Submission to the *Australia Primary Health Care Plan 2022-2032* consultation

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Background

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the Australian Government Department of Health's *Australia's Primary Health Care Plan 2022-2032* consultation.

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 in outer metropolitan, rural, and regional areas.

Please provide your response to the listed actions under reform stream 1: Future-focused health care – Action area A: Support safe, quality telehealth and virtual health care.

The Continence Foundation of Australia (the Foundation) supports the incorporation of patient reported outcomes (PROMS) and patient reported experience measures (PREMS) to improve delivery of primary health care overall including telehealth and virtual care. Both PROMS and PREMS must be widened to capture highly prevalent but under-reported experiences of conditions such as incontinence. Incontinence can be stigmatising, affect mental health and quality of life and lead to withdrawal from social contact, physical activity and work.[1,2] Several Australian studies have found that 70% of individuals do not seek help from health professionals for urinary incontinence[3,4] and this is even more likely for faecal incontinence. Given that 1 in 4 Australian adults experience incontinence[5] and its impact, the provision of quality health care for this condition necessitates the introduction of routine screening for urinary incontinence in primary care. Screening for urinary and faecal incontinence in at-risk consumers should be undertaken with fully validated international standard screening questionnaires: International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form© (ICIQ-SF) and International Consultation on Incontinence Questionnaire Anal Incontinence© (ICIQ-B) included in PROMS facilitated health questionnaires. Consumers should be supported, through PREMS, to articulate and be engaged in achieving their health care objectives, with referred access to qualified continence professionals as required. Given the significant impact of hidden, stigmatised and unglamorous conditions like incontinence, utilising PROMS and PREMS to prompt for and identify these conditions will facilitate better health outcomes for individuals and better prevent and manage longer term health care needs.

The Foundation supports the integration of clinically appropriate, quality telehealth and virtual health care into primary care. Telehealth for continence issues has been shown to be effective in management, assessment and follow up care of incontinence.[6-8] For many people experiencing incontinence, it is a reliable option for effective primary care interventions.

Please provide your response to the listed actions under reform stream 1: Future-focused health care – Action area B: Improve quality and value through data-driven insights and digital interaction.

Data recording at the primary care level and person held digital devices (and other) information accessible to other health care providers will improve people's experience of care and deliver cost-efficiencies to the health system. An Australian study of consumers in a hospital setting (mean age 70 years) found 35% of those with bladder problems and 46% of those with bowel problems prior to admission had no documentation of these health issues. Further, 57% and 62% of those who experienced urinary and faecal incontinence respectively during hospitalisation had no documentation in their progress notes.[9] Poor record keeping contributes to suboptimal continence-related health care and higher continence-related health complications. This adds to costs borne by consumers without an adequate health system response.

The Foundation supports the development of a minimum primary care national data set, inclusive of continence-related indicators, to facilitate policy and practitioner awareness and responses to issues and trends efficiently and effectively. These can be used to improve service quality, referrals for continence care and adjustments to improve health outcomes and cost efficiency.

Expanding the Distribution Priority Area (DPA) criteria to include a range of primary healthcare professionals as well would provide a mechanism for distributing specialist staff including Nurse Continence Specialists (NCS) and Pelvic Floor Physiotherapists to meet currently unmet needs in rural and remote areas. UK studies have found that there is approximately one Nurse Continence Specialist (NCS) per 2,500 people with faecal incontinence and one per 8400 people with urinary incontinence[10,11] with Australia likely to have similarly high ratios. In addition, the expansion of the DPA to include the workforce required to address specific and prevalent conditions, particularly those which are perceived as stigmatised and hidden such as incontinence would promote the workforce capabilities required to implement proactive care.

Please provide your response to the listed actions under reform stream 1: Future-focused health care – Action area C: Harness advances in health care technologies and precision medicine.

While advances in health care technologies should be taken advantage of to deliver well-resourced and efficient health care, the Foundation considers there are significant knowledge gaps among GPs about existing health needs. One Australian study found that 79% of GPs self-rated their knowledge of faecal incontinence as poor or very poor.[12] This is despite 1.3 million people in Australia experiencing faecal incontinence[5] leaving a large demographic without access to contemporary, effective and quality primary health care. Introduction of adequate continence content into foundational and professional education and training for general practitioners would improve access to appropriate health care for people with incontinence.

