Continence Health Australia

A Scan of Factors Shaping the Continence Health Landscape

Policy

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List of Acronyms

ABS:	Australian Bureau of Statistics
AIHW:	Australian Institute of Health and Welfare
CALD:	Culturally and Linguistically Diverse
CAPS:	Continence Aids Payment Scheme
CDM:	Medicare Chronic Disease Management Plan
CHA:	Continence Health Australia (formerly the Continence Foundation of Australia
CoNSA:	Continence Nurses Society of Australia
FI:	Faecal Incontinence
GFI:	Global Forum on Incontinence
LGBTI+:	Inclusive acronym used to refer to lesbian, gay, bisexual transgender and intersex individual, as well as other sexual orientations and gender identities
NDIS:	National Disability Insurance Scheme
NGOs:	Non-governmental organisations
PFD:	floor dysfunction (PFD), which includes urinary incontinence (
POP:	pelvic organ prolapse
UI:	Urinary Incontinence

Summary

This paper updates the findings of a high-level scan of the changing landscape for continence health, first undertaken by the Continence Foundation of Australia in 2018. The organisation was renamed Continence Health Australia (CHA) in 2025. The paper describes shifts in national policy, epidemiology, economics, society, services, technology and the environment; all of which will have impacts on continence health needs and therefore on public demand for and the supply of continence health services and support in the future. These include:

- Prevalence and costs of incontinence in Australia.
- Aspects of public awareness of continence health in Australia.
- Continence health within the policy, funding and service delivery environment.
- Policy reforms in primary care, and aged care
- Workforce supply and access to continence training, education and professional development
- Evolving technologies in this area
- Environmental considerations
- Areas for future research and data collection.

Methods

The scan has drawn on five main sources of data and information:

1. The findings of a report on the economic cost of incontinence in Australia from Deloitte Access Economics, commissioned by CHA in 2023 and presented in 2024
2. Evidence reviews of pelvic floor health & dysfunction from the Trezona Consulting Group, also commissioned by CHA in 2023
3. The findings of the 2024 nationally representative survey of consumers undertaken by CHA.
4. The findings of the recent (March 2025) options report of the of the Continence Policy and Research Project by Healthcare Management Advisors (HMA) commissioned by the Department of Health and Aged Care.
5. The findings of the 2024 nationally representative survey of consumers undertaken by CHA.

Extensive use was made of a range of research platforms including EBSCOHost, PubMed, ProQuest Centra and Google Scholar as well as web-based searches including government departments and institutions. Internal data from the Continence Health Australia were also used. These included Helpline statistics and media analytics.

Limitations

The scan is a broad-brush discussion of several factors which have the potential to affect the costs and other consequences of incontinence in Australia. More detailed evidence briefings will follow. Significant gaps in data and other sources of information were revealed in undertaking this scan. The lack of data is a ubiquitous feature of the operating environment for continence health in Australia.

Headline Messages

The headline messages of the environmental scan are summarised below:

Incontinence is a common condition

- New data from Deloitte Access Economics (2024) demonstrate that incontinence is a highly prevalent but under recognised public health problem affecting Australians of all ages.
- 7.3 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 or faecal incontinence in 2023. This is an estimated 53% increase in the number of people suffering from some level of incontinence in Australia since the last national study was completed in 2010.
- These figures are broadly aligned with those of a review of pelvic floor health conducted by the Trezona Consulting group in 2023. This review provides figures which estimate that women experience incontinence at greater rates than men and that prevalence overall increases with age. In Australia, it is suggested that urinary incontinence occurs in 10% of women aged 45 to 64 increasing up to 12% in women aged 65 to 74.
- For most, continence is established in childhood, but people of all ages are at risk of developing 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. 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 treatments for a range of conditions.
- People who suffer from incontinence generally experience more severe disability and health problems than other people with disability. Regardless of the cause of incontinence, the experiential consequences include negative impacts on emotional and psychological wellbeing, quality of life and the ability to participate in normal activities of daily living.

Without preventative action, it is estimated that 8.6 million people (or 34.1% of the population) ***will have some degree of urinary and/or faecal incontinence in 2032. This represents an 18.6% increase from 2023.***

Incontinence is costly

- Deloitte Access Economics estimated the financial cost of incontinence in 2023 at $66.6 billion, with an additional $33.8 billion in lost wellbeing for people living with incontinence. These costs arise from utilisation of healthcare and other

social support systems, the costs of aids and adaptations, impacts on employment from various sources, and losses associated with lower productivity of people who suffer from incontinence and poor quality of life. These costs are met by the taxpayer, society as a whole and by individuals. Additional costs fall to informal carers, who play a large role in meeting the needs of people with incontinence.

Incontinence: underreported, under researched, poorly managed and distressing

- Incontinence is a stigmatised experience, frequently under-reported to health care services by those affected and often misdiagnosed or not diagnosed by clinicians.
- There are significant financial and mental health impacts associated with the experience of living with incontinence including for carers.
- Incontinence has complex causes. 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 treatments for a range of conditions.
- People who suffer from incontinence generally experience more severe disability and health problems than other people with disability. Regardless of the cause of incontinence, the experiential consequences include negative impacts on emotional and psychological wellbeing, quality of life and the ability to participate in normal activities of daily living.

Lack of investment in primary and secondary prevention

- Prevention is only now being addressed for some population groups, and there are concerns that, overall, there may be over-reliance on pads and products instead of effective prevention and treatment and management strategies.
- International evidence demonstrates how risks and costs are reduced where continence care is delivered by high quality, integrated community continence services.
- The associated increased costs and consequences of the increasing burden of incontinence in the population can be mitigated by effective policy, reformed clinical practices, and by achieving the full potential for prevention of these conditions.

Fragmented service landscape

- The continence health landscape in Australia is complex, with a mix of public and private health provision, geographical variations in demand and supply and a far-reaching social policy reform agenda in play. Historically, Australia has been a world-leader in responding to continence health. However, as the diversity and needs of the population change, and prevalence and costs associated with incontinence continue to rise, current arrangements and associated funding are under increasing strain. There are reports of significant gaps in the accessibility of services, particularly in rural and remote areas and there have been cuts in some states to specialist continence services. There are, in addition, concerns amongst stakeholders of a lack of capability in the generic health and aged care workforce

and loss of capacity in the specialist workforce. The lack of capability and poor quality of continence care was referred to in the Report of the Royal Commission on Aged Care (2021)

- There is international evidence that continence health is not a priority for healthcare planners, commissioners or policy makers. To some extent this may be a consequence of the persistent stigma which surrounds the issue. Moreover, the complexity of incontinence, which can have multiple causes, symptoms, range of at-risk populations and whole life-course aspects means that there can be no 'one-size fits all' solutions. The provision of personalised care may challenge health care planners and providers but is an essential step in enabling people who live with incontinence to participate fully and productively in society.

New policy agendas

- New policy streams in primary care reform, Medicare, aged care and women's health may have the potential to improve the prevention and management of incontinence, but this will not happen without strategic effort by CHA and others to raise awareness of the needs, promote the evidence of what works in preventing and managing incontinence, and establish culturally and age-appropriate service pathways which are accessible to all Australians, irrespective of where they live.

Research and Knowledge Gaps

- There are significant data gaps associated with incontinence. These gaps include:
    - Consistently updated information on prevalence
    - Consistently updated information on costs
    - Service data – numbers, scope and location
    - Outcomes data - the return on investment in continence services and support
    - Trends affecting the specialist continence workforce
    - Assessment of continence capability in pre-and post-qualifying training for the generic health workforce.
    - Contemporary evidence to support best treatment and management practice in all settings.
- There are no contemporary prevalence data for incontinence other than the 2023 data from Deloitte Access Economics, commissioned by the Continence Foundation (now CHA), which estimated prevalence in the adult population. These figures update 2010 data, also from Deloitte Access Economics. There is currently no mechanism for regularly assessing whole population prevalence of incontinence in Australia.
- There is a worrying lack of data on the specific continence health needs of children, Aboriginal and Torres strait Islander, CALD, LGBTQI+ and other priority populations.

Conclusions

1. The costs and consequences of incontinence are significant for individuals, families, the taxpayer and for healthcare systems. The costs and associated negative consequences will rise inexorably in the absence of policy measures to curb them. Chronic diseases and obesity are continuing to rise in Australia's expanding and ageing population. This will impact on the prevalence of incontinence without effective policy action focused on better prevention, treatment and management. There are therefore strong public health and economic arguments to be made for better primary and secondary prevention of incontinence.

2. Gaps in data obscure the full scale of need in the community and the ways in which broader social changes are impacting on continence health of the population overall and for specific population groups, including women, children and young people, First Nations, CALD and LGBTI communities. CHA is well placed to publicise these data gaps and to initiate a series of strategic conversations with governments, research funders and clinical partners about how best to drive forward a systematic research agenda for continence health, appropriate to Australia's population health needs.

3. There is an urgent need for significant investment in research into the causes, and consequences of incontinence in a range of Australian populations and to establish the evidence for effective prevention and management across the life course. This needs to be accompanied by strategies for incentivising researchers to address incontinence and other unglamorous health conditions.

4. Additional research is also required to clarify the complex linkages between incontinence and other chronic diseases. However, the evidence that is already available strongly suggests that it is time for a new understanding and classification of incontinence as a chronic disease with significant implications for the health of the nation and not just as a symptom of other conditions.

5. More data is required to understand the impact of deprivation on the experience of incontinence amongst communities in Australia and to analyse the equity of outcomes of current arrangements for support, management and treatment of incontinence. There is also a need for policy guidance and support for health service planners to ensure the equitable provision of high-quality continence care across the life course, irrespective of geographical location. It is important to understand the extent to which financial support provided to individuals living with incontinence is equitable between states. It is important also to explore the extent to which current arrangements through the NDIS provide robust support to individuals with a disability who also live with incontinence.

6. Policy reforms in Medicare, primary care and aged care, women's health, early years and chronic disease are part of a broader effort to create a more

sustainable, equitable, and high-quality health and aged care system in Australia and to address the avoidable causes of disease. There are number of opportunities for CHA to promote the issue of continence health within this emerging policy landscape. Firstly, the language of the reforms and the principles which drive them are important levers for CHA to deploy to continue to make the case for person-centred, high-quality continence care as a cross-cutting health need which is central to the experience of care delivery in a broad range of health and care settings. This sets a challenging policy development and advocacy agenda for CHA in the next 5 to 10 years.

7. The delivery of high quality, effective and personalised continence healthcare is a core capability for all staff working in health and care services, in all settings. There is an urgent need to establish capability standards for the multidisciplinary health and care workforce, and to initiate strategies to upskill the current and future workforce in continence care. Incentives and support are required to enable the national rollout of My Continence Care and the National Continence Quality Standard, developed by CHA. Widespread adoption of the National Continence Quality Standard for continence care can drive a transformative shift towards person centred, evidence based and high-quality continence care.

8. In addition, urgent action is required to tackle the erosion of specialist continence nursing expertise by establishing incentives for specialisation in continence nursing, the development of valued qualifications and career paths, and the establishment of relief nurse programs to enable continence nurses to enhance skills through continuous professional development, as well as targeted programmes to address gaps in the provision of continence pathways for adults and children in remote and rural areas.

9. Technological developments have demonstrable potential for supporting people to self-care, including self-monitoring, but this will require substantial research to develop an evidence base. CHA has a key role to play in brokering a dialogue between industries, consumers and professionals to ensure that technological development is responsive to needs, supports the goals of independence and participation and the promotion of wellbeing. There is an emerging research and policy agenda to understand and mitigate the environmental impacts of incontinence across the life course.

10. The development of strong partnerships and strategic alliances will be key to achieving future strategic goals. Given the wide range of the factors impacting on the continence health landscape as revealed by the environmental scan, CHA needs to reach out beyond its traditional territory to forge new alliances with a range of stakeholders particularly in the emerging areas of technology and environmental management.

Recommendations

The following high-level recommendations are made to the CHA Board for noting and comment.

1. Commit to the development of a National Continence Plan for 21st century Australia. This plan should address the distinct and separate needs of women, men, children and minority groups and communities and set out an agenda for the development of appropriate services at both primary and specialist levels of care.

2. Request the Australian Bureau of Statistics to embed questions on continence health in the National Health Survey to ensure that information about incidence, prevalence and impacts is updated regularly.

3. Establish incontinence as a research priority through the National Medical and Health Research Council and the Medical Research Future Fund.

4. Escalate efforts to achieve the recognition of incontinence as a long-term condition and not just a symptom of other conditions or an unavoidable consequence of certain life transitions.

5. Set achievable priorities to address the needs of specific populations, whilst continuing to address key cross-cutting issues. It is particularly important to continue to bring forward proposals to address the challenges of continence health workforce supply, accreditation and capabilities as well as the evident skills and capabilities gap in the generic healthcare workforce. A capable workforce is required to deliver effective prevention, support, and treatment to all populations. There is a particularly urgent need to address continence health workforce supply, support and capabilities in remote and rural locations.

Section 1: Overview

Purpose and Scope

This paper summarises some of the key characteristics of the changing landscape for continence health in Australia. These encompass the domains of national policy, epidemiology, economics, society, technology and the environment.

The discussion is structured as follows:

- Summary of the prevalence and costs of incontinence in Australia.
- Summary of aspects of public and political awareness of continence health in Australia.
- Consideration of continence health within the evolving policy, funding and service delivery environment.
- Consideration of workforce changes and developments including workforce supply and access to training and professional development.
- Consideration of the actual or potential impacts of technology.
- A consideration of the potential environmental impacts of incontinence.
- Identification of opportunities for future research and data collection, by CHA and others.

This overview identifies significant shifts in policy, epidemiology, economics, society, and technology; all of which will impact on continence health needs and therefore on public demand for and the supply of continence health services and support in the future.

Methods and Limitations

This scan has drawn on three main sources of data and information:

- The findings of a report on the economic cost of incontinence in Australia from Deloitte Access Economics, commissioned by CHA and published 2024
- Evidence reviews of pelvic floor health & dysfunction, including incontinence, from the Trezona Consulting Group, also commissioned by CHA in 2023
- The findings of the 2024 nationally representative survey of consumers undertaken by CHA.

Extensive use was made of a range of research platforms including EBSCOHost, PubMed, ProQuest Centra and Google Scholar as well as web-based searches including government departments and institutions. Internal data from CHA were also used. These include Helpline statistics and media analytics.

Significant gaps in data and other sources of information were revealed in undertaking this scan. These include:

- Lack of data on the prevalence of faecal incontinence or other bowel health issues. including amongst women during pregnancy.
- Lack of data on prevalence of incontinence health in men, children and young people, Aboriginal and Torres Strait Islander, CALD and LGBTQI+ communities.
- Lack of benchmarking data to assess the adequacy of specialist continence service provision against need and/or recommended best practice standards.
- Lack of data regarding investment in specialist continence services by states and territories including data on cuts to specialist services.
- Lack of data about numbers and ages of the multi-disciplinary, specialist continence workforce
- Lack of data regarding the availability and appropriateness of training to the multi-disciplinary, specialist continence workforce, or standards for training in continence management for the generic health workforce.
- Data on Medicare-subsidised continence physiotherapy services (via GP Chronic Disease Management Plans) is not available in the MBS data repository, so it is not possible to ascertain the use of these services.
- Lack of data to understand the extent to which the NDIS supports people with disabilities who also have incontinence. (data awaited)

There is an urgent need to begin to fill these gaps in essential information. This sets a challenging future research agenda for CHA, in partnership with Federal, State and Territory governments, research communities, Primary Health Networks, industry bodies. NGOs and others.

Australia's Response to Incontinence

Australia has a strong history of leadership and investment in the promotion of continence health and the management of incontinence in the last thirty years. Since 2006, the Australian Government has supported the prevention and management of incontinence through three initiatives: The National Continence Program, (NCP), the Continence Aids Payment Scheme (CAPS), which replaced the Continence Aids Assistance Scheme in 2010, and the Stoma Appliance Scheme. The NCP was initiated in 2011. It supports CHA which represents the interests of Australians affected by, or at risk of, bladder and bowel control problems and acts as an advocate for their interests. CHA delivers a range of health promotion, education and marketing activities, and manages the National Continence Helpline, World Continence Week, the annual National Conference on Incontinence, the National Public Toilet Map, Australian and New Zealand Continence Journal, and the Bladder& Bowel resources webpage. CAPS assists people with permanent and severe incontinence to meet some of the costs of their incontinence products. The Stoma Appliance Scheme provides stoma-related products, free, to people with stomas.

