Continence Foundation of Australia

Submission to the *Inquiry into the provision of GP and related primary health services to outer metropolitan, rural, and regional Australians* consultation.

September 2021

Background

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the Senate Community Affairs Reference Committee *Inquiry into the provision of GP and related primary health services to outer metropolitan, rural, and regional Australians*.

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.

Recommendations in brief:

The Foundation makes the following recommendations to enable essential continence-related issues in outer metropolitan, rural and regional areas to be adequately addressed:

- The expansion of DPAs to be informed by a national minimum dataset inclusive of continence-related issues and expansion to include relevant health professionals including Nurse Continence Specialists and Pelvic Floor Physiotherapists.
- The introduction of RACCHOs to develop adaptable, person-centred service provision to enable better healthcare, including for continence-related care, and reduce barriers to services.
- All primary and health care professionals should receive education and training about evidence-based, contemporary and effective continence-related care.
- Fellowship and continuing professional development education and training for GPs in relation to continence-related issues be required, including education and training in contemporary evidence-based prevention, safe and effective management, treatment and referral options.
- Development of a national minimum data set, inclusive of continence-related measures, to enable efficient and effective policy and practitioner responses.

- Greater support in terms of educational opportunities, funding and workforce planning for much needed primary health care roles including Nurse Continence Specialists.

Incontinence affects one in four Australian adults[1], 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 identify or distinguish 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]
- People with incontinence have a 6 to 43% likelihood of comorbid depression.[3]
- People with chronic conditions[4] including cancer, diabetes, asthma, heart/cardiovascular disease and constipation are all at higher risk of incontinence.[2,5]

The Foundation considers that the following education and training recommendations are necessary quality enhancements to enable essential primary health care continence-related issues for individuals in outer metropolitan, rural and regional Australia to be adequately addressed:

- All staff and health professionals working in primary care, including Aboriginal and Torres Strait Islander Health Workers (ATSIHWs), should receive education about evidence-based, contemporary 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 evidence-based, contemporary and effective continence-related care.
- Development of a minimum national data set, in consultation with the Foundation, inclusive of continence-related issues in outer metropolitan, rural and regional Australia to facilitate appropriate policy and practitioner awareness and policy and practice responses to issues and trends efficiently and effectively.

Note: There are different types of incontinence and many differing causes. In primary care, effective continence-related care means assessing the incontinence, the underlying bladder or bowel dysfunctions and contributing factors and addressing and treating these initially with conservative management.

We have addressed selected areas of the Terms of Reference outlined below:

(a) the current state of outer metropolitan, rural, and regional GPs and related services;

Primary health care services and consumers in outer metropolitan, rural and regional Australia are not adequately supported to address continence-related issues. While GPs remain at the centre of the existing primary health care model, the Foundation believes that inherent barriers exist in ensuring safe and effective continence-related care is delivered. For consumers, incontinence can be stigmatising, affect mental health, quality of life and may lead to withdrawal from social contact, physical activity and work[6-7] making it difficult to raise the topic with health professionals. Several Australian studies have found that roughly 70% of individuals do not seek advice or treatment from

health professionals for urinary incontinence[8-9], even if they are sitting in a GP waiting room.[10] Faecal incontinence is even less likely to be raised as an issue by either consumer or health professional. These barriers to care are likely compounded for people from culturally and linguistically diverse backgrounds facing multiple other barriers, including cultural differences, difficulty navigating the health system, lack of access to interpreters, costs of care and prior experiences of adverse events during health care encounters.[11] De-stigmatisation of incontinence should be addressed at a national level across all community groups, genders and age groups to enable better care access.

Even if the topic is raised, general practitioners have been shown to have suboptimal preparation to address incontinence. Despite 4.2 and 1.3 million Australians experiencing urinary and faecal incontinence respectively[1], the self-reported knowledge and skills of general practitioners can be inadequate. 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. Additionally, 56% self-reported insufficient skills to address faecal incontinence[12] highlighting large gaps in proficiency for both types of incontinence. The reason for the wide gap between readiness to address urinary compared to faecal incontinence may be due to limitations found in existing educational resources such as the RACGP *Guidelines for Preventive Activities in General Practice* which includes an entire section on urinary incontinence but makes no reference to faecal incontinence at all.[13] Without additional funding and reviews of education and training for GPs, it is not likely they will be able to deliver evidence-based, contemporary and effective continence-related care.