The Foundation supports the action item to engage peak organisations, professional colleges and bodies and educational institutions in developing resources for service providers but is concerned that this is the only mention of engagement with such bodies in the discussion paper. These bodies represent both consumer and professional interests. The Primary Health Care Plan 2022-2032 (the Plan) should emphasise the importance of engagement and consultation with these bodies in every area. Engaging with peak bodies to ensure evidence-based practices informed by industry expertise,

including health peak bodies such as the Foundation, is congruent with government intentions to develop a holistic primary health care system that supports contemporary, effective and quality health care for all.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area A: Incentivise person-centred care through funding reform, using VPR as a platform.

The Foundation supports the provision of funding incentives to ensure patient-centred evidence-based care is delivered as usual care for people with chronic or complex conditions. Virtual Patient Registration should ensure that funding supports provision of evidence based continuing patient-centred care for chronic or complex conditions such as incontinence. This should include a Chronic Disease Management (CDM) plan. Currently, incontinence is not recognised as a chronic condition despite the often-long-term nature of the condition. One in four Australian adults experience incontinence[5] and recent results from a Nationally Representative Consumer Survey show that of people who have current or previous experience of incontinence, 85% have experienced it for 6 months or more.[13] This means that most people who have ever experienced incontinence have experienced it as a chronic condition. Recognition of incontinence as a chronic disease will lead to better health professional support, case management and experience of care for consumers. Incontinence is also a key indicator of individual frailty for older people. A systematic review found that urinary incontinence is twice as likely in frail people compared to those without.[14] Considering this is a common co-morbidity, funding support via VPR for ongoing, evidence based and person-centred care for this condition would enhance health status and management of factors leading to increased frailty. As stated previously, the Foundation recommends the introduction of routine screening for urinary incontinence in primary care using the ICIQ-SF© and screening for faecal incontinence in at-risk consumers to be introduced using the ICIQ-B© or via PROMS facilitated health questionnaires. Screening will enable provision of appropriate care through a CDM plan and appropriate funding incentives for that care.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area B: Boost multidisciplinary team-based care.

A multidisciplinary approach to health care should be embedded within the overarching frameworks and strategies being implemented at all levels of Government. The Plan must be cognisant of, and actively engage with, other national strategies including the Stronger Rural Health Strategy, the Educating the Nurse of the Future report and the National Stigma and Discrimination Reduction Strategy. The Educating the Nurse of the Future report's call for Enrolled and Registered Nurses to be introduced to the basics of continence care[15] is one key recommendation which will facilitate higher quality multidisciplinary continence care across the primary health sector. The National Women's Health Strategy's includes as a key success measure the de-stigmatisation of urinary and faecal incontinence and improved access for women to specialist continence care[16]. This should be expanded to include access for both men and women, across the life course, to multidisciplinary continence health care.

Specialist roles, such as NCSs and Pelvic Floor Physiotherapists, within multidisciplinary teams are necessary to address shortfalls in primary health care. However, several factors are hindering adequate workforce development for a sustainable primary health sector including cutbacks, downgrading of positions, lack of funding related to NCS roles[17] and limited opportunities to be supported in upskilling to become a NCS. This is despite evidence to show the introduction of a NCS as part of a multidisciplinary home care service makes significant positive impacts on team outputs and interventions.[18] Health professionals have reported having had a high level of interdisciplinary collaboration with NCS who also played a strong role in referrals, case conference participation and

outcome focused care planning.[18] Utilising existing models of multidisciplinary care such as this will lead to better coordinated supports that are person-centred and available for scaling up nationally.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area C: Close the Gap through a strong community controlled sector.

Incontinence in Aboriginal and Torres Strait Islander communities is an under-reported, under-served and under-researched health condition despite being of high incidence and impact. Studies have shown between 23 and 54% of Aboriginal and Torres Strait Islander people experience incontinence.[19,20] Incontinence within indigenous communities is significantly associated with dementia, stroke, head injury, falls, depressive symptoms, epilepsy and poor mobility.[20-22] Its impact is also clear. Forty percent of Indigenous Australians experiencing incontinence reported incontinence incidents at least daily, 32% reported soiled clothes or bed clothing and 20% indicated it impacted on their everyday activities at least some of the time.[20] Health care services should be augmented to provide culturally appropriate health care including effective screening, assessment and treatment of incontinence to enable better quality of life and care to improve the health of indigenous populations.