Australia has been – and continues to be – a leader in continence health promotion and management. However, as the prevalence and costs associated with incontinence increase, it is vitally important that the investment and leadership shown in recent decades is continued in ways appropriate to the changing needs and expectations of citizens in 21st century Australia.

Understanding Continence and Incontinence

Continence is the ability to have voluntary control over bladder and bowel functioning and to manage these functions in a socially acceptable and hygienic way. [1] [2] For most, continence is established in childhood, but people of all ages are at risk of developing incontinence. 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 mental and both chronic & acute physical illness. Pregnancy and childbirth are some of the contributory factors for women. Problems with achieving and maintaining control of bladder and bowel functions can significantly affect children's progress at school and their social relationships with peers.[3] [4]

Effective management of the bladder and bowel is essential for those with spinal injury, some congenital disorders, neurological illness, stroke, diabetes, dementia and end-of-life care, to identify some relevant dimensions of human experience. Many people rely on the management of symptoms to enable them to work, have satisfactory relationships, participate in sports and social activities and live an independent life. Many people can regain continence with appropriate treatment. People live with incontinence in all settings and locations, including their own homes, residential care establishments, hospitals and schools. Incontinence also affects vulnerable groups of people, such as the homeless and prisoners. Although incontinence becomes increasingly prevalent with age, it is not an inevitable consequence of ageing.

Incontinence has complex causes.[5] 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.[6] Regardless of the cause,

the experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in activities of daily living. [7] [8]

Incontinence can be managed effectively and does not always reduce quality of life. Variables such as type, severity and frequency of incontinence, success of any treatment and the effect of any attempted management strategies, quality of social support and individual differences in coping skills may all influence wellbeing outcomes. [9]

The Trezona Consulting Group, in an unpublished report for CHA has summarised the extensive evidence that a comprehensive, integrated approach to the prevention of incontinence and effective management of continence needs can significantly improve the quality of life for individuals and deliver significant cost savings. [10] The prevention and management challenges associated with the prevalence of incontinence in the population require a comprehensive policy approach and equal access to continence health service pathways for all Australians.

Section 2: Epidemiological Factors

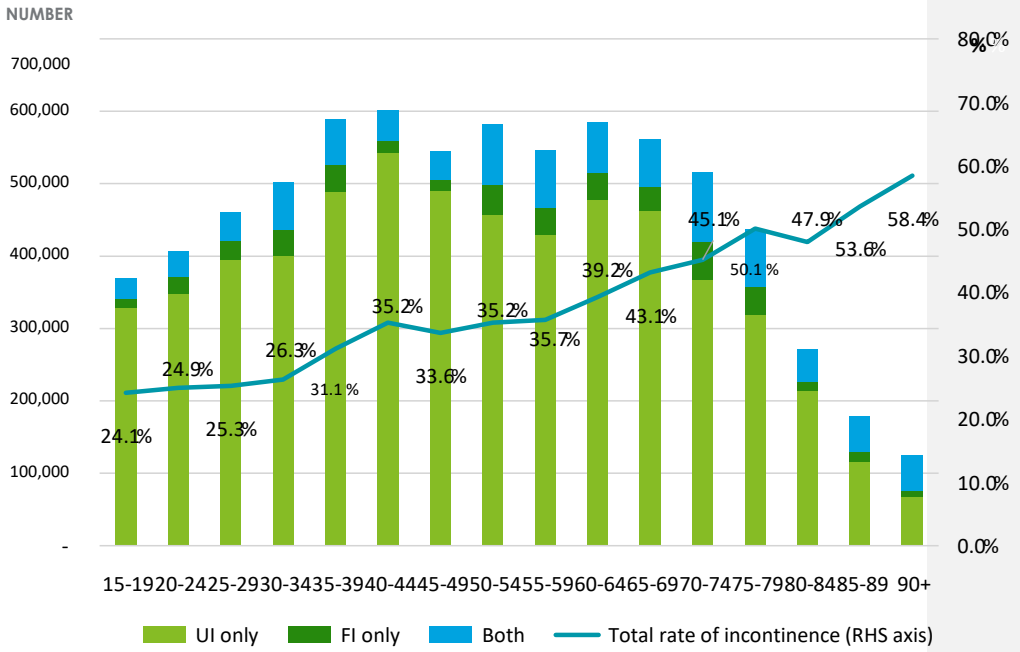
Prevalence of Incontinence

Incontinence is a highly prevalent but under-recognised public health problem affecting Australians of all ages. In 2023, Deloitte Access Economics, in a report commissioned by the former Continence Foundation of Australia, estimated that over 7 million Australians, aged 15 or over, experienced some level of urinary or faecal incontinence.[11]

2.4 million men (33% of the total population of men) and 4.8 million women (67% 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 figures 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. These figures reflect those identified in a systematic review of the evidence for pelvic floor health and dysfunction conducted by the Trezona Consulting Group in 2023. [12]

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 (See Chart 1 below). UI is much more prevalent than FI. People living in residential care experience incontinence at higher rates than the general population. Of residential aged care residents, 70.9% experience UI and/or FI. Looking ahead, the projected number of Australians living with some degree of UI/FI 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 (all figures from Deloitte Access Economics, 2023).

Chart 1. Prevalence of Incontinence in Australia in 2023 by Age and type



Source: Deloitte based on ABS (2024),[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]

Severe Incontinence

Ther are several definitions of severe incontinence in the literature and severity can be assessed using various methods including:

- **Frequency of leakage:** How often the urge leads to urine loss.
- **Quantity of leakage:** How much urine is lost during each incident.
- **Impact on daily life:** How much the urgency and leakage interfere with daily activities, such as work, social events, and sleep.

Severity levels can be categorized as:

- **Mild:** Occasional leakage with a strong urge.
- **Moderate:** More frequent leakage and potentially larger amounts of urine loss.
- **Severe:** Frequent, significant leakage that significantly impacts quality of life. [13]

The Australian Institute for Health and Welfare (AIHW), in a summary published in 2016, cited the following figures for prevalence of severe incontinence from the 2013 report Incontinence in Australia. In 2009, 316,500 people (1.5% of the Australian population) experienced severe incontinence.[14] Of these people, 91.0% also had a severe or

profound core activity limitation, indicating they had high-care needs. About 1 in every 14 people aged 65 and over (7.2%) and nearly 1 in 4 people aged 85 and over (24.5%) experienced severe incontinence, compared with 1 in 166 people aged under 65 (0.6%). The prevalence of severe incontinence was higher in females (2.0%) than males (1.0%). About 72,900 primary carers provided help with managing someone else's incontinence— 4 in 5 carers were female (81.2%), and 3 in 4 spent 40 hours or more per week caring (73.0%) (AIHW, 2013). These figures are now over ten years old and require updating.

Avery et al (2021) report that 9.4% of women responding to the 2001 South Australian Health Omnibus Survey, a representative sample of the adult South Australian population, reported severe incontinence. Respondents with any UI, who considered their condition to be very or moderately serious, were more likely to report severe incontinence. Women whose lifestyle was limited by incontinence were more likely to perceive their condition to be very serious. Together, severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious. [15]

Self-reported continence health needs

Data from a nationally representative survey of the public commissioned by CHA to gauge levels of public awareness and attitudes towards incontinence adds additional detail to the data on prevalence (n=2000) (CFA, 2024).[16] The survey included people who have, or have had, incontinence and carers.

See Box 1 Below.

Box 1. The Incidence of incontinence

Self-Reported Continence Health Needs

- 43% of respondents have experienced some bladder or bowel leakage.
- Twice as many women experience some bladder or bowel leakage compared to men.
- 77% of respondents who currently have incontinence & 82% of respondents who have had incontinence had urinary incontinence
- 11% of respondents reported that they have had faecal incontinence and 10% reported that they were currently experiencing both faecal and urinary incontinence
- 29% of carers reported that they were currently caring for someone with incontinence. Of these 31% reported that they were caring for a person with both urinary and faecal incontinence
- Incontinence increases with age, with 80% being aged 40 plus, 60% aged 50 plus and 39% aged 60 plus.
- Four in ten of respondents currently experiencing incontinence have given birth to one or more children
- 16% have a physical disability and 14% have been diagnosed as having incontinence.
- Every at-risk group, including parous women, women who have had a hysterectomy, the elderly, men post-prostate surgery, people living with disabilities including intellectual or cognitive impairment demonstrated higher rates of incontinence than the general population.

Box 1. National Consumer Survey 2024: Source: Continence Foundation of Australia, 2024

Incidence of incontinence in specific populations

Aboriginal and Torres Strait Islander people

Evidence is limited about the incidence of incontinence among Aboriginal and Torres Strait Islander people and results are mixed. While some groups have higher risk factors for incontinence, additional research is needed to know whether this translates to higher prevalence. Benness and Manning (1999)[17] reported an UI prevalence of 54% in a sample of 281 community-dwelling, nonurban Indigenous women. Half of the women (49%) experienced stress incontinence. LoGiudice et al. (2010) reported a much lower rate of incontinence in their sample of 363 Indigenous Australians aged over 45 (9%), however, the authors suggest that this is an underestimate of the true value because the methods used to determine incontinence had not been tested for the Indigenous population concerned. [18] These authors suggest that falls, urinary incontinence and pain are common in older indigenous people living in remote regions and that '*the presence of these syndromes in ages over 45 may be due to accumulation of health insults during the life course*'.

More recent studies indicate that prevalence and incidence rates of urinary incontinence in Aboriginal Australians are high and are associated with the key risk factors of older age and female sex. UI and stress urinary incontinence are both highly

prevalent. [19] There is evidence of high levels of shame and underreporting of these conditions in the Aboriginal population.[20] [21]

AIHW figures indicate that the Indigenous population experiences many chronic conditions at a higher rate than the non-Indigenous population, including conditions that are risk factors for incontinence. [22] Diabetes is 3 times as common in Indigenous people than non-Indigenous people. Obesity is almost twice as common in Indigenous people (33.6%) than non-Indigenous people (17.9%). [23] Dementia is more common in the Indigenous population than the non-Indigenous population, with one study citing a prevalence of 12.4% in Indigenous people aged 45 and older living in Western Australia—5 times greater than in the non-Indigenous population.[24] These conditions are risk factors for incontinence.

Despite limited research regarding the Indigenous population and incontinence, the higher rates of risk factors in this population supports the proposition that there may be a higher prevalence of incontinence. Addressing the research gap in this area is an urgent national challenge.

Culturally and linguistically diverse people

The experience of incontinence in people from culturally and linguistically diverse (CALD) communities can differ depending on their cultural practices, English-language abilities and health literacy skills. Prevalence rates are also variable. For example, in people aged 60 and older in the United States, the prevalence of UI was higher in non-Hispanic white women (41%) than non-Hispanic black (20%) or Mexican-American women (36%), while non-Hispanic black men had the highest prevalence of incontinence (21%) compared with non-Hispanic white (16%) and Mexican-American men (14%) [25] [26] An equivalent study comparing the prevalence of incontinence in people from different cultural backgrounds has not been conducted in Australia although the AIHW (2013 & 2016) and others provide evidence that culture and belief systems may be implicated in varying kinds of continence health challenges. [27]

Results from a large community survey undertaken by CHA in 2017 showed that CALD respondents were slightly less likely to experience incontinence than the general population.[28] However, they were more likely to avoid discussing incontinence with their family and friends, possibly indicating a level of culturally influenced silence on this issue. [29] [30]

In 2012, CHA started an incontinence education and awareness project targeting CALD communities. The project aims to develop effective engagement with CALD communities to improve their awareness of incontinence and encourage help-seeking behaviours.

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Lesbian, gay, bi-sexual, transgender and intersex populations

Research regarding the continence health needs of the LGBTI+ population is scarce, particularly in relation to LGBTI+ elders,[31] but observational * and probabilistic †studies indicate that specific groups within the LGBTI+ population may be at increased risk of incontinence. [32] There is some evidence that people who have had gender reassignment surgery may be at increased risk of incontinence. [33] [34] [35]

Concerns about the gaps in research knowledge are compounded by evidence from the third national survey on the health and wellbeing of gay, lesbian, bisexual and transgender Australians completed in 2020, that LGBTI+ Australians experience high rates of discrimination and mental ill health and occasionally or usually hide their sexuality or gender identity when accessing services. [36] Several studies provide evidence that clinicians can have negative attitudes towards people who are sex or gender diverse.[37] [38] A national survey of transgender adults conducted in 2017/18 identified a wide range of barriers faced by transgender individuals including widespread discrimination and unemployment, which contribute to health inequity and prevalent mental health conditions.[39] In the absence of robust research in this area, it is only possible to speculate that LGBTI+ people continue to face double jeopardy; concealing their continence health needs as well as sexual orientation in their interactions with health services.

Impacts on Adult Mental Health & Wellbeing

Deloitte Access Economics provide figures that suggest that in 2023, 45.3 % of health care costs provided to community dwelling adults living with incontinence was related to consultations with GPs and 20% with mental health professionals.

See Chart 2 below. Other health service costs comprised the largest proportion of health system costs, accounting for $1.5 billion (55.0% of the total cost. This included visits to general practice, allied health, and mental health professionals in relation to incontinence.

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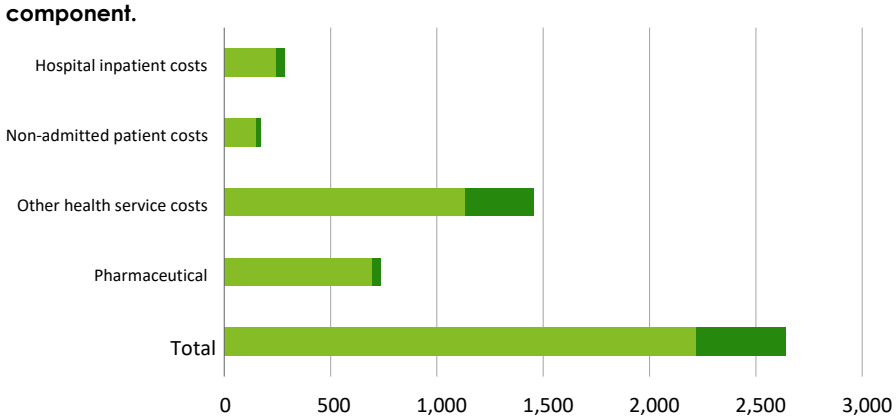
* An **observational study** is a type of research where the investigator observes subjects and measures variables of interest without assigning treatments to the subjects. The key characteristic is that the researcher does not control the independent variable or assign subjects to different groups. Instead, they observe and measure outcomes as they naturally occur. This type of study is often used when it is unethical or impractical to conduct an experiment

† **Probabilistic studies** involve the use of probability theory to make inferences about populations based on sample data. These studies often use statistical methods to estimate the likelihood of various outcomes and to make predictions. Probabilistic approaches are essential in fields like epidemiology, risk assessment, and decision-making under uncertainty.

Chart 2: Health System Costs attributable to incontinence in 2023 by cost component.



Source: Deloitte Access Economics, 2024, based on data from AIHW, NHCDC, PBS, Chemist Warehouse, and Deloitte consumer survey.

These figures are reflected in the findings of CHA's 2024 Consumer Survey which indicated that there is a substantial impact on the mental health of respondents who live with incontinence.

See Chart 3 below.

Chart 3: Reasons why People Living with Incontinence Report Poor Health

2024 themes (n=298)			
Mental health struggles	6.9%	Heart conditions	4.8%
Multiple painful conditions	6.6%	High Blood Pressure	4.8%
Chronic back pain	6.2%	Physical health struggles	4.8%
Arthritis	5.5%	Type one diabetes	4.8%
Breast cancer	5.2%	Chronic health conditions	3.8%

Source: Continence Health Australia. National Consumer Survey 2024

There is growing evidence of the associations between incontinence and psychosocial factors, including depression.

