

Response ID ANON-PR8U-2NEP-4

Submitted to **Draft National Preventive Health Strategy**

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Introduction

1 What is your name?

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3 What is your organisation?

Organisation:

Continence Foundation of Australia

VISION

4 Do you agree with the vision of the Strategy? Please explain your selection. (1000 word limit)

Strongly Agree

Vision Text:

The Continence Foundation of Australia (the Foundation) agrees with the Draft National Preventive Health Strategy's vision to improve the health of all Australians as part of a life course approach. Incontinence is a whole of life issue and can be experienced by anyone at any stage in life irrespective of age, gender or any other demographics. It is because of this that the National Preventive Health Strategy (the Strategy) should integrate incontinence prevention and continence care into every aspect of its plan.

Incontinence has a significant burden on Australians across the life course yet its impact largely remains obscured at a national level:

- One in four Australians above the age of 15 experience incontinence (Deloitte, 2011).
- Incontinence costs Australians \$67 billion annually in terms of health system expenditure, productivity losses and burden of disease (Deloitte, 2011).
- The burden of disease of incontinence is associated with almost 140,108 Disability Adjusted Life Years (DALYs) or years of life lived with disability (Deloitte, 2011).
- People experiencing incontinence (urinary and faecal) are significantly more likely to report lower quality of life (Mundet, 2016; Pizzol et al 2021).

Being continent represents a state of wellbeing for millions of Australians. People at risk of or experiencing incontinence must be adequately supported by a system wide health approach. The Foundation considers there is significant unrealised scope for improved prevention of incontinence and prevention of the negative impacts of incontinence among the Australian population.

Noting this, the Foundation calls for the inclusion of continence-specific programs, tools and interventions as part of a coordinated approach by all stakeholders: governments, non-government organisations, advocacy groups, service providers and the community to ensure that appropriate action is implemented as part of this Strategy.

AIMS

5 Do you agree with the aims and their associated targets for the Strategy? Please explain your selection. (1000 word limit)

Agree

Aims Text:

The Foundation agrees with the four aims and associated targets outlined in the Strategy in principle. Continence specific issues with each of the aims and their targets have been highlighted under the headings below.

Australians have the best start in life

The Foundation believes that Australians should be supported to have the best possible start to life which includes preventing incontinence and providing continence care. National data shows that 5-10% of Australian males aged between 15-29 are likely to experience incontinence while this increases to 11-18% for females in the same age group (Deloitte, 2011). Moreover, over one third of men and half of women living in the community with incontinence are aged under 50 (Deloitte, 2011) highlighting the need for early intervention and preventive programs across younger demographics and genders.

Earlier toilet training for children who display signs of toilet-training readiness is also a key measure that must be implemented to avoid social and health

consequences in later life. Initiation of toilet training after 32 months of age is significantly associated with urge incontinence and recurrent urinary tract infections in older children (Bakker et al 2004; Barone et al, 2009). Other consequences include daytime and night-time wetting and urinary tract infections which were independently associated with a lower ability to manage homework and normal daily hygiene on their own (Bakker et al, 2003). In contrast, initiating toilet training at an earlier age has not been found to be associated with negative consequences such as constipation, withholding or refusal to defecate (Blum et al, 2003).

Australians live as long as possible in good health

The National Preventive Health Strategy must support all aspects of health-related quality of life to enable good health for all Australians who are at risk of incontinence.

As has been highlighted previously, incontinence is associated with almost 140,108 DALYs or years of life lived with disability (Deloitte, 2011). One DALY can be thought of as one lost year of a 'healthy' life (WHO, 2020). However, it should not be assumed that incontinence is only significantly associated with a reduced quality of life. It is also associated with significantly lower perceptions of general health, physical and social function, mental health and vitality (Pizzol et al, 2021) which all add to its overall impact. Supporting people who are at risk of incontinence maintain their continence status will contribute to greater quality of life for Australians by 2030.

Health equity for target populations

The Foundation recognises and agrees with the need to support target populations, including people in lower socio-economic groups and regional and remote areas, to have additional years of life lived in full health by 2030.

However, the Foundation queries why the target for Aboriginal and Torres Strait Islander communities focuses on an increase in the rate of indigenous-specific general practitioner health checks and neglects to aim for an increase the additional years of life lived in full health unlike other demographic groups. The Foundation believes the Australian Government must not sidestep its responsibilities and instead use all available opportunities to demonstrate leadership on improving Indigenous health and well-being.

