burden of incontinence in the adult population of Australia and the associated financial costs and consequences. It provides an update to the analysis in the previous report on the economic impact of incontinence in Australia, also by Deloitte, which was published in 2011. For this report, Deloitte surveyed people with incontinence to supplement the limited existing sources of information with direct reports of the impacts of incontinence on mental health, use of healthcare services, employment, care needs, and the associated economic costs.

While the prevalence rate of incontinence increases with age (particularly for those 75 years and over), 71% of people with incontinence are 65 years and younger (Chart i, Table i). Urinary incontinence is much more prevalent than faecal incontinence. People living in residential care experience incontinence at higher rates than the general population. Of residential aged care residents, 70.9% experience urinary and/or faecal incontinence. Looking ahead, the projected number of Australians living with some degree of urinary and/or faecal incontinence is estimated to rise by 8.6 million (34.1% of the 2032 population) in 2032 based on the expected changes in age profile of the Australian population.

Incontinence is common

Incontinence is a highly prevalent but under-recognised public health problem affecting Australians of all ages. It is estimated that 2.4 million men (19% of the total population of men) and 4.8 million women (37% of the total population of women) had some degree of urinary and/or faecal incontinence (UI / FI) in 2023. This is an overall increase of 53% since 2010. These are likely to be underestimates as incontinence is frequently under-reported to healthcare services by those affected and often misdiagnosed or not diagnosed by clinicians.

Chart 1: Prevalence of incontinence in Australia in 2023, by age and type of incontinence



Source: Deloitte based on Sharma et al. (2016), Linde et al. (2016), Botlero et al. (2009), Hawthorne (2006) and ACFI (2009).

Table 1: Summary of prevalence and costs in 2023 by sex, cost type and incontinence type

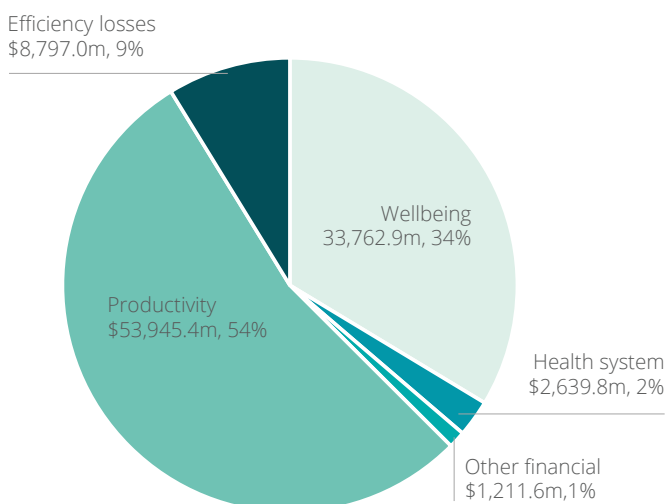
		UI	FI	Total	% of total
Prevalence		Number	Number	Number	%
	Male	1,948,626	487,537	2,436,164	33
	Female	4,417,715	422,876	4,840,591	67
	Persons	6,366,341	910,413	7,276,754	
Costs		\$millions	\$millions	\$millions	%
Health system	Hospital inpatient costs	\$243.0	\$41.3	\$284.2	0.4
	Non-admitted patient costs	\$149.6	\$19.3	\$168.9	0.3
	Other health service costs	\$1,131.1	\$321.8	\$1,452.9	2.2
	Pharmaceutical	\$695.6	\$38.2	\$733.8	1.1
Productivity	Reduced employment	\$10,116.1	\$1,323.4	\$11,439.5	17.2
	Absenteeism	\$12,557.5	\$1,808.8	\$14,366.4	21.6
	Presenteeism	\$19,392.6	\$3,195.4	\$22,588.0	33.9
	Informal care	\$4,409.2	\$1,142.2	\$5,551.5	8.3
Other financial costs	Formal home care	\$53.3	\$17.0	\$70.3	0.1
	Residential aged care	\$254.3	\$181.2	\$435.4	0.7
	Aids and equipment	\$613.3	\$92.5	\$705.8	1.1
Efficiency costs		\$7,540.6	\$1,256.5	\$8,797.0	13.2
Total costs excluding wellbeing costs		\$57,156.2	\$9,437.6	\$66,593.8	100.0
Wellbeing		\$25,951.5	\$7,811.4	\$33,762.9	

Source: Deloitte. Totals may not sum due to rounding.

Incontinence is costly

The estimated economic cost of incontinence per person experiencing incontinence was \$9,152 in 2023. This figure includes both direct and indirect costs arising from poor continence health. These include costs arising from the utilisation of healthcare and other social support systems, the costs of aids and adaptations, impacts on employment and work, and lost wellbeing.

Chart 2: Economic cost of incontinence in Australia in 2023, by cost component



Source: Deloitte

Productivity includes the labour impacts directly experienced by people with incontinence and their informal carers. Because most people with incontinence are in the working age population (i.e., between 15 and 64 years old), productivity losses from lower employment, reduced efficiency, and time off work represent the largest (\$48.4 billion) cost. In addition to this, 24.1% of people with incontinence surveyed for this report said that they received informal care from their spouse or family member. This equates to \$5.6 billion in lost productivity for informal care.

Healthcare costs due to incontinence were estimated to be \$2.6 billion, more than ten times the sum estimated by Deloitte in 2012. The findings of the survey of people with incontinence undertaken for this report suggest that people living with incontinence access a much wider range of healthcare services at much higher rates than previously estimated.

- Two-thirds of the survey respondents reported seeing a general practitioner at an average of 5 times in the last year for their incontinence (whether specifically or in addition to other health concerns).
- More than 40% of survey respondents reported seeing allied health professionals an average of 3 times in the last year.
- 13% of survey respondents reported seeing a mental health professional for issues associated with their incontinence, with an average of 5 visits in the past year, highlighting the emotional toll that incontinence has on individuals.

Of those in residential aged care or receiving home care packages, it was estimated that 45.5% and 14.5%, respectively, had incontinence in 2023. The estimated cost of incontinence in the context of residential aged care and formal care costs was \$505.8 million in 2023. In addition, the cost of aids and equipment to manage incontinence was estimated to be \$705.8 million.

These costs are borne by individuals, State Governments via state-based subsidy schemes and the Federal Government via the Continence Aids Payment Scheme (CAPS).

Incontinence is under-reported and under-researched.

Incontinence is often poorly documented in clinical records and is under-reported in administrative datasets. There are notable gaps in the available data on incontinence in Australia. These gaps include contemporary information on prevalence, and service data including numbers, scope, and location. In this challenging context, the estimates in this report are based on publicly available data and research evidence as well as the survey run by Deloitte especially for this report.

There are significant gaps in information about prevalence and needs amongst groups and communities with special characteristics; Aboriginal and Torres Strait Islanders, children, and young people, culturally and linguistically diverse (CALD) and lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) populations.

Conclusions

This report provides a much-needed update on the prevalence and costs associated with incontinence in Australia, especially given the absence of routine data collection on the burden of incontinence in the Australian population and widespread underreporting of healthcare needs by those affected. Those with incontinence have reported gaps in the accessibility of services, particularly in rural and remote areas, referral pathways are not in place, and challenges with coordinating care in many healthcare settings, including those in groups at high risk of persistent bladder and bowel problems. There are, in addition, widespread concerns about a lack of capability in the generic health and aged care workforce and a loss of capacity in the specialist workforce.

It is time for action in Australia to address this changing landscape. With the evidence pointing to incontinence being a substantially costly challenge for Australians, it is an imperative to

ensure that investment is commensurate to the size of the challenge. There is an urgent need to enhance efforts in data collection to enable better understanding of the burden of disease, the impacts of incontinence on those affected and of the costs and consequences for them and for Australian society.



01

Background

This chapter provides a definition of incontinence. It summarises what is **known about the risk factors for incontinence in the adult Australian population and the costs** and other consequences for individuals, health services and the Australian governments.



1.1 Purpose of this report

This study, commissioned by the Continence Foundation of Australia (“the Foundation”), aims to estimate the number of adults with incontinence in Australia in 2023 and the financial and non-financial impacts associated with incontinence for individuals, health services and governments. It updates previous estimates of the economic impact of incontinence in the adult Australian population and the economic costs and consequences using more recent research, data and a consumer survey run specifically for this study. This does not include the cost of incontinence for children. It also does not provide costs specific to a range of priority population groups, including Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse communities and LGBTQIA+ communities. Further work is required to understand how the needs, experiences and costs differ for these groups compared to other Australians.

The report is organised as follows:

- **Chapter 2 – Methodology:** Summarises the approach and methods used to estimate the socioeconomic cost of incontinence.
- **Chapter 3 – Prevalence of incontinence:** Describes the prevalence of incontinence in Australia in 2023.
- **Chapter 4 – Health costs:** Describes the costs associated with healthcare (hospital inpatient costs, out-of-hospital health services, and pharmaceuticals) used by people experiencing incontinence.
- **Chapter 5 – Other financial costs:** Describes costs other than healthcare such as formal home care, residential aged care, government programs, aids and equipment, productivity losses, and efficiency losses.
- **Chapter 6 – Burden of disease:** Describes non-financial costs such as the loss of wellbeing because of experiencing incontinence.

• Chapter 7 – Conclusion and next steps:

Highlights the key findings and opportunities for further investment into data collection and research.

1.2 What is Incontinence?

Incontinence describes any accidental or involuntary loss of urine (urinary incontinence) or faeces (faecal incontinence). The severity of incontinence can vary. Although incontinence grows more common as individuals age, it should not be seen as an inevitable consequence of ageing. It can affect people of all ages, including children and young people.

The definition of incontinence varies in the literature. This reflects the breadth and complexity of the conditions involved and the heterogeneous nature of research studies. Both urinary and faecal incontinence have several sub-categories. For example, the International Continence Society reports 12 sub-categories of urinary incontinence and eight sub-categories of faecal incontinence. Studies on incontinence do not typically include all sub-categories.

This report uses definitions of incontinence adopted by the Foundation and The International Continence Society which encompass the various categories of incontinence described in Table 1.1.

- **Faecal incontinence** is defined as ‘the involuntary loss of liquid or solid stool that is a social or hygienic problem’.
- **Urinary incontinence** is defined as ‘a complaint of involuntary loss of urine’.

Table 1.1: Categories of urinary and faecal incontinence

Types of incontinence	Urinary	Faecal
Urgency incontinence	Complaint of involuntary loss of urine associated with urgency.	Complaint of involuntary loss of faeces associated with faecal urgency.
Overflow incontinence	Complaint of urinary incontinence in the symptomatic presence of an excessively (over-) full bladder.	Complaint of involuntary loss of stool due to an overfull rectum or faecal impaction.
Stress incontinence	Complaint of involuntary leakage of urine on effort or exertion, or on sneezing or coughing.	Complaint of involuntary loss of faeces on effort or physical exertion including sporting activities, or on sneezing or coughing.
Mixed urinary incontinence	Complaint of involuntary leakage associated with urgency, with exertion or effort, sneezing, or coughing.	NA.

Source: D'Ancona, C., et al. (2019), ¹ Gajewski, J., et al. (2017). ²

The measurement of the severity of urinary and/or faecal incontinence also varies across studies. The Incontinence Severity Index (ISI) is a commonly used tool that enables a graded assessment of urinary incontinence (slight, moderate, severe, and very severe) taking into account frequency and volume. ³

Faecal incontinence severity measurement is frequently undertaken with the use of the Wexner Faecal Continence Grading Scale, graded from 0 (perfect continence) to 20 (complete incontinence) based on the type of incontinence (gas, solid stool, or liquid stool), and the need for lifestyle modifications and pad usage. ⁴

1.3 The experience of incontinence

Incontinence is heavily stigmatised, frequently under-reported to healthcare services by those affected, often misdiagnosed, or not diagnosed by clinicians and frequently endured in silence by those affected. ⁵ It is projected in this report that a growing proportion of adults will experience incontinence as the Australian population ages.

People with incontinence use a wide range of healthcare services delivered by multi-disciplinary health professionals. These could include:

- Specialist continence support services,
- Allied health professionals,
- Nursing staff who assist with continence care and incontinence treatment and management including nurse continence specialists, practice nurses, registered nurses, enrolled nurses, and assistants in nursing, and
- Carers who help persons with incontinence with activities ranging from light mobility assistance to the toilet, to full toileting care (i.e., changing pads, clothing, and bed linen to full hygiene care).

The analysis in this report suggests that incontinence is a costly condition for individuals, families, businesses, and the Australian Government, that could be better managed with access to high-quality services, support and treatment, including in primary prevention. Currently, despite the existence of multiple support payments and subsidies, such as the Continence Aids Payment Scheme (CAPS), people who experience incontinence can find it hard to navigate the system, as emphasised by the following quotes from a survey of consumers undertaken by Deloitte for this report. ⁶

"I'd like to know if I am eligible for financial assistance. It is very hard to tell."

"I would like to get financial support but don't know how."

Furthermore, these payments often fail to cover the costs associated with severe incontinence.⁷

"I spend many more dollars than CAPS and [state level scheme] to purchase the aids needed for my incontinence."

"The CAPS allowance nowhere near covers my incontinence-related expenses."

"I get \$500 from the Federal Government and \$500 from the NSW Government towards buying catheters. I spend close to \$4000 on catheters. These should be on the Pharmaceuticals Benefits Scheme."

1.4 Causes of incontinence

Continence is established in childhood for the majority, but people of all ages are at risk of developing a measure of incontinence for a range of reasons. Dysfunctions of the bladder and bowel affect men, women, adolescents, and children, those without any other disability or illness and people with varying degrees of learning or physical disability or illness. Incontinence has complex causes.⁸ It may be a symptom of an underlying mental or physical health condition or illness, a consequence of life transitions such as pregnancy and childbirth or a side effect of treatment. People who suffer from incontinence generally experience more severe disability and health problems than other people with disability.

The major causes of incontinence are identified below.

- Pregnancy and childbirth (both urinary and faecal incontinence)^{9, 10, 11}
- Severe constipation (faecal incontinence)¹²
- Prostate problems (urinary incontinence)¹³
- Impaired mobility (both urinary¹⁴ and faecal¹⁵ incontinence)
- Underlying musculoskeletal conditions such as arthritis and lower back pain (urgency incontinence)¹⁶
- Acquired brain and spinal injury (both urinary and faecal incontinence)^{17, 18}
- Neurological disorders such as stroke, Parkinson's disease, multiple sclerosis, and spinal cord injuries (both urinary and faecal incontinence)¹⁹
- Cognitive impairment, such as dementia (both urinary and faecal incontinence)^{20, 21, 22}
- Congenital conditions such as congenital neurogenic bladder and congenital bowel conditions (both urinary and faecal incontinence)^{23, 24, 25}
- Trauma to pelvic organs: Trauma to pelvic organs due to accidents or assault (both urinary and faecal incontinence)²⁶
- Other health and lifestyle issues such as diabetes,²⁷ cardiovascular disease,²⁸ obesity,²⁹ smoking and chronic coughing,³⁰ psychological, heavy lifting and impact³¹ (e.g., some sporting activities, and developmental disorders).³²
- Recurrent urinary tract infection.³³

Regardless of the cause of incontinence, the experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in the normal activities of daily living.