In summary the literature identifies the following:

Well Being Impacts:

- Quality of Life: the constant struggle to manage incontinence can significantly affect an individual's overall quality of life, including relationships, work performance, and emotional well-being. [40] [41] There is evidence that incontinence can lead to psychological distress and depressive symptoms. [42]
- Loneliness: People with incontinence are at higher risk of loneliness. [43] [44]
- Fear of Embarrassment: People experiencing incontinence often fear public embarrassment or stigma related to leakage episodes. This fear can lead to anxiety and avoidance of social situations, ultimately resulting in social withdrawal and isolation. [45] [46]
- Mortality: Strikingly, urinary incontinence is also a predictor of higher mortality.[47]

Association with Anxiety and Depression

- Prevalence: Studies show a strong association between UI and both anxiety and depression. A Norwegian study found that moderate to severe anxiety or depression increased the prevalence of UI from 27.6% to 37.8% for anxiety and from 28.0% to 43.7% for depression.[48]
- 30% of women with incontinence will also suffer from depression, [49] which is three times more likely than the general population.[50]
- A cross-sectional study evaluated the relationship between UI and depression among men. [51] The odds of depression were significantly higher for men with UI: Compared to no UI, the odds were 4.46 for mixed UI, 3.15 for stress UI, and 2.43 for urge UI.
- Severity: The severity of UI is correlated with higher odds of depression. Severe UI was associated with an odds ratio of 2.04 for depression compared to no UI. [52] The odds increased with more severe UI (e.g., very severe UI had an odds ratio of 3.85 compared to slight UI). [53]
- Chronic Stress: The ongoing stress of managing incontinence can contribute to the development of anxiety disorders.[54] [55]
- Biological Mechanisms: Reduced serotonin levels and inflammation (linked to anxiety and depression) may also affect bladder functioning.[56]

Anxiety and Functional Impairment

- Increased anxiety: Severe UI can lead to a four-fold increase in the prevalence of anxiety, particularly when it impairs daily functioning. [57] [58]

Impact of Medications

- Antidepressants: The use of antidepressants is associated with an increased prevalence of UI. However, the use of anxiolytics was found to be associated with less UI. [59]
- Oher Medications: Some medications used to treat mental health conditions might cause urge incontinence or reduce the bladder sensation that signals the need for urination. [60]

Impacts on the Health & Wellbeing of Carers

There is extensive evidence that caring for a person with incontinence can have significant and negative impacts on carer's quality of life, through social isolation, financial problems as well as psychological and physical exhaustion.[61] Lack of appropriate support and the general silence regarding the problem, which is still considered a taboo by many, aggravate the carers' situation. [62]

CHA's Consumer Survey (2024) provides additional insight into the multi factorial, nature of the burden faced by carers. See Table 1 below

Table 1. Impact on The Health & Wellbeing of Carers

Carers	• 30% of Australians currently care for or have cared in the past for someone who has incontinence. • 44% of carers say that caring for someone with incontinence impacts their mental health and well-being and makes them less confident to leave the house. • 40% of carers say that caring for someone with incontinence prevents them from going about their day-to-day activities (compared to 57% in 2022). • 12% of carers indicated it affects their mental health and wellbeing. • Carers are far more likely to have incontinence now (21%) or in the past (13%) than those who never had it (4%). • 52% of the care is provided by a spouse or partner. • There is a higher incidence of having incontinence (10%) in carers or past carers of someone with it (16% combined with 7% if never been such a carer).	• Over 29% of survey respondents have cared for or are caring for someone with incontinence. Of these, 49% are male, 51% are female, and 55% are over 40. • Caring for – Parent or parent-in-law 42% – Grandparent 22% – Spouse/partner 18% • Over 77% of the carers discussed their caring experience and about incontinence with someone. Nearly 68% were with a health professional, and 48% were with a GP or family doctor. In contrast, 23% did not discuss it with anyone. • While most of the carers (64%) feel supported to participate in community activities, there is a sizeable number of just under 50% who feel less confident leaving home and have reported it affecting their mental health and

	• There is a higher incidence of having had incontinence (29%) in carers or past carers of someone with it (45% combined with 23% if never been a carer). • Those more likely to receive care/support for incontinence (14%) are current or past carers (23%) than others (6%). • Those more likely to receive care/support for incontinence (14%) are current or past carers who tend to have looked after an older generation, a parent/parent-in-law (43%) or grandparent (18%) more than contemporaries like their spouse/partner (20%) or a younger generation like a child or adolescent. • Nearly half of carers cited some financial impact (12% significantly impacted). The 2022 survey found that 7% of carers struggled financially, and 42% reported some impact.	their relationships with family and friends. Impact on caring for someone: • Feel supported to participate in community activities-64% • Less confident to leave home- 46%. • Affects mental health & wellbeing - 51% • Affects day-to-day activities - 46% • Impacts my relationship with family and friends- 38%.

Source: CHA National Consumer Survey, 2024

Impacts on Children's Mental Health and Wellbeing

Continence problems are common in childhood and often persist into adolescence. For instance, around 3% of 14-year-olds have daytime urinary incontinence and 2.5% experience bedwetting. [63]

- According to data collected in the first full year of school by teachers through the Australian Early Development Census (AEDC),[64] the incidence of children not being fully toilet trained by the time they start school is increasing over time (from 1.96% in 2012 to 2.86% in 2021).‡
- Young people with incontinence often feel pessimistic about their condition and they report experiencing shame, social isolation, peer victimisation, restricted social lives, and disrupted education. [65] [66]
- Many clinicians are unaware of the wider issues affecting adolescents with incontinence, leading to negative clinical care experiences and inadequate treatment. [67]

‡ Note that this data is not a medical diagnosis, it is based on teacher observations and has not been validated as a measure of child development.]

- The impacts of incontinence on the daily lives of young people place them at an increased risk of developing mental health problems. A recent study (2023), based on data from the Avon Longitudinal Study of Parents and Children, found that young people with incontinence are at greater risk of developing mental health problems in early adulthood. [68]
- There is also evidence that mental health problems can increase the risk of new onset incontinence in children [69] and have an adverse effect on treatment adherence. [70]
- There is increasing evidence for the association between childhood and adult incontinence and pelvic pain. [71] [72]

These findings have important clinical implications because they highlight the need for treatment of incontinence and mental health support for young people with incontinence, which is currently lacking.

Risk Factors for Incontinence

Incontinence and other disorders affecting the bowel and bladder are extremely complex health issues with multifactorial determinants. The voluminous report of the 7th International Consultation on Incontinence (2023) provides a textbook of high-quality studies for clinicians and others interested in understanding the epidemiology and clinical aspects of these conditions.

The Trezona systematic review of the evidence on pelvic floor dysfunction, commissioned by CHA (refs) cites over 70 studies addressing the range of risk factors potentially involved in these complex conditions. This review notes several of the ubiquitous problems affecting research on incontinence across the board, including the low quality of many research studies. Reasons for this include the extreme heterogeneity of the studies in terms of study design, sample sizes, inclusion criteria, assessment of outcomes and inconsistencies in definitions of incontinence. These challenges were also noted in the Deloitte report.

Various attempts have been made to summarise evidence to provide a classification of potential risk factors.

The AIHW suggests that risk factors for incontinence are stratified based on the basic processes in the body that cause incontinence.[73] This system suggests five categories:

- physical status (for example, age,§ sex, obesity),
- genetic factors (for example, family history),
- neuropsychiatric conditions (for example, multiple sclerosis, dementia, depression, stroke,

§ It is important to note that incontinence is not an inevitable part of ageing. However, as reported by the AIHW (Australian *incontinence data: analysis and development 2006),* age is the most commonly cited factor associated with incontinence. §

- diabetic neuropathy),
- trauma (for example, childbirth, prostatectomy), and associated conditions (for example, diarrhoea, inflammatory bowel disease, menopause, smoking, constipation, urinary tract infections).

These categories are limited and include overlaps, with some risk factors falling in two categories. It is important to note that some of these risk factors are modifiable and some are not. [74] Trezona provides a broader classification beyond individual-level factors (sex, gender, age, weight, physical activity levels, overall health status) to address the following:

- **Environmental and social determinants** - sociocultural environmental factors influencing toileting behaviours, pelvic health knowledge, attitudes and awareness among professionals and the public, inequities in care and treatment, stigma and patriarchal attitudes.
- **Health System Factors** - workforce capacity and capabilities, the attitudes and beliefs of health professionals, inadequate communication and information provision, discrimination within healthcare systems towards marginalised groups.

Chronic Disease and Incontinence

AIHW data (2023) shows that chronic disease in Australia is increasing. Chronic diseases are the leading cause of disability and are responsible for 9 in every 10 deaths.[75] Almost half of adult Australian males have one or more of the 10 most common chronic conditions. About 1 in 3 males aged 15 and over have one chronic condition, 13% have two and 7% have three or more. The number living with chronic disease increases with age. 37% of males aged 15–44 have one or more chronic conditions, followed by 53% of males aged 45–64, and 75% of men aged 65 or older will experience at least one chronic condition.

Continence health problems are not identified often amongst the range of resulting symptoms of several chronic diseases, however there is strong evidence of increased prevalence of incontinence in populations living with chronic disease. [76] These include Type 2 diabetes, cardio vascular and lung diseases, [77] [78] various cancers, neurological disorders and musculo-skeletal disorders that can impact on movement and activity, such as arthritis and osteoporosis.[79] Some medications, prescribed commonly for treating and managing chronic diseases, can cause problems with the normal process of storing and voiding urine and bowel function, including medications to lower blood pressure, diuretics, antidepressants, hormone replacement therapy, analgesics and some sedatives.[80] [81] There is growing evidence that overweight and obesity are significant, risk factors associated with a higher prevalence of incontinence including severe incontinence amongst both men and women. [82] [83] [84]

Appendix 1 provides examples of the associations between a range of chronic diseases and incontinence.

Most chronic diseases share the same group of modifiable risk factors, diet, physical activity, alcohol consumption and tobacco use. [85] Age is a significant, non-modifiable risk factor, with Australia's ageing population demonstrating a direct correlation with an increasing chronic disease burden.[86] Three quarters of Australians over the age of 65 have at least one chronic condition that puts them at risk of serious complications and premature death and many have complex, multimorbidity, all of which have implications for continence as well as other areas of functional health.[87] See Box 2 below.

Box 2: Comorbid Chronic Diseases and Incontinence

The terms 'comorbidity' and 'comorbid conditions' refer to the presence of more than one medical condition in an individual. For example, a person with diabetes may also have incontinence.

Research supports the effective management of some comorbid conditions as a method of decreasing the prevalence or symptoms of incontinence. This includes the effective management of:

- obesity
- diabetes mellitus
- irritable bowel syndrome, inflammatory bowel disease, diarrhoea and constipation
- neurological conditions
- impaired mobility.

Box 2: Source: AIHW 2016

Prevention

There is some evidence that some risks for FI and UI are modifiable and the likelihood of developing incontinence can be reduced through a range of preventive measures including lifestyle change, enhanced self-care, improved management in community and residential care settings, physical therapies to strengthen the pelvic floor muscles in a number of at-risk groups and surgical and technological interventions.[88] Overall, there is, currently, stronger evidence for the treatment and prevention of UI than for FI, however this is notably a significant public health issue where rigorous evidence is thin on the ground. [89] [90]

Evidence is emerging about the impacts of behavioural and lifestyle changes to address issues with a known relationship to incontinence; including obesity, physical inactivity, poor diet, and smoking.[91] [92] Workers in some occupations and participants in high-impact recreational activities are at increased risk for incontinence and provide an opportunity for testing interventions that reduce risk in these groups.[93] [94] There may be significant scope for prevention from better management of a range of co-morbid conditions including chronic lung conditions, cardio vascular diseases, diabetes, irritable bowel syndrome, inflammatory bowel disease, neurologic conditions, impaired mobility, diarrhoea and constipation. [95] Effective treatment of depression may relieve incontinence as well as depressive symptoms.[96]

More research is needed into the mechanisms by which these conditions lead to incontinence and the strategies to reduce the risk. Research is also needed related to treatments that are known to increase the risks for incontinence (for example, anorectal surgery, prostatectomy, pelvic radiation therapy, oral oestrogen therapy).[97] [98] [99] [100] Although many treatments, including medications and surgical procedures, are known to adversely affect continence, there is also evidence that clinicians do not always address these risks with patients and that patients sometimes do not understand these risks when consenting to treatments.[101] [102]

In addition, there is limited research evidence describing how access to preventive interventions for incontinence influences the incidence, severity, and duration of incontinence in the Australian context, nor about economic, geographical, or other blocks in access to evidence-based prevention. This research is needed to inform public policy and clinical practices and to ensure that inequalities in access to prevention do not escalate, to the detriment of population health and the Australian economy.

Economic Case for Prevention

There is good international evidence about the risks and rising costs of untreated incontinence and of how these can be reduced by proper management within an integrated service framework. [103] [104] Integrated continence pathways can deliver cost savings and improve health by reducing:

- Unnecessary catheterisations and associated urinary tract infections (UTI).
- Pressure ulcers linked to poor continence care and incontinence associated dermatitis.
- Acute hospitalisations for UTI, urinary retention, renal failure, faecal impaction.
- Care home admissions precipitated by incontinence.
- The use of incontinence products through low-cost interventions such as bladder retraining, pelvic floor muscle training and the appropriate use of medications for incontinence. [105]

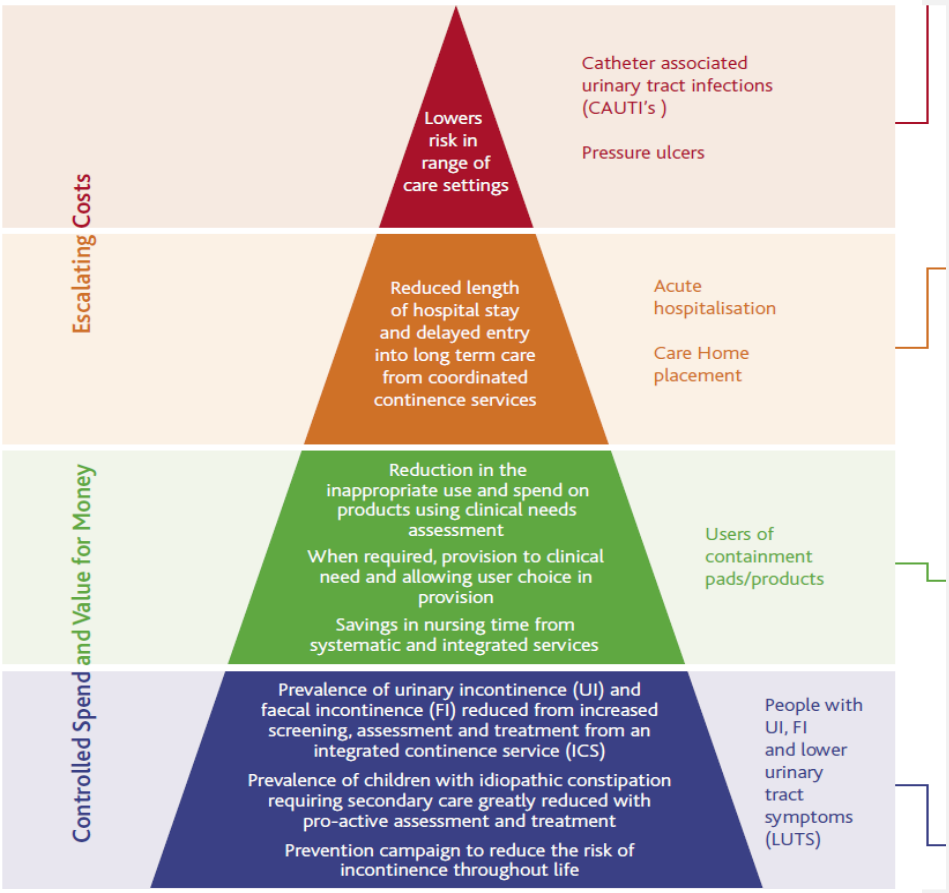
No data exist to measure the potential impacts of alleviating mental distress and improving wellbeing.