Quality of life, and life lived in full health is an essential aspect to Aboriginal and Torres Strait Islander people that must be addressed. While evidence is limited about the incidence of incontinence among Aboriginal and Torres Strait Islander people, the available evidence of a higher prevalence compared to the general population means it must be considered as part of closing the gap on health inequities. Studies have shown between 23 and 54% of Aboriginal and Torres Strait Islander people experience incontinence. In one study of older Indigenous Australians, 45% of the participants who currently experience incontinence reported urinary incontinence on a daily basis and one in five stated it interfered with everyday activities some or all of the time (Benness and Manning, 1999; Smith et al, 2018) highlighting the consistent impact incontinence has in this demographic.

Investment in prevention is increased

The Foundation is very concerned that the Strategy will not be given the support that it needs to become an effective tool to support the health of Australians with a target to increase preventive health funding to only five percent of total health expenditure by 2030.

Currently:

- An estimated one in two Australians have a chronic condition and account for nine in ten deaths in Australia (Mitchell Institute, 2019).
- Estimates place the cost of potentially preventable hospital admissions from chronic conditions at \$322 million per year (Grattan Institute, 2016).
- The dominant health service delivery model focuses on treatment of acute illness and injury but not long-term or chronic conditions (Grattan Institute, 2016).

People living with chronic conditions, like incontinence, often experience a fragmented health system as well as uncoordinated, absent or delayed care, and a low uptake of health technology by providers (Primary Health Care Advisory Group, 2015) which is suboptimal. At its best, our primary care system only provides half the recommended care for patients with chronic conditions. Often it is much less (Grattan Institute, 2016).

Furthermore, it is likely to exacerbate the minimal health response for people who live with multiple co-morbidities including incontinence. The Foundation conducted a nationally representative consumer survey in 2020 and found that, compared with the general population, people living with cancer, diabetes and heart/cardiovascular disease are twice as likely to be currently experiencing incontinence (CFA, 2020).

These facts lead to the question as to why prevention is being given a secondary, rather than a primary role within the health system. Investment in preventive health should be increased to match the needs of Australians in order to be viewed as a viable intervention opportunity.

PRINCIPLES

6 Do you agree with the principles? Please explain your selection. (1000 word limit)

Agree

Principles Text:

The Foundation agrees with the principles outlined in the Strategy. The six principles will act as a sound basis to provide and sustain preventive action across the health system and for Australians. Where relevant, further comment has been made on specific principles that the Foundation wishes to highlight.

Multi-sector collaboration

As a national peak body representing Australians with or at risk of incontinence, their carers and health professionals, the Foundation can provide significant leadership which can be leveraged to coordinate, develop and act on a continence-specific preventive approach as part of the Strategy. This can lead to

evidence-based practices informed by industry expertise being utilised across a range of preventive health programs to support the Strategy across the health, disability, aged care and mental health sectors.

Enabling the workforce

All staff and health professionals within the health system, including aged care, disability, mental health care who provide direct care must be appropriately educated and/or trained in safe and effective continence care and incontinence management in their foundation courses (VET and undergraduate courses). Nurses, registered midwives, personal care workers and health professionals including allied health professionals have all been found to have inadequate training in continence care (Paterson, 2006; Australian Government, 2015; Royal Commission into Aged Care Quality and Safety, 2019) reducing opportunities in prevention that must be addressed as a priority.

Community engagement & Empowering and supporting Australians

The Strategy's approach must be closely linked to other national health strategies to promote community engagement and empowering and supporting Australians. The National Women's Health Strategy states that key measures to take are the de-stigmatisation of urinary and faecal incontinence and improved access for women to specialist care (Australian Government Department of Health, 2018). Although the focus for these initiatives is only on maternal, sexual and reproductive health, both issues should be highlighted and implemented for both men and women across the life course to facilitate higher quality preventive interventions at all stages in life.

It is particularly important that de-stigmatisation of incontinence is addressed at a national level across all genders and age groups. One Australian study has found that 65% of women and 30% of men sitting in a GP waiting room report some type of urinary incontinence, yet only 31% of them report seeking help from a health professional (Byles et al, 2003). Two other Australian studies reiterate this stating 70% of people with urinary incontinence do not seek advice and treatment for their problem (Avery et al, 2014; Millard, 1998).