1.5 Treatment, management, and care for people with incontinence

Continence support and services are provided by a range of specialist and generalist healthcare professionals, including urologists, urogynecologists, colorectal surgeons, paediatricians, geriatricians with a special interest in continence, nurse continence specialists, and physiotherapists working in pelvic health.

There is some evidence that an erosion of teaching and assessment of continence capabilities for support staff in residential care and in pre-and post-registration healthcare education for all disciplines, including nurses and doctors, has meant that the broad healthcare workforce lacks the skills to deliver effective continence-related care. This, along with the loss of specialist continence education and training programs and an ageing and maldistributed continence specialist workforce, results in significant inequities in access to continence services.³⁴

1.6 The state of existing research on the prevalence and costs of incontinence

Very few studies have attempted to estimate the prevalence of multiple subtypes of incontinence in the whole population or estimated the costs and consequences at national level. Previous Australian and international economic studies typically focused on specific subsets of incontinence (e.g., faecal incontinence, urgency urinary incontinence) or incontinence in specific populations (e.g., women and older people).

Cost estimates differ markedly across studies because different definitions of incontinence are used, as well as different methods for ascertaining severity. Table 1.2 shows the scope of recent data on the number of people experiencing a degree of incontinence within Australia and the United States and the differing definitions of incontinence used.

In Australia, the only previous study to address the costs associated with both urinary and

faecal incontinence at the population level was commissioned by the Continence Foundation of Australia from Deloitte Access Economics and published in 2011. This new study, also commissioned by the Continence Foundation of Australia, provides updated robust, contemporary information to governments and healthcare planners about the level of continence health need in the population and the level of investment required to meet it in the context of an ageing and changing population.



Table 1.2: Previous estimates of the economic costs of incontinence

Author	Location	Focus of study	Definition of incontinence	Findings
Deloitte, 2011 ³⁵	Australia	Economic cost of incontinence	Incontinence was defined according to the ICS as the unwanted and involuntary leakage of urine or stool	In 2011, around 4.2 million Australians aged over 15 years were experiencing urinary incontinence and 1.3 million with faecal incontinence, representing 21% of the community population. The prevalence of incontinence is higher among older age groups, especially in residential aged care facilities (RACF) and among women. The total economic costs of incontinence equated to \$66.7 billion in 2010. The calculation was split between the total financial cost and monetary value of the burden of disease, which were \$42.9 billion and \$23.8 billion, respectively. This was approximately \$14,014 per person with incontinence.
Australian Institute of Health and Welfare (AIHW), 2013 ³⁶	Australia	Cost of incontinence on the healthcare system	Incontinence is defined according to the definition of the International Classification of Diseases. See Section 1.1	In 2008–09, the estimated total expenditure on incontinence was \$1.6 billion, with the largest share spent on residential aged care (\$1.3 billion), followed by hospitals (\$145.5 million), the Stoma Appliance Scheme (\$67.6 million) and the Continence Aids Payments Scheme (formerly the Continence Aids Assistance Scheme) (\$31.6 million).
Coyne et al., 2014 ³⁷	United States	Economic burden	Urgency urinary incontinence (subtype of urinary incontinence) i.e., involuntary loss of urine associated with urgency	The estimated total national cost of overactive bladder (OAB) with urge urinary incontinence (UUI) in 2007 was USD\$65.9 billion, with projected costs of USD\$76.2 billion in 2015 and USD\$82.6 billion in 2020. This 2007 estimate was markedly higher than those reported in older studies. Direct costs are the main driver of the overall cost of UUI in the United States.
Xu et al., 2012 ³⁸	United States	Economic cost per person	Faecal incontinence i.e., at least monthly leakage of solid, liquid, or mucous stool (International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis code of incontinence)	The average annual cost for faecal incontinence was USD\$4,110 per person in 2010. Of these costs, direct medical and non-medical costs averaged USD\$3,353 and USD\$209, whereas the indirect cost associated with productivity loss averaged USD\$1,549 per patient annually.

02

Methodology

This section presents a summary of the methodology and information sources used **to estimate the prevalence of incontinence** in Australia in 2023 and the associated costs.

2.1 Overview of approach

The aim of this study is to estimate the costs relating to the socioeconomic impact of urinary and/or faecal incontinence in Australia in calendar year 2023. These costs were estimated using a cost-of-illness methodology based on a prevalence approach outlined in Figure 2.1. Within this framework, the costs associated with incontinence are seen to be borne by individuals, families and carers, governments, and society. These include health system costs, productivity costs, transfers, and other

financial costs. Individuals who have incontinence also experience significant loss of wellbeing from a reduced quality of life. These costs are then multiplied by the relevant number of people with incontinence for each category of costs to determine a total cost for Australia in 2023.

The following discussion describes the approach to estimating these components and the sources of information used to inform the methodology followed by a discussion of limitations.

Figure 2.1: Methodology framework to estimate the economic impact of incontinence in Australia



Source: Deloitte.

2.2 Data and information collection

This study relies on literature and data obtained through a comprehensive review of publicly available sources, as well as primary data collection conducted by surveying individuals experiencing incontinence and their carers. The purpose of the survey was to fill identified data gaps and validate other data points, particularly for those where there is no recent data.

Several critical gaps in the availability of data and information were identified when undertaking research for this report. Data on incontinence is not collected routinely in national health surveys. Notably, no information exists on the 'incontinence system' - the types, availability and level of services involved in responding to incontinence currently or about the pathways which individuals might undertake to obtain advice, support, management, and treatment. Little information is available on the impact of incontinence on an individual's employment status and productivity. The consumer survey was conducted to address some of these gaps.

2.2.1 Review of existing literature and data

An extensive literature review focusing on peer-reviewed studies (including systematic reviews and meta-analyses) was conducted to gather the best available research on the prevalence and impacts of incontinence on the individual, their family and carers, and the broader community.

There is a range of recent literature, including systematic reviews and meta-analyses, investigating many aspects of incontinence.^{39, 40, 41, 42, 43} Many of these studies are not set in Australia or do not provide data and information in sufficient granularity to support the modelling in this study. This study has drawn as far as possible on recent Australian literature which addressed both urinary and faecal incontinence and provided age and sex disaggregated data. Given the gaps in the currently

available data and literature, it was necessary to combine inputs from multiple sources and balance the recency, representativeness, and coverage of the studies in selecting inputs.

2.2.2 Primary data collection

Limited information is available to enable an understanding and measurement of healthcare utilisation by people with incontinence or the impact that incontinence has on productivity, so a survey was developed jointly by Deloitte and the Continence Foundation of Australia. The survey was distributed to individuals experiencing incontinence and their carers. The survey included questions about personal characteristics, health service utilisation, productivity impacts and out-of-pocket expenses associated with incontinence. The survey was distributed by the Foundation via social media and weekly newsletters to members.

Table 2.1 provides an overview of the characteristics of the survey sample. There was a total of 232 respondents. While the survey sample was not nationally representative, the distribution of respondents by type of incontinence, sex, and age largely aligns with previous research in terms of greater prevalence of urinary incontinence and greater prevalence among women and older age groups.⁴⁴



Table 2.1: Descriptive statistics of survey respondents

Variable	No. of respondents	% of respondents
Incontinence type		
Urinary (no faecal)	144	62.1
Faecal (no urinary)	17	7.3
Both faecal and urinary	51	22.0
Continence related condition only*	20	8.6
Sex		
Women	170	75.2
Men	54	23.9
Intersex	2	0.9
Age		
<15	3	1.3
15-17	3	1.3
18-24	1	0.4
25-34	8	3.5
35-44	23	10.2
45-54	27	12.0
55-64	37	32.3
65-74	73	32.3
75-84	34	15.0
85+	17	7.5
Employment status		
Full-time work	35	15.8
Part-time work	47	21.3
Casual work	7	3.2
Not employed, but looking for work	5	2.3
Not employed and not looking for work	118	53.4
Prefer not to say / Unsure	9	4.1

Source: Deloitte.

**e.g., bowel dysfunction, overactive bladder syndrome.

Note: Not all categories sum to the same total as participants able to select multiple responses

A detailed description of the survey approach, including a full questionnaire, is provided in Appendix A. es.

2.3 Prevalence of incontinence

Prevalence is the total number of individuals experiencing a disease/condition in a population. A prevalence rate is the total number of individuals experiencing a disease/condition in a population divided by the total population. Prevalence in this report is estimated for people aged 15 years and over in 2023. The prevalence rate was identified by applying point-in-time estimates of the prevalence of incontinence (based on current literature) to the estimated resident population of Australia in 2023. These components are discussed in further detail below.

Full results on estimated prevalence are presented in Section 3.

2.3.1 Point-in-time estimates for prevalence

Estimates of the prevalence of incontinence vary widely across studies. Previous studies have used different definitions of incontinence and different methods of assessing severity, leading to disparate prevalence estimates that are not fully comparable. For example, Milsom and Gyhagen (2018) found that prevalence estimates of urinary incontinence ranged from approximately 5% to 70%, with most studies reporting in a range of 25-40%.⁴⁵ Further, many studies focus only on population subsets with particularly high rates of incontinence (e.g., focus only on women or older people). These studies are not comparable because of differences in measures and methodology and could not be used in the modelling for this report.

The sources for estimating the prevalence of urinary incontinence only in a community setting, faecal incontinence only in a community setting, combined urinary and faecal incontinence in a community setting, and urinary and/or faecal incontinence in a residential aged care setting are summarised below in Table 2.2.



Table 2.2: Approach to estimating prevalence

Type of incontinence	Approach to estimating prevalence
Community setting	
Urinary incontinence	The prevalence of urinary incontinence among women in Australia was estimated using an average of Botlero et al. (2009)⁴⁶ and Linde et al. (2016).⁴⁷ • The Botlero et al. (2009)⁴⁸ paper was chosen because it contains age and sex splits and was set in an Australian context. • Linde et al. (2016)⁴⁹ was used because it is a more recent study containing age and sex splits. As the Netherlands has a similar living standard to Australia, this paper was considered appropriate to use as an input. The prevalence of urinary incontinence among men in Australia was also estimated based on Botlero et al. (2009)⁵⁰ and Linde et al. (2016).⁵¹ • No recent Australian study on men's urinary incontinence could be located. • Instead, using the gender ratio contained in Linde et al. (2016)⁵² and the female prevalence estimates in Botlero et al. (2009),⁵³ proxy values for men's urinary incontinence were created. This value was averaged with the estimate in Linde et al. (2016)⁵⁴ to determine rates of male urinary incontinence by age.
Faecal incontinence	The overall prevalence of faecal incontinence in the general community was estimated using the pooled prevalence rate in Sharma et al. (2016)⁵⁵ of 5.9% and then distributed by Australian age and sex ratios from Hawthorne (2006).⁵⁶ • Sharma et al. (2016)⁵⁷ is a recent international systematic meta-analysis, making it highly reliable. However, it does not contain age and sex splits. Thus, it was necessary to distribute the overall prevalence rate to the population based on the age and sex ratios in Hawthorne (2006).⁵⁸
Both	Hawthorne (2006) ⁵⁹ was used to determine the size of the group of people with both urinary and faecal incontinence.
Residential aged care setting	
Urinary and/or faecal incontinence	The prevalence of urinary incontinence and/or faecal incontinence in residential aged care was estimated using the Aged Care Funding Instrument (ACFI) (2009) data. ⁶⁰

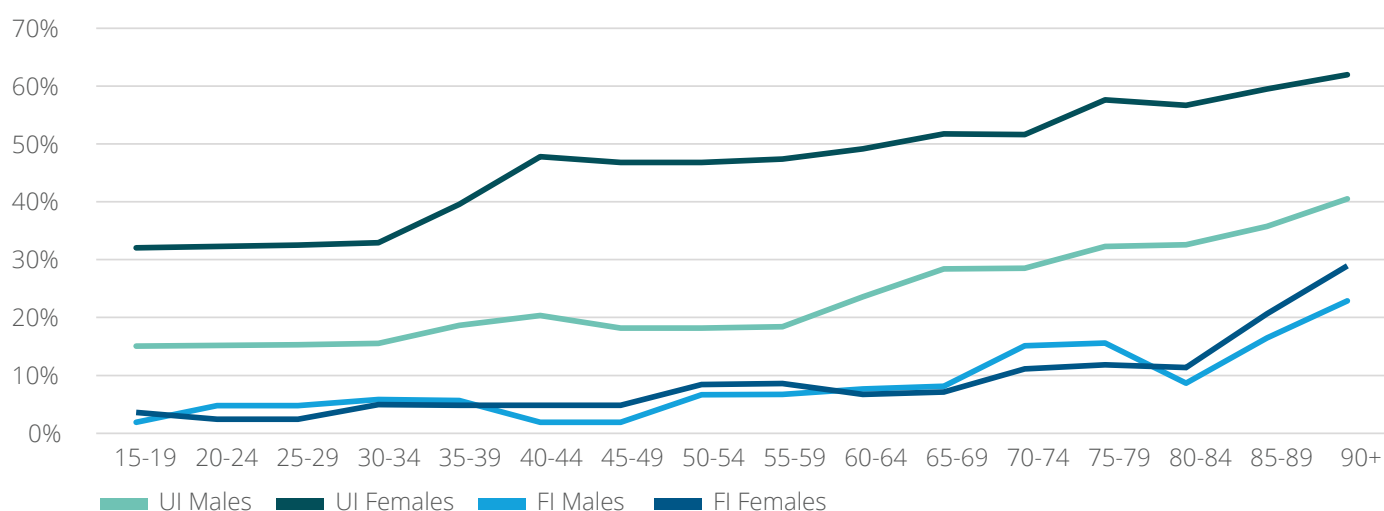
Based on the approaches outlined in Table 2.2, the resulting age-sex standardised prevalence rates estimated for this report are set out in Table 2.3. Total prevalence rates are calculated as a weighted average of prevalence for men and women. Prevalence across age groups is broadly a linear relationship with older population groups experiencing higher prevalence of incontinence. Dips across age groups are due to variations in sampling across the age groups.