The scope for prevention is illustrated in the Prevention Pyramid in Figure 1 below. This model demonstrates how risks and costs are reduced where care is underpinned by high quality integrated community continence services. These services not only provide expert treatment within the community but support active self-help strategies. Movement up the pyramid can be delayed or prevented by an integrated continence service with a traffic light system illustrating the risks and rising costs of untreated continence needs.

This service model was developed in response to a National Audit of Continence Care in the UK, undertaken by the Royal College of Physicians (RCP, 2012) which documented extremely variable, often poor-quality, continence care at all levels of service. It has not been possible to locate equivalent Australian data to quantify the

preventative potential of this model if it were systematically across Australia but there are good grounds, based on international evidence for assuming that this could be significant.[106] [107]

Figure 1: The Prevention Pyramid



Source: NHS England, June 2018

Conclusions

Chronic diseases and obesity continue to rise in Australia's expanding and ageing population. This will impact on the prevalence of incontinence without effective policy action focused on better prevention, treatment and management.

Gaps in data obscure the full scale of need in the community and the ways in which broader social changes are impacting on continence health of the population overall and for specific population groups, particularly ATSI, CALD, LGBTI+. CHA is well placed to publicise these data gaps and to initiate a series of strategic conversations with governments, research funders and clinical partners about how best to drive forward

a systematic research agenda for continence health, appropriate to Australia's population health needs. Including questions in longitudinal National health studies.

Additional research is required to clarify the complex linkages between incontinence and other chronic diseases. However, the evidence that is already available suggests that it is time for a new understanding and classification of incontinence as a chronic disease with significant implications for the health of the nation and not just as a symptom of other conditions.

Section 3: Economic Factors

Costs of incontinence

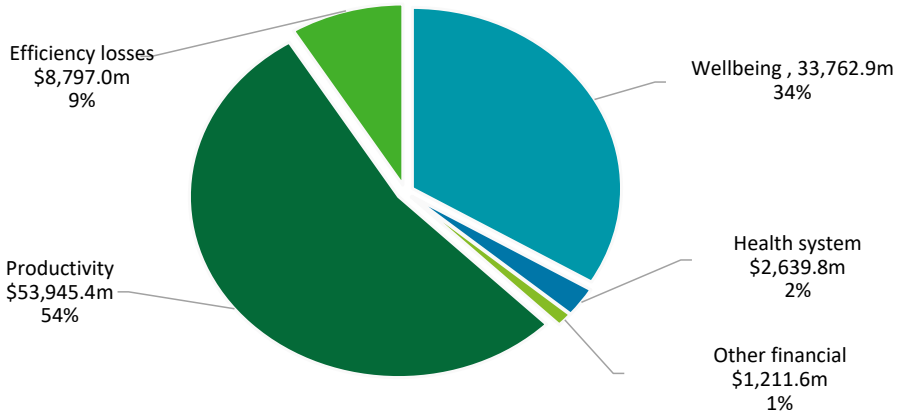
According to the Deloitte Access Economics report (2023) "*The financial cost of incontinence in 2023 was $66.6 billion, with an additional $33.8 billion in lost wellbeing for people living with incontinence.*[108]

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. These costs are paid by governments and health systems and ultimately by taxpayers and individuals. These figures are not disaggregated by sex. Data compiled by the European Union indicates that the economic burden for females was four times higher than males, and the economic burden increases by 16% when accounting for the informal support provided by caregivers—who are often family members.[109]

These figures also do not include the considerable financial and environmental costs associated with the disposal of continence aids and products, which are discussed briefly below.

See Chart 4 below.

Chart 4: Costs of Incontinence in Australia.



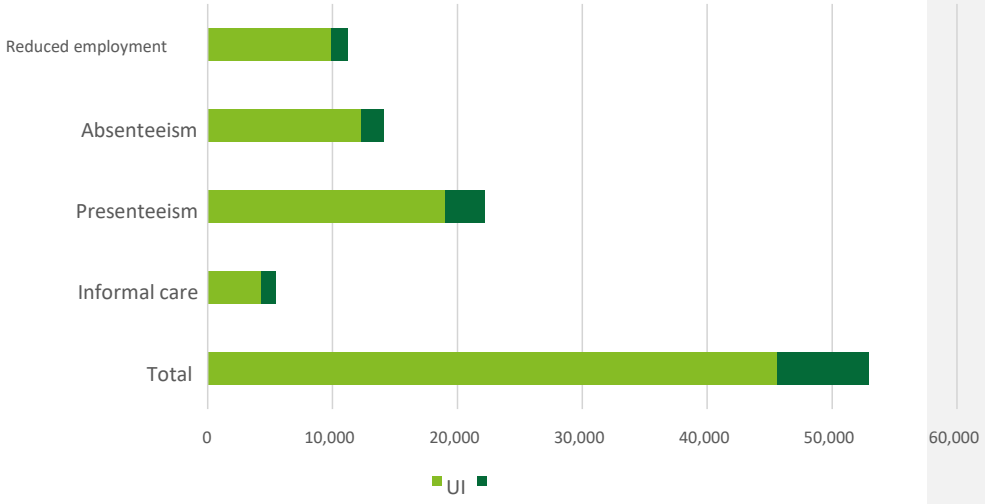
Source: Deloitte Access Economics, 2024

Productivity Impacts

Productivity includes the labour impacts directly experienced by people with incontinence and their informal carers. Deloitte Access Economics (2024) have provided figures to demonstrate that 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 to the Australian economy. In addition to this, 24.1% of people with incontinence surveyed by Deloitte in 2013 for the report into the economic cost of incontinence in Australia said that they received informal care from their spouse or family member. This equates to $5.6 billion in lost productivity for informal care. 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. UI accounts for 86.2% of total costs. These costs mostly arise from the impact on women.

People with severe incontinence experience more severe disability and health problems than other people with disabilities. Regardless of the cause, the experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in the usual activities of daily living. AIHW figures suggest that the labour force participation rate for people with severe incontinence was 26.1% and considerably lower than for people without severe incontinence (55.8%).[110] People aged 15 and over with severe incontinence were more likely to report being in fair (34.0%) or poor (22.2%) general health than people without severe incontinence (24.8% and 10.4% respectively). Primary carers who assist people with severe incontinence are more likely to report strained relationships with those they care for, to need more respite care, and to report lower labour force participation. See Chart 5 below.

Chart 5: Productivity costs due to incontinence by cost component in 2023



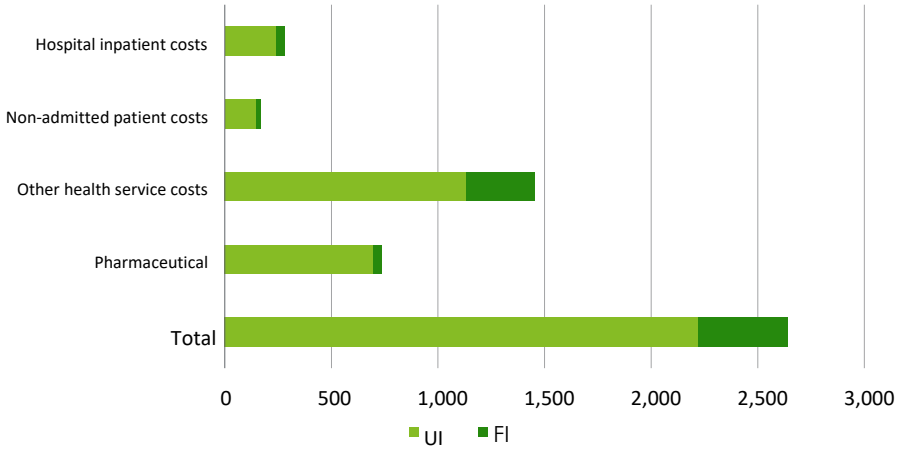
Source: Deloitte Access Economics, 2024

Health System Costs

Deloitte Access Economics estimated that Australian health system costs attributable to incontinence were an estimated $2.6 billion in 2023.

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. (See Chart 6 below). This includes visits to general practice, allied health, and mental health professionals in relation to incontinence. However these are likely under reported as often categorised under an associated diagnosis, not incontinence.

Chart 6: Healthcare costs due to incontinence by cost component in 2023



Source: Deloitte Access Economics. 2024

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%).

See Table 2 below.

Table 2: Other financial costs of incontinence in Australia in 2023 ($ millions)

	UI (millions)			FI (millions)			Total	
Cost component	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. 2024; Totals may not sum due to rounding.

Deloitte estimate that since 2010, the economic cost of incontinence has increased by 57%. Table 3 provides a summary of the costs of incontinence in Australia in 2023.

Table 3. Economic cost of incontinence in Australia in 2023 (millions)

	UI ($millions)			FI ($millions)			Total ($millions)	% of total
Cost component	**Men**	**Women**	***Total UI***	**Men**	**Women**	***Total FI***		
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**

				UI ($millions)			FI ($millions)			Total ($millions)	% of total
Total (excluding wellbeing costs)	**20,117.2**	**37,039.0**	**57,156.2**	**,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. 2024. Note: All figures in millions of dollars unless otherwise specified. Totals may not sum due to rounding.

Conclusions

The costs and consequences of incontinence are significant and highly negative for individuals, families, the taxpayer and for healthcare systems. These costs and associated negative consequences are rising and will continue to do so in the absence of effective measures to curb them. There are strong public health and economic arguments to be made for better primary and secondary prevention and treatment of incontinence.

It is time for action in Australia to address this changing landscape. 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.

Section 4. Societal Factors

Demographic Change

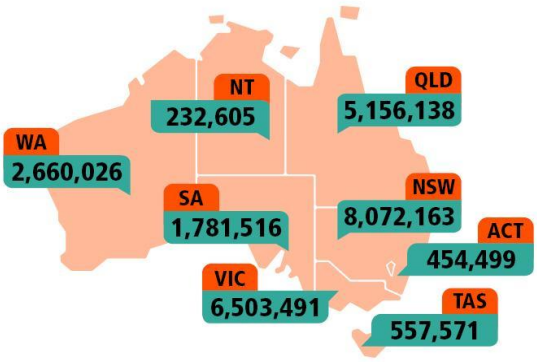
Rapidly changing characteristics of the population bring with them significant implications for continence health as Australia moves into the mid-21st century. Population growth, population ageing, the shifting ratio of men to women and increasing diversity all carry demands for the promotion of continence health and access to specialist and generalist health care services to which governments and communities will need to respond.

Growing Population

The 2021 Census counted 25,422,788 people in Australia, excluding overseas visitors. This is more than double the number counted 50 years ago, with the 1971 Census covering 12,493,001 people. The Census provides insight on cultural diversity, families and homes, and how the country changed during the pandemic.

- Almost 80 per cent of Australian residents live in eastern Australia in New South Wales, Victoria, Queensland and the Australian Capital Territory.
- NSW continues to be the largest state with over 8 million people, with Victoria not far behind with 6.5 million people.
- ACT had the fastest growth with a 14.4 per cent (57,102 people) increase since 2016.
- 66.9 per cent of people counted were in Greater Capital Cities and 33.1 per cent were in the rest of Australia.
- Greater Sydney remains the largest city in Australia with 5.2 million people, followed by Melbourne with 4.9 million people and Brisbane with 2.5 million people. See Figure 2 below.

Figure 2: Estimated resident population for each state and territory in August 2021.



Source: ABS 2021 Census; Greater Capital City Statistical Area (GCCSA).

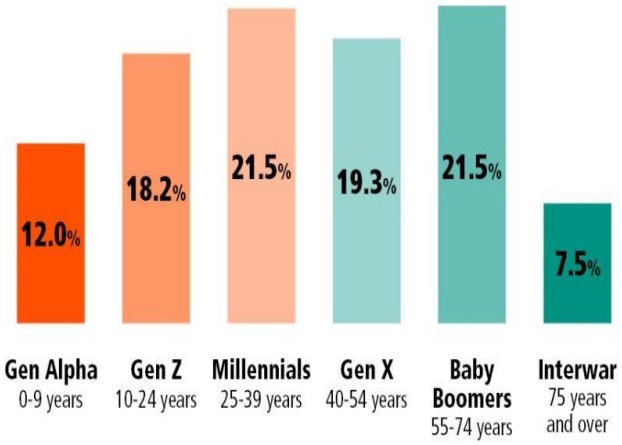
Age & Sex

The median age of all Australians was 38 years in 2021. Males make up 49.3 per cent of the population with a median age of 37 years and females make up 50.7 per cent with a median age of 39 years.

Australia is undergoing a significant generational shift. Baby Boomers and Millennials each have over 5.4 million people, with only 5,662 more Baby Boomers than Millennials counted on 10 August 2021.

See Figure 3 below.

Figure 3: Age profile of the Australian population 2021



Source ABS. Census of Population & Housing. AGEP. 2021

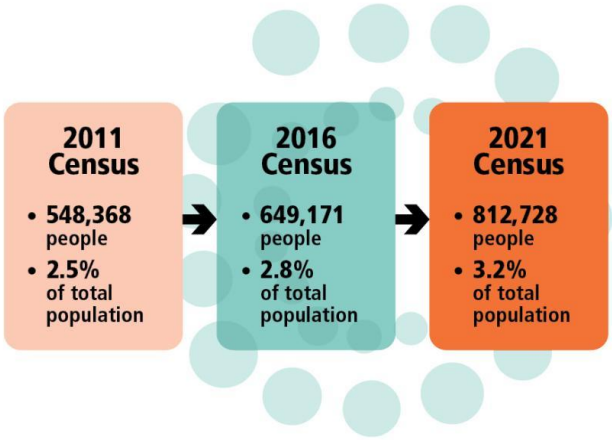
Aboriginal and Torres Strait Islander populations

The Census found that:

- 812,728 people identified as Aboriginal and/or Torres Strait Islander. This is an increase of 25.2 per cent since 2016, with Aboriginal and Torres Strait Islander people now representing 3.2 per cent of the Australian population.
- Of the Aboriginal and Torres Strait Islander people counted: 91.4 per cent identified as Aboriginal; 4.2 per cent identified as Torres Strait Islander; 4.4 per cent identified as both Aboriginal and Torres Strait Islander.
- Two thirds (515,347) of the Aboriginal and Torres Strait Islander population live in New South Wales and Queensland.
- There were 167 Aboriginal and Torres Strait Islander languages used at home in 2021 by 76,978 Aboriginal and Torres Strait Islander peoples. The most widely reported language groups used were Arnhem Land and Daly River Region

Languages (14.5 per cent) and Torres Strait Island Languages (12.0 per cent). See Figure 4 below.

Figure 4: Aboriginal and Torres Strait Islander populations 2011-2021



Source ABS. Census of Population and Housing. Indigenous status (INGP) 2021

Migration and Ancestry

Australia has a rich mix of cultural backgrounds and heritage, with the number of people living in Australia who were born overseas continuing to increase.

- The proportion of Australian residents that are born overseas (first generation) or have a parent born overseas (second generation) has moved above 50 per cent (51.5 per cent).
- The top five most commonly reported ancestries in the 2021 Census followed previous trends and included English at 33.0 per cent, Australian at 29.9 per cent, Irish at 9.5 per cent, Scottish at 8.6 per cent and Chinese at 5.5 per cent.

CALD Communities

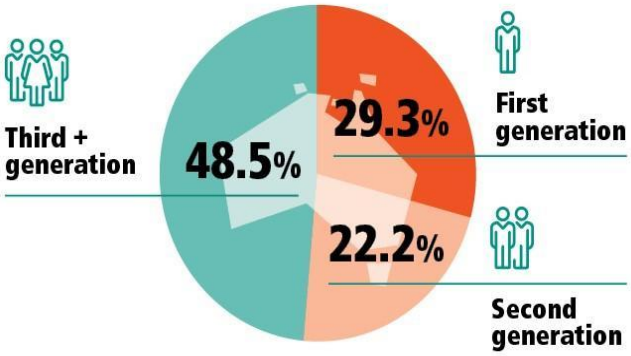
Australia continues to be a culturally and linguistically diverse country with the growth of communities from Nepal, India, Pakistan, Iraq and the Philippines.