ENABLERS

7 Do you agree with the enablers? Please explain your selection. (1000 word limit)

Agree

Enablers Text:

The Foundation agrees, in principle, with the seven enablers in the Strategy. Further detail on the Foundation's position on the enablers has been outlined in the next question on the specific policy aims.

8 Do you agree with the policy achievements for the enablers? (1000 word limit)

Agree

Enablers - Policy Achievements Text:

Leadership, governance and funding

The Foundation calls for greater detail to be provided on the national, independent governance mechanism that will help determine preventive health action. It is currently unclear how independent this mechanism will be, how much external input will play a role and the level of funding it will oversee. More detail on how the independent mechanism will review submissions, reports and advice will also need to be provided to facilitate greater confidence in its operations within health prevention.

As a national health peak body, the Foundation has been calling for the development of a national, collaborative approach to the promotion of continence care and incontinence management for well over a decade (CFA, 2011). The Foundation is well placed to manage, facilitate, guide and coordinate continence-specific aspects of the National Preventive Health Strategy to inform the independent mechanism on concrete actions to take in addressing the significant risk of incontinence for the Australian community.

Prevention in the health system

The Foundation agrees with the need for greater education and training for the health workforce to facilitate inherent preventive health capabilities in the health system. The Foundation reiterates its view that all staff and health professionals providing direct care in the health sector, including aged care, disability and mental health should receive education about safe and effective continence care and incontinence management, including prevention, in their foundation courses (VET and undergraduate courses).

Information and health literacy

The Foundation agrees with the need to inform and develop the health literacy of the general public and health services, including incontinence prevention and continence care. The Foundation has developed a suite of educational and training resources which have been informed by health professionals which cater to both the general population, and various target populations such as pregnant women, older Australians and Aboriginal and Torres Strait Islanders. These act as credible sources of information for the Australian public which underpin actions taken to prevent incontinence. In recognition of this, it is vital to utilise such resources to deliver and develop tailored actions for target groups as part of the proposed national health literacy strategy.

Furthermore, the Foundation has developed independent, evidence-based resources for on-the-job support, ongoing training and professional development in continence care including a continence screening and assessment tool to assess the continence status of older Australians, an online pocket guide, learning units

and webinars which may be utilised to support the health literacy of the workforce and subsequently, consumers.

Research and evaluation

The Foundation is encouraged by the following policy aims suggested in the Strategy:

- The development, testing and evaluation of preventive health interventions in Australia are enhanced.
- Partnerships with those that are affected, drive the development, implementation and evaluation of interventions.
- National guidelines are developed to ensure high-quality evaluation is a key part of preventive health policy and program development and implementation.

Ongoing work with the National Ageing Research Institute to develop a Model of Continence Care (MoCC) that is evidence-based and best practice is one example of the Foundation's work in this area. The MoCC, which includes a specific preventative care plan, has been informed by industry experts, in-depth research and will be tested in local settings and is expected to be scaled up nationally. It is hoped that the 'national guidelines to ensure high-quality evaluation' will inform the independent governance mechanism proposed in the 'Leadership, governance and funding' to ensure consistent examination of evidence is facilitated and trust developed in the mechanism.

Monitoring and surveillance

A national prevention monitoring and reporting framework should be utilised by all levels of government. This should include continence-specific prevention monitoring indicators such as the number of times a residential aged care consumer is assisted to toilet as opposed to the number of times they experience incontinence.

FOCUS AREAS

9 Do you agree with the seven focus areas? Please explain your selection. (1000 word limit)

Agree

Focus Areas Text:

The Foundation agrees with the inclusion of the seven focus areas included in the Strategy although a greater focus on incontinence as both a risk factor and as a focus area is warranted. It is important to note that incontinence should be acknowledged in the Strategy as an associated risk factor for both tobacco use and being overweight or obese:

- Both current and ex-smoking women have significantly higher overactive bladder symptoms compared to non-smokers (Kawahara et al, 2020).
- Young to middle-aged women who are overweight or obese have a 35% or 95% increase in risk of urinary incontinence respectively compared to women who were not (Lamerton et al, 2018).