Table 2.3: Age-sex standardised prevalence rates in 2023

Age	UI only (%)			FI only (%)			Both (%)		
	Men	Women	Total	Men	Women	Total	Men	Women	Total
15-19	14	29	21	1	1	1	1	3	2
20-24	13	30	21	2	0	1	2	2	2
25-29	13	30	21	2	0	1	2	2	2
30-34	12	28	20	3	1	2	3	4	3
35-39	16	36	26	3	1	2	3	4	3
40-44	19	44	32	1	1	1	1	4	2
45-49	17	43	30	1	1	1	1	4	2
50-54	15	40	27	3	2	2	3	7	5
55-59	15	40	27	3	2	2	3	7	5
60-64	20	43	32	4	1	3	4	5	5
65-69	23	44	34	4	1	3	4	5	5
70-74	20	41	31	7	2	4	8	9	8
75-79	23	47	35	7	2	4	8	9	9
80-84	27	47	38	3	2	2	5	9	8
85-89	24	40	33	6	3	4	10	17	15
90+	22	35	30	6	3	4	16	25	22
Total	14	31	22	2	1	2	3	4	4

Source: Deloitte based on Sharma et al. (2016),⁶¹ Linde et al. (2016),⁶² Botlero et al. (2009), Hawthorne (2006)⁶³ and ACFI (2009).⁶⁴

Chart 2.1: Age-sex standardised prevalence rates in 2023



Source: Deloitte based on Sharma et al. (2016),⁶⁵ Linde et al. (2016),⁶⁶ Botlero et al. (2009),⁶⁷ Hawthorne (2006)⁶⁸ and ACFI (2009).⁶⁹

2.3.2 Estimated resident population in 2023

Australian Bureau of Statistics population data from 2021 was used to estimate the size of the general population, split by age and sex.⁷⁰ A growth rate was then applied to this data to forecast the Australian population from the year 2023 onwards.⁷¹ The residential aged care population was based on data from 1997 onwards contained in GEN Aged Care data (2022).⁷²

2.3.3 Limitations of prevalence estimates

As with any economic analysis, the estimated prevalence of incontinence by age, sex, and type of incontinence in this report has several limitations. These are:

 The prevalence estimates included in this report include information from self-reported survey data sources. A limitation of self-reported data sources is that they may underestimate the true prevalence of incontinence due to underreporting.^{73, 74, 75}

 There is no comprehensive population-based prevalence study of incontinence in Australia in the literature. As such, the prevalence estimates rely on several data sources and studies, some of which focus on specific cohorts (e.g. women only, or urinary incontinence only).

 The prevalence of incontinence was estimated using a mix of recent and more dated (i.e., pre-2016) evidence. Dated evidence may not be completely representative of people experiencing incontinence in 2023. There is some evidence that sub-categories of incontinence are becoming more prevalent over time. This suggests that the prevalence estimates included in this report may be conservative.⁷⁶



The prevalence of incontinence was estimated using a mix of Australian and international literature as the most recent Australian-based study covering both faecal and urinary incontinence with results stratified by age and sex was published in 2006.⁷⁷ There may be societal, economic, and demographic differences between Australia and other countries that could lead to variation in the definition and extent of incontinence.



There are limitations to accessing prevalence data for population groups such as Aboriginal and Torres Strait Islanders, CALD, and LGBTQIA+ communities. There is a need to understand better the experiences of these cohorts and whether there is differing prevalence. However, the analysis here does not address the prevalence or needs of these cohorts due to data limitations.

2.4 Cost of incontinence 2023

The report addresses the costs of incontinence to the health system, costs through home and residential care, and productivity costs. It also estimates the non-financial cost of loss of wellbeing for people affected by incontinence and for carers. These costs are estimated based on costs incurred in the base year of 2023. The methodology used for estimating these costs and associated assumptions and limitations are discussed below.

2.4.1 Health system costs

The following components of health expenditure are captured in the health system costs for this study:

- Inpatient hospital costs (both same day and overnight).
- Non-admitted patient costs.
- Other healthcare costs such as General Practitioner (GP) visits, allied health, and mental health professionals.

- Prescribed and over-the-counter pharmaceuticals.

A summary of the estimate approach for each health system cost component is provided in Table 2.5 below.

Table 2.4: Calculation method and data sources for health system costs

Component	Calculation	Details
Inpatient hospital costs	Total number of bed stay days for UI and FI X Ratio of total cost to costs associated with bed days where incontinence was the principal diagnosis X Average cost per bed day	Total number of bed stay days for UI and FI: Inpatient costs attributable to UI was based on the sum of patient days for individuals with the following ICD-10 codes as their primary diagnosis: • N39.3 Stress Incontinence • N39.4 Other specified urinary incontinence • N32.8 Other specified disorders of bladder (including overactive bladder) • R32 Unspecified urinary incontinence • R35 Frequency of micturition • R15 Faecal incontinence ⁷⁸ These were disaggregated by sex: female and male, and across two age groups: 0 – 64 years, and 65+ year groups. Ratio of total cost to costs associated with bed days where incontinence was the principal diagnosis: This ratio captures additional hospital costs attributable to UI and/or FI incontinence in hospitals beyond what is captured in the patients with the principal diagnosis of incontinence. This ratio was derived from a previous AIHW report ⁷⁹ which included short and long stays in hospital where incontinence was an additional ICD-10 code. Average cost per bed day: This was the average cost per bed day across all jurisdictions, obtained from the NHCDC report Round 24. ⁸⁰ Costs were in 2020 values and inflated to 2023 values based on inflation values from AIHW. ⁸¹

Table 2.4 continued: Calculation method and data sources for health system costs

Component	Calculation	Details
Non-admitted	Number of non-admitted care separations X Total cost per separation X Proportion of people experiencing incontinence who reported accessing specific health professionals	Number and average cost of non-admitted patient separations: The number and average cost of separations for incontinence-related outpatient care was obtained from the 2019-20 National Hospital Costs Data Collection (NHCDC).⁸² The codes that mentioned incontinence or continence care included: • 40.32 Continence • 10.06 Endoscopy – Gastroenterology (for FI only) • 20.36/40.50 Urology (for UI only) • 20.09/20.49/40.02/40.36 Geriatrician (for 65+ only) • 20.38 Gynaecologist (for females only) Proportion of people experiencing incontinence who reported accessing specific health professionals: Apart from 40.32 Continence, the other outpatient separations and costs were attributed to incontinence using prevalence rates and the percentage of people with incontinence who reported accessing specific health professionals (e.g., gastroenterologist, urologist, geriatrician, and gynaecologist) from the Deloitte Access Economics consumer survey.
Other healthcare costs	Proportion of people experiencing UI or FI that have seen a health professional X The number of times the health professional was seen in 2023 X Average cost of the health professional per service	Proportion of people experiencing UI or FI that have seen a health professional: Derived based on the Deloitte Access Economics survey. The healthcare professionals of interest in this cost component includes general practitioners, mental health professionals, and allied health professionals (includes physiotherapist, occupational therapist, and exercise physiologists). The number of times the health professional was seen in 2023: Derived based on the Deloitte Access Economics survey. The healthcare professionals of interest in this cost component include general practitioners, mental health professionals, and allied health professionals. The cost of the health professional per consultation: The cost of a general practitioner, mental health professional, and allied health was based on the AIHW⁸³ average cost per service of \$53, \$126, and \$82, respectively. This includes both MBS subsidised and out-of-pocket costs.

Table 2.4 continued: Calculation method and data sources for health system costs

Component	Calculation	Details
Pharmaceuticals	Proportion of survey respondents who report using medications to manage UI or FI X Proportion of those who use each type of medication X Average cost for each medication type over 12 months	Proportion of survey respondents who report using medications to manage UI: Derived based on the Deloitte Access Economics survey. The medications of interest associated with UI include oxybutin, solifenacin, ovestin vaginal cream, estradiol vaginal inserts, tolterodine, desmopressin, tamsulosin, dutasteride/tamsulosin, mirabegron and darifenacin. Ovestin vaginal cream and estradiol vaginal inserts were applied to the female population only. Proportion of survey respondents who report using medications to manage FI: Derived based on the Deloitte Access Economics survey. The medications of interest include diphenoxylate/atropine, loperamide, laxative, enemas, suppositories, and prucalopride succinate. Annual cost per person per medication associated with either UI or FI: the cost of each medication is pulled from a variety of publicly available sources. The first port of call is the pharmaceuticals benefits scheme (PBS),⁸⁴ followed by Chemist Warehouse.⁸⁵

2.4.1.2 Limitations of health system costs

The following limitations are noted:

- Some health conditions can increase the risk of developing either urinary or faecal incontinence, such as chronic heart failure, dementia, diabetes, Parkinson's, stroke, arthritis, and mental health. This means incontinence is generally not well captured in health administrative datasets, and the inpatient and outpatient costs in this study may be underestimated.
- Unit costs were based on average costs and self-reported utilisation rates. Similarly, frequency and amounts, such as for pharmaceuticals, were based on assumptions (e.g., number of tablets per day, and cost per packet for pharmaceuticals).

2.4.2 Home care and residential aged care costs

Costs relating to incontinence can also vary depending on setting. Below we outline how costs in a home care setting, as well as in a residential care setting, are calculated.

2.4.2.1 Home care costs

Total government expenditure on home care packages taken from the Report on Government Services was attributed to incontinence using the percentage of those receiving home care packages who have incontinence and the proportion of survey respondents who reported having a formal carer to assist them with their activities of daily living specifically or including for their incontinence.

Table 2.5: Calculation method and data sources for continence care costs in formal home care

Component	Calculation	Details
Formal care	Total home care package costs X Prevalence rate of incontinence of those with home care packages X Proportion of survey respondents who reported having a formal carer to assist them with their activities of daily living specifically or including for their incontinence	• Total home care package costs: The total cost of the home care package in Australia in 2022 was \$6.7 million, as published in the Report on Government Services (2022).⁸⁶ This is equivalent to \$6.8 million adjusted for inflation to 2023. • Prevalence rate of incontinence of those with home care packages: Based on Deloitte prevalence estimates, 14.5% of those receiving home care packages in 2021-22 had incontinence. • Proportion of survey respondents who reported having a formal carer to assist them with their activities of daily living specifically or including for their incontinence: The proportion of survey respondents that receive formal home care was 5.1% (Deloitte survey).

2.4.2.2 Residential aged care costs

Total government expenditure on residential aged care taken from the Report on Government Services was attributed to incontinence using the percentage of those in residential aged care who have incontinence and the proportion of time spent on continence care activities while in a residential aged care setting.

Table 2.6: Calculation method and data sources for continence care costs in residential aged care

Component	Calculation	Details
Residential aged care	Time spent on continence care activities X Total residential aged care costs X The proportion of people with incontinence in residential aged care	• The time spent on incontinence activities: Based on research from Qian et al. (2014),⁸⁷ the time spent on incontinence activities in residential aged care is 6.35%. For the purposes of modelling in this report, this value is representative of the proportion of costs attributable to incontinence in residential aged care. • Total residential aged care costs: The total residential aged care cost in Australia was \$14.3 billion, as published in the Report on Government Services (2022).⁸⁸ This is equivalent to \$14.6 billion adjusted for inflation to 2023. • The proportion of people with incontinence in residential aged care: This was determined by dividing the total prevalence of people with incontinence in residential aged care as determined by Deloitte modelling, by the total number of people in residential aged care in 2021 (that is, those reported in permanent care and respite care).⁸⁹

2.4.2.3 Limitations of continence care costs through home care and residential aged care

Given existing data restraints on the costs of formal and residential aged care attributable to incontinence, there are several limitations to note:

- Formal care costs only account for the costs attributable to the age group 65+. This means that for any individual who received formal home care outside of the home care package, their incontinence related costs are not accounted for in this analysis.
- For formal care costs, the prevalence of the incontinence population of those with home care packages is based on the prevalence rates of people within residential aged care. Noting that while there are similarities in care needs across

the two cohorts, it is likely an overestimation of the true prevalence rate. However, due to data limitations, the residential aged care prevalence rate was viewed as the most relevant proxy.

- For residential aged care, the time spent on managing incontinence needs may vary widely from person to person. Some residential aged care homes may have residents with more extensive care needs. Given limited data and information available about the distribution of time spent on incontinence activities, the analysis does not take into account this variation of care needs.

2.4.3 Aids and equipment

A summary of the estimate approach for aids and equipment is provided in Table 2.8 below.

Table 2.7: Calculation method and data sources for continence care costs in residential aged care

Component	Calculation	Details
Aids and modifications	Prevalence of people with UI or FI X Proportion of people in the community that use aids and modifications to manage incontinence X Proportion of people with incontinence using each aid X Number of units of aids and equipment used per year X Cost per unit	• Prevalence of people with UI or FI: Estimated by Deloitte as outlined in 2.2 • Proportion of people in the community that use aids and modifications to manage incontinence: 6.1% of people in the community with a disability use aids and equipment to manage their incontinence, as per the Survey of Disability, Ageing and Carers, 2018. ⁹⁰ • Proportion of people with incontinence using each aid: This was derived using the Deloitte survey, taking into account the difference in aids and modifications usage between males and females experiencing UI and FI. • Number of units used: This was based on the assumption that an individual experiencing incontinence would need aids and equipment throughout the year, and the total units of a product used is based on the product recommendations (see links to product sources in cost per unit description below). • Cost per unit: Costs were pulled from publicly available sources from a selection of the following: – Independence Australia ⁹¹ – Coloplast Australia ⁹² – Medimart ⁹³ – ePharmacy ⁹⁴ – Chemist Warehouse website ⁹⁵ – Paralogic. ⁹⁶

2.4.4 Limitations to aids and equipment

There are limitations to the approach taken to cost aids and equipment:

- The proportionate use of each unit of aid or equipment by individuals does not take into account any variations in the use of aids and modifications to manage their incontinence over the year (2023).
- The use of a product is based on product guidelines and recommendations and may not reflect the true usage by an individual experiencing incontinence, which will vary from person to person.

2.4.5 Productivity costs

A human capital approach was adopted to estimate productivity losses. This involves the calculation of the attributable difference in employment of people experiencing incontinence compared to that of the general population, multiplied by average weekly earnings (AWE).

There are four potential types of productivity losses relating to incontinence:

- Reduced employment – where a worker retires early or exits the workforce due to incontinence. This cost estimates the earnings lost by people forced to exit the workforce due to incontinence. It is calculated by multiplying the not-in-employment rate for people with incontinence by the proportion attributable to incontinence and average yearly earnings.
- Absenteeism – where a worker may be unwell more often and take time off work due to incontinence while remaining in the workforce. This cost captures the value of the work time missed due to incontinence by multiplying days missed by average daily earnings.

- Presenteeism – where workers produce less due to incontinence, lowering their capacity to work. This cost captures the loss in productivity due to incontinence by multiplying the estimated loss of productive time by average yearly earnings (excluding earnings during sick leave and annual leave).
- Informal care – where an individual (generally a family member or friend) partially or completely foregoes participation in the paid labour force to care for someone experiencing incontinence. This cost captures the opportunity cost of providing informal care, measured by what the carer could have earned had they been in the workforce.

Further details on the calculation, data sources and assumptions are set out below in Table 2.9.