- Mandarin continues to be the most common language other than English with 685,274 people using Mandarin at home.
- This is followed by Arabic (367,159 people), Vietnamese (320,758 people), and Cantonese (295,281 people).
- Punjabi had the largest increase, with the 2021 Census showing 239,033 people using Punjabi at home.

- Nepali featured in the top five languages used at home in both ACT (1.3 per cent) and Tasmania (1.3 per cent). [111]

See Figure 5 below.

Figure 5: Australian ancestry profiles



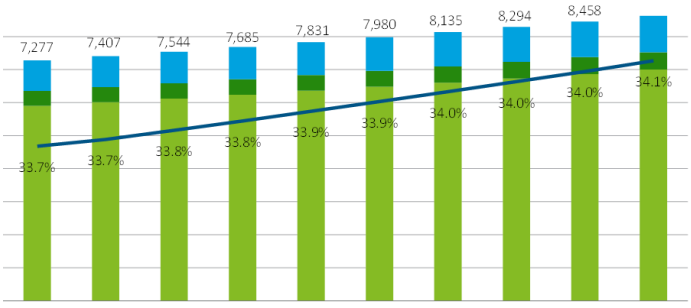
Source : ABS: Census of Population & Housing: 2021

Projection of incontinence prevalence to 2032

Deloitte access economics estimate that, assuming the estimated 2023 prevalence rates hold over the next 10 years to 2032, there will be 8.6 million people (or 34.1% of the population) with some measure of UI and/or FI in 2032, an 18.6% increase from 2023.

This estimate reflects the changing age profile of the Australian population. Current estimates may therefore be conservative as there is some evidence that sub-categories of incontinence are becoming more prevalent over time. The age structure of the population, including the numbers of people who are younger and therefore of working age suggests that there will be continuing a significant productivity impact from the burden of incontinence without effective action to remediate and reduce it. See Chart 7 below.

Chart 7: prevalence of urinary and / or faecal incontinence 2023 to 2032



Source: Deloitte Access Economics based on ABS (2023), ABS (2019) Sharma et al. (2016), Linde et al. (2016), otlero et al. (2009) Hawthorne (2006), ACFI (2009)

Public Knowledge & Understanding of Continence Health

Stigma

Incontinence has been a stigmatised area of human experience.[112] This is damaging to the overall psychosocial well-being of affected individuals and their carers. This personal impact is influenced by cultural, social, and psychological factors along with concepts of self-image, self-worth, and health expectations.[113]

There is extensive body of literature which demonstrates that Individuals who suffer incontinence will go to great lengths to keep their condition a secret if they are able. They may be subjected to gossip, hostility, and other forms of social exclusion. [114] Elderly people are frequently relocated to other living arrangements and are at risk for institutionalisation. [115] FI may be one of the most common reasons for social isolation and institutionalisation of the elderly. Incontinent patients have been reported to be less likely to marry and hold a normal job. In the workplace, in addition to lost productivity, individuals face stigmatisation and reduced self-esteem. [116] Stigmatisation is a dimension of suffering added to the illness experience, and has been found to lead to social isolation, limited life chances, and delayed help-seeking. [117] Caring for incontinent patients is thought to be 'dirty work' and delegated to the lowest paid staff. [118]

The stigma of incontinence and the taboos which surround it, combined with lack of knowledge and shame are powerful inhibitors of help-seeking even when people are suffering intensely from these conditions.[119] It is estimated that 50% to 70% of incontinent persons do not seek help for their condition. The stigma surrounding incontinence also affects doctors and other health care workers. A study of primary care physicians in the USA found that most asked only 25% or fewer of their patients about incontinence. Significantly, while up to 70% of incontinent patients did not voluntarily report the problem, more than 75% did report the condition when asked about it by their physician.[120] CHA has recently undertaken a large survey which found a similar picture amongst GPs in Australia. [121]

Other barriers to help-seeking have been investigated for UI. The most common theme that emerges is a lack of knowledge of the condition and of available treatments by both men and women. [122] Urinary symptoms are commonly considered a normal part of ageing or childbirth, or people feel that these types of symptoms are inappropriate for medical intervention. Older people are more likely to be fatalistic, accept their symptoms and feel that they don't want to bother their doctors. [123] [124] Patients do not always communicate their concerns about urinary symptoms to their general practitioner, either because of embarrassment or misconceptions of what constitutes a medical problem - impact of symptoms on quality of life appears to be the main trigger for seeking help for UI.[125] Few studies have been done to evaluate this in FI.[126]

Recommendations have been made by a working group for the International Continence Society, regarding population-based prevention.[127] It has suggested that "*primary prevention should be the goal of all healthcare professionals as it means taking an active part in preventing the initial development of incontinence* ''and that "*all preventive measures require a high level of community awareness, public education and health professional education.*" Shaw et al (2007) reinforced this, designating incontinence a 'hidden problem' often not identified in general practice records.[128] The evidence suggests that attitudinal and behavioural change needs to occur amongst health care staff as well as the public.

Given this broad context, it is encouraging that the CHA's large, nationally representative survey (n=2000) conducted in 2024, found signs of greater public awareness and acceptance of incontinence. Over 70% of respondents suggesting that they had become more accepting of it and understood that incontinence is a common condition for which help can be provided.

It would appear from the findings of this survey that social attitudes may be shifting in relation to incontinence. CHA is extensively involved in attempting to raise public awareness and to tackle the silence on this issue through campaigns and the use of social media. These include powerful awareness raising interventions including Bins4Blokes, Go Against the Flow, Great Dunny Hunt. More transparent marketing of incontinence aids and other products may also be helping to improve public awareness and understanding.

Despite this, the survey suggests that many people who live with some degree of incontinence find it difficult to discuss the condition or to seek help. 30% of respondents said that they had not discussed the condition with anyone, either because they did not consider their incontinence a serious enough problem or from embarrassment. Some respondents reported receiving negative reactions from family and friends when they did discuss their incontinence.

See Figure 6 below for some key insights from the survey:

Figure 6: Source: Continence Health Australia. National Consumer Survey 2024

Continence Health Literacy

There is limited Australian data on community awareness of continence health, but what exists suggests that this is an area that people know little about and are reluctant to engage with. Research conducted to inform the implementation of the National Continence Program (NCP) in 2011 found that "*community continues to be ill-informed with poor levels of awareness, engagement and understanding of the basic elements of bladder and bowel health, incontinence, its prevention and management*". [129] Whilst CHA's nationally representative consumer survey, 2024 provides some indications that this may be changing to some degree, it seems appropriate to suggest that there is still a lot of work to do.

Poor awareness of continence health in the population reflects a broader picture of poor health literacy generally. The ABS, which in 2006 undertook a national survey of adult literacy and life skills, reported that 60% of Australian adults have low health literacy (as a by-product of poor literacy and life skills in other domains).[130] A stocktake of health literacy initiatives, undertaken by the Australian Commission on Safety and Quality in Health Care (ACSQHC) in 2011–12, criticised Australian activities to improve health literacy as "largely fragmented" and lacking local collaboration and national leadership.[131]

Increasing the ability of Australians to undertake self-care, across the board is, very clearly, dependent on raising levels of health literacy in the population and particularly amongst those most at risk of poor health. However, it appears that despite evidence and advocacy, advancing health literacy has generally failed to find political or community traction. Tangible actions to advance health literacy are hard to identify. Responses to these challenges may have been put aside because the concept of health literacy has been considered too difficult to define and measure in terms of providing a practical basis for programmatic responses. In

addition, when such responses have been developed it has been suggested that they have been narrowly conceived as health mass communication campaigns and not as development programs requiring whole-of-government responses and action across the life course and in all settings.[132] In this context, embedding awareness of continence health in the population must be considered a significant challenge.

CHA has attempted to develop a better understanding of community attitudes and values through a combination of market research, member surveys, program evaluations and media scanning. These nationally representative surveys of consumers and carers conducted annually, analysis of Helpline data and media monitoring activities. Information from all of these is summarised below. The National Continence Program, which funds all of these activities, has been independently evaluated (February 2025), to measure program impacts on awareness, attitudes, behaviour and access to services, information and support, and findings are helping to inform a new action plan currently under development.

Healthcare professional awareness – general practitioners

CHA also surveyed over 500 General Practitioners (GPs) in three phases in 2016, using a combination of online and hard copy survey methods. [133] The three-phase survey, involving modified questionnaires for each phase was designed to explore the characteristics of patients presenting with incontinence, patient behaviours, common referral pathways as well as GP perceptions and attitudes towards incontinence. There were additional questions aimed at gauging GP awareness of specific CFA activities/resources or of the resources available to support patients.

Box 3 below sets out the key findings from the general practitioner survey.

Awareness of continence health amongst GPs

- 69% of GPs stated that male patients never or rarely brought up continence issues in a standard consultation.
- Over half of the surveyed GP's identified at least one barrier to raising the issue of incontinence with patients. 'Lack of time' (49%), 'not sure what resources I could offer' (27%) and 'not feeling up to date in this area' (18%) were some of the most common barriers. Additionally, 8% of respondents stated that they did not feel comfortable bringing up the issue of incontinence with patients.
- >15% of surveyed GPs agreed or strongly agreed that incontinence was a normal part of ageing and that all children who wet the bed will be dry by age 10.
- 46% of GPs were not familiar with any local continence services.
- 84% of GPs would value more information and education on incontinence.
- 'Factsheets you can provide to your patients', 'information about local continence specialist services for referral' and 'information on funding for continence supplies' were identified as the three most valuable measures to improve bladder and bowel care at GP practices.
- 50% of respondents were not aware of the National Continence Helpline.
- Frail elderly people or long-term care residents, men following treatment for prostate cancer and postnatal women were the three groups of patients with whom GPs were most likely to explore issues of continence health.

Box 3: Awareness of continence health amongst GP's: Source Continence Foundation, 2017

Continence awareness and the media

Media monitoring activities are also used by CHA as an additional tool to understand and measure public awareness. The following comparative data provides an indication of the scale of current awareness of continence health and the scope for improving this. See Box 4 below:

Traditional and online media

Between January 2024 and November 2024 there was 4,664 press, radio, TV and digital media mentions captured by Meltwater media monitoring. This is a decrease of 2,110 from the previous year. However, the total potential editorial reach for 2024 is 870 million opposed to the previous year which was 124 million. This suggests CHA has been more strategic in targeting relevant media outlets to ensure wider reach of its message.

Social media

Across the 2023-2024 period, 1,996 posts were scheduled across the CHA's social media platforms, reaching over 10 million impressions and 186,321 engagements. This is a growth of 286.7% in terms of impressions and 201.3% in terms of engagements, in comparison to the previous two years, due to a renewed strategic approach to social media channels.

From 2023 to 2024, audience numbers grew by 10.9% reaching a total number of 9,740 accounts. This is in comparison to the previous 2021-2022 period, where audience numbers sat at 7,772.

Website

Box 4: Analytical data on media, publications and online communications statistics during 2023 -2024. Source: CHA, 2024

These statistics illustrate that continence health achieves a reasonable presence in the media and that there appears to be a consistent level of public interest in continence health, however, improving public awareness through both mainstream and social media remains a considerable challenge. There is, clearly, potential to change the narrative and promote public awareness in relation to continence health and to challenge the associated stigma at the same time.

Conclusions

Over the next several decades, demographic changes are projected to have significant implications for health, broader social policy and essential services in Australia. In conjunction with changing epidemiology, there are likely to be significant impacts on continence health given the higher incidences of both of complex, multimorbid chronic disease and incontinence across the life course. No modelling data are available to enable a quantification of how the changes in population size, structure and diversity will impact on the current web of service provision and other resources. There is no routinely collected, publicly available data on distinct geographical population needs for continence health support or planning guidelines to calculate the level of services required at local, regional or state levels. There is anecdotal evidence of cutbacks in continence services and support in some states and territories, access problems in remote and rural areas and of strain and burn-out amongst specialist incontinence staff. To plan properly for the future of continence health there is an urgent need to acquire a better understanding of current and future population needs in each state and territory.

The age structure of the Australian population, and in particular the increasing proportion of the population who are younger and therefore of working age, means that the productivity impacts of incontinence will be significant and unlucky to increase unless there is remedial preventative action.

Improving community and professional awareness, knowledge and understanding of incontinence is vital to challenging the stigma surrounding incontinence, the invisibility of the issues in public and personal discourse and the reluctance of services, in all settings, to engage proactively with the primary and secondary prevention of incontinence and evidence-based management. It is also essential in improving self-care and self-management of continence health across the life course. There may be value in repeating the survey of general practitioners and primary care teams to assess the extent to which professional attitudes may have shifted since 2017.

These statistics illustrate that continence health achieves a reasonable presence in the media and that there appears to be a consistent level of public interest. Improving public awareness through both mainstream and social media clearly requires effort and investment of resources. There is, clearly, continuing potential to challenge and change the stigmatising narrative in relation to continence health and promote public awareness at the same time.

Section 5: Services and Workforce Factors

A Postcode Lottery

A wide range of continence specialist services exist throughout Australia but there is no agreed definition or set of standards against which the scope of these services can be understood, or quality and performance assessed. CHA has, with support of the Australian Government, addressed this through the development of My Continence Care, (formerly known as the Model of Continence Care), which is a continence care program targeted for staff and residents of residential aged care services, and is currently being adapted for in-home or community care. CHA has also developed and is testing a suite of standards for health professionals providing continence assessment, treatment and management, supports and service (2025). Policy support is required to enable national adoption and implementation of these models.

CHA's data suggests that a continence specialist service can range from a medical practice employing one continence nurse advisor to a dedicated multi-disciplinary clinic specialising in comprehensive continence care, employing continence nurses, urologists, urogynaecologists, physiotherapists, dietitians and other allied health professionals.[134] Comprehensive continence services may also offer urodynamic investigation and complex bowel dysfunction testing.

In some cases, individuals living with incontinence can access additional funding and assistance (beyond the CAPS Program) via various state-based schemes or the National Disability Insurance Scheme (NDIS). These schemes vary from state to state in the amount of financial support provided and have different eligibility criteria. There is effectively a post code lottery in the level of support available to people who live with incontinence. There are no data to judge the equity of current arrangements between states, territories and communities and between rural, remote and urban areas although anecdotal evidence suggests that specialist services are under severe strain nationally.

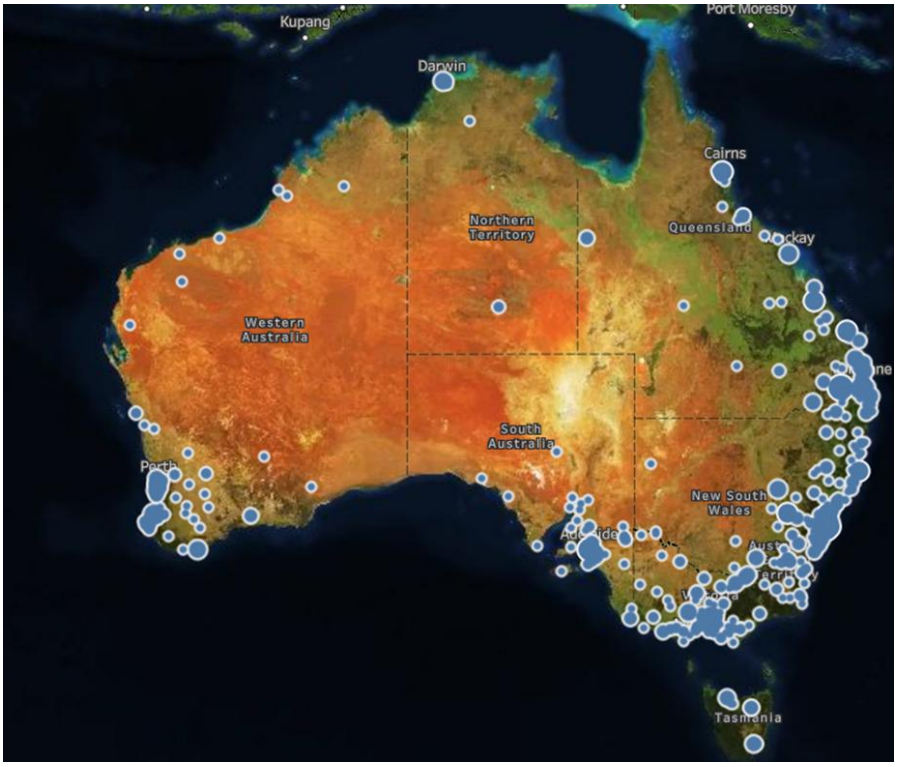
CHA's online provider directory can only include continence service providers that wish to be listed online.** Figure 7 below provides a 'heatmap' of the location of services which have chosen to be listed in CHA's directory. This map does not enable a judgment about the adequacy of supply to demand, even where services appear to be concentrated, as there is no way of understanding what is provided by identified services nor the level of need in the local or regional population. Detailed information on what services are provided at each location is frequently

** Minimum service requirement to be considered a continence service was employing at least one clinician providing continence specific services.

unavailable or incomplete on provider websites, making it difficult to assess the service capability and comprehensiveness. However, even where detailed information is provided, the lack of national service standards, comparative data on the level and capacity of the service in relation to local prevalence and incidence and lack of outcomes and performance data means that it is impossible to make an assessment about the overall efficiency or effectiveness of Australia's service response to continence health.