Given this deficit, improved access to specialist primary care services for people with incontinence, particularly in rural and remote areas is warranted. The Foundation's National Continence Helpline, staffed by qualified Nurse Continence Specialists (NCS), provides a significant avenue in advice for health professionals and consumers around Australia on assessment, care, management, treatment and referral to continence services. The Foundation can play a significant role in coordination of primary health services, including continence services, to facilitate better consumer health and primary health service provision.

The Foundation recommends that fellowship and continuing professional development education and training for GPs in relation to continence-related issues be required, including education and training in contemporary evidence-based prevention, quality, safe and effective management and treatment and referral options such as the National Continence Helpline.

(b) current state and former Government reforms to outer metropolitan, rural and regional GP services and their impact on GPs, including policies such as:

(i) the stronger Rural Health Strategy,

The Stronger Rural Health Strategy (the Strategy) must be broadened further to facilitate significant positive impacts on the lives of outer metropolitan, rural and regionally located consumers with continence health needs. The delivery of high-quality continence care requires a focus on the multi-disciplinary primary care workforce. International evidence suggests that the best-performing healthcare services are locally responsive and led by motivated individuals with specific interests and skills. Initial assessment and treatment are optimally delivered by a dedicated, local nurse-led continence service, situated either in the community or adjacent to a specialist clinic.[14] Review and enhancements of primary health workforce roles, capabilities and development must take into account the high level of population wide need for continence-related recognition, treatment and care. Currently, 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 inadequately prepared in their education and/or training to provide quality and effective continence-related care.[15-19] This lack of awareness and engagement in a pervasive and debilitating health issue in primary care provision means continence-related care is remarkable and reflects the lack of education and training on this issue.

To address this care gap, the Foundation propose the introduction of Rural Area Community Controlled Health Organisations (RACCHOs) to coordinate multidisciplinary primary health care in rural and remote regions. With rural areas having a higher burden of disease, lower life expectancies, lower bulk billing rates compared to major cities and a $4 billion rural health deficit[20], innovative solutions such as a single centre for service coordination can form the basis for better health outcomes.

Aboriginal Community Controlled Health Organisations (ACCHOs), on which we base our recommendation, were established to redress the inadequacy of mainstream health services in delivering for the health needs of Aboriginal people[21] and have shown the capacity to reorientate primary health services from acute reactive care to a comprehensive and proactive approach[22]. Further, ACCHOs provide culturally safe health care in addition to addressing structural determinants of health including racism, housing, income insecurity and employment[23] thereby delivering person-centred care. ACCHOs have achieved coverage of more than 60% of the Aboriginal population outside major metropolitan areas, consistent improvement in best-practice indicator performance and show superior performance to mainstream general practice.[24]

Similar to ACCHOs, the establishment of RACCHOs for outer metropolitan, rural and remote communities would enable better orientation and primary 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 primary health care clinicians and other health professionals to communities that are currently adversely impacted by low workforce capacity, and could be provided with targeted support to deliver coordinated and comprehensive health services, including continence-related care.

Locally led and tailored solutions for communities with particular needs and disadvantages are effective. In 2019, Eurobodalla Shire Council in NSW passed a resolution to 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.[25] 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 Nurse Continence Specialist can significantly increase access to improved prevention and management of incontinence across a regional population at risk of poor outcomes.

A combination of community-led place-based care services, 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 outer metropolitan, rural and regional 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 supports the implementation of RACCHOs to develop adaptable, person-centred service provision to enable better healthcare, including for continence-related care, and reduce structural barriers for consumers and health professionals.

(ii) Distribution Priority Area and the Modified Monash Model (MMM) geographical classification system,

The Distribution Priority Area (DPA) classification is currently only applicable to general practitioners and needs to be expanded to enable the delivery of an adequate level of responsive health workforce capacity including allied health services. To achieve this, the DPA criterion needs to be expanded beyond gender, age and socioeconomic status to include specific and prevalent conditions, particularly those which are perceived as unglamorous and stigmatised, including incontinence. These conditions are poorly served nationally and in locations with clinical workforce shortages, people with incontinence needs are doubly disadvantaged. Expanding the scope of the DPA system to ensure that primary and community health services in outer metropolitan, rural and regional areas are adequately staffed with a multidisciplinary range of health professionals will enable more appropriate responses to the assessed needs of local communities. The wide prevalence of incontinence, across all age groups, requires interventions aimed at prevention, treatment and management from generalists supported by specialists including Nurse Continence Specialists and Pelvic Floor Physiotherapists. The outputs from expanded DPA indicators will provide granular information about a range of health needs which are currently not well understood. These data will enable local services, such as RACCHOs to develop and target their approaches to respond strategically to these local needs.