Table 2.8: Calculation method and data sources for productivity losses in 2023

Component	Calculation	Details
Reduced employment	Incontinence not-in-employment rate X Attribution to incontinence X Average weekly wage X 52 weeks	• Incontinence not-in-employment rate: Based on the Deloitte survey, 26.2% of people with incontinence are not in employment (i.e., unemployed, or not in the labour force).⁹⁷ Many of the respondents indicated that they are not in the labour force (i.e., retired). • Attribution to incontinence: 12% of these people believe their incontinence impacts their labour force status (Continence Australia survey).⁹⁸ • Average weekly wage: Average weekly earnings of all employees split by age and sex (ABS, 2021).⁹⁹
Absenteeism	Absenteeism days in a year X Daily wage	• Absenteeism days (UI): Urinary incontinence causes, on average, 8.8 additional days off work per year (Deloitte survey).¹⁰⁰ • Absenteeism days (FI): On average, faecal incontinence causes an additional ten days off work per year (Bouin et al., 2022).¹⁰¹ • Daily wage: Average weekly earnings of all employees split by age and sex (ABS, 2021)¹⁰² divided by five days. This assumes a work week of five days.
Presenteeism	Productivity impact X AWE X 46 weeks (52 weeks – 4 weeks annual leave – 2 weeks sick leave)	• Productivity impact (UI): Urinary incontinence causes, on average, a 9% reduction in productivity (Tang et al., 2016).¹⁰³ • Productivity impact (FI): Faecal incontinence causes, on average, a 12% reduction in productivity (Deloitte survey).¹⁰⁴ • Average weekly wage: Average weekly earnings of all employees split by age and sex (ABS, 2021).¹⁰⁵
Informal care	Proportion needing assistance X Proportion of people with incontinence requiring informal care X Hours of informal care per week X Average weekly wage	• Proportion needing assistance: The proportion of people with incontinence requiring assistance, as reported in the ABS Survey of Disability, Ageing, and Carers, is approximately 25%.¹⁰⁶ • Proportion of people with incontinence requiring informal care: The proportion of people needing informal care of those receiving assistance is 77% (Deloitte survey).¹⁰⁷ Thus, the proportion of people with incontinence who require informal care is 19% (25% x 77%). • Hours of informal care per week: This is on average 5.43 hours per week for people experiencing UI, and 5.17 hours per week for people experiencing FI based on the Deloitte survey¹⁰⁸ conducted for this study. • Average weekly wage: Average weekly earnings of all employees split by age and sex (ABS, 2021).¹⁰⁹

2.4.6 Limitations

There are several limitations to the estimated productivity costs of incontinence. These limitations include:

- The productivity impacts for people with both urinary and faecal incontinence may have been underestimated. To avoid double counting, individuals with both conditions were assumed to only experience productivity costs from one. For individuals with both conditions, the productivity impacts of urinary and faecal incontinence are not additive. As such, the estimates are likely to be conservative.
- Several productivity inputs were taken from the Deloitte survey. While this survey had an appropriate sample size, it was not nationally representative. Therefore, these inputs may not entirely reflect the impact of incontinence on productivity across Australia.
- In instances where recent Australian data could not be located, inputs were taken from international sources (e.g., Bouin et al. (2022) ¹¹⁰ and Tang et al. (2016) ¹¹¹). There may be societal, economic, and demographic differences between Australia and other countries that could lead to variation in an individual's likelihood of withdrawing from the workforce or being absent from work.

2.4.7 Efficiency losses

Incontinence creates healthcare costs and reduces income tax revenues (through lower productivity). As such, taxation rates must be higher to achieve a neutral budget position. This additional tax and subsidy revenue is not an economic cost but a transfer of payments from one individual to another. However, increasing tax revenue reduces the efficiency with which the economy's resources are used. For example, an increase in income tax rates will increase the relative price of work compared to leisure and, therefore create a disincentive to work. Alternatively, an increase in the sales tax increases the price of goods and services, resulting in a loss of sales.

Consequently, there is an associated reduction in consumer and producer surplus. Efficiency losses capture the reduced economic efficiency (i.e., this reduction in consumer and producer surplus) associated with the need to levy taxes to fund the provision of government services and replace lost employment taxes.

For information on how efficiency losses were calculated for this report, see Table 2.9.



Table 2.9: Calculation method and data sources for efficiency losses in 2023

Component	Calculation	Details
Consumer taxes	(Reduced employment costs + Absenteeism costs borne by employees) X Average personal income tax rate X Deadweight loss of income tax	• Reduced employment costs: Estimated by Deloitte as outlined in Table 2.9. • Absenteeism costs borne by employees: Estimated by Deloitte as outlined in Table 2.9. • Average personal income tax rate: 22.3% (ATO, 2013-14) ¹¹² • Deadweight loss of income tax: 25.0% (Cao et al. 2015) ¹¹³
Company taxes	(Absenteeism costs borne by employers + Presenteeism costs + Informal care costs) X Company tax rate X Deadweight loss of company tax	• Absenteeism costs borne by employers: Estimated by Deloitte as outlined in Table 2.9 • Presenteeism costs: Estimated by Deloitte as outlined in Table 2.9. • Informal care costs: Estimated by Deloitte as outlined in Table 2.9. • Company tax rate: 29.2% (ATO, 2013-14). ¹¹⁴ • Deadweight loss of company tax: 50.7% (Cao et al. 2015). ¹¹⁵
Government health expenditure	Health system costs X Proportion of health system costs paid by the government X Deadweight loss of welfare payments	• Health system costs: Estimated by Deloitte as outlined in Table 2.5. • Proportion of health systems costs paid by the government: 41.6% for the Federal Government and 26.7% for the State Government (AIHW, 2016) ¹¹⁶ • Deadweight loss of welfare payments: 42.6% (Cao et al. 2015) ¹¹⁷
Other government programs	(Formal home care expenditure + Residential aged care expenditure + Government programs expenditure) X Deadweight loss of welfare payments	• Formal home care expenditure: Estimated by Deloitte as outlined in Section 2.3.2. • Residential aged care expenditure: Estimated by Deloitte as outlined in Section 2.3.2. • Government programs expenditure: Estimated by Deloitte by extrapolating previous years estimates on CAPS payments ¹¹⁸ to 2023 values. • Deadweight loss of welfare payments: 42.6% (Cao et al. 2015). ¹¹⁹

2.4.8 Burden of disease (loss of wellbeing)

The burden of disease methodology is a non-financial approach to quantifying the loss of wellbeing, where life and health are measured in terms of disability-adjusted life years (DALYs).¹²⁰ DALYs combine the years of healthy life lost due to living with a disability (YLD) and the years of life lost due to mortality (YLL). One DALY (the summation of YLD and YLL) is equivalent to one year of healthy life lost.

In the burden of disease methodology, various health states are assigned a disability weight, where zero represents perfect health and one is equivalent to death. Other health states are given a weight between zero and one to reflect the loss of wellbeing from a particular condition relative to perfect health. For example, a disability weight of 0.2 is interpreted as a 20% loss in wellbeing relative to perfect health for the duration of the condition.

DALYs can be converted into a dollar figure using an estimate of the value of a statistical life year (VSLY), an estimate of the value society places on an anonymous life. The Department of Prime Minister and Cabinet (2022) estimated the net VSLY (that is, subtracting financial costs borne by individuals) to be \$231,540 adjusted for inflation to 2023.¹²¹

2.4.9 Estimating the loss of wellbeing due to incontinence

DALYs typically capture the sum of YLDs and YLLs. Evidence does not conclusively suggest that incontinence causes a higher risk of mortality, so YLLs are not included in the analysis. Therefore, in this context, the loss of wellbeing comprises only the wellbeing impacts of living with incontinence and excludes potential mortality impacts. As such, the calculation for loss of wellbeing becomes:

Loss of wellbeing = YLDs (disability weight x prevalence of incontinence by severity level) x VSLY

Each of the components for loss of wellbeing is detailed below in Table 2.10. Specific details relating to the components are set out in Table 2.11, Table 2.12, and Table 2.13.

Table 2.10: Key inputs for estimating loss of wellbeing

Component	Details
Disability weights	Disability weights varied for UI and FI and severity (moderate, severe, and very severe). These weights were based on Hawthorne (2006) ¹²² and AIHW (2006) ¹²³ and are outlined in detail below in Table 2.12.
Prevalence of incontinence by severity level	Formal home care: Hawthorne (2006) Residential aged care: GEN aged care data (2022), ¹²⁴ converted from complex care needs to incontinence based on Hawthorne (2006) ¹²⁵ See Table 2.13 and Table 2.14 for further details.
Value of a statistical life year (VSLY)	The value of a statistical life in 2023 was \$231,540. ¹²⁶

Source: Hawthorne (2006),¹²⁷ AIHW (2006),¹²⁸ GEN Aged Care data (2022)¹²⁹ and Australian Government (2022)¹³⁰

Table 2.11: Disability weights for urinary and faecal incontinence

Severity	UI	FI
Very severe	0.31	0.20
Severe	0.24	0.06
Moderate	0.02	0.02

Source: AIHW (2006) ¹³¹ and Hawthorne (2006) ¹³²

Table 2.12: Prevalence by severity and type among people with formal home care

Severity	UI Prevalence (%)		FI Prevalence (%)	
	Male	Female	Male	Female
Very severe	0	1	4	9
Severe	1	4	3	7
Moderate	11	16	12	22
Slight	88	78	81	62

Source: Hawthorne (2006) ¹³³

Table 2.13: Prevalence by severity among people living in residential aged care

Severity	Prevalence (%)
Profound problems	56
Severe problems	31
Difficulty	13

Source: GEN Aged Care data (2022) ¹³⁴

2.4.10 Limitations of wellbeing component

There are several limitations to the estimated wellbeing costs. These limitations include:

- Due to a lack of recent Australian evidence, the disability weights for incontinence were taken from older sources. The estimates included in these sources may not reflect the impact of incontinence on a person's wellbeing in 2023 if severity levels have increased over time.
- Further, it is noted that the disability weights for urinary incontinence are higher than for faecal incontinence. Anecdotally, allied health professionals report that faecal incontinence has a more significant impact on quality of life than urinary incontinence. This suggests that further research is needed and could result in a higher disability weight for faecal incontinence.



03

Prevalence of incontinence

Over **7.2 million Australian adults experienced some degree of urinary and/or faecal incontinence** in 2023. If current prevalence trends remain constant, an estimated 8.6 million people will experience some degree of incontinence by 2032.

3.1 Prevalence of incontinence in 2023

In 2023, over 7.2 million people had experienced some degree of urinary and/or faecal incontinence, which is approximately 33.7% of the population aged 15 years and over. Most of these people (6.8 million) experienced urinary incontinence only, and women were more likely than men to experience incontinence, making up 67% of all people with incontinence (Table 3.1).

- Just over 5.9 million Australian adults experienced urinary incontinence only in 2023. This represents 28% of the population aged 15 years and over.
- Nearly 0.5 million Australian adults experienced faecal incontinence only in 2023, which is equivalent to 2% of the population.
- Around 0.9 million people experienced both urinary and faecal incontinence in 2023, which is equivalent to 4% of the population.

Table 3.1: Prevalence of incontinence by sex and type, 2023

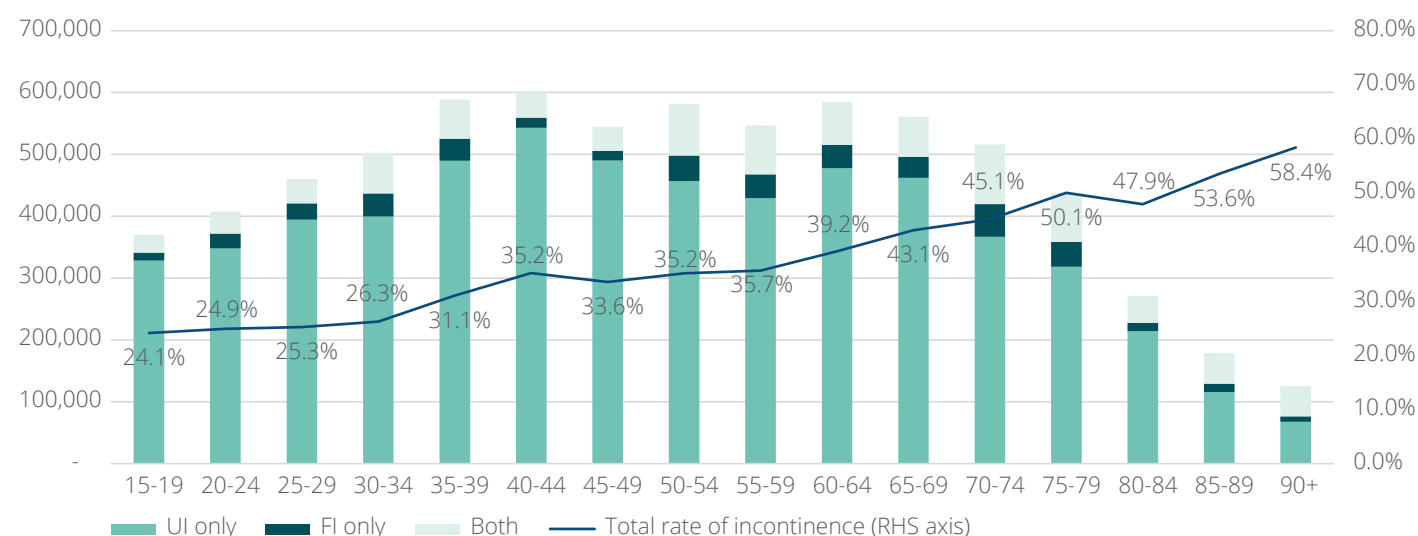
	UI only (thousands)	FI only (thousands)	Both UI and FI (thousands)	Total (thousands)
Men	1,775	314	347	2,436
Women	4,128	133	580	4,841
Total	5,903	447	927	7,277

Source: Deloitte based on ABS (2023), ¹³⁵ ABS (2019), ¹³⁶ Sharma et al. (2016), ¹³⁷ Linde et al. (2016), ¹³⁸ Botlero et al. (2009) ¹³⁹ Hawthorne (2006), ¹⁴⁰ ACFI (2009). ¹⁴¹

As shown in Chart 3.1, the prevalence rate of incontinence increases with age. However, as there are a larger number of people between 15 to 64 years in Australia than over 65 years, the distribution of people with incontinence is concentrated in this

age range with 71% of the people with incontinence in 2023 aged between 15 and 64 years. The average age for men and women experiencing incontinence is 51 years.

Chart 3.1: Prevalence of incontinence by sex and type, 2023



Source: Deloitte based on ABS (2023), ¹⁴² ABS (2019), ¹⁴³ Sharma et al. (2016), ¹⁴⁴ Linde et al. (2016), ¹⁴⁵ Botlero et al. (2009) ¹⁴⁶ Hawthorne (2006), ¹⁴⁷ ACFI (2009). ¹⁴⁸

3.1.2 Prevalence in community settings

Over 7.2 million people in the community live with some degree of incontinence. While prevalence rates are higher among those in residential aged care, the vast majority (98%) of people with incontinence live in the community.