There is, in addition, no publicly accessible information on investment in continence specialist services, however defined, in any state or territory. CHA has anecdotal evidence of cuts to specialist continence services in several states, but it is not possible currently to substantiate this. The absence of these data means that no robust assessment can be made about the ability of current continence care services to meet demand, reinforcing concerns about equity and service strain, particularly in a context of high-impact policy reforms in disability and ageing, discussed below. [135] Compounding the problem, it has not been possible to obtain reimbursement or outcome data on continence-related consultations and treatments undertaken in the private health care system or in long-term residential care. There is an urgent need to improve the volume and quality of information about service availability, scope and investment to ensure the resilience of continence care in Australia and to provide an accurate baseline upon which to plan.

Figure 7: Continence service location heatmap



Source: Continence Health Australia. 2023

A Framework for high quality continence care

The Global Forum on Incontinence (GIF) has developed an internationally applicable service specification for continence care, based on a systematic review of the evidence and expert consensus.[136] The service specification framework developed by the GIF states that the characteristics of a high-quality continence service should have eight core components.

These were: 1) case detection, 2) initial assessment and treatment, 3) case co-ordination, 4) caregiver support, 5) community-based support, 6) specialist assessment and treatment, 7) use of containment products, and 8) use of technology.

See Figure 8 below

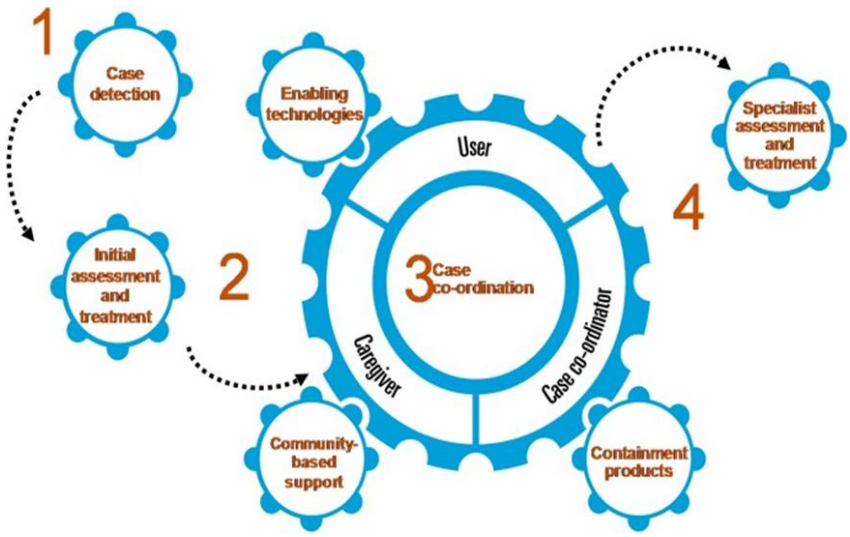


Figure 8: Components of an Optimum Continence Health Service: Source: Wagg et al: 2014

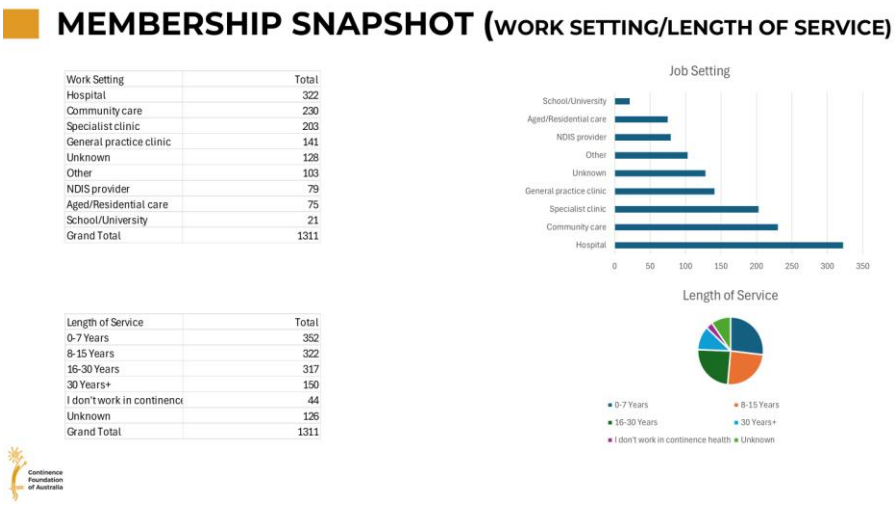
Specialist and non-specialist workforce

A continence specialist can be a professional who possesses a post-graduate qualification or is undertaking postgraduate training in a speciality such as urology or urogynaecology or is a physiotherapist with a Master's/PhD degree in women's, men's and pelvic floor health.

CHA has data on the characteristics of its members which illuminate the range of disciplines involved in delivering continence services, levels of education and both sectoral and geographic locations. However, there are currently no available data on numbers of specialists across the relevant disciplines nationally.

See Figure 9 below.

Figure 9: Characteristics of CHA Members



CHA is aware of concerns amongst its membership that the multi-disciplinary workforce is ageing and shrinking and is not being replaced by newer entrants. However, it is not possible, currently, to substantiate these concerns through research with a comprehensive national reach.

Training and Education

A lack of Australian data impedes robust assessment of the overall capability of the multidisciplinary health and care workforce to deliver high quality continence care. 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 physiotherapists, nurses and doctors, has meant that the broad healthcare workforce lacks the skills to deliver effective continence-related care in any setting. 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. [137] [138]

The Continence Nurses Society Australia has recently updated its practice standards for continence nurse specialists (CoNSA, 2021) [139] but there are no Australian practice standards for multi-disciplinary continence care in primary, secondary and tertiary care in Australia including for GPs who receive funding from the MBS for continence needs assessments. Worryingly, CHA staff have drawn attention to the fact that no system or mechanism exists to define capabilities or to regulate qualifications continence specialists.

Nursing

Most evidence relates to the nursing workforce. The Educating the Nurse of the Future Report (Schwartz, 2019) acknowledged that nursing curricula at pre and post registration levels are inadequate in relation to continence care. The Report recommended that modules on incontinence are strengthened within nursing curricula, and that both enrolled and registered nurses be introduced to the basics of continence care.[3]

A national review of Australian undergraduate nursing and midwifery courses, undertaken as part of the work of the National Continence Management Strategy, found, similarly, that registered nurses are not adequately prepared to provide safe and effective continence care and manage incontinence. [140]

There has also been a systematic loss of nationally recognised and accredited continence courses and units of competency in continence care. Understanding of the issue is hampered by the fact that there is no recent publicly available information on the depth and coverage of current curriculum content regarding continence care in undergraduate nursing courses in Australia. [141] Such gaps in evidence demonstrates the scarcity of training available to nurses who are entering the workforce, as well as those seeking to specialise in continence care An internal review conducted by CHA of available courses at the undergraduate and postgraduate level found that only four institutions offer courses or units in continence care across Australia. The most comprehensive of these is the Australian College of Nursing's (ACN) Continence Management Unit, offered under several Graduate Certificates and which has a duration of 150 hours.

Some studies suggest that Enrolled Nurses have most direct care responsibilities for continence care in the aged care sector yet have limited opportunities to develop capabilities in continence care (Norton, 2007). Most VET-trained enrolled nurses currently hold the Diploma of Nursing (*HLT54121 - Diploma of Nursing)* which has no specific education or training regarding continence care. Some enrolled nurses who hold the Advanced Diploma of Nursing (*HLT64121) - Advanced Diploma of Nursing*) can choose to do one unit of competency which may cover continence, but this is an elective. *HLTENN050 Apply nursing practice in the rehabilitation care setting* expects trainees to have knowledge of genitourinary disorders and gastrointestinal disorders which may include knowledge about urinary and faecal incontinence.[142] Enrolled nurses are currently unlikely to have sufficient knowledge and skills to provide safe and effective continence care.[143] A high proportion of enrolled nurses in rural and remote areas, have insufficient education and training to provide the level of care required to meet the needs of those they care for. [144]

In a changing demographic and services landscape, there is anecdotal evidence that personal care workers also have extensive responsibilities for continence care in the aged care sector where in residential aged care this is 'supervised' by the enrolled nurses and registered nurses. In the in-home community aged care sector this is undertaken predominantly by care workers and identified changes are reported/escalated to the Care Manager for appropriate referral and follow up. Certificate courses offer some education in continence support; however the training is reduced to basic toileting and the use of continence aids. At the end of

each Core unit a competency is completed that may or may not include something directly linked to bladder/bowel and or continence. CHA has developed the website Continence Support Now. This is described as a '*pocket Guide for disability and aged care workers providing bladder and bowel support'*.

Figures 10 and 11: CHA Members comments on training need & supply

SURVEY 1:

- Rural and Remote accessibility
- *"It is crucial to partner with local health districts to help promote continence services, especially in areas where there is a lack of access to community or hospital-based continence nurses. By working together, we can assist with recruitment and retention efforts, which are vital for preserving continence nursing as a specialty. Securing funding for these efforts is essential to ensure the sustainability of continence services and to address shortages in the profession."*
- Nurse Continence Specialist course
- "*There is no dedicated pathway for nurses to up skill to a continence career"*
- Paediatrics
- "I would love to see more resources and training forpaediatric continence"
- More research
- *"Building links between CFA and public health-lot : 1. assist with translation of research into service provision in public health 2. benchmarking with other health services (globally)"*

SURVEY 2: (EVENTS BASED)

- Enrolled Nursing
- *"Please consider scholarships for Enrolled Nurses and not just RN's or Graduate RN's or Allied Health Professionals. I find this very disheartening and feel that I am of no value to the Health Profession because I don't have higher qualifications, so therefore I mustn't be interested in expanding my knowledge in Continence."*
- Rural and Remote
- *"Online best as all events are metro based. When you have a family and live away from metro very limiting on attendance"*
- Rural and Remote/Paeds
- *"Please think of regional areas when organising face to face events. Topics I would love include- children and toilet training, enuresis, children with special needs and toileting."*

It is important to provide all nurses with the opportunity to upgrade their qualifications to enable them to provide high quality care. Bridging programs, provided through distance education and which involve collaboration between a university and the Technical and Further Education (TAFE) sector in rural areas can provide enrolled nurses with the advanced standing for Bachelor of Nursing programs.[145]

Anecdotal information held by CHA suggests that minimal attention to continence care is paid in nursing training for both enrolled and registered nurses. If proven to be the case, this deficit seems to be at odds with the needs of health care services, in all sectors, to address and manage the undoubted challenges of incontinence or the expectations of consumers to have their needs assessed comprehensively and responded to respectfully, with evidence-based treatments and support. CHA has evidence (from an examination of training resources) that support worker training in the VET sector at the Certificate III level also pays minimal attention to continence care and management even though these courses must be approved for delivery and have industry input to their development as required by the Australian Skills Quality Authority (ASQA). To illustrate, the Australian Government's training website, which stipulates the competencies which are required for a VET certificate do not address continence health care. This compares negatively with other areas of care including skin, foot and nail care. Consequently, there are concerns amongst CHA members that continence-related tasks, including assessments of continence health needs, are increasingly being delegated to unqualified, low-paid staff in both homecare and residential care settings.

CHA has attempted to address some of these gaps by offering various online education and industry-focused online training modules to registered nurses and support workers. These courses and other resources are identified here. In addition, CHA has hosted and promoted the development of the Continence Support Now app for personal carers and disability support workers providing support for bladder and bowel conditions. CHA has purchased the Hollywood Health training program, a short course which enables registered nurses to become Nurse Continence Specialists. This will be available in 2026 and has the potential to become a flagship training program for Australia. CHA is working to have this course registered with The Australian College of Nursing.

These developments are underpinned by the development of My Continence Care by CHA. This provides opportunity for direct care aged care workforce to extend their skills in the provision of continence care and support. My Continence Care will support the workforce in meeting the new National Aged Care Quality and Safety Standard (Outcome 5.3 Clinical Safety – Continence) and the National Continence Quality Standard, under development by CHA. Widespread adoption of the National Continence Quality Standard can drive a transformative shift towards person centred, evidence based and high-quality continence care.

Physiotherapy

In Australia, physiotherapists are trained to be first contact practitioners and as such treatments are rebated by Medicare Chronic Disease Management Plan (CDM) and private health insurers. Pelvic floor physiotherapy originally comes from a

background of Women's Health Physiotherapy, but training now includes the treatment of all people including children.

Pelvic floor physiotherapy addresses the conservative management of pelvic floor dysfunction (PFD), which includes urinary incontinence (UI), pelvic organ prolapse (POP), bowel disorders, sexual dysfunction, and pelvic pain, with an understanding of the biopsychosocial approach and trauma informed care.

Conservative management of PFD includes assessment (i.e. history, physical examination and investigations), diagnosis, prevention and treatment. Conservative physiotherapy management includes interventions such as pelvic floor muscle training, bladder training, lifestyle modifications and fitness, adjunctive use of e-stims and neuromodulation, electromyography, real time ultrasound, rectal balloon training as indicated, ideally working in a multidisciplinary team. It is an area of physiotherapy practice which has a growing evidence base of clinical effectiveness and for which there is an increasing community demand.

The evidence for conservative therapies to treat PFD is strong. Level 1 evidence underpins the recommendation of pelvic floor muscle training as the first line intervention in the treatment of UI and POP. [146] [147] [148] [149] [150] [151] The evidence base to support physiotherapy management of PFD continues to grow, with the most recent International Consultation on Incontinence concluding that as more trials accumulate, there is increasing evidence to support conservative management as first line treatment for UI in men and women, and for POP. Despite the need, the supply of trained pelvic floor physiotherapists is insufficient to meet current demand. [152]

The assessment and management of the pelvic floor complex is not addressed as a core component of most entry to- practice physiotherapy programs despite being within the scope of physiotherapy practice which is in contrast with the knowledge and skills that physiotherapists graduate within core areas of clinical practice. This results in a registration-competency gap, and the need for postgraduation training to ensure clinicians are appropriately skilled to practice safely and effectively in this area. No agreed standard defining clinical competence exists. This subject has been discussed at international forums in recent years and is still under consideration.

Post graduate training is at several levels in Australia – from university accredited qualifications, professional body Australian Physiotherapy Association (APA) courses and an increasing number of independent courses. In the meantime, the CHA Physiotherapy Special Interest Group (which has presented high level PD for 30 years), only admits University accredited Pelvic Health Physiotherapists to the Groups' register, but it is planned that within the next 6 months others who have completed the APA courses will be listed with a clear explanation delineating the two groups so the general public and referring professionals have a clear understanding of the difference.