The Foundation recommends DPAs be expanded to include and be informed by a national minimum data set identifying prevalent health conditions and health risks within communities, including incontinence and be expanded to include relevant health workforce requirements based on these indicators, including Nurse Continence Specialists and Pelvic Floor Physiotherapists.

(d) any other related matters impacting outer metropolitan, rural, and regional access to quality health services

An overemphasis on general practitioners will not translate into the care required for many consumers, including people experiencing incontinence. GPs have been shown to lack skills and knowledge in incontinence and continence health which can further inhibit consumers from discussing it. Specialist roles including NCSs and Pelvic Floor Physiotherapists are necessary to address such shortfalls in primary health care. However, cutbacks, downgrading of positions, lack of funding related to NCS roles[26] and limited opportunities to be exposed to and supported in upskilling in a NCS are hindering workforce development to ensure a sustainable primary health sector, including in rural and remote regions. This is despite evidence to show the introduction of a NCS as part of a multidisciplinary home care service makes significant positive impacts on both consumers and teamwork.[27] Not only did consumers experiencing incontinence and their carers report better quality of life, education, effective management of incontinence and better access and choice in continence products, health professionals said they had a high level of interdisciplinary collaboration and team work between the NCS and the rest of the team including community nurses, allied health practitioners and medical practitioners. Greater support in terms of opportunities, funding, education and training to facilitate Nurse Continence Specialist development will result in better coordinated primary health care and health outcomes for consumers.

The Foundation recommends that there be greater support, in terms of educational opportunities, funding, and inclusion in future workforce planning, for much needed primary health care roles, including Nurse Continence Specialists, to enable sustainable and comprehensive primary health care reform in outer metropolitan, rural and regional areas.

Conclusion

Primary health care for Australians living in outer metropolitan, rural and regional areas must be rapidly improved to meet community needs and improve the capacity of all relevant health care providers for these communities. Continence-related care is an essential health requirement that should not be ignored or overlooked at any stage of life or anywhere in Australia. Access to high quality primary and community continence health services should not be a post code lottery. The Foundation believes that focused strategic action is required urgently to address this longstanding geographical inequity in access to supportive health care.

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

Yours sincerely

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Chief Executive Officer

References:

1. Deloitte Access Economics. The economic impact of incontinence in Australia. The Continence Foundation of Australia; 2011.
2. Continence Foundation of Australia (CFA). Nationally Representative Consumer Survey 2020. Continence Foundation of Australia Internal report. Unpublished.
3. Avery, JC, & Stocks, N. Urinary incontinence, depression and psychological factors-A review of population studies. European Medical Journal Urology 2016;1(1): 58–67.
4. Jacob L, López-Sánchez GF, Oh H, Shin JI, Grabovac I, Soysal P, Ilie PC, Veronese N, Koyanagi A, Smith L. Association of multimorbidity with higher levels of urinary incontinence: a cross-sectional study of 23089 individuals aged ≥15 years residing in Spain. British Journal of General Practice. 2021; 71(702): e71-e77.
5. Vollebregt PF, Wiklendt L, Dinning PG, Knowles CH, Scott SM. Coexistent faecal incontinence and constipation: a cross-sectional study of 4027 adults undergoing specialist assessment. EClinicalMedicine. 2020;27:100572.
6. Garcia JA, Crocker J, Wyman JF. Breaking the cycle of stigmatization: managing the stigma of incontinence in social interactions. Journal of Wound Ostomy & Continence Nursing. 2005 Jan 1;32(1):38-52.
7. Avery JC, Stocks NP, Duggan P, Braunack-Mayer AJ, Taylor AW, Goldney RD, MacLennan AH. Identifying the quality of life effects of urinary incontinence with depression in an Australian population. BMC urology. 2013 Dec;13(1):11.
8. Avery JC, Gill TK, Taylor AW, Stocks NP. Urinary incontinence: severity, perceptions and population prevalence in Australian women. Australian and New Zealand Continence Journal. 2014;20(1):7-13.
9. Millard R. The prevalence of urinary incontinence in Australia. Aust. Continence Journal. 1998;4:92-99.
10. Byles J, Chiarelli P, Hacker A, Bruin C. Help seeking for urinary incontinence: a survey of those attending GP waiting rooms. Australian and New Zealand Continence Journal. 2003;9(1):8-13.
11. Harrison R, Walton M, Chitkara U, Manias E, Chauhan A, Latanik M, Leone D. Beyond translation: engaging with culturally and linguistically diverse consumers. Health Expectations. 2020;23(1):159-168.
12. Ng KS, Soares DS, Koneru S, Manocha R, Gladman MA. Knowledge, skills, and barriers to management of faecal incontinence in Australian primary care: a cross-sectional study. BJGP Open. 2021;5(3):1-10.