Significant efforts are required when implementing relevant strategies involving Aboriginal and Torres Strait Islander workforces. One study assessing the knowledge of 100 Indigenous health services found 22% believed there was no incontinence within their community while 52% did not provide continence services.[23] Lack of awareness of supports and resources was also clear as 87% were not aware of state and federal funding schemes for incontinence products and 88% did not know of any Aboriginal and Torres Strait Islander continence resources and had not heard of the National Continence Helpline (NCHL)[23], an Australia-wide no-cost telephone information, advice and support service staffed by Nurse Continence Specialists who also provide a wide range of continence-related resources and referrals to local services.

Considering Aboriginal and Torres Strait Islander health workers are vital to the delivery of health interventions in their communities, they must be empowered to address continence health in culturally appropriate ways.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area D: Improve access to primary health care in rural areas.

Access to primary health care in rural areas can be greatly strengthened by the introduction of Rural Area Community Controlled Health Organisations (RACCHOs) in rural and remote regions. Similar to ACCHOs, the establishment of RACCHOs for rural and remote communities would enable better orientation and responsive health care services to communities with specific needs not being addressed by the current primary health care system. They would also facilitate recruitment and support of relevant primary health care clinicians including NCSs and Pelvic Floor Physiotherapists located in locally-led organisations informed by population health needs data. This would ensure that there is capacity to distribute services and resources fairly, according to the needs presented. Broadening access to specialist health professionals will ensure that that there are better health outcomes in under-served communities.

Similarly, governments at all levels, especially those in rural areas, should be encouraged to develop their own solutions to address community needs and disadvantages. In 2019, Eurobodalla Shire Council in rural NSW passed a resolution to re-employ a NCS after assessing the risk of incontinence to their population as being much higher than the national and state average.[24] This 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 NCS can significantly increase access to improved prevention and management of incontinence across a regional population at risk of poor

outcomes.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area E: Improve access to appropriate care for people at risk of poorer outcomes.

The Foundation appreciates the intent behind establishing nationally networked centres of excellence for information and referral for primary care service provision to demographics at risk of poorer outcomes. However, we urge that care should be taken not to reinvent the wheel. Effort must be made to use existing resources and expertise. To illustrate this point, as a health peak body, the Foundation develops information resources for all people living with incontinence including people in the CALD community and people who live with disability. With appropriate support from the Australian Government, the Foundation could build upon existing expertise and resources, which include a significant online presence and develop existing partnerships with relevant primary care practices to become a nationally networked centre of excellence. Recognition and expansion of this existing resource capability would efficiently and effectively expand access to high quality information on continence needs and care including for people at risk of poorer outcomes.

Please provide your response to the listed actions under reform stream 2: Person-centred primary health care, supported by funding reform – Action area F: Empower people to stay healthy and manage their own health care.

The Foundation endorses the commitment that primary care should empower people to stay healthy and manage their own health care. This must include a focus on the start to life, with emphasis on continence health during pregnancy and postpartum and for people who live with multiple co-morbidities that include incontinence. Empowering parents to recognise the need for toilet training readiness is a key measure that must be implemented to avoid negative social and health consequences. Delayed toilet training for children has been shown to lead to significantly higher risk of urinary incontinence and urinary tract infections which are independently associated with a lower ability to manage homework and normal daily hygiene.[25] Empowering and supporting women to engage in pelvic floor exercises during pregnancy and postpartum is also necessary. 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[26] highlighting its effectiveness. Better self-management of continence health should be facilitated for people living with multiple chronic conditions including incontinence. Current evidence points to the significantly higher likelihood of incontinence for people with chronic conditions such as cancer and diabetes[27] and likely lower health outcomes.

Targeted interventions to address these needs include education for primary health care professionals through the NCHL. A survey of GPs who had engaged with the Foundation's NCHL found more than 60% were very or extremely satisfied with the experience[28], highlighting how access to a NCS provides opportunities to improve for health professionals to acquire knowledge and skills to recognise, treat and support people at risk of or living with incontinence through timely support for self-care and self-management of incontinence across the life-cycle.

Please provide your response to the listed actions under reform stream 3: Integrated care, locally delivered – Action area A: Joint planning and collaborative commissioning.