Conclusions

The possible loss of specialist continence expertise is alarming given the findings of the Royal Commission on Aged Care and others regarding the lack of capability amongst the generic healthcare workforce in delivering basic continence care

either in the identification of cases or in the adherence to evidence-based recommendations and the critical importance of dedicated, local, nurse and/or pelvic health physiotherapist-led continence services, situated either in the community or adjacent to a specialist clinic. It is of vital importance that CHA consults with its membership and relevant partners about how best establish the size and age-profile of the specialist continence workforce and initiates immediate actions to undertake continence workforce planning. This should encompass steps to address the career opportunities available to continence specialists in all disciplines. There is an important role for CHA to play in defining the capabilities required by a multi-disciplinary and multi sectoral workforce in caring for people with incontinence and in promoting the case for better training in continence health care for all workers in health and care settings and in setting accreditation standards for training curricula at all levels.

Section 6: National Policy Impacts

Grasping the Policy Opportunities

This section identifies the key characteristics and mechanisms of the overarching national policy context within which continence is located. A full list of national and State-based sources of funding to individuals including eligibility criteria can be accessed at the website of the Continence Nurses Society of Australia (CoNSA).

National Continence Program

the National Continence Program is a national program supporting the prevention and management of incontinence. The aims of the NCP are to:

- Promote bladder and bowel control health and prevention for all age groups.
- Increase awareness of bladder and bowel control health and promote access to information and support.
- Include the needs of all people in our communities.
- Improve access to the best incontinence care available.
- Develop a national, shared approach to the promotion of bladder and bowel control health and incontinence support.

The NCP works with all levels of government, Continence Health Australia, community and industry groups and health professionals to achieve this. It also supports a range of initiatives to promote continence awareness and health in Australia, including World Continence Week, the National Conference on Incontinence, the BladderBowel website and National Public Toilet Map website, the Continence Aids Payment Scheme (CAPS) and publicly funded specialist continence clinics.

CAPS was introduced in 2010, replacing previous arrangements. The scheme provides a payment to eligible Australians to assist with the cost of some of their continence products. Funding is also provided through the NDIS (discussed below) or other State and Territory based support schemes may also contribute to continence care, but data demonstrating the specific breakdown of funding within these schemes is not readily available. The details vary from state to state. but eligibility and exclusion criteria tend not to be coordinated with other schemes or states, and gaps in coverage may exist. Details of the variations between the states can be can be found here.

CHA has developed a policy position statement which identifies the problems with existing arrangements with the CAPs scheme. The full statement, with a summary of the differential arrangements between States and territories can be found at

Appendices 2 and 3. In summary, CHA believes the following reforms are required to ensure equity for all beneficiaries of the CAPs.

- Safe and effective continence care that promotes choice and dignity is a fundamental human right.
- People who live with incontinence face unique barriers to participating in society, including workforce and economic participation.
- CHA identifies the Continence Aids Payment Scheme as a vital program for people living with incontinence, which should be maintained and expanded to meet demand.
- CHA advocates for increasing financial assistance for continence aids for those who are impacted by financial barriers.
- All people who have access to Medicare should have access to CAPS.
- The CAPS payment is insufficient to address the costs associated with living with incontinence

National Disability Insurance Scheme

During the preparation of the environmental scan, and in the absence of publicly available data on the numbers of people with disability who also experienced incontinence and are receiving support through the National Disability Insurance Scheme (NDIS,) CHA approached the National Disability Insurance Agency (NDISA) for information. NDISA provided the following clarifications,

Relationship of the NDIS to the CAPs programme

- A National Disability Insurance Scheme (NDIS) participant in receipt of funding for continence supports would generally not be eligible for funding under the Continence Aids Payment Scheme. [††]

Assessment of continence health needs for NDIS

- The NDIS provides funding for Clinical Nurse Consultant and/or Pelvic Health Physiotherapy hours for participants with disability related continence support needs.
- This funding is intended to support a Clinical Nurse Consultant or Pelvic Health Physiotherapist specialising in continence to complete an assessment of the participant's continence support needs and provide a comprehensive report that outlines their support requirements, the most appropriate carer aligned with these supports, and any consumables or assistive technology that may be required to support the participant in their continence needs.

[††] For more information, see NDISA webpage: Not meeting eligibility for the Continence Aids Payment Scheme - Continence Aids Payment Scheme - Services Australia

- Ideally these supports are to encourage as much independence as possible where their function allows. Refer Our Guideline – Continence Supports, page 7.
- The report is then considered against the NDIS Act, and Transitional Rules, and the NDIS (Supports for Participants) Rules to ensure they are within NDIS responsibility and would meet the requirements of reasonable and necessary NDIS funding.
- Continence assessment hours are funded annually to ensure available funding for ongoing assessment of the participant's needs and to ensure evidence is available should their needs change.

Support provided by NDIS for people with continence health needs

The support provided through the NDIS is highly personalised.

- The participant may require a support worker that has further training in disability support work to that of a standard support worker. This is guided by the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018 (Schedule 2. Module 1. 1-9) which outlines the High Intensity Daily Personal Activities (HIDPA) that should be completed by a High Intensity Support Worker. This is **NDIS Support for Continence Health Needs** further detailed by the NDIS Quality and Safeguards Commission NDIS Practice Standards: High Intensity Support Skills Descriptors, pages 7-17.
- Any task that is not listed in these documents, and is not considered a standard level of support, the NDIS may consider funding a Registered Nurse to provide support for these disability-related tasks, such as indwelling catheter changes and catheter flushes.
- Support workers completing HIDPA are supported with training and supervision from a health care provider (currently a Registered Nurse) regarding the participant's individual support needs. ‡‡

The Agency does not compile data specifically on the number of participants with continence health problems who have been assessed and/or supported under the NDIS. Agency data indicates that 133,863 participants (who are not self-managed) who have a consumables budget, who have made a continence claim in 2024.

Policy Reforms in Medicare, Primary Care and Aged Care

Next year will conclude the current (2020–25) National Health Reform Agreement (NHRA) and work is progressing rapidly to develop the next addendum. Established in 2011, the agreement binds all jurisdictions to cooperate on providing and expending $252.5 billion [153] per year in health funding to the nation's best advantage.

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‡‡ This model is outlined in Our Guideline – Disability Related Health Supports, page11.

As the historical focus has been primarily on hospital resourcing, recent addenda have struggled to deliver the broad reform and improved intergovernmental efficiency initially sought. In an environment of public dissatisfaction and apparent health delivery shortcomings, a mid- term review was commissioned in 2023 to "*consider whether the addendums' health funding, planning and governance architecture remains fit- for- purpose, given the shared priorities for better integrated care and more seamless interface*".[154]

The review, released in late 2023, is comprehensive and makes 45 recommendations to address the flaws in the concluding agreement and overcome ongoing dysfunction in the national health system. The Review leans heavily on the nation's Medicare principles to promote the following health system reform architecture. [155]

See Box 5 below:

Box 5: Key Principes of the National Reform Agreement

Whole of system agreement. Establishing the National Health Reform Agreement (NHRA) as a strategic reform agreement, with the remit and governance to take a whole of health system view.

Intersectoral collaboration. Delivering integrated, coordinated and responsive patient-centred care that reduces fragmented patient care pathways, suboptimal patient experiences and outcomes, and bottlenecks in hospital flows.

3. Optimal blended models of care. Providing sustainable, innovative and scalable public hospital funding and holistic, blended models of care that can deliver the right care in the right place at the right time.

4. Financing reform. Ensuring a transparent and accountable funding model that generates the right incentives and is fit for purpose for future challenges.

5. Long term health reforms. Building innovation and options for future reform and associated governance.

6. Rural and remote service delivery. Ensuring equitable access to health care that meets rural and remote community needs and service delivery.

7. First Nations people. Strengthening and addressing culturally responsive support, access and equity of services provided to First Nations people within the health system

8. Workforce and digital health. Enabling and incentivising a sufficient and skilled health professional workforce providing digital health services and accessing comprehensive health information about patients across the health sector at the point of care.

Measuring success. Embedding a performance framework as a proactive monitoring and planning tool to measure the performance of the health system, understand future pressures, and the capacity of the system to respond to these pressures.

10. Coronavirus disease 2019 (COVID-19). Providing flexibility in the agreement to respond to large external shocks and major disruptions to the system, such as COVID-19.

Source: Mid- term review of the National Health Reform Agreement Addendum 2020- 2025 final report. 24 Oct 2023. NHRA Mid-term Review Final Report

Medicare Reforms

1. **Strengthening Medicare**: The government is investing $11.8 billion over three years to improve primary health care. This includes tripling bulk billing incentives, increasing the number of Medicare Urgent Care Clinics, and expanding the nursing workforce.
2. **Multidisciplinary Team-Based Care**: Encouraging collaboration among healthcare professionals to provide high-quality, integrated care.
3. **Modernising Primary Care**: Implementing measures to make primary care more accessible and efficient, such as reforming after-hours programs.
4. Focus on **Mental Health** **and** **Women's Health**: Addressing specific health needs and ensuring equity and access to care.

Royal Commission into Aged Care Quality and Safety

The Royal Commission into Aged Care Quality and Safety was established in 2018 to investigate the quality and safety of Australia's aged care system. The final report was published on 26 February 2021 and contained 148 recommendations for fundamental and systemic aged care reform [268]. The report highlights that aged care residents receive substandard care in many areas, including (in)continence. It found that 71 per cent of residents have experienced incontinence, and that some aged care providers contribute to incontinence issues among residents by using poor incontinence management practices, including using continence pads rather than supporting residents to access toilets. The report noted that this not only increases the risk of adverse health outcomes of residents but also reduces their quality of life. In response to these findings, *Recommendation 19* from the Commission called for the urgent review of Aged Care Quality Standards, including best practice for continence care. Since the final report and recommendations were handed down, the Government has now initiated a comprehensive series of

reforms aimed at improving the safety and quality of aged care. These are summarised in Box 6 below.

Box 6: Summary of Aged Care Reforms . Source: Australia Government. Department of Health & Aged Care. 2024

National Preventive Health Strategy 2021-2030

The National Preventive Health Strategy 2021-2030 is a framework for action to improve the health and wellbeing of all Australians at all stages of life, through a systems-based approach to prevention that addresses the wider determinants of health, reduces health inequities, and decreases the overall burden of disease. Its aims are:

1. **Aged Care Reform Roadmap (2022-2025)**: A comprehensive plan to improve the quality of aged care, reduce wait times for Home Care Packages, and ensure a well-resourced workforce.
2. **New Aged Care Act**: Legislation aimed at putting older people at the centre of aged care, with a focus on person-cantered care.
3. **Support at Home Program**: Designed to provide better support for older Australians to remain independent in their homes.
4. **Regulatory Changes**: Implementing a new regulatory framework to ensure high standards of care and safety.
5. **Workforce Initiatives**: Investing in the aged care workforce to attract and retain skilled professionals, especially in regional and remote areas.
6. **Quality Standards** Continence health is now included in the quality standards that will be implemented alongside the new Aged Care Act in July 2025. This is the first time continence has been included in the Aged

- All Australians have the best start in life
- All Australians live in good health and wellbeing for as long as possible
- Health equity is achieved for priority populations
- Investment in prevention is increased

The Strategy includes eight immediate priorities to build key infrastructure and establish policy directions to mobilise the prevention system and realise its ambitions. These are:

- Governance mechanisms
- Increased investment in prevention
- A national platform providing credible and reliable health information
- Embedding prevention in primary health care and aligning with the Primary Health Care 10 Year Plan

- National consumer engagement strategy
- National health literacy strategy
- Enhanced public health workforce planning
- Ongoing national data sets to support the monitoring and evaluation of this Strategy and a national prevention monitoring and reporting framework

The health priorities identified in the Strategy are:

- Reducing tobacco use and nicotine addiction
- Improving access to and the consumption of a healthy diet
- Increasing physical activity
- Increasing cancer screening and prevention
- Improving immunisation coverage
- Reducing alcohol and other drug harm
- Promoting and protecting mental health.

While continence does not feature as a health priority, the Strategy aligns to CHA's prevention and health promotion framework and focus.

Conclusions

These reforms are part of a broader effort to create a more sustainable, equitable, and high-quality healthcare and aged care system in Australia and to address the avoidable causes of disease. There are number of opportunities for CHA to promote the issue of continence health provided by the policy landscape. Firstly, the language of the reforms and the principles which drive them are important levers for CHA to deploy to continue to make the case for person centred high quality and efficient continence care which needs to be seen as a cross-cutting health need which is central to the experience of care delivery in a broad range of settings. This sets the challenging policy development and advocacy agenda for CHA in the next 5 to 10 years.

The inequity of current service provision arrangements and the availability of financial support to people with incontinence is an injustice which undermines the rhetoric and the intention of the reforms. Once again, CHA has a vital role to play in developing proposals for reform which will address these inequities and injustices and enable better pathways of continence care for all Australians across the life course.

CHA could play an equally valuable role and developing a relationship with the NDIS to strengthen the data on the needs of people with disabilities supported by the NDIS who also have incontinence and the adequacy of current approaches to supporting them. To fulfil these functions and to have impact CHA will need a properly resourced policy development function supported by high quality research, communication, and advocacy skills.

Section 7: Technological Factors

Threat & Opportunity

Evolving technologies are increasingly becoming part of the continence assessment and management landscape to support both the client and the continence health professional. Current research on innovative treatments for urinary incontinence indicates significant advancements in enhancing patients' quality of life. These cutting-edge methods encompass behavioural therapies like pelvic floor muscle training, state-of-the-art medical technologies such as nerve stimulation, new pharmacological treatments with high efficacy and minimal side effects, and advanced surgical interventions, including artificial sphincter implants and urinary tract modifications. [156] [157]

There is emerging evidence to support the use of mobile application-based pelvic floor muscle training (PFMs) to aid the adherence to exercise routines, treat stress urinary incontinence and improve quality of life. [158] These technologies can provide flexibility to consumers, allow a means of overcoming barriers to accessing healthcare, and have a place in the conservative management of urinary incontinence with the support of a relevant continence health professional.[159]

There is also some emerging evidence of the value of assistive technologies in managing otherwise intractable incontinence, particularly addressing toilet use problems and supporting people to remain independent. Relatively inexpensive products such as absorbent pads or handheld urinals can help maintain function and independence, potentially preventing unnecessary care home admission. [160] The World Health Organisation has recognised the importance of assistive technologies in incontinence management recognising absorbent continents products as one of its top 50 priority assistive technologies.[161] This is a new area of inquiry and currently, there is no single source of information guiding decision-making.

Sensor-based continence pads are also increasingly being developed and reviewed in the continence space, especially with older people and in the residential aged care space. The sensors in continence pads can indicate when a continence pad requires changing or helps with the development of a continence management plan. [162] There is not yet clear evidence that the sensors improve incontinence in clients or any other outcomes such as quality of life, [163] but they may have a role in supporting conservative measures, such as prompted voiding, in continence care.

There is, currently, only limited evidence about the use of artificial intelligence and supporting professionals and consumers with the treatment and management of incontinence. The evidence that exists is mixed. One study found that the use of ChatGPT by clinicians results in 'favourable performance across the evaluated domains of accuracy, comprehensiveness, and safety within the context of UI

queries. [164] However, despite this broadly positive outcome, the study also signals a need for improvement, particularly in the precision of the provided information. A broadly similar result was found in another recent study exploring the accuracy and completeness of ChatGPT in addressing frequently asked questions related to the management and treatment of female urinary incontinence compared to recommendations from guidelines. The results showed an inconsistency when evaluating the accuracy of answers generated by ChatGPT compared to scientific guidelines, raising concerns amongst healthcare professionals and scientific community about using artificial intelligence in patient support. [165]

Emerging technologies are having a profound effect on available treatments, service delivery and health data collection throughout the Australian healthcare system. The national roll-out of My Health Record in the context of the newly endorsed National Digital Health Strategy and the formation of the National Digital Health Agency potentially provide platforms to promote patient empowerment and enhance continence care self-care through digital and interactive tools. Technology also has enormous potential to build public awareness and challenge the stigma of incontinence and support workforce development and impact assessments.

