Submission to the General Practice Data and Electronic Clinical Decision Support consultation

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Rowan Cockerell, CEO, Continence Foundation of Australia
r.cockerell@continence.org.au

Summary

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the *General Practice Data and Electronic Clinical Decision Support* consultation by the Australian Government Department of Health.

The Foundation 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 recognises the need to implement adequate support systems including for Electronic Clinical Decision Support (eCDS) to enable optimal outcomes for primary health care professionals and consumers. Despite most healthcare interactions for people experiencing incontinence being in primary care, evidence suggests that it is not a high priority[1], not often raised as an issue[2,3] and that a much higher level of support, training and education for health professionals is required to enable optimal continence care.[4-7] eCDS systems, developed for Australian primary care settings, can help facilitate better decision making, service delivery, identify key health issues and inform service and system planning thereby addressing inherent gaps in the system and the needs of people experiencing incontinence.

Incontinence currently affects one in four Australian adults[8], is often a chronic condition[9] and is recognised as a disability under the Disability Discrimination Act 1992. Despite its prevalence and impact, there are no predisposing personal or socioeconomic characteristics that define a person living with incontinence. Combined with an ongoing stigmatisation and often neglect of the condition by both health professionals and consumers alike, incontinence becomes a 'hidden' condition that is not effectively addressed nationally. Early detection can lead to a greater opportunity for evidence-based, contemporary and effective treatment and management.

The Foundation advocates for the need to implement eCDS systems that support the identification, investigation and management of highly prevalent yet stigmatised conditions such as incontinence in

order to better assist and facilitate an optimal health system and service provision. The Foundation calls for the following recommendations to be implemented as part of this consultation:

- Incorporating continence-specific indicators into general practice data, including history taking, diagnosis, treatment, health outcomes and how the issue was raised, and recording them in eCDS systems.
- Inclusion of alerts for continence-specific assessments and post-prostate cancer treatment in eCDS systems when one or more related risk factors are recorded in primary care.
- Developing appropriate continence-specific indicators in consultation with relevant stakeholders, and with consideration of existing clinical indicators, for inclusion into eCDS systems.
- Continence-specific assessments and plans of care should be included in eCDS systems when one or more related risk factors are recorded in primary health care.

The eCDS should support a holistic level of primary care service provision

Electronic Clinical Decision Support systems can help guide, facilitate and deliver contemporary, evidence-based and effective continence care within the primary care sector. eCDS systems are critically important in this respect because they can lead to systemic reform and drive positive changes in terms of privacy and consent, recording relevant data, highlighting trends in health conditions including for incontinence, care outcomes and need for education and training with the primary care workforce.

eCDS-related privacy concerns must be addressed appropriately

Raising the issue of incontinence can be a challenge for consumers. Incontinence can be stigmatising, affect mental health and quality of life and lead to withdrawal from social contact, physical activity and work.[10,11] Even broaching the issue of incontinence can be difficult. Several Australian studies have found that 70% of individuals do not seek help from health professionals for urinary incontinence[2,3] and this is even more likely for faecal incontinence.

Privacy for all consumers of publicly funded services is essential and privacy for people with incontinence is often deeply personal and important. As pointed out by the Productivity Commission report on *Data Availability and Use* (2017), an eCDS system should be developed in a way that is cognisant of the risks of identification where information linkages occur.[12] Risk of identification increases with each separate piece of data being linked to an individual and steps should be taken to reduce the chance of genuine harm coming to the individual and subsequent emotional and mental impact. Steps to be taken include providing clarity on how information is used, shared, secured and provide a clear understanding of what is being consented to. This will lead to a more sensitive and consumer-centric health care system which can facilitate trust and transparency leading to higher quality data and insight into the primary care sector.

Electronic clinical decision support systems that are cognisant of the deeply personal nature of stigmatising conditions such as incontinence should be developed to ensure consumer control, understanding and privacy is given utmost attention so that the risk of genuine harm is greatly reduced. Consumers should be able to give consent to sharing of their data with clear understanding of what it will be used for.

eCDS indicators must facilitate person-centred care

The Foundation holds that eCDS systems should be inclusive of continence-specific indicators to support benchmarking and quality improvements in primary care services. Data that does not capture highly prevalent conditions such as incontinence may exacerbate the gap between need and service provision. As stated previously, one in four Australian adults experience incontinence[8]; however, three recent Nationally Representative Consumer Surveys have each found that one in three Australian adults experience incontinence currently[9,13,14] which indicates a much higher proportion of people affected by incontinence and therefore needing care. Given that experience of urinary and/or faecal incontinence is significantly more likely to result in a reported lower quality of life[15,16], this translates to significantly more interactions with primary care services unlikely to be experienced or qualified. This highlights the increasingly urgent need to improve data collection to enable person-centred care at a population level through eCDS systems. eCDS systems inclusive of appropriate continence-specific indicators can provide prevalence and incidence