3.1.3 Prevalence in residential aged care settings

Aged care residents experience incontinence at significantly higher rates than the general population. In fact, Aged Care Funding Instrument (ACFI) 2009 data reveals that 70.9% of RACF residents experience urinary and/or faecal incontinence. This is equivalent to almost 144,000 residents.

Table 3.2: Prevalence of incontinence in community settings by sex and type, 2023

	UI only (thousands)	FI only (thousands)	Both UI and FI (thousands)	Total (thousands)
Men	1,764	311	311	2,387
Women	4,107	128	511	4,746
Total	5,871	439	823	7,133

Source: Deloitte based on ABS (2023), ¹⁴⁹ ABS (2019), ¹⁵⁰ Sharma et al. (2016), ¹⁵¹ Linde et al. (2016), ¹⁵² Botlero et al. (2009) ¹⁵³ Hawthorne (2006). ¹⁵⁴ Totals may not sum due to rounding.

Table 3.3: Prevalence of incontinence in residential aged care by sex and type, 2023

	UI only (thousands)	FI only (thousands)	Both UI and FI (thousands)	Total (thousands)
Men	11	3	36	49
Women	21	5	69	95

Source: Deloitte based on ACFI (2009). ¹⁵⁵ Totals may not sum due to rounding.

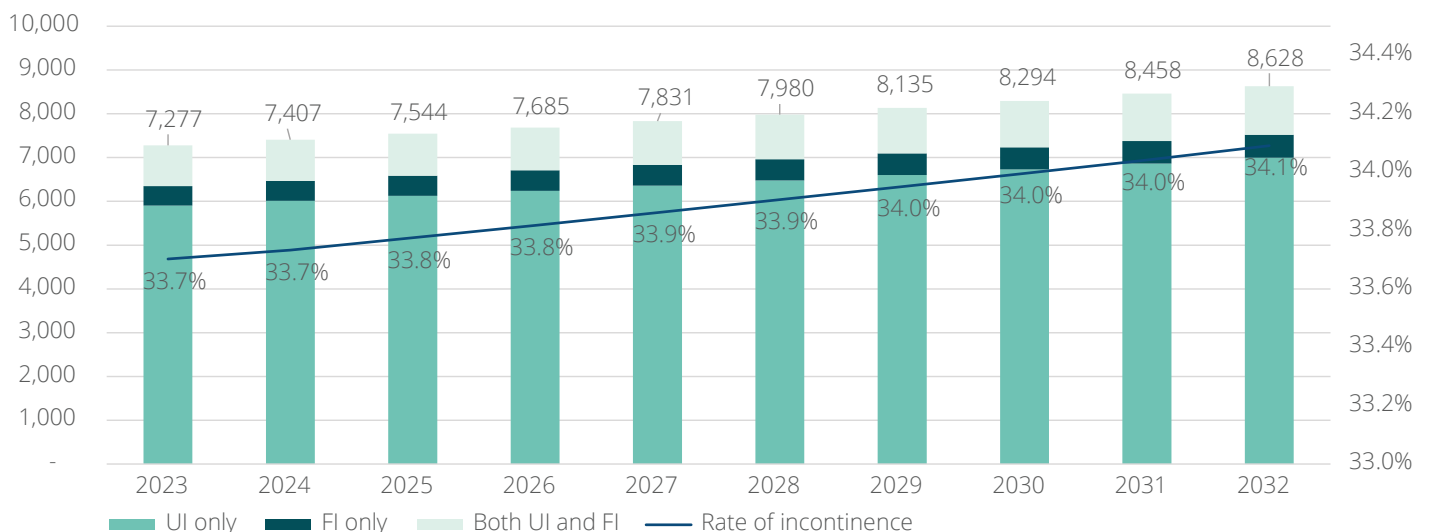
3.2 Prevalence projections to 2032

Assuming the estimated 2023 prevalence rates hold over the next ten years to 2032, it is estimated that there will be 8.6 million people (or 34.1% of the population) with urinary and/or faecal incontinence in 2032 (Chart 3.2). This represents an 18.6% increase from 2023.

The underlying assumption for this projection is that prevalence rates will remain constant from 2023 with future changes being driven by forecasted

changes to the age profile of the Australian population. This does not consider any potential shift in policy to enable investment in continence care pathways, incentives to recruit and retain a specialist continence workforce and a change in emphasis on risk factor reduction. The key drivers for the age profile are expected to be the ageing population and the increase in mean life expectancy. Current estimates may, therefore, be conservative as there is some evidence that sub-categories of incontinence are becoming more prevalent over time.¹⁵⁶

Chart 3.2: Projected prevalence by urinary and/or faecal incontinence, 2023 to 2032



Source: Deloitte based on ABS (2023),¹⁵⁷ ABS (2019),¹⁵⁸ Sharma et al. (2016),¹⁵⁹ Linde et al. (2016),¹⁶⁰ Botlero et al. (2009)¹⁶¹ Hawthorne (2006).¹⁶²

04

Health costs

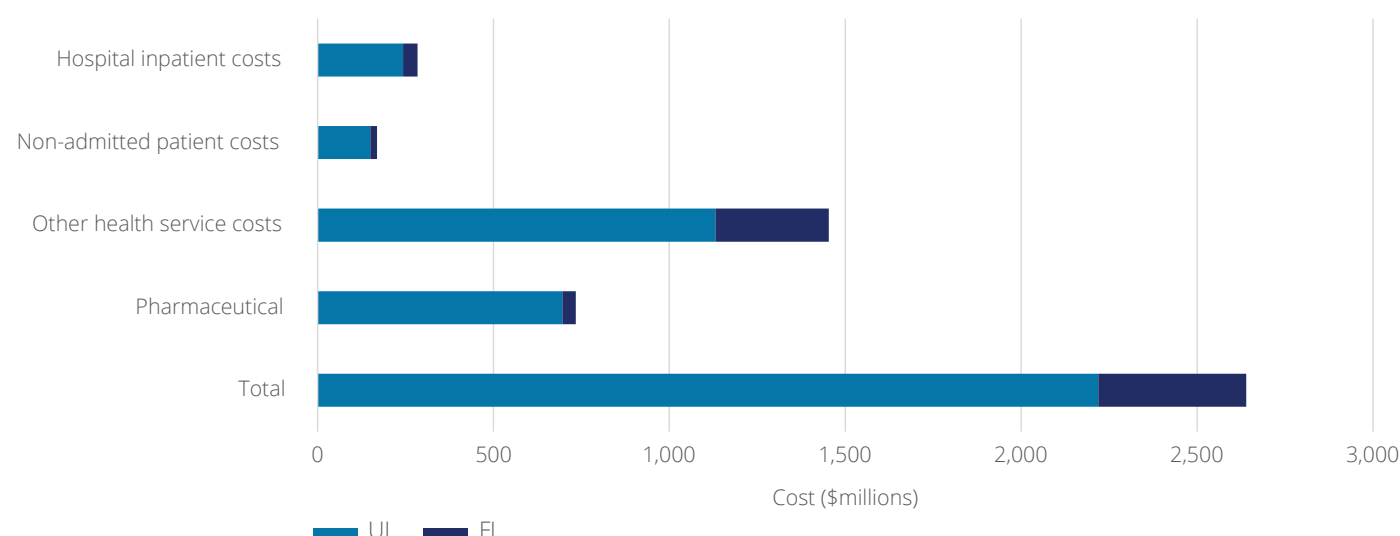
Australian **health system costs attributable to incontinence** in 2023 were an estimated \$2.6 billion.



Health system costs include hospital inpatient costs, non-admitted outpatient costs, other health services costs such as primary care and allied health, and pharmaceuticals. Other health service costs comprised the largest proportion of health

system costs, accounting for \$1.5 billion (55.0% of the total cost; Chart 4.1, Table 4.2). This includes visits to general practice, allied health, and mental health professionals for issues associated with their incontinence.

Chart 4.1: Health system costs due to incontinence by cost component in 2023



Source: Deloitte analysis based on data from AIHW, NHCDC, PBS, Chemist Warehouse, and Deloitte consumer survey.

Table 4.2: Annual health system cost of incontinence in 2023, by incontinence type and sex

Cost component	UI (millions)			FI (millions)			Total	
	Males	Females	Subtotal	Males	Females	Subtotal	Total (\$millions)	% of total
Hospital inpatient costs	160.7	82.3	243.0	23.0	18.3	41.3	284.2	10.8
Non-admitted outpatient costs	45.8	103.8	149.6	10.3	8.9	19.3	168.9	6.4
Other health service costs	346.2	784.9	1,131.1	168.6	153.2	321.8	1,452.9	55.0
Pharmaceuticals	208.8	486.8	695.6	20.5	17.7	38.2	733.8	27.8
Total	761.4	1,457.8	2,219.3	222.4	198.2	420.5	2,639.8	100.0

Source: Deloitte analysis based on data from AIHW, NHCDC, PBS, Chemist Warehouse, and Deloitte consumer survey. Totals may not sum due to rounding.

4.1 Hospital inpatient costs

Using data from the AIHW, the total number of inpatient bed days associated with incontinence were as follows:

Table 4.3: Total inpatient bed days by incontinence type, sex, and age groups in 2021-22

Description	UI	FI
Female, 0-64	6,478	934
Female, 65+	5,969	1,537
Male, 0-64	2,299	234
Male, 65+	4,314	751

Source: Principal diagnosis data cube 2021-22.

Using an average per bed day cost of \$2,646 adjusted for inflation to 2023 from the AIHW, this amounted to a total cost of \$59.6 million for inpatient costs where incontinence was the principal diagnosis. Since incontinence can be an additional diagnosis to inpatient costs, information from the AIHW Principal diagnosis data cubes ¹⁶³ was used to extrapolate a total cost, including short and long hospital stays where incontinence was the principal and additional diagnosis, to **\$284.2 million** in 2023.

4.2 Non-admitted patient costs

Using data from the National Hospital Cost Data Collection 2019-20, the total number of separations and average cost per separation are as follows:

Table 4.4: Total separations and average cost per separation by Tier 2 classification in 2021-22

Tier 2 code	Separations (Number)	Average cost per separation adjusted for inflation to 2023 (\$)
40.32 Continence	83,809	\$226
10.06 Endoscopy - Gastroenterology	129,227	\$1,637
20.36/40.50 Urology	215,135 32,821	234 \$258
20.09/20.49/40.02/40.36 Geriatrician	75,212 48,564 47,17 93,958	\$508 \$559 \$763 \$281
20.38 Gynaecologist	347,403	\$357

Source: AIHW (2023) Principal diagnosis data cube 2021-22. ¹⁶⁴

Tier 2 code 40.32 Continence was fully assigned to incontinence. The other Tier 2 codes were attributed to incontinence using prevalence rates and the percentage of people who reported seeing each health professional according to respondents to the Deloitte survey. Based on this, **non-admitted patient costs totalled \$168.9 million in 2023.**

4.3 Other health service costs

Other health services costs relate to a range of health services that people with incontinence may access specifically for their incontinence or where incontinence is an additional issue. These include GPs, mental health professionals and allied health professionals.

As the survey shows, people with incontinence see a broad range of health professionals in relation to

their incontinence. While many see professionals with specialist interest and qualifications in continence health, such as nurse continence specialists, pelvic health physiotherapists and urologists, most people with incontinence saw their general practitioner and allied health professionals most frequently. Mental health professionals treat issues associated with incontinence, not incontinence itself.

Table 4.5: Survey responses on health professional utilisation and frequency

	Percentage reporting seeing health professional (%)		Median number of times in past year	
	UI	FI	UI	FI
GP	57	68	4	6
Mental health professional	8	23	4	6.5
Allied health (incl physio, OT)	42	39	3	2.5

Source: Deloitte survey (2023).

Other health costs totalled \$1.5 billion. General practitioner visits make up the greatest component

(45%), followed by allied health professionals (34%) and mental health professionals (20%) (Table 4.6).

Table 4.6: Other health costs in 2023, by cost component

Cost component	UI (\$millions)	FI (\$millions)	Total (\$millions)	% of total
General practitioner	517.8	140.5	658.3	45.3
Allied health	440.4	58.7	499.1	34.3
Mental health professional	173.0	122.6	295.5	20.3
Total	1,131.1	321.8	1,452.9	100

Source: Deloitte based on data from NHDC. (2020). Non-admitted care summary, Tier 2 Version 6.0, Round 24; Medicare Benefits Schedule online. (2023). Totals may not sum due to rounding.

Other financial costs

There are a range of **other financial costs attributable to incontinence in Australia beyond direct expenditure on health systems**. These costs amount to \$1.2 billion in 2023.

Other financial costs include formal home-based care costs, RACF costs, government expenditure on support programs, and expenditure on aids and equipment to manage incontinence.

These other financial impacts attributable to incontinence were estimated to cost \$1.2 billion

in Australia in 2023, as outlined in Table 5.1. The largest contributor to this was expenditure on aids and equipment to manage incontinence at \$705.8 million or 58.3% of total cost. RACF costs amounted to \$435.4 million (35.9%) and formal home care costs amounted to \$70.3 million (5.8%).

Table 5.1: Other financial costs of incontinence in Australia in 2023 (\$ millions)

Cost component	UI (millions)			FI (millions)			Total	
	Men	Women	Subtotal	Men	Women	Subtotal	Total (\$millions)	% of total
Formal home care	12.0	41.3	53.3	4.4	12.6	17.0	70.3	5.8
Residential aged care	86.8	167.4	254.3	61.9	119.3	181.2	435.4	35.9
Aids and equipment	231.6	381.7	613.3	56.9	35.6	92.5	705.8	58.3
Total	330.4	590.5	920.9	123.1	167.6	290.7	1,211.6	100.0

Source: Deloitte. Totals may not sum due to rounding.

5.1 Formal home care

Formal home care includes government provided services to help older people remain, or return to living independently, in their homes. This includes the Commonwealth Home Support Program (CHSP), Home Care Packages Program, and the Department of Veterans' Affairs community care for eligible veterans, Veteran Home Care services.

Total government expenditure on home care packages taken from the Report on Government Services was attributed to incontinence using the percentage of those receiving home care packages who have incontinence (14.5%) and the proportion of survey respondents who reported having a formal carer to assist them with their activities of daily living specifically or including for their incontinence (5.1%).

The cost of incontinence in the context of formal home care in 2023 was \$70.3 million.

5.2 Residential aged care

Total government expenditure on residential aged care taken from the Report on Government Services was attributed to incontinence using the percentage of those in residential aged care who have incontinence (45.5%) and the proportion of time spent on continence care activities while in a residential aged care setting (6.35%).¹⁶⁵

The costs associated with incontinence related activities in residential care was \$435.4 million in 2023.