There have, in addition, been advances in surgical and diagnostic technologies related to some bladder and bowel conditions that, in time, could result in benefits to continence health in the population as well as to individuals.[166] While there are obvious opportunities for improved healthcare systems and outcomes utilising the newest technologies, concerns have been expressed by CHA members that technologies may pose threats to care and the skills of health workforce, which will need to be managed. Evidence is very limited in this area though this will emerge in the years ahead. There is anecdotal information that sensor pad technology encourages aged care facilities to keep residents in wet pads for longer to make their incontinence appear more severe, consequently receiving more funding via the Aged Care Funding Instrument. Lending weight to this, the GFI has stated that 'containment products' are frequently used inappropriately and may undermine independence and dignity. [167]

Other evidence points to positive impacts of technologies. There has been a significant amount of research into the efficacy of telehealth services, including several studies looking specifically at the provision of continence care via telehealth.[168] [169] [170] There are anecdotal concerns amongst continence sector stakeholders that while telehealth can improve access to care, it also has the potential to increase variation in the quality of assessment and treatment. Face to face interaction is still considered to be most conducive to best practice care.

Supporting self-care and self-management

There is a plethora of online and interactive resources available in Australia and internationally to support self-care generically and in relation to specific behaviours and risks. Young people are particularly likely to use online resources.[171] A 2013 study counted more than 13,500 smartphone-based health apps (certain to be much smaller than the corresponding figure for 2018).[172] Mobile Health Apps are emerging rapidly - these are used to locate public health toilets and track urinary habits,

symptoms and medication. Whilst the beneficial impacts of some technologies may only be realised in the future, there are promising developments in relation to gene and stem cell therapy to address the causes of bowel and bladder dysfunctions and to provide treatments. [173] [174] [175] The use of technology-based continence care is to enhance the delivery of care. It should not be a substitution for continence care. Technological devices used in continence care for older people and their carers may help improve the care provided if delivered in a way that suits the recipient and carer and are sustainable to use with education and training supporting the use.[176]

Data on the use and impact of these resources are scarce, but the literature highlights the increasing use of on-line resources by professionals, patients and citizens. These tools and technologies all have the potential to enhance population awareness of continence heath, to improve prevention and to support evidence-based, self-management of incontinence. The impact of these technologies on the consumer–provider relationship and their design for special user groups, including those with continence health needs, is to be explored.[177]

Conclusions

Technological developments have demonstrable potential for supporting people to self-care, including self-monitoring, but this will require substantial research to develop an evidence base. CHA has a key role to play in brokering a dialogue between industries, consumers and professionals to ensure that technological development is responsive to needs, supports the goals of independence and participation and the promotion of wellbeing and is based on scientific evidence.

Section 8: Environmental Impacts

Beyond the Burden of Incontinence on Individuals

There is an emerging understanding of the bidirectional relationship of the environment and incontinence. Incontinence has an impact on the environment and the environment can also affect and damage continence health.

The impact of incontinence of the environment.

Incontinence in Australia has environmental impacts, primarily due to the disposal of incontinence products.

Key environmental impacts include.

1. Waste Generation: Incontinence products, such as disposable pads and diapers, contribute significantly to landfill waste. These products are often made from non-biodegradable materials, leading to long-term environmental concerns.
2. Resource Use: The production of incontinence products requires substantial resources, including water, energy, and raw materials like plastics and superabsorbent polymers.
3. Carbon Footprint: The manufacturing, transportation, and disposal of incontinence products contribute to greenhouse gas emissions, adding to the overall carbon footprint.
4. Recycling Challenges: Incontinence products are difficult to recycle due to their mixed material composition and contamination with bodily fluids. This limits the potential for reducing their environmental impact through recycling.

Brewster et al (1922) in an important Australian study, estimate that adult incontinence products are a larger and faster growing waste issue than disposable infant nappies.[178] The destination of these products in Australia's waste management systems was estimated from national audits of waste disposal facilities. This information was combined to estimate greenhouse gas emissions and the environmental burden of landfill. The findings of this study estimate that waste generated by adult absorbent hygiene products (AHPs) already outweighs infant AHP waste in Australia, even with the most conservative use estimates of incontinence products by adults and excluding menstrual hygiene products. Furthermore, the study suggests that an ageing population demographic means that by 2030, the mass of adult AHP waste is estimated to be 4–10 times the amount of infant AHP waste being produced.

Studies that explore the environmental impact of incontinence in Australia include:

- CHA's Australian Continence Needs Analysis: This study provides an overview of research related to UI and FI in Australia. It highlights the lack of research on

the environmental impact of incontinence products, suggesting a need for more focused studies in this area. [179]

- Australian Institute of Health and Welfare (AIHW) Report (2013): This report discusses the prevalence and impact of incontinence in Australia, including the costs associated with managing the condition. While it primarily focuses on the social and economic impacts, it also touches on the environmental burden due to the disposal of incontinence products. [180]
- The National Continence Management Strategy: Funded by the Australian Government, this initiative aims to improve continence treatment and management. The strategy includes efforts to address the environmental impact of incontinence products through better waste management practices and promoting the use of more sustainable products.

This is an emerging area of research and innovation and there is yet limited literature to draw upon to estimate the full impact of incontinence on the Australian environment. The international literature is similarly limited. Some recent international studies include:

- Work by TheEuropean Association of Urology focused on the economic and environmental impact of incontinence in Europe. This analysis suggests that the economic cost of either recycling or incinerating incontinence pad waste in all study countries (EU and non-EU European) is similar, at €83.4 billion for recycling and €83.3 billion for incineration in 2023. The suggestion is that shifting to 100% recycling of incontinence waste could reduce the overall carbon footprint of continence health in Europe by 157.2 million kg CO2e in 2023 and an accumulated reduction of 1.1 billion kg CO2e across 2024–2030.[181]
- Environmental Scan by the Agency for Healthcare Research and Quality (AHRQ): This study focuses on the dissemination and implementation of nonsurgical urinary incontinence treatments for women in primary care. It highlights the environmental burden of incontinence products and the need for sustainable solutions. [182]
- Humanitarian Context Research: This research explores the experiences and needs of people living with incontinence in humanitarian settings. It underscores the environmental challenges posed by the disposal of incontinence products in these contexts. [183]

Management of incontinence waste

Different countries have adopted various strategies to manage incontinence waste, focusing on reducing environmental impact. Here are a few examples:

1. Japan: Japan has implemented advanced recycling technologies to manage incontinence waste. Some facilities use mechanical recycling to separate and process the materials in disposable nappies and pads, converting them into fuel or other reusable materials.[184]
2. Netherlands: The Netherlands has introduced specialised recycling plants that process used incontinence products. These plants can extract valuable

materials like plastics and cellulose, which are then repurposed for other uses.[185] [186]

3. Germany: Germany emphasizes waste separation and recycling. Incontinence products are often incinerated in waste-to-energy plants, which helps reduce landfill use and generates energy.[187]
4. United Kingdom: The UK has pilot programs for the collection and recycling of incontinence products. These programs aim to divert waste from landfills and explore sustainable disposal methods.
5. Sweden: Sweden focuses on incineration with energy recovery. Incontinence products are burned in high-efficiency incinerators, which generate heat and electricity while minimizing environmental impact. [188]

There is limited information available about Australian initiatives in this area. Global incontinence product manufacturer Essity launched an Australian-first trial, Project Divert, to find sustainable disposal solutions as a 6-week trial in 2023. Project Divert, was created in response to a lack of sustainable solutions for incontinence product waste from Australia's residential aged care sector. The outcomes of this trial are not available publicly.

These approaches highlight the importance of innovative waste management solutions and the potential for recycling and energy recovery to mitigate the environmental impact of incontinence products.

Individual action to reduce the Environmental impact of Incontinence

There are several sustainable incontinence products and other options available that aim to reduce environmental impact. Here are some of the most popular choices:

1. Reusable Incontinence Pads and Underwear: These products can be washed and reused multiple times, significantly reducing waste compared to disposable options. They are often made from eco-friendly materials that are gentle on the skin
2. Biodegradable Incontinence Products: Some brands offer biodegradable pads and liners that break down more easily in the environment. These products are designed to minimize the long-term impact on landfills
3. Absorbent Underwear, these products offer a sustainable alternative to traditional pads and liners.

The impact of the environment on continence health.

Environmental factors can also significantly influence the development and management of incontinence in both children and adults. A comprehensive summary of the literature by von Gontard et al (2017), highlights the evidence which points to the importance of living and working conditions in promoting good continence health. There is increasingly strong evidence of the impact of low levels of physical exercise and of obesity and incontinence in adults [189] and particularly

strong association between sedentary behaviour and urinary incontinence across populations of different particularly in older women, who are twice as likely to have urinary incontinence than older men.[190] There is evidence that women are particularly affected by lack of access to clean, private toilet facilities.

Other environmental factors may include

- **Working Conditions**: Jobs that limit access to toilets or involve heavy lifting can increase the risk of incontinence.
- **Fluid Intake**: Both insufficient and excessive fluid intake can influence bladder control.
- **Hormonal Variations**: Changes due to work shifts or other factors can affect the likelihood of incontinence.

Multiple environmental factors can contribute to incontinence in children and there is evidence that stressful life events and trauma and family dysfunction highly correlated with incontinence. Children in the public care system have higher rates of both urinary and faecal incontinence than others. However poor housing conditions, and lack of easy access to school toilets are also implicated.

For both children and adults, the impact of climate change on overall health and well-being including risks to bladder and bowel functioning should not be discounted. There is some evidence emerging from the global South of the impact of climate change and extreme weather events on personal hygiene.[191] Australian data in this area is limited. Overall, the interactions between biological factors, the immediate environment, and intervening variables need to be explored in greater detail to develop effective interventions.

Conclusions

These studies indicate a growing awareness of the environmental challenges posed by incontinence products and highlight the need for further research and innovative solutions. Australia can adopt several strategies from other countries to improve the management of incontinence waste and reduce its environmental impact including:

1. Advanced Recycling Technologies: Like Japan, Australia could invest in mechanical recycling facilities that separate and process materials from incontinence products. This could help convert waste into reusable materials or fuel.
2. Specialized Recycling Plants: Following the Netherlands' example, Australia could establish specialized plants to extract valuable materials from used incontinence products. This would promote recycling and reduce landfill waste.
3. Waste-to-Energy Incineration: Germany and Sweden's approach of incinerating incontinence products in waste-to-energy plants could be beneficial. This method not only reduces landfill use but also generates energy, contributing to a more sustainable waste management system.

4. Pilot Collection Programs: The UK's pilot programs for collecting and recycling incontinence products could serve as a model for Australia. Implementing similar programs would help explore sustainable disposal methods and divert waste from landfills.
5. Public Awareness and Education: Increasing public awareness about the environmental impact of incontinence products and promoting the use of sustainable alternatives, such as reusable pads and biodegradable products, can also make a significant difference.

CHA can play a vital role in bringing together industry partners with consumers, carers and service providers to explore the scope for innovation in sustainable product development, waste management. The findings of the Deloitte study which suggest an increasing prevalence of incontinence amongst all age groups in the next decade and beyond highlights the importance of urgent action to prevent avoidable incontinence, tackle the risk factors and create more sustainable and environmentally friendly aids and products for containment and management.

SECTION 9: Potential Partners

Building Alliances

As part of this environmental scan, a web search and review were conducted to identify organisations, initiatives, and networks at international, national, and state levels with the potential to develop an alliance with the CHA to promote a new conversation and a new policy approach to the prevention and treatment of incontinence. This is not an inclusive map of potential alliances needs and is as a starting point. See Appendix 4 for a preliminary list of these organisations' networks, and campaigns.

CHA has recently reviewed its strategic direction 2025 to 2030 and identified the following priorities, all of which are supported by the information in this scan. The new strategic direction stresses the importance of strong alliances. The organization is mapping current and potential stakeholders based on the list in Appendix 4.

Endnote

This scan of the forces and factors which are affecting the landscape for continence health in Australia suggests that, without radical, preventive action, demographic, lifestyle and clinical trends will mean that the prevalence of incontinence (both urinary and faecal) is likely to increase sharply in the coming years. Patient and carer expectations of the availability and quality of continence care will also continue to increase. In parallel, an increasing need to constrain health and social care spending is obliging public and private payers to reconsider the overall structure and extent of provision in health and social care. There is evidence that continence health is not a priority for health care planners, payers or policy makers. To some extent this is impacted by the persistent stigma surrounding the issue. It must also be acknowledged that the very complexity of incontinence with multiple causes, symptoms, range of at-risk populations and whole-life course aspects ensures that there can be no 'one-size fits all' solution. Yet the suffering for affected individuals and carers is real and intense and there are negative impacts on the economy, society and environment as a direct consequence of poor management of incontinence. The evidence suggests that there is significant, unrealised scope for prevention in all age groups, yet there is limited evidence to provide guidance to payers and providers about how care might best be configured to deliver cost-effective, evidence-based, and high-quality patient-centred care.

This scan highlights the complexities of the landscape in Australia with its mix of public and private health provision, huge geographical variations in demand and supply and a far-reaching policy reform agenda in play. Historically, Australia has been a world leader in responding to continence health. However, as the needs of the population change, and prevalence and costs associated with incontinence continue to rise, the current policy settlement and associated funding is under increasing strain. There are evident inequities between the states and territories in the level of financial support provided to individuals affected by incontinence and it is unclear how effective NDIS policy and practice is at supporting individuals with disabilities who also have incontinence. Gaps are also evident in the accessibility of services, particularly in rural and remote areas, referral pathways are not in place, there is little evidence of coordinated care in most health care settings even amongst groups at high risk of persistent bladder and bowel problems, and there have been cuts in some states to specialist continence services. 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. Prevention is only now being addressed for some, but not all population groups, and there are concerns that, overall, there is an over-reliance on pads and products instead of effective prevention and management strategies.

New policy streams in aged care and primary care may have the potential to improve the prevention and management of incontinence but the evidence suggests that this will not happen without a focused, partnership-driven, strategic effort to raise awareness of the needs, promote the evidence of what works and establishment of pathways of locally responsive services. Moreover, as new policy streams in health and aged care are implemented, there is a lack of clarity about the ways in which

these policies will interact with the current National Continence Program or the associated funding provided to eligible individuals for aids through the CAPs Scheme. The CAPs scheme itself requires urgent reform to ensure equitable treatment of all individuals with continence health needs, irrespective of where they live.

It is important that a powerful case is made for a new settlement for continence health in Australia, to address this changing landscape. This must be based firmly on evidence of the impacts of poor continence health in the population and of the economic and social benefits of investing in world-class primary and secondary prevention across the whole prevention pyramid.

Alarming data gaps have been uncovered in undertaking this scan. It is vital that these gaps are addressed as part of the continuing effort to maintain and elevate the policy profile of continence health. These gaps include:

- Consistently updated information on prevalence amongst all population groups and across the whole life course
- Consistently updated information on costs
- Service data – numbers, scope and location
- Outcomes data- the return on investment in continence services and support
- Trends affecting the specialist continence workforce
- Requirements or continence capability in pre and post qualifying training for the generic health workforce
- The potential of technologies to prevent incontinence or support self-management and treatment of incontinence
- The environmental impact of incontinence and the evidence for strategies to mitigate these.

Finally, and as matter of urgency, there is a need to ensure that the profile of continence health is not obscured within the complex web of policy reform programmes taking place in healthcare, primary care and the care of older people.

Recommendations

The following high-level recommendations are made to the CHA Board for noting and comment.

1. Commit to the development of a National Continence Plan for 21st century Australia. This plan should address the distinct and separate needs of women, men, children and minority groups and communities, and set out an agenda for the development of appropriate services at both primary and specialist levels of care.
2. Request the Australian Bureau of Statistics to embed questions on continence health in the National Health Survey to ensure that information about incidence, prevalence and impacts is updated regularly.
3. Establish incontinence as a research priority through the National Medical and Health Research Council and the Medical Research Future Fund.

4. Escalate efforts to achieve the recognition of incontinence as a long-term condition and not just a symptom of other conditions or an unavoidable consequence of certain life transitions.
5. Set achievable priorities to address the needs of specific populations, whilst continuing to address key cross-cutting issues. It is particularly important to continue to bring forward proposals to address the challenges of continence health workforce supply, accreditation and capabilities as well as the evident skills and capabilities gap in the generic healthcare workforce. A capable workforce is required to deliver effective prevention, support, and treatment to all populations. There is a particularly urgent need to address continence health workforce supply, support and capabilities in remote and rural locations.

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