



Continenence
Foundation
of Australia

2024–2025

Pre-Budget Submission

**Shaping the Future in
Continence Policy**

About Us

The Continence Foundation of Australia links:

- People experiencing incontinence and their families, friends and carers with **information** through our Bridge Magazine, website resources including 17 fact sheets translated into 29 different languages and the National Public Toilet Map.
- People experiencing incontinence with **individualised support** from Nurse Continence Specialists through our National Continence Helpline and National Clinical Services team.
- Practitioners across nursing, allied health, medical and other professions with the **latest international research** through our scientific peer-reviewed Australian and New Zealand Continence Journal, fortnightly membership newsletter, as well as education resources and events.
- **Practitioners, researchers and policy makers** through inter-professional networking opportunities, including our annual National Conference on Incontinence which is now in its 32nd year.
- **Service providers** with the latest, evidence-based information on continence care and support through organisational memberships and other partnerships.
- **Innovative service providers** with funding through our Health Promotion Community Grants.
- **Clinicians and the non-specialist workforce** to education via hybrid, online modules, webinars and skills-based training.

Our annual National Consumer Survey provides insight into public and community attitudes, behaviours and/or preferences about how continence services are accessed. We have calculated the high economic cost of incontinence in Australia through commissioning the 2023 Continence Health in Australia Impact Report by Deloitte Access Economics¹.

The Foundation has had a positive impact on the support and inclusion of people experiencing incontinence through a range of initiatives strengthened by contributions from our Consumer Advisory Committee. Our initiatives span all ages and experiences of incontinence. Recent initiatives include:

- The development of My Continence Care model for residential aged care and the national delivery of skills-based training in catheterisation with contribution to the catheter care improvement study (IDC-IMPROVE) for residential aged care, in collaboration with the National Ageing Research Institute (NARI)².
- Toilet training and Go Against The Flow projects funded through the Victorian Government's Home and Community Care Program for Younger People³.
- The BINS4Blokes Campaign has seen incontinence product disposal bins installed in male public toilets in venues run by local councils across Australia⁴.
- The Great Dunny Hunt Campaign continues to raise awareness and contributes to the database of the National Public Toilet Map⁵.

2022–2023 Performance Highlights

Clinical Support

22,115 HELPLINE CALLS

706 CLIENTS supported by National Clinical Services

Membership

1,485 TOTAL MEMBERS of the Foundation

Membership Breakdown

1,440 PROFESSIONAL MEMBERS

45 CORPORATE AND ORGANISATIONAL MEMBERS

Health Promotion

4 NEW LOCAL COUNCIL AREAS installed men's incontinence product disposal bins in response to BINS4Blokes campaign

4 VENUES installed men's incontinence product disposal bins in response to BINS4Blokes campaign

Education

28,743 LEARNERS

Events

516 ATTENDEES at the Joint 31st National Conference on Incontinence and 4th Functional Urology Symposium

367 ATTENDEES at State and Territory Advisory Committee educational events

Marketing and Communications

2,496,461 TOTAL WEBSITE USERS

3,871,867 IMPRESSIONS across all social media

51,328 DIGITAL COPIES of Bridge Magazine distributed

OVER 23,000 TOILET FACILITIES now featured on the National Public Toilet Map

Research

75% INCREASE IN AWARENESS of pelvic floor muscle exercises

Policy and Advocacy

13 SUBMISSIONS to government

See our Annual Report 2023 for more information on these and other recent activities.

The Negative Impact of Incontinence

A prevalent condition

Incontinence is a highly prevalent but under recognised public health issue affecting Australians of all ages. The 2023 Deloitte Access Economics report commissioned by the Foundation from Access Economics estimates that over **1 in 3 (33.7%, 7.3 million) Australians over the age of 15 years were affected to some degree by incontinence, ranging from moderate to very severe**¹.

About 6.8 million people experienced urinary incontinence only, 0.5 million experienced faecal incontinence only, and 0.9 million experienced both urinary and faecal incontinence¹.

The prevalence of incontinence increases with age. However, reflecting the demographic profile of the population, 71% of people experiencing incontinence in 2023 were younger than 65 years of age¹.

Nearly 70% of all urinary incontinence cases were in women¹. Faecal incontinence is more equally distributed by sex, with about 52% of cases in women and 48% in men¹.