5.3 Aids and equipment

The total costs of aids and equipment were determined using a mix of data surrounding usage from the Deloitte survey and publicly available sources for the costs. A comprehensive list of the types of aids and equipment used for incontinence was determined based on previous economic studies of incontinence¹⁶⁶ and confirmed with clinicians at a methodology workshop attended by Foundation staff, board members and clinicians nominated by the Foundation.

Table 5.2 and Table 5.3 present the aids and equipment utilisation rate and average annual

cost per person by sex and incontinence type. Use is calculated as proportion of respondents to the Deloitte survey that indicated that they use a particular aid or modification at some point. e.g., 99% of men with UI used pads, liners, pull ups etc (Table 5.2). To derive the level of use per annum, it was assumed that individuals who use aids and equipment to manage their incontinence would do so consistently throughout the year. The costs of aids and modifications were extracted from a variety of online sources, varying from pharmacies to continence product specific related websites. Based on this, the costs of aids and modifications totalled **\$705.8 million** in 2023.

Table 5.2: Aids and modifications use and cost for males reporting to use aids and modifications

Type of aid / modification	UI use (%)	FI use (%)	Annual cost per person in 2023 dollars (\$)
Pads, liners, pull ups etc.	99.0	91.0	\$1,835
Bed and chair protection including bedpads, chairpads, mattress, pillow and doona protection, floor mats - washable	18.0	33.0	\$144
Hygiene and odour control products	13.0	24.0	\$76
Indwelling urinary catheters	0.0	-	\$595
Intermittent/nelaton catheters	0.9	-	\$6,570
Drainage system including leg bags, overnight bags, catheter valves	2.7	0.0	\$590
Transanal irrigation	-	1.8	\$11,101
Anal plugs	-	0.0	\$388
Penile clamps	2.0	-	\$70
Urinal (men)	4.0	-	\$18
Condom drainage/external sheath	0.9	-	\$120
Skin care including barrier cream and wipes	24.0	44.0	\$48

Source: Chemist Warehouse,¹⁶⁷ Independence Australia,¹⁶⁸ Incontinence products¹⁶⁹, Medimart¹⁷⁰; Deloitte Survey (2023).

Table 5.3: Aids and modifications use and cost for females reporting to use aids and modifications

Type of aid / modification	UI use (%)	FI use (%)	Annual cost per person in 2023 dollars (\$)
Hygiene and odour control products	13.0	24.0	\$76
Pads, liners, pull ups etc.	99.0	91.0	\$1,273
Bed and chair protection including bedpads, chairpads, mattress, pillow and quilt protection, floor mats - washable	18.0	33.0	\$288
Indwelling urinary catheters	0.0	-	\$595
Intermittent/nelaton catheters	0.9	-	6,570
Drainage system including leg bags, overnight bags, catheter valves	2.7	0.0	\$590
Transanal irrigation	-	1.8	\$11,101
Anal plugs	-	0.0	\$388
Urinal (female)	4.0	-	\$22
Skin care including barrier cream and wipes	24.0	44.0	\$48

Source: Chemist Warehouse, ¹⁷¹ Independence Australia, ¹⁷² Incontinence products ¹⁷³, Medimart ¹⁷⁴; Deloitte Survey (2023).

5.4 Government subsidies and funding for aids and equipment

Aids and equipment for incontinence are funded through individual out-of-pocket costs or government subsidies and funding. Government support is available for aids and modifications for people experiencing severe incontinence. The main scheme is the **Continence Aids Payment Scheme (CAPS)** which is a Commonwealth subsidy provided directly to individuals with incontinence to help with the cost of continence care products. Eligibility for the payment is determined by an assessment and confirmation from a registered health professional.¹⁷⁵ In addition to the Commonwealth CAPS scheme, there are also state-level schemes. These include:

- **Enable NSW** provides assistance to individuals with incontinence through the provision of aids supports. Individuals will only receive funding from Enable NSW if their aids and equipment needs are greater than what would be covered by the CAPS.¹⁷⁶

- **Medical Aids Subsidy Scheme (MASS) QLD** provides aids assistance for eligible adults and children with incontinence. Individuals are not eligible for assistance under MASS if they receive assistance or funding under one or more state / territory or federal government funded programs.¹⁷⁷

- **Victorian Aids and Equipment Program** provides subsidised aids and equipment to eligible individuals. Individuals who receive aids and equipment through other government programs are not eligible for this program.¹⁷⁸

- **Continence Management Advice Service (CMAS) WA** provides advice at service clinics on how to manage incontinence and access subsidies for aids with Silver Chain. Those on CAPS may receive the Continence Management and Support Scheme (CMASS) subsidy.¹⁷⁹

- **ACT Equipment Scheme (ACTES)** provides equipment aids and appliances, including incontinence aids for people with a disability. Those who receive incontinence aids and equipment from NDIS are not eligible.¹⁸⁰
- **Northern Territory Disability Equipment Program (DEP)** provides aids and equipment to assist individuals with a long-term disability.¹⁸¹
- While the **National Disability Insurance Scheme (NDIS)** can also provide support for continence care, the scheme is more focused on disability.¹⁸²

Government subsidies totalled \$46.2 million for Federal Government as part of CAPS escalated to 2023 dollars, and \$17.5 million escalated to 2023 dollars as part of state-based schemes (Report on Government Services, 2022).¹⁸³ Average maximum subsidy amounts per person were applied to the percentage of survey respondents who reported receiving CAPS or state-based subsidies and those with severe or very severe incontinence (based on eligibility criteria). This means that \$630.3 million is funded out-of-pocket by people with incontinence, escalated to 2023 dollars.





06

Productivity losses

Incontinence can have a negative impact on an individuals' ability to participate in employment. This cost the Australian economy \$53.9 billion in 2023.

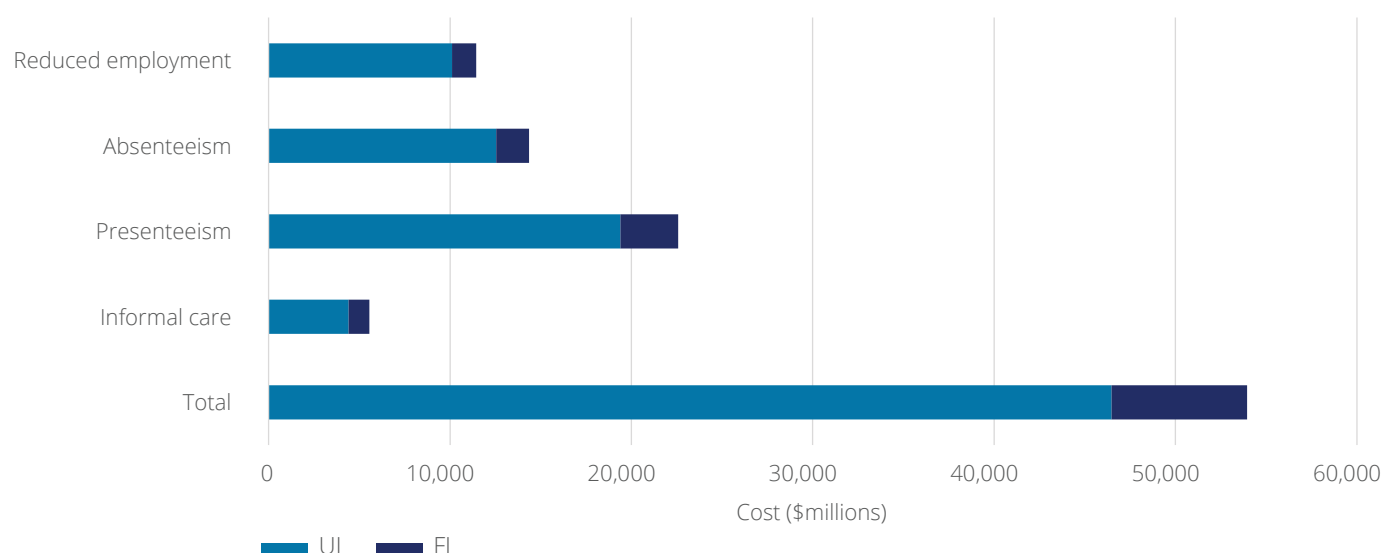


In this report, productivity losses owing to lower-than-average employment rates for those living with incontinence have been estimated. Illness and disease, more generally, may lead to productivity losses where they result in higher-than-average absenteeism and lower-than-average productivity at work.

Productivity loss for people experiencing incontinence was estimated to be \$53.9 billion, equating to a cost per person of \$7,413, (Chart 6.1). Of the productivity losses, presenteeism accounted

for \$22.6 billion (41.9%), absenteeism for \$14.4 billion (26.6%) and reduced employment for \$11.4 billion (21.2%). The impact on the productivity of informal carers was estimated to be \$5.6 billion (10.3%). These are large costs reflecting that 71% of people living with incontinence are of working age (i.e., aged 15-64) and the significant impact incontinence has on the productivity of workers who experience it. Urinary incontinence accounts for 86.2% of total costs, of which costs mostly arise from the impact on women.

Chart 6.1: Productivity costs due to incontinence by cost component in 2023



Source: Deloitte.

Table 6.1: Productivity costs on incontinence in 2023, by incontinence type and sex, (\$millions)

Cost component	UI (millions)			FI (millions)			Total	
	Men	Women	Subtotal	Men	Women	Subtotal	Total (\$millions)	% of total
Reduced employment	3,750.7	6,365.4	10,116.1	809.8	513.6	1,323.4	11,439.5	20.6
Absenteeism	4,407.1	8,150.4	12,557.5	1,070.9	737.9	1,808.8	14,366.3	25.9
Presenteeism	7,190.2	12,202.5	19,392.7	1,955.2	1,240.2	3,195.4	22,588.1	40.8
Informal care	1,344.1	3,065.2	4,409.3	626.8	515.5	1,142.3	5,551.6	12.7
Total	16,692.1	29,783.4	46,475.6	4,462.7	3,007.2	7,469.9	53,945.5	100.0

Source: Deloitte. Totals may not sum due to rounding.

6.1 Employment impacts, absenteeism and presenteeism

Incontinence can affect employment by reducing employment entirely or reducing productivity of those who are in employment through increased absenteeism and/or presenteeism.

Total employment impact was \$48.4 billion with most of the cost attributed to UI. These costs were mostly for presenteeism (46.7%), followed by absenteeism (29.7%) and reduced employment (23.6%).

Table 6.2: Employment impacts of incontinence in 2023, by incontinence type

Cost	UI (\$ millions)	FI (\$ millions)	Total (\$ millions)	Cost per person (\$)	% of total
Reduced employment	10,116.1	1,323.4	11,439.5	1,572	23.6
Absenteeism	12,557.5	1,808.8	14,366.4	1,974	29.7
Presenteeism	19,392.6	3,195.4	22,588.0	3,104	46.7
Total	42,066.2	6,327.6	48,393.8	6,650.5	100.0
% of total	86.9%	13.1%	100.0%	-	-

Source: Deloitte. Totals may not sum due to rounding.

6.2 Informal care

Almost a quarter (24%) of those surveyed for this report reported they required assistance from an informal carer for their incontinence. This was

predominantly undertaken by spouses and family members or relatives. From this, it was estimated that informal care costs totalled \$5.6 billion in 2023.

Table 6.3: Percentage of people who responded requiring assistance from an informal carer for their incontinence, by incontinence and informal carer type

	UI (%)	FI (%)	Total (%)
Spouse	12.8	21.1	15.5
Family member or relative	4.3	12.3	6.9
Friend or other informal carer	.	.	.
Other	1.7	1.8	1.7
No informal care	81.2	64.9	75.9

Source: Deloitte survey (2023).



07

Efficiency losses

Efficiency losses occur because of governments needing to raise taxation revenue to fund services.

In relation to the provision of continence care, efficiency losses in 2023 amounted to \$8.8 billion.



Efficiency losses, or deadweight losses, are defined as losses of economic efficiency that occur when equilibrium is not achieved in a market. In the case of incontinence, this may arise due to the government's need to collect additional tax revenue to fund costs that would otherwise not have been incurred such as Federal and State health expenditure, and lost consumer and company taxes. There are frictions associated with the collection of this additional tax revenue. Specifically, levying taxes reduces the efficiency with which resources are allocated within an economy. This may be through higher income taxes, which increases the price of work relative

to leisure and therefore creates a disincentive to work. Additionally, higher sales taxes increase the cost of goods and services and results in a loss of sales for businesses (such as pharmacies). These mechanisms result in a reduction in consumer and producer surplus, respectively, which is known as the deadweight loss, or excess burden, of tax. Deadweight losses increase when taxes are raised above the level that they would otherwise have been in the absence of incontinence. It was estimated that these efficiency losses due to incontinence totalled \$8.8 billion, as shown in Table 7.1.

Table 7.1: Efficiency losses due to incontinence in 2023, by incontinence type and sex

Cost component	UI (millions)			FI (millions)			Total	
	Men	Women	Subtotal	Men	Women	Subtotal	Total (\$millions)	% of total
Consumer taxes	242.2	1,377.3	1,619.5	53.2	121.5	174.8	1,794.3	20.4
Company taxes	1,827.2	3,316.5	5,143.7	519.3	355.5	874.8	6,018.5	68.4
Government health expenditure	221.7	424.5	646.2	64.7	57.7	122.5	768.7	8.7
Other government programs	42.1	89.0	131.1	28.2	56.2	84.5	215.6	2.5
Total	2,333.3	5,207.3	7,540.6	665.5	591.0	1,256.5	8,797.0	100.0

Source: Deloitte. Totals may not sum due to rounding.

08

Burden of disease

Incontinence also **creates a substantial loss of wellbeing due to reduced quality of life**. In 2023, the cost of lost wellbeing was estimated to be \$33.8 billion.



The costs that result from loss of wellbeing as a result of poor health are frequently described as the burden of disease.¹⁸⁴ These losses are measured in terms of disability-adjusted life years (DALYs). DALYs combine the years of healthy life lost due to living with a disability (YLD) and the years of life lost due to mortality (YLL). One DALY (the summation of YLD and YLL) is equivalent to one year of healthy life lost. The analysis in this report uses a burden of disease approach to estimate the costs associated with loss of wellbeing due to incontinence.¹⁸⁵

The total YLDs attributable to urinary or faecal incontinence were 112,170 and 33,763 respectively. The total of 145,933 YLDs is equivalent to 0.02 per

person who experienced incontinence in Australia in 2023. This indicates an average reduction in wellbeing of 2%, reflecting that most people experience slight incontinence.¹⁸⁶ Converted to a dollar estimate using the VSLY, the total value associated with this loss of wellbeing was estimated to be \$33.8 billion in 2023. The distribution of these YLDs and the associated value by age and sex is presented in Table 8.1. Urinary incontinence overall accounts for a greater share of loss of wellbeing than faecal incontinence (\$26 billion compared to \$8 billion), and women account for a greater share of loss of wellbeing than men (\$26.8 billion compared to \$7.0 billion).

