

Submission to the *Primary Health Reform Steering Group draft* recommendations consultation

July 2021

Background

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the *Primary Health Reform Steering Group Draft Recommendations* to the Australian Government to guide the development of the Primary Health Care 10 Year Plan.

The Continence Foundation of Australia is the peak body for promoting continence (bladder and bowel control) health. The expertise of the Foundation in education, awareness, information and advocacy alongside representation in each state and territory means that we are best placed to represent the interests of individuals, carers and health professionals in relation to continence and primary health care.

The Foundation acknowledges the progressive stance of the Primary Health Reform Steering Group with the discussion paper including proposals for the introduction of Rural Area Community Controlled Health Organisations (RACCHOs) and aligning implementation of the Primary Health Care 10 Year Plan with the National Preventive Health Strategy and the National Agreement for Mental Health and Suicide Prevention.

The reforms listed will deliver significant changes across the primary health care landscape in Australia. However, the Foundation is concerned they will not deliver the systemic change required for improved prevention and management of incontinence. Adequate knowledge and support from primary health workers, targeted funding and appropriate education and training must underpin the proposed changes in order to transform to the intended value-based health system. This is of particular concern for stigmatised health conditions such as incontinence which have been

neglected, ignored and chronically underfunded in the past, and which may be sidelined again without additional supports.

Incontinence currently affects one in four Australian adults¹, is frequently a chronic condition that would benefit from a Chronic Disease Management (CDM) plan and is recognised as a disability under the Disability Discrimination Act 1992. In 2010, 4.6 million Australians aged 15 and over experienced incontinence but this is projected to grow rapidly to 6.2 million by 2030 representing a 35% increase in prevalence.¹ Crucially for such a hidden health condition, there are no predisposing personal or socioeconomic characteristics that define a person living with incontinence:

- Over half of women and more than one in three men living in the community with incontinence are under 50 years of age.¹
- One in three Australians with a disability currently experience incontinence.²
- 75-81% of residential aged care consumers experience incontinence, with most at higher severity levels.³
- People with other chronic conditions⁴ including cancer, diabetes, asthma, heart/cardiovascular disease and constipation are all at higher risk of incontinence.^{2,5}

The Foundation advocates for capacity building supports for primary care health workers, including GPs, nurses and allied health professionals, to be able to appropriately screen, identify, support and make referrals for people experiencing symptoms such as urgency, frequency, constipation and nocturia as well as urinary and faecal incontinence. This should be supported with:

- Continence education as a mandatory requirement for all primary health care professionals who provide care and treatment to people at risk of or experiencing incontinence, noting that due to multiple risk factors, most of the population is at risk at some stage of their life.
- All staff and health professionals working in primary care, including Aboriginal and Torres Strait Islander Health Workers (ATSIHWs) should receive education about safe and effective continence-related care in respective VET and undergraduate courses.
- On-the-job support, training and professional development that is unbiased, evidence-based and best practice should be included in the workplace to enable primary care workers to remain competent and current in safe and effective continence-related care.

The Foundation recommends that improved prevention and management of incontinence is both a goal and measured outcome of the Primary Health Care 10 Year Plan.

We have addressed selected areas of improvement through the lens of the Quadruple Aim:

Patient experience

Experience of incontinence can mean that appropriate care is never requested in primary care let alone received, diminishing the patient experience. Incontinence is stigmatised, affects mental health and quality of life and may lead to withdrawal from social contact, physical activity and work.⁶⁻⁷ Talking about incontinence can be difficult, but sensitive inquiry from a health professional can help. 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.⁸ Two other Australian studies reiterate this, finding 70% of people with urinary incontinence do not seek advice and treatment for their problem.⁹⁻¹⁰ Faecal incontinence is even less likely to be raised as an issue by either patient or health professional.

These barriers to care are likely compounded for people from culturally and linguistically diverse backgrounds facing multiple other barriers, including difficulty navigating the health system, lack of access to interpreters, costs of care and prior experiences of unprofessional behaviour and/or adverse events during health care encounters.¹¹. A primary health care system which can sensitively elicit requests for care for conditions such as incontinence must be a goal of reform.

Evidence suggests that incontinence is not a high priority in primary care despite the impact it has on individuals, families and the Australian population. A Canadian survey of GPs found 26% reporting that improving the treatment and management of incontinence was a fairly low or low priority while 33% stated improving incontinence care to be a low or very low priority for their organisation.¹² This is unsurprising as primary health care professionals and people working with populations at high risk of incontinence, including doctors, nurses, midwives and personal care workers have all been shown to be unlikely to be adequately prepared in their education and/or training to provide safe and effective continence-related care.¹³⁻¹⁷ This disengagement in primary care provision means continence-related care is often neglected to the detriment of consumers and carers.

The Foundation recommends the patient experience of continence care in primary care is measured through the following additions to the ABS National Health Care Survey:

- Adding incontinence to the list of long-term health conditions
- Adding 'I was embarrassed' to the response options for the question: What were all the reasons you did not see a health professional for your physical health?

Population health

Population health care and services, when influenced by consumer choice can be effective and drive person-centred care. A UK study on young people aged 12-18 years with spina bifida found that telehealth for continence management support by a Nurse Continence Specialist facilitated greater self-confidence, was an effective means to engage young people in self-care activities and assert their role as partners in care planning as compared to face to face consultations.¹⁸ Community-driven solutions can also deliver much needed care. In 2019, Eurobodalla Shire Council in NSW passed a resolution that Southern NSW Local Health District (SNSWLHD) re-employ a nurse continence specialist after assessing the risk of incontinence to their population as being much higher than the national and state average.¹⁹ This community-led initiative was part of a wider campaign to understand the issues and concerns of people living with incontinence and delivered services based on need. Employing just one nurse continence specialist can significantly increase access to improved prevention and management of incontinence across a regional population at risk of poor outcomes.