It is estimated that 3–12% of children over 5 years of age experience daytime urinary incontinence, 1–3% experience faecal incontinence and nearly 20% experience nocturnal enuresis (bedwetting)⁷. However, the exact prevalence is difficult to determine due to underreporting and inconsistent definitions.

These figures are likely to be underestimates of the extent to which incontinence affects the health and wellbeing of the Australian population. There is evidence that many people are reluctant to report incontinence to health professionals and do not seek health services for treatment or management advice. Data on incontinence in the population is not collected routinely.

A complex issue with significant impacts

Incontinence may be a symptom of an underlying mental or physical health condition or illness such as prostate disease, a consequence of life transitions such as pregnancy and childbirth, or a side effect of treatment.

Regardless of the cause of incontinence, the experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in normal activities of daily living^{8 9 10}.

Lack of community awareness

The Foundation's 2023 National Consumer Survey revealed that 3 in 4 respondents (74%) hold the view that people in the community lack awareness about incontinence¹¹.

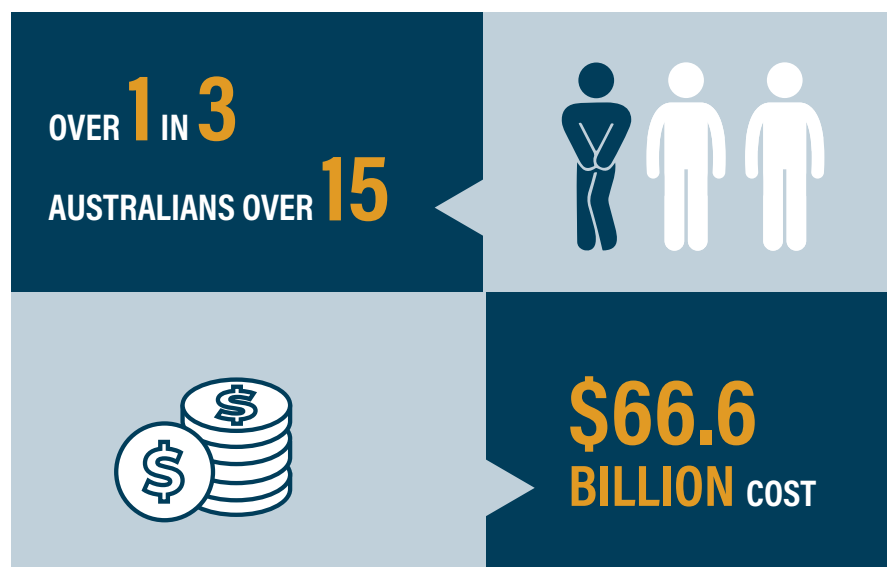
Stigmatisation negatively impacts health seeking behaviours

46% of respondents to the Foundation's 2023 National Consumer Survey said they had not discussed incontinence with family and friends, thereby hindering 'word of mouth' sharing about incontinence and awareness of where to access supports¹¹.

Furthermore, 1 in 3 people had not discussed their experiences of incontinence with primary care providers, which means they never receive appropriate referral for treatment and supports¹¹.

The economic impact

Deloitte Access Economics estimates that in 2023, **the financial cost of incontinence was \$66.6 billion, with an additional \$33.8 billion in lost wellbeing for people with incontinence¹.**



Solution 1

National Continence Action Plan

The National Continence Program Action Plan for 2011 to 2014, recognised that incontinence is a significant health issue that has physical, social and economic implications for women and men of all ages, as well as children, carers, families and the community. The Action Plan initiated a comprehensive series of policy actions which positioned Australia as a world leader in addressing continence health¹².

However, there has been no updated National Continence Action Plan since 2014. The absence of a focus on national continence policy in recent years has resulted in a fragmented and reactive approach to the planning and delivery of services.

Prevention and support services for incontinence have been overlooked in successive reviews of health services and reform measures. This is despite incontinence being recognised by these reviews as having a significant negative impact on a high proportion of Australians and requiring complex policy and service solutions to address the varying causes and impacts of incontinence.

Compounding these factors, there are reports of significant gaps in the accessibility of services, particularly in rural and remote areas and there have been decreases in funding in some states to specialist continence services. There are, in addition, widespread perceptions amongst stakeholders of a lack of capability in the generic health and aged care workforce and a loss of capacity in the specialist workforce.