Table 8.1: YLDs and cost of lost wellbeing due to incontinence in 2023 by sex

Cost component	UI (millions)			FI (millions)			Total	
	Men	Women	Subtotal	Men	Women	Subtotal	Total (\$millions)	% of total
YLDs	18,343	93,827	112,170	11,829	21,935	33,763	145,933	0.02
Cost of YLDs (\$million)	4,243.9	21,707.6	25,951.5	2,736.7	5,074.8	7,811.4	33,762.9	4,640
% of total	12.6	64.3	76.9	8.1	15.0	23.1	100.0	-
Cost per person (\$)	2,178	4,914	4,076	5,613	12,001	8,580	4,640	-

Source: Deloitte. Total costs are calculated as weighted averages.

009

Conclusion

This report highlights the financial and wellbeing costs of incontinence in Australia.

Despite its sizeable costs, there continues to be insufficient attention to data collection and other research into its causes and consequences.

More effort and investment is required to ensure that the impact of incontinence, especially for priority cohorts, is better monitored and suitable supports and treatments are made available.



9.1 Prevalence and cost of incontinence has increased in Australia

This study has found that the prevalence of incontinence has increased over the past 10 years. In 2023, 7.3 million Australians aged 15 and over had some measure of incontinence, compared to 4.8 million in 2010. This represents a 53% increase since 2010.

Most people with incontinence in 2023 experienced urinary incontinence (6.8 million). Women were still much more likely than men to experience incontinence (37% of women compared to 19% of men). While the prevalence rate increases with age, a majority (71%) of people with incontinence are aged between 15 and 64 years. If this prevalence rate is maintained it is estimated that there will be 8.6 million people with some level of incontinence by 2032, driven by population growth and ageing.

Increasing prevalence has impacts on costs. People with incontinence need to access services to manage their incontinence, and symptoms can impact a person's work and wellbeing. In 2023, the total cost of incontinence in Australia was \$66.6 billion, with an additional \$33.8 billion in lost wellbeing. The largest proportion of costs were due to lost productivity, particularly since a large proportion of people with incontinence (71%) are in the working-age population and those living in the community with incontinence requiring informal care.

Since 2010, the economic cost of incontinence has increased by 57%. Table 9.1 provides a summary of the costs of incontinence in Australia in 2023.

Table 9.1: Economic cost of incontinence in Australia in 2023 (millions)

Cost component	UI (millions)			FI (millions)			Total	
	Men	Women	Subtotal	Men	Women	Subtotal	Total (\$millions)	% of total
Health system	761.4	1,457.8	2,219.3	222.4	198.2	420.5	2,639.8	4.0
Other financial	330.4	590.5	920.9	123.1	167.6	290.7	1,211.6	1.8
Productivity	16,692.1	29,783.4	46,475.5	4,462.7	3,007.2	7,469.9	53,945.4	81.0
Efficiency losses	2,333.3	5,207.3	7,540.6	665.5	591.0	1,256.5	8,797.0	13.2
Total (excluding wellbeing costs)	20,117.2	37,039.0	57,156.2	5,473.6	3,963.9	9,437.6	66,593.8	100
Burden of disease (loss of wellbeing)	4,243.9	21,707.6	25,951.5	2,736.7	5,074.8	7,811.4	33,762.9	-

Source: Deloitte. Note: All figures in millions of dollars unless otherwise specified. Totals may not sum due to rounding.

9.2 Explore new data collection methods for incontinence

There is very little recent data on incontinence prevalence and costs (e.g., health, productivity, efficiency, and financial costs) in Australia. There are many reasons for this, including the fact that incontinence may be overlooked when diagnosing other conditions and consequently may not be recorded as a separate comorbidity in administrative data. Continence health questions are not consistently asked in national health surveys.

To bridge the gap in data availability, a survey of people living with incontinence and carers was conducted. The survey provided some information to address these gaps, and the responses have informed the estimates of the economic cost of incontinence in Australia. However, there are still many uncertainties relating to the experiences of people experiencing incontinence, particularly among priority groups (e.g., Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse communities (CALD), children, and LGBTQIA+ populations). The survey data included responses from individuals from some of these groups, but the small sample size does not allow for inferences to be applied to the broader population.

9.3 Further research into specific priority groups

People in priority groups (Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse, LGBTQIA+ communities and children) may have different experiences with respect to incontinence care when compared to the general population. These differences typically relate to diagnosis, prevalence, and access to treatment.

There is a severe lack of evidence and data on the needs of these groups and, necessarily, these gaps have limited the analysis in this report. A summary of what is known about the experiences of these population subgroups in relation to continence health is provided below. There is an urgent need

for research into the experience of these groups to understand prevalence and incidence rates, health service utilisation and barriers and the direct and indirect costs of incontinence.

9.3.1 Aboriginal and Torres Strait Islander communities

The experience of accessing healthcare for Aboriginal and Torres Strait Islander populations may be different to that of the general population with a number of barriers noted in the literature, including:

- Large geographic distance between health services (for people living in remote areas),
- A lack of access to appropriate transport in some remote areas,
- Financial barriers,
- A lack of culturally appropriate services,
- Limited understanding of the healthcare system,
- Low awareness that incontinence is a treatable condition,
- Limited English ability to convey their health concerns and lack of language support, and
- The availability of Indigenous staff at healthcare services.¹⁸⁷

There is little data to estimate prevalence of incontinence among Aboriginal and Torres Strait Islander populations.¹⁸⁸ There are some indications in current literature that these populations may have a higher rate of urinary incontinence than the general population due to higher associated risk factors such as obesity.¹⁸⁹ One study provides self-reported prevalence of incontinence to be 14% - 25%, and incidence to be 23.6% after 7 years which is higher than comparison populations.¹⁹⁰

Standard methods of data collection may not be appropriate for measuring the experiences and outcomes of Aboriginal and Torres Strait Islander populations. For example, in the survey conducted for this report, only 1.56% identified as Aboriginal

populations, and 0% identified as Torres Strait Islander. This small sample size is insufficient to determine reliable cost estimates for these populations. This underscores the need for more comprehensive data collection for this population to better understand their experiences with continence care utilisation.

9.3.2 Culturally and linguistically diverse communities

In 2021, three in ten people were born overseas and 23% of Australians spoke another language at home.¹⁹¹ Despite the fact that large segments of the Australian population are from CALD backgrounds, evidence of the prevalence of incontinence among the various CALD population groups is lacking. In the survey conducted for this report, 24% of the respondents to the survey reported that they identified as being from one of the following ethnic groups: Asian, Indian, European, South American, or African. However, the heterogeneous nature of these groups and the relatively small sample of respondents in each CALD sub-group means that it is not possible to extrapolate findings to draw further conclusions.

There are several reasons to believe that the CALD experience with diagnosis and access to incontinence treatment might be different from that of the general population. CALD populations may under-utilise health services due to a lack of familiarity with and support to navigate the Australian health system and cultural and linguistic barriers.¹⁹² These challenges are difficult to explore given inconsistent CALD population definitions which lead to inadequate data collection.¹⁹³ Better data collection is required to understand the scale of continence health needs amongst CALD communities. In addition, given the persistent stigma that is attached to incontinence in all communities, it is vital that cultural sensitivity is inculcated in incontinence training for all health professionals.

9.3.3 Lesbian, gay, bisexual, transgender, queer, intersex, and asexual plus (LGBTQIA+)

Lesbian, gay, bisexual, transgender, queer, intersex, and asexual plus (LGBTQIA+) people are more likely to avoid seeking healthcare and have lower medical adherence than the general population.¹⁹⁴ This disparity reflects, at least in part, the stigma and discrimination faced by LGBTQIA+ people in healthcare settings. In fact, a 2017 survey found that 8% of LGBTQIA+ people had avoided or postponed needed healthcare in the past year due to disrespect or discrimination from healthcare staff.¹⁹⁵ Discrimination can impede the access of LGBTQIA+ people to appropriate care – in fact, an Australian survey of 928 transgender people found that 26% had experienced discrimination in accessing healthcare.¹⁹⁶ While there is limited available evidence on the help-seeking behaviours of LGBTQIA+ people with incontinence, underdiagnosis for this group is likely.¹⁹⁷ The sample size of the survey conducted by Deloitte was too small to provide detailed insights into the experiences of LGBTQIA+ people with incontinence, with only 4.87% of the 252 people surveyed identifying as LGBTQIA+. More research is needed to determine if stigma causes LGBTQIA+ community members to avoid seeking help for incontinence.

The prevalence of incontinence within the LGBTQIA+ community is likely to differ from the general population for sub-groups within the community. For example, individuals who have a vaginectomy are more likely than the general population to experience urinary incontinence – one study found that 52.7% of patients who underwent a vaginectomy experienced lower urinary tract symptoms.¹⁹⁸ As such, further research is required to determine the prevalence of incontinence among LGBTQIA+ people.

9.3.4 Children

There are three main symptoms of incontinence in children aged 5-14. These are summarised in Table 9.2.¹⁹⁹

Table 9.2: Incontinence types in children

Type of incontinence	Definition	Common causes
Daytime wetting	Involuntary passing of urine during the day	• Overactive bladder • Underactive bladder • Leakage (i.e., child puts off going to the toilet, so bladder overfills) • Incomplete emptying of the bladder
Bedwetting	Involuntary passing of urine that occurs at night during the main sleep period.	• Inability to wake to a full bladder • Bladder becomes overactive at night • Kidneys make a large amount of urine at night that the bladder has difficulty holding
Soiling (faecal incontinence)	Emptying of the bowels in places other than the toilet	• Constipation associated faecal incontinence • Non retentive faecal incontinence

Source: Continence Foundation of Australia (2022)

There are several reasons to believe that the experiences of children with incontinence are different to those of adults. Diagnosis of childhood incontinence is often delayed by the perception that daytime wetting, bedwetting, and, to a lesser extent, soiling is normal in childhood. There are anecdotal reports of erroneous and damaging advice that may be provided by health professionals reassuring parents that children will 'grow out of it'.²⁰⁰ As a result, family members may attempt to manage the incontinence privately and be less likely to seek help for their child.²⁰¹ The Continence Foundation of Australia and the International Children's Continence Society have estimated that 3-12% of children experience day wetting, 1-3% experience soiling and nearly 20% experience bedwetting.²⁰² However, the prevalence is difficult to determine due to underreporting, inconsistent definitions, and regional variations.²⁰³ Treatment for incontinence is also different for children, reflecting age-specific considerations and differences in the causes of incontinence.²⁰⁴ Further research into children's experience of incontinence is needed urgently.

9.3.5 Further research on demand-supply of services and supports across Australia

While it is evident from this report that the overall cost of incontinence has grown in Australia, more information is required about the adequacy of services to meet local and regional needs. Survey participants indicated they have experienced a lack of available public support, obliging them to fund private options.²⁰⁵

"I contacted the local healthcare centre to be told they did not have a continence nurse in my area. Eventually, I found a nurse through Catholic Care. This is a condition I've had to deal with mostly on my own."

Survey participants also experience extended waits for an appointment.

"There is a distinct lack of specialists in urogynecology in Sydney. I've waited 12 months to get an appointment."

“It is very hard to access appointments in the public health system for incontinence.”

Most incontinence care is delivered to people living in community settings, and there is a need to invest in additional capacity and capability in community-based services. Nearly half (48%) of Australia's population who report experiencing a degree of incontinence are ineligible for government-funded aged care (i.e., under 65 or 50 if Aboriginal or Torres Strait Islander) and less than 2% live permanently in aged care homes.²⁰⁶ Demand-supply analysis is required to determine if the right types of services are being provided and to highlight service gaps.



Appendix A

Prevalence approach

A.1. Prevalence

A short online survey hosted in Qualtrics was distributed to people experiencing incontinence and their carers through the network of the Continence Foundation of Australia. The survey sought to better understand the diversity of people experiencing incontinence and its impacts, including how it is managed and how it impacts on people's productivity.

Deloitte is assisting the Continence Foundation of Australia to better understand the real impact of incontinence. This survey aims to evaluate the economic and social cost of incontinence in Australia. The findings from this survey will inform a report.

A.2. Mortality

A.2.1. Introduction

Information collected through this survey will inform knowledge and understanding of:

- the impact on the wellbeing of individuals affected; and
- the economic cost of incontinence to health and social care, employment, and carers.

A.2.2. Purpose of the study

You are invited to participate in an online survey, which is being conducted to better understand incontinence impacts.

This survey will take approximately 15 minutes to complete.

This survey will collect personal information about you including demographic information (such as your age, sex and gender) and details about your work. It will also collect personal information about you that

may be considered special category (or "sensitive") personal information, including details about your condition, how you manage your condition, your use of healthcare services and your wellbeing.

Your personal information will be used to estimate the economics costs of incontinence and to describe the characteristics of groups of people (not individuals) who have incontinence.

A.2.3. Confidentiality

Your personal information and special category information collected as part of this survey will be kept strictly confidential. Your identity will not be revealed, and your confidentiality will be protected in any reviews and reports of this study which may be published.

While we use a third-party survey platform provider to assist us in administering this survey, this provider is bound by strict confidentiality and privacy obligations. This means that your information will only be accessed by authorised personnel where required for the purpose of administering the survey and conducting the analysis described above.

A.2.4. Voluntary participation/right to refuse or withdraw

Your participation in this survey is voluntary; and you can withdraw at any time if you change your mind. If you decide to withdraw your consent by exiting the survey mid-way through, your responses will not be recorded. You have various rights in relation to your personal information, including the right to seek access to, or to correct your information (for more information, please see our Privacy Statement).

A.2.5. Summary of survey questions

	Demographics	Incontinence type, sex at birth, age, identity, pregnant, birth history
	Work	Employment status, reason for not working, hours worked, income, work missed, job performance relative to average worker
	Healthcare utilisation	Healthcare providers, type of provider, number of visits, surgeries, type of surgery
	Use of medications and equipment	Medications, type of medication, out-of-pocket costs, aids, type of aids, number of aids
	Care needs e.g., residential, formal, and informal care	Residential aged care, hours of care, formal care, hour of formal care, informal care, hours of informal care

A.2.6. Incontinence status

1. Which of the following best describes how you will respond to this survey?

- If you are answering the survey on behalf of someone with incontinence, please answer all other questions in the survey from their perspective.

	Categories	Response
01	As myself, a person with incontinence or a continence condition (e.g., bowel dysfunction or overactive bladder syndrome)	
02	As the parent/guardian of a child (aged up to 18 years old) with incontinence or a continence condition	
03	As the carer of a person with incontinence or a continence condition	
99	None of the above	GO TO END OF SURVEY

2. Which of the following types of incontinence or continence conditions have you experienced within the past month? Please select as many as apply.

- Urinary incontinence is the involuntary loss of urine.
- Faecal incontinence is the involuntary loss of liquid or solid stool.