13. The Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice. 9th edn. East Melbourne, Victoria: RACGP; 2016.
14. Wagg, A.S., Newman, D.K., Leichsenring, K. and van Houten, P., 2014. Developing an internationally-applicable service specification for continence care: systematic review, evidence synthesis and expert consensus. *PloS one*, *9*(8), p.e104129
15. Australian Government. CHC33015 – Certificate III in Individual Support (Release 2). 2015. Available from: https://training.gov.au/Training/Details/CHC33015 [Accessed 2019 December 12].
16. Australian Government. HLT54115 - Diploma of Nursing (Release 1). 2015. Available from: https://training.gov.au/Training/Details/HLT54115 [Accessed 2019 December 12].
17. Australian Government. HLT64115 – Advanced Diploma of Nursing (Release 1). 2015. Available from: https://training.gov.au/Training/Details/HLT64115 [Accessed 2019 December 12].
18. Paterson J. Consultation, consensus and commitment to guidelines for inclusion of continence into undergraduate nursing and midwifery curricula. Final report submitted to The Commonwealth Department of Health and Ageing; 2006.
19. Royal Commission into Aged Care Quality and Safety. Transcript of proceedings (11 July 2019). 2019. Available from: https://agedcare.royalcommission.gov.au/sites/default/files/2019-12/transcript-11-july-2019.pdf [Accessed 2021 July 19].
20. National Rural Health Alliance. A new model of care: Rural Area Community Controlled Health Organisations. 2021. Available from: https://www.ruralhealth.org.au/sites/default/files/Infographic-proposal-for-better-health-care-a4v2.pdf [Accessed 2021 September 21].
21. National Aboriginal Community Controlled Health Organisation (NACCHO). NACCHO submission to the Inquiry into Human Services: Identifying sectors for reform. 2016. Available from: https://www.pc.gov.au/__data/assets/pdf_file/0007/204964/sub227-human-services-identifying-reform.pdf [Accessed 2021 September 29]
22. Reeve C, Humphreys J, Wakerman J, Carter M, Carroll V, Reeve D. Strengthening primary health care: achieving health gains in a remote region of Australia. Medical Journal of Australia. 2015;202(9):483-487.
23. Pearson O, Schwartzkopff K, Dawson A, Hagger C, Karagi A, Davy C, Brown A, Braunack-Mayer A. Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia. BMC Public Health. 2020;20(1):1-13.
24. Panaretto KS, Wenitong M, Button S, Ring IT. Aboriginal community controlled health services: leading the way in primary care. Medical Journal of Australia. 2014; 200(11):649-652.Eurobodalla Shire Council. Ordinary meeting of council minutes 10 December 2019. 2019. Available from: Minutes of Ordinary Meeting - 10 00 2019 (nsw.gov.au) [Accessed 2021 July 19]
25. Eurobodalla Shire Council. Ordinary meeting of council minutes 10 December 2019. 2019. Available from: Minutes of Ordinary Meeting - 10 00 2019 (nsw.gov.au) [Accessed 2021 July 19]
26. Thompson J. Professional profile and workforce issues of nurse continence specialists in Australia. Australian and New Zealand Continence Journal. 2019;25(2):45-49.
27. Allen J, Fabri AM. An evaluation of a community aged care nurse practitioner service. Journal of Clinical Nursing. 2005; 14(1):1202-1209.