An example highlighting these issues and lack of policy response is the Royal Commission into Aged Care Quality and Safety. The Commission's Final Report reflected on what they described as the "terrible examples" of substandard continence care and lack of supports to regain continence in aged care. However, no actions were proposed to address these issues¹³.

The Foundation and its members provide valuable services but there is an urgent need to upskill the broader aged care, health and disability service workforces in continence care with a focus on prevention and reablement.

Overall, there is an over-reliance on the provision of pads and other symptom management products instead of effective prevention and treatment strategies for all age groups.

A coordinated approach to training and education to ensure capability in the delivery of evidence-based continence care is urgently required in training for all aged care, health and disability workers.

New policies in disability and aged care are being implemented nationally but there is no guidance about the ways in which these policies interact with the current National Continence Program, or the associated funding provided to eligible individuals for aids through the Continence Aids Payment (CAP) scheme.

Incontinence requires a sustained, proactive and targeted program of additional support and capability if the Australian Government wishes to achieve its overall objective to improve the health and wellbeing of the population.

In support of this objective, a five year National Continence Action Plan is proposed, to provide a comprehensive national strategy to improve continence care to population groups at risk of and living with incontinence through integration of policies, education and training and service development. The National Continence Action Plan would have the following objectives:

1. Greater awareness and understanding that incontinence can be prevented, better managed and very often cured.
2. Increased and equitable access to appropriate and integrated continence health services leading to greater economic participation by people experiencing incontinence.
3. Improved access to education and training to improve early detection, early intervention, management and treatment.
4. Improved collection and integration of data to inform health care and service quality, planning, monitoring and evaluation and to inform clinical services research.

As the only recognised impartial and apolitical national peak body for continence health, the Foundation has the leadership credibility and relationships to support the development of a nationally coordinated approach across multiple agencies which support the disability, aged care, health and social services sectors.

The Foundation will work with the Department of Health and Aged Care in the development of the National Continence Action Plan by bringing together the key organisations and individuals in Australia and internationally.



**Proposed funding for the development of a five-year
National Continence Action Plan**

\$450,000

Solution 2

National Continence Data Strategy

Currently, there are significant data gaps affecting all aspects of continence health which impede clinical and societal responses to continence health. These include:

- Regularly updated information on prevalence.
- Regularly 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.


A clear area in need of action under any future National Continence Action Plan is improvement in the collection of information about the prevalence and treatment of incontinence. The Foundation therefore proposes that a National Continence Data Strategy should be developed in parallel with the National Continence Action Plan. This would allow synergy between the two projects, including the utilisation of consultation opportunities for both purposes.

The National Continence Data Strategy would expand on the strategic actions required to address the significant gaps in data on incontinence in Australia, including these already well-known areas:

- The inclusion of questions about continence in official government statistics, for example in the Census Health Conditions and National Survey of Disability, Ageing and Carers.
- The collection and reporting of continence service provision through federal, state and territory governments' administrative data sources (e.g. aged care, the National Disability Insurance Scheme and Medicare).
- Service provider data collection and reporting.
- Academic research gaps and a lack of dedicated funding stream options.
- The connection of industry research findings with academics, policymakers and practitioners to ensure the efficient and appropriate uptake of technological advancements.

The development of the National Continence Data Strategy should involve extensive consultations and collaboration with Australian Government departments and agencies and service providers, professionals and researchers across the disability, aged care, health and social services sectors.

The Foundation has invested significant resources in endeavoring to improve and compensate for lack of data on incontinence in Australia and is well positioned to undertake development of the National Continence Data Strategy.



Proposed funding for a National Continence Data Strategy

\$350,000

Solution 3

Continued Funding of National Continence Program

The Foundation is seeking continued funding for the National Continence Program (NCP) to continue and build on the achievements of the Foundation in the past twelve years since the NCP establishment in 2011. The NCP supports a wide range of Foundation activities including awareness raising, addressing stigma and discrimination, providing information, education and promoting and implementing an agreed set of research priorities.