	Categories	Response
01	Urinary incontinence	
02	Faecal incontinence	
03	A continence condition (e.g., bowel dysfunction or overactive bladder syndrome)	
99	None of the above	GO TO END OF SURVEY

3. Which of the following has a health professional ever diagnosed you with? Please select as many as apply.

Categories		Response
01	Urinary incontinence	
02	Faecal incontinence	
03	A continence condition (e.g., bowel dysfunction or overactive bladder syndrome)	
99	None of the above	GO TO END OF SURVEY

A.2.7. Demographics and related conditions

4. What was your biological sex at birth?

Categories		Response
01	Female	
02	Male	
03	Intersex	
04	Other, please specify:	
99	Prefer not to say	

5. What is your age?

Categories		Response
01	Under 15	
02	15 to 17	
03	18 to 24	
04	25 to 34	
05	35 to 44	
06	45 to 54	
07	55 to 64	
08	65 to 74	
09	75 to 84	
10	85 or older	
99	Prefer not to say / Unsure	

6. Do you identify as LGBTQIA+ (e.g., lesbian, gay, bisexual, transgender, queer, intersex, asexual and other identities)?

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

7. How would you define your sexual orientation? ASK IF Q6= 01.

	Categories	Response
01	Heterosexual (e.g., straight)	
02	Homosexual (e.g., gay or lesbian)	
03	Bisexual	
04	I use a different term. Please specify:	
99	Prefer not to say / Unsure	

8. How would you describe your gender? ASK IF Q6= 01.

	Categories	Response
01	Man or male	
02	Woman or female	
03	Non-binary	
04	I use a different term. Please specify:	
99	Prefer not to say / Unsure	

9. With which ethnic group(s) do you identify? Please select up to two.

	Categories	Response
01	Aboriginal	
02	Torres Strait Islander	
03	Australian	
04	New Zealander	
05	Asian	
06	Indian	
07	Middle Eastern	
08	European	
09	North American	
10	South American	
11	African	
04	I use a different term. Please specify:	
99	Prefer not to say / Unsure	

10. Please select which, if any, of the following apply to you:
ASK IF Q4 DOESN'T EQUAL 02.

	Categories	Response
01	I am currently pregnant	
02	I have given birth to one or more children	
03	I have experienced or am currently experiencing menopause	
04	I have had a hysterectomy	
05	I have or have had a prolapsed bladder, vagina or uterus	
06	I have or have had rectal prolapse	
07	I have a neurological disorder (e.g., multiple sclerosis, Parkinson's disease, a stroke or a brain tumour)	
08	I have been diagnosed with chronic constipation	
09	I have been diagnosed with irritable bowel syndrome, or an inflammatory bowel condition such as Crohn's disease or ulcerative colitis	
10	I currently live with a physical disability	
11	I currently live with an intellectual disability	
12	Prefer not to say / Unsure	
13	I have been diagnosed with a congenital condition	

10 continued. Please select which, if any, of the following apply to you:
ASK IF Q4 DOESN'T EQUAL 02.

	Categories	Response
14	None of the above	
99	Other, please specify	

11. Please select which, if any, of the following apply to you:
ASK IF Q4=02.

	Categories	Response
03	I have or have had a prolapsed bladder, vagina or uterus	
04	I have or have had rectal prolapse	
05	I have a neurological disorder (e.g., multiple sclerosis, Parkinson's disease, a stroke or a brain tumour)	
06	I have been diagnosed with chronic constipation	
07	I have been diagnosed with irritable bowel syndrome, or an inflammatory bowel condition such as Crohn's disease or ulcerative colitis	
08	I have been diagnosed with prostate cancer or an enlarged prostate	
09	I currently live with a physical disability	
10	I currently live with an intellectual disability	
11	Prefer not to say / Unsure	
12	I have been diagnosed with a congenital condition	
13	None of the above	
99	Other, please specify	

A.2.8. Work

12. Which of the following best describes your current state of work?

	Categories	Response
01	Full time work	
02	Part time	
03	Casual work	
04	Not employed, but looking for work	
05	Not employed and not looking for work	
99	Prefer not to say / Unsure	

13. Which of the following best describes the influence of your incontinence or continence condition on your employment status? ASK IF Q12=04, 05

	Categories	Response
01	My incontinence is the primary reason I am not employed	
02	My incontinence is one of the main reasons I am not employed	
03	My incontinence has had little or no impact on my employment status	
99	Prefer not to say / Unsure	

14. What are your average weekly earnings after tax? ASK IF Q12 = 01, 02, 03.

	Categories	Response
01	Less than \$250	
02	\$250 to \$499	
03	\$500 to \$999	
04	\$1,000 to \$1,499	
05	\$1,500 to \$1,999	
06	\$2,000 or more	
99	Prefer not to say / Unsure	

15. How many hours does your employer expect you to work in a typical 7-day week?

- If your hours vary, estimate the average.
- If you are self-employed, estimate the number of hours you would consider a full work week.
- If you have more than one job, combine total number of hours for all jobs. ASK IF Q12 = 01, 02, 03, OE-NUM (RANGE 1-168).

	Categories	Response
01	OPEN NUMERIC	

16. During the past 7 days, how many hours did you actually work? ASK IF Q12 = 01, 02, 03, OE-NUM (RANGE 1-168).

	Categories	Response
01	OPEN NUMERIC	

17. During the past 7 days, how much did your incontinence or continence condition affect your productivity while you were working?

- Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.
- Choose a high number if incontinence affected your work a great deal.
 - A score of 10 reflects that your incontinence completely prevented you from working, while a score of 0 signals that your incontinence had no effect on your work.

ASK IF Q12 = 01, 02, 03.

Categories		Response
01	1	
02	2	
03	3	
04	4	
05	5	
06	6	
07	7	
09	8	
09	9	
10	10	

18. Now please think of your work experiences over the past 4 work weeks. In the past 4 weeks, how many full and partial days of work (e.g., 1.5 days) did you miss because of your incontinence or continence condition?

- For example, work missed due to being too sick to work or attending doctor appointments.
- Please only include days missed for your own health, not someone else's health.

ASK IF Q12 = 01, 02, 03, OE-NUM (RANGE 1-168).

Categories		Response
01	OPEN NUMERIC	

A.2.9. Healthcare utilisation

19. Have you seen any health providers (e.g., general practitioner, urologist, physiotherapist) specifically for or relating to the management of your incontinence or continence condition in the last year?

ASK ALL.

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

20. Which health providers have you seen for management specifically or including for your incontinence in the last year? ASK IF Q19= 01.

	Categories	Response
01	Gastroenterologist	
02	Urologist	
03	Obstetrician	
04	Gynaecologist	
05	Colorectal surgeon	
06	General surgeon	
07	Paediatrician	
08	Urogynaecologist	
09	Geriatrician	
10	Continence nurse specialist	
11	Physiotherapist working in pelvic health	
12	Occupational therapist	
13	General practitioner (GP)	
14	Mental health professional (e.g., psychologist, counsellor)	
97	Other, please specify:	
99	Prefer not to say	

21. How many times have you seen each of the following health providers in the past year? ASK IF THE HEALTH PROFESSIONAL IS SELECTED IN Q20.

	Categories	Response
01	Gastroenterologist	OPEN NUMERIC
02	Urologist	OPEN NUMERIC
03	Obstetrician	OPEN NUMERIC
04	Gynaecologist	OPEN NUMERIC
05	Colorectal surgeon	OPEN NUMERIC
06	General surgeon	OPEN NUMERIC
07	Paediatrician	OPEN NUMERIC
08	Urogynaecologist	OPEN NUMERIC
09	Geriatrician	OPEN NUMERIC
10	Continence nurse specialist	OPEN NUMERIC
11	Physiotherapist working in pelvic health	OPEN NUMERIC
12	Occupational therapist	OPEN NUMERIC
13	General practitioner (GP)	OPEN NUMERIC
14	Mental health professional (e.g., psychologist, counsellor)	OPEN NUMERIC
15	Other	OPEN NUMERIC

22. Have you had any surgical procedures or day procedures (e.g., colposuspension) for your incontinence in the last 12 months?

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / don't know	

23. Which of the following surgical procedures or day procedures (e.g., colposuspension) have you had for your incontinence? ASK IF Q22 = 01.

	Categories	Response
01	Sphincteroplasty	
02	Sacral nerve modulation (SNM)	
03	Artificial urinary sphincter	
04	Male urethral sling	
05	Midurethral slings (female)	
06	Colposuspension/Burch colposuspension	
07	Urethral bulking agents eg macroplastique	
08	Rectus fascial sling / pubovaginal sling	
09	Percutaneous Tibial Nerve Stimulation	
10	Intravesical Botox (ie into the bladder)	
11	Magnetic chair (i.e., pelvic floor stimulation)	
12	Urodynamics/fluoroscopic urodynamics	
13	Anal manometry	
14	Anal ultrasound	
15	Defaecating proctogram	
97	Other, please specify:	
99	Prefer not to say / don't know	

A.2.10. Medication and equipment

24. Do you use any medications to help manage your incontinence or continence condition?

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

25. Which of the following medications do you take to manage your incontinence? ASK IF Q24= 01.

	Categories	Response
01	Oxybutynin (i.e., Ditropan/Oxytrol Patch)	
02	Solifenacin (i.e., Vesicare)	
03	Ovestin vaginal cream	
04	Estradiol vaginal inserts (i.e., Vagifem)	
05	Tolterodine (i.e., Detrusitol)	
06	Desmopressin (i.e., Minirin)	
07	Tamsulosin (i.e., Flomaxtra)	
08	Dutasteride/Tamsulosin (i.e., Duodart)	
09	Diphenoxylate/Atropine (i.e., Lomotil)	
10	Mirabegron (i.e., Betmiga)	
11	Darifenacin (i.e., Enablex)	
12	Loperamide (i.e., Gastro-Stop, Imodium)	
13	Laxatives (i.e., Coloxyl, Movicol, Senokot, Actilax etc)	
14	Enemas (e.g., Microlax, Microenema, Fleet Enema)	
15	Suppositories (e.g., Glycerol, Dulcolax, Bisacodyl)	
16	Prucalopride succinate (i.e., Resotrans)	
97	Other, please specify:	
99	Prefer not to say / Unsure	

26. Approximately how much money, on average, have you spent on medications specifically or including for your incontinence in a typical month?

- Please only include out of pocket costs (e.g., after refunds, reimbursements and financial supports).

ASK IF Q24 = 01.

	Categories	Response
01	OPEN NUMERIC	

27. Do you use any equipment or aids to help manage your incontinence (e.g., menstrual liners, incontinence pad, hygiene control products)?

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

28. Which of the following aids and equipment do you use to manage your incontinence? ASK IF Q27= 01.

Categories		Response
01	Incontinence pads - disposable	
02	Incontinence liners - disposable	
03	Incontinence pull up pants - disposable	
04	Incontinence underwear - washable	
05	Incontinence pads - washable	
06	Menstrual pads	
07	Menstrual liners	
08	Bed and chair protection including bedpads, chairpads, mattress, pillow and doona protection, floor mats - washable	
09	Hygiene and odour control products	
10	Indwelling urinary catheters	
11	Intermittent/nelaton catheters	
12	Drainage system including leg bags, overnight bags, catheter valves	
13	Transanal irrigation	
14	Anal plugs	
15	Penile clamps	
16	Urinals including male, female and portable	
17	Condom drainage/external sheath	
18	Skin care including barrier cream and wipes	
97	Other, please specify:	
99	Prefer not to say / Unsure	

29. How many units of the following aids do you use per week, on average, to manage your incontinence?

- Please count each individual aid (e.g., a single incontinence pad, a single menstrual liner) as one item.

ASK IF THE AID IS SELECTED IN Q28.

	Categories	Response
01	Incontinence pads - disposable	OPEN NUMERIC
02	Incontinence liners - disposable	OPEN NUMERIC
03	Incontinence pull up pants - disposable	OPEN NUMERIC
04	Incontinence underwear - washable	OPEN NUMERIC
05	Incontinence pads - washable	OPEN NUMERIC
06	Menstrual pads	OPEN NUMERIC
07	Menstrual liners	OPEN NUMERIC
08	Bed and chair protection including bedpads, chairpads, mattress, pillow and doona protection, floor mats - washable	OPEN NUMERIC
09	Hygiene and odour control products	OPEN NUMERIC
10	Indwelling urinary catheters	OPEN NUMERIC
11	Intermittent/nelaton catheters	OPEN NUMERIC
12	Drainage system including leg bags, overnight bags, catheter valves	OPEN NUMERIC
13	Transanal irrigation	OPEN NUMERIC
14	Anal plugs	OPEN NUMERIC
15	Penile clamps	OPEN NUMERIC
16	Urinals including males, female and portable	OPEN NUMERIC
17	Condom drainage/external sheath	OPEN NUMERIC
18	Skin care including barrier cream and wipes	OPEN NUMERIC
97	Other	OPEN NUMERIC
99	Prefer not to say / Unsure	

A.2.11. Residential, formal and informal care

30. Do you live in a residential aged care home?

	Categories	Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

31. Approximately, how many hours per week do you receive assistance from a residential aged care worker specifically for your incontinence (e.g., assistance with toileting, pad changes and/or showering)?

ASK IF Q30 = 01.

Categories		Response
01	OPEN NUMERIC	

32. Do you have a formal carer (a person who is paid to give care) to assist you with your activities of daily living specifically or including for your incontinence?

ASK if Q30=02,99.

Categories		Response
01	Yes	
02	No	
03	Prefer not to say / Unsure	

33. Approximately, how many hours per week do you receive assistance from a formal carer specifically for your incontinence? ASK IF Q32 = 01.

Categories		Response
01	OPEN NUMERIC	

34. Do you receive any assistance from an informal carer for your incontinence? If so, from whom? Please select all that apply.

- An informal carer includes any person who is giving regular, ongoing assistance to another person without payment for the care given. This can include a family member, friend or neighbour.

Categories		Response
01	Yes, from my spouse	
02	Yes, from a family member or relative	
03	Yes, from a friend or other informal carer	
05	Yes, from someone else. Please specify:	
97	I do not receive any assistance from an informal carer	
99	Prefer not to say / Unsure	

35. Approximately, how many hours per week do you receive assistance from an informal carer specifically for your incontinence? ASK IF Q34 = 01,02,03,04.

Categories	Response
01	OPEN NUMERIC

A.2.12. Government support

36. Do you currently receive any government support specifically or including for your incontinence? If so, which of the following forms of assistance do you receive? Please select all that apply.

Categories	Response
01	Yes, Continence Aids Payment Scheme (CAPS)
02	Yes, the National Disability Insurance Scheme (NDIS)
03	Yes, Department of Veteran Affairs Rehabilitation Appliances Program (RAP)
96	Yes, a state specific scheme (e.g., Enable NSW, MASS QLD, CMASS WA, SWEP Vic). Please specify:
97	Yes, a different government support. Please specify:
98	No, I do not receive government support for my incontinence.
99	Prefer not to say / Unsure

End of survey.

Endnotes

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