Greater detail will be provided on the Foundation's specific position on the focus areas in the following two questions

10 Do you agree with the targets for the focus areas? (1000 word limit)

Agree

Focus Areas - Targets Text:

Increasing physical activity

On increasing physical activity, the Foundation believes it is essential to outline an increase in the prescription of pelvic floor exercises for women during pregnancy and postpartum as an additional target. A Cochrane systematic review stated that women randomised to pelvic floor muscle training groups prenatally are 62% less likely to report urinary incontinence in late pregnancy and 29% less likely to report it three to six months postpartum compared to control groups (Woodley et al, 2020) highlighting its effectiveness.

Protecting mental health

The Foundation recognises that mental health is a key aspect of health and wellbeing that must be protected and supports the proposed target towards zero suicides for all Australians.

11 Do you agree with the policy achievements for the focus areas? (1000 word limit)

Agree

Focus Areas - Policy Achievements Text:

Increasing physical activity

In line with the information provided in the previous question, the Foundation believes pelvic floor exercises should be introduced as a first line of prevention of incontinence as part of the proposed national policy document on physical activity action. This would target all groups considered to be at risk of incontinence including older people, women during and after pregnancy, culturally and linguistically diverse communities, people living with mental illness and/or disability.

Cancer

While the Foundation supports the inclusion of screening for a number of cancers including bowel cancer as targets in the Strategy, there is a need to understand and address the different risk factors related to cancer. For instance, a Danish study found that within one year of diagnosis of faecal incontinence, the relative incidence for any cancer and bowel cancer was 1.32 and 2.31 respectively compared to the general population (Adelborg et al, 2019).

The Strategy should promote greater education of both urinary and faecal incontinence as key risk factors of cancer for health care providers and consumers through targeted health promotion programs.

Protecting mental health

The relationship between incontinence and mental health is not well understood or acknowledged within the wider health and mental health sectors. An Australian study found a significantly higher rate of depressive disorders in people with urinary incontinence (21%) compared to those without (14%) (Avery et al, 2013). Likewise, a review of global studies found people with incontinence had a 6 to 43% likelihood of comorbid depression (Avery et al, 2016). While depression and incontinence both reduce quality of life independently, when they occur together, there appears to be an additive effect on both physical and mental health.

Incontinence is stigmatised, affects quality of life and may lead to withdrawal from activities like exercise and work (Garcia et al, 2005; Avery et al, 2013). The shame and embarrassment of revealing their incontinence prevents people from seeking help and advice (Horrocks et al, 2004). In light of this, a National Stigma Reduction Strategy should be developed and designed to reduce stigma towards people with mental illness and accompanying stigmatised conditions like incontinence.

The Strategy should also work towards improving coordination and integration between health services and other supports which involves nurse continence specialists and pelvic floor physiotherapists specialising in continence care. It has already been highlighted that health professionals and care workers who provide direct care often lack appropriate training in continence care which can translate to poorer care. However, a Hong Kong study found that a continence nurse-led care programme for people with lower urinary tract symptoms (LUTS) resulted in significantly lower LUTS severity and higher health-related quality of life compared to the usual medical care group. The usual care group experienced significantly higher mental health deterioration but the intervention group did not experience any, highlighting the mental health protective effect of specialist continence care (Chin et al, 2016). From the perspective of consumers and carers, input from continence specialists into mental health should be integrated into service provision as necessary.

CONTINUING STRONG FOUNDATIONS

12 Do you agree with this section of the Strategy? Please explain your selection. (1000 word limit)

Agree

Continuing Strong Foundations Text:

The Foundation believes that the most effective prevention strategies will involve all relevant governments, non-government organisations and communities in partnership. It should be reiterated that the Foundation is the national peak body representing all Australians experiencing incontinence, their carers and health professionals in the sector. It has a strong capacity to utilise its health professional membership base, a high level of expertise in incontinence prevention and continence care across a range of sectors such as health, disability and mental health. It is with these in mind that the Foundation can support and lead the efforts to address incontinence prevention across the lifespan of Australians.

The Foundation also welcomes the opportunity to consult and review the National Preventive Health Strategy focus areas to be responsive and adaptable to the health issues landscape. While the inclusion of 'kidney/urinary' as a disease group is well received, a 'bowel/faecal' focus area should also be included as it is being overlooked despite affecting 1.3 million Australians (Deloitte, 2011) with many more at risk. Addressing this oversight will ensure the Strategy will be truly responsive and adaptable to the bladder and bowel health issues so prevalent in the Australian population.

FEEDBACK

13 Please provide any additional comments you have on the draft Strategy. (No word limit)

Comments Text:

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