The National Continence Program will continue to excel in the delivery of:

- **Clinical Services** through growth and delivery of the National Continence Helpline service.
- **Knowledge Development** through gathering and reporting on data measuring the adoption and/or impacts of advice provided by the Foundation through its clinical services.
- **Health Promotion, Access and Information** through evidence-informed outputs co-designed with consumers to promote and support self-care and self-management of incontinence across the life course. The Foundation will also develop the capacity of community connectors and agencies to provide evidence-informed resources and signposting to appropriate support and treatment.
- **Workforce Development** will occur in part through the annual delivery of the National Conference on Incontinence. Further tailored professional development and professional networking opportunities will be developed in partnership with relevant training organisations, stakeholders and communities of practice.
- **Communications** including continuing to expand on successful current campaigns and campaigns for new populations through multiple communication channels, with a focus on reducing stigma, prevention, early intervention and reablement.
- **Policy, Research and Knowledge** through the ongoing peer reviewed publication of the Australian and New Zealand Continence Journal, National Conference on Incontinence, annual National Consumer Survey, and analysis of Foundation service provision data and other publicly available datasets. We will consult with Foundation members, partner agencies and consumers and carers to define, promote and implement an agreed set of research priorities to meet the objectives of the National Continence Program.

The Board of the Continence Foundation of Australia has committed to increasing its strategic capacity to inform future policy and research with the next round of National Continence Program funding.

The proposed Foundation contribution to the National Continence Action Plan and National Continence Data Strategy will not only inform our future collaborative policy and advocacy directions, but also demonstrate the leadership and capacity of the Foundation to work with all stakeholders. This will ensure consistent improvement in relevant policies, service models and care to prevent and reduce the impact of incontinence; for people living with incontinence and on health care services.



References

1. Deloitte Access Economics (in press). Continence Health in Australia. The Continence Foundation of Australia 2023.
2. National Ageing Research Institute. IDC-IMPROVE: Improving indwelling catheter care (IDC) in residential aged care homes. Accessed 22 January 2024, available at <https://www.nari.net.au/idc-improve>
3. Department of Health, Victorian Government. Home and Community Care Program for Younger People. Accessed 22 January 2024, available at <https://www.health.vic.gov.au/home-and-community-care/hacc-program-for-younger-people>
4. The Continence Foundation of Australia. Bins4Blokes. Accessed 22 January 2024, available at <https://bins4blokes.org.au/>
5. The Continence Foundation of Australia. National Public Toilet Map. Accessed 22 January 2024, available at <https://www.continence.org.au/National-Public-Toilet-Map-Summer-Plan>
6. The Continence Foundation of Australia, 2023. Annual Report 2023. Available at <https://www.continence.org.au/about-us/our-work/annual-reports>
7. Continence Foundation of Australia. Incontinence in children. Accessed 22 January 2024, available at <https://www.continence.org.au/toilet-tactics/facts>
8. Pizzol D, Demurtas J, Celotto S, Maggi S, Smith L, Angiolelli G, Trott M, Yang L, Veronese N. 2021. Urinary incontinence and quality of life: a systematic review and meta-analysis. *Aging Clin Exp Res.* 33(1):25-35. doi: 10.1007/s40520-020-01712-y.
9. Bartlett L, Nowak M, Ho YH. 2009. Impact of fecal incontinence on quality of life. *World J Gastroenterol.* 15(26):3276-82. doi: 10.3748/wjg.15.3276.
10. Collis D, Kennedy-Behr A, Kearney L. 2019. The impact of bowel and bladder problems on children's quality of life and their parents: A scoping review. *Child Care Health Dev.* 45(1):1-14. doi: 10.1111/cch.12620.
11. The Continence Foundation of Australia (in press). 2023 National Consumer Survey.
12. Australian Government Department of Health and Ageing. The National Continence Program: Action Plan 2011-2014. 2011. Available from: The National Continence Program Action Plan 2011-2014 | Continence Foundation of Australia [Accessed 2022 January 13]
13. Royal Commission into Aged Care Quality and Safety. 2021. Final Report: Care, Dignity and Respect. Volume 1, p.27. Summary and Recommendations. Commonwealth of Australia. Available online at https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

Continenence Foundation of Australia

ABN 84 007 325 313
ACN 007 325 313

Contact

Rowan Cockerell, Chief Executive Officer

E R.Cockerell@continenence.org.au

Suite 1, 407 Canterbury Road, Surrey Hills VIC 3127

P +61 3 8692 8400

continenence.org.au