The Foundation agrees that joint jurisdiction-wide planning of primary health care services is a pre-requisite for person-centred, quality, coordinated and efficient primary health care. The development of shared and linked data to underpin this planning should include input from relevant peak bodies such as the Foundation to ensure the inclusion of indicators on prevalent, hidden and stigmatised conditions such as incontinence. There are no predisposing personal or socioeconomic characteristics that distinguish a person living with incontinence:

- Over half of women and more than one in three men with incontinence are under 50 years of age.[5]
- One in three people in Australia with a disability have incontinence.[27]
- 75-81% of residential aged care consumers experience incontinence, with most at higher severity levels.[29]
- People with other chronic conditions[30] including cancer, diabetes, asthma, heart/cardiovascular disease and constipation are all at higher risk of incontinence.[27,31]
- People with incontinence have a 6 to 43% likelihood of comorbid depression.[32]

Given these high rates of incidence and the impact of incontinence on health and quality of life, continence-related risk indicators and measures should be incorporated in joint planning and collaborative commissioning for primary care services especially for:

- Mental health stepped care pathways
- Dementia care pathways
- Rural primary and community health care services
- Complex chronic condition pathways, including hospital avoidance and outreach approaches.

For joint planning and commissioning to deliver on the objectives of the Plan for people living with or at-risk of incontinence, the following are essential:

- Population health needs at local level to address under-reported and diagnosed conditions
- Effective resourcing of local continence health services as an integrated service within primary care
- Development of evidence-based care pathways emphasising early risk assessment with stepped levels of intervention and support
- Active engagement of individuals in management and treatment of incontinence
- Diverse approaches to care delivery, including electronic and telecommunication.
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Please provide your response to the listed actions under reform stream 3: Integrated care, locally delivered – Action area B: Research and evaluation to scale up what works.

The Foundation advocates for the implementation of a baseline evaluation framework to help conduct major evaluations of the plan's effectiveness over the next ten years. The inclusion of a specific priority in relation to both urinary and faecal incontinence, will ensure that people who experience it will be better supported by related translational research into primary care and health system innovation on continence-related care.

The research and evaluation aspects of the plan must be pivoted towards enhancing communication, and thereby strengthening partnerships, between relevant stakeholders. However, the relevant stakeholders listed in the action items should include health peak bodies such as the Foundation. Robust communication, facilitated by the Foundation, with all relevant stakeholders including policy-makers, professional bodies and health service commissioners can then lead to coordinated operations that support the development of an independent, contemporary and evidence-based research agenda. This can then be utilised to help operationalise and facilitate the transformation of current primary care practices and deliver better health outcomes.

The Plan should also take advantage of existing best practice innovations to monitor and report on primary health and continence-related care. The Foundation has developed a Best Practice Model of Continence Care (MoCC) in residential aged care facilities informed by the best available evidence from scientific literature, consultation with industry and clinical experts, staff and residents and is currently being piloted in local settings. Against a background of growing interest and concern about how to address the perceived gaps between research evidence and decision making at a practice and policy level in health care, this is a key instrument that can not only address continence-related

care for consumers in residential aged care but provide a sound basis for extrapolating an evaluation framework and dataset to inform primary health service, practice and care provision.

Please provide your response to the listed actions under reform stream 3: Integrated care, locally delivered – Action area B: Cross-sectoral leadership.

The Foundation strongly endorses the Primary Health Care Plan commitment to cross-sectoral leadership. The Foundation's member organisations and health professionals are well positioned to contribute to that. The Foundation's existing expertise and strong relationships with stakeholders in the sector can be leveraged to support the development of sustainable continence care through commissioning arrangements and the education and training of health professionals who are central to the delivery of primary health diagnosis, treatment and care for incontinence and continence health. In particular, there is an established need for contemporary, evidence-based and effective cross-sectoral information provision and service development of an adequately trained and resourced continence health workforce, with clearly identified need for education and training in continence health and chronic care for general practitioners and other primary care health professionals.

The existing primary care workforce is underprepared to deliver the continence-related care required by the 4.2 and 1.3 million Australians who experience urinary and faecal incontinence respectively.[5] The primary care workforce, including personal care workers, nurses, midwives and doctors are all unlikely to have had an appropriate level of continence training and education.[33] Additionally, GPs who are often the first point of contact[13,27] rate themselves as having low levels of training in continence-related care. An Australian study found 43% of GPs received a moderate or higher level of training or education in urinary incontinence but only a lowly 9% for faecal incontinence.[12] Additionally, 56% self-reported insufficient skills to address faecal incontinence highlighting large gaps in proficiency for both types of incontinence.

Cross-sectoral planning and commissioning needs to address these issues.

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