Population health outcomes are also improved through evidence-based screening of people at higher risk of incontinence. The Royal Australian College of General Practitioners (RACGP) 'Red book' identifies higher risk populations including: Prenatal and postnatal women; women who have had children; women who are overweight; women reporting constipation; people with respiratory conditions, diabetes, stroke, heart conditions, recent surgery, neurological disorders; and frail older people or long-term care residents.²⁰ This list excludes some at risk populations such as men with prostate problems and would benefit from updating.

Assessment of incontinence using a valid, reliable and responsive tool is essential. Incontinence is a sensitive issue and using an internationally validated tool like the International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form (ICIQ-UI SF)[©] enables people to

discuss and describe their incontinence with a primary health care provider utilising four questions. The Foundation supports use of this and other internationally recognised tools (including the ICIQ-B© for faecal incontinence) to obtain a summary of the level, impact and perceived cause of symptoms of incontinence and to facilitate patient-clinician discussions.²¹⁻²⁴

A research project using the ICIQ-UI SF[©] in all health assessments for Indigenous women aged 18 years and over is currently being conducted by the Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care (Personal communication from Dr P Lakhan, July 20 2021). Anecdotally, using the tool in assessment for all patients aged 15 years and above has helped identify more patients with urinary incontinence, highlighting its benefits.

A combination of consumer and community-led reporting of health measures, alongside the introduction of screening tools, clinical guidelines and care pathways, and a national minimum data set that includes continence-related data, can act as a comprehensive foundation from which to respond to and support population primary health care needs. The Foundation would be happy to consult with the Australian Government to leverage its expertise on continence-related issues and how to better integrate it within the primary health care sector.

The Foundation recommends introduction of routine screening for urinary incontinence in primary care using the International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form[©] and screening for faecal incontinence in at-risk consumers.

Cost efficiency

Inadequate continence care and incontinence management can lead to substantial but unnecessary health system costs. A Victorian study of potentially avoidable hospitalisation found that the cost of care episodes for constipation at emergency departments totalled \$8.3 million.²⁵ It found there were 3978 episodes of care in 2010-11, which is a 31% increase in episodes of care from 2005-06. Urinary incontinence has also been associated with a significantly greater risk in falls, longer periods of hospitalisation and higher mortality rates in older people receiving home care services.²⁶⁻²⁷ These examples highlight the growing continence needs of the population and are indicative of the need to provide appropriate primary health care earlier to reduce costs. In total, the burden of disease for incontinence was estimated to cost \$23.8 billion in 2010 which is associated with 140,108 Disability Adjusted Life Years¹ though this is expected to be much higher now. The overall burden on the primary health care sector therefore is already considerable and without effective solutions will continue to put pressure on consumers and health workers alike.

The Foundation recommends measures of improved primary care efficiency include reductions in preventable hospital admissions due to unidentified risk factors or injury resulting from untreated continence health symptoms.

Work life of health care providers

Appropriate support for primary health care professionals is also necessary and will provide indispensable assistance to consumers. A survey by the Foundation of Australian GPs found a concerning proportion believed incontinence is a normal part of ageing and that all children who experience bedwetting will be continent by age ten.²⁸ Neither of these are supported by evidence but GPs holding such beliefs are unlikely to appropriately screen, identify and refer individuals with incontinence to ensure better care. As a result, both younger and older people will miss opportunities for benefit from GP prevention and treatment interventions. Despite this, it is welcome news that 84% of GPs would value more information and education on incontinence.²⁸ The

Foundation offers a number of appropriate continence resources suitable for health workers across a range of roles. For example, of GPs who had engaged with the Foundation's National Continence Helpline, more than 60% were very or extremely satisfied with the experience, highlighting how access to phone consultation with a Nurse Continence Specialist provides opportunities to improve worklife satisfaction through providing timely, appropriate care for consumers.

Greater provider collaboration and teamwork will lead to greater empowerment and worklife of primary care providers. The introduction of a NCS as part of a multidisciplinary home care service made major positive impacts on both consumers and teamwork.²⁹ Not only did this result in better quality of life and effective management of incontinence for consumers but health professionals who worked with the NCS said they played a strong role in referrals, case management participation and outcome focused care planning. A high level of interdisciplinary collaboration and teamwork was identified between the NCS and the rest of the team including community nurses, allied health and medical practitioners.²⁹ Developing and adopting similar models of care which can be scaled up effectively to support a collaborative team environment can result in greater competency and the ability to provide holistic care.

The Foundation recommends team-based models of care which recognise the skills and expertise of continence specialists in primary care and support development of continence care specialisation for GPs, nurses and allied health professionals, particularly those with an interest in women's and men's health, pelvic floor health and care of older people.

Conclusion

Primary health reform must be comprehensive and systemic to be able to cater to all consumers and providers adequately. A lack of integration with key health issues of concern, including incontinence, will not lead to the all-inclusive health system and more holistic care that is envisaged. The Foundation believes that greater collaborative consultation efforts need to be made so that primary care health workers, including GPs, can act as a cornerstone of support and appropriate referral to consumers seeking health care.

Please do not hesitate to contact me at <u>r.cockerell@continence.org.au</u> to discuss these recommendations or any other matter related to improved continence care.

Yours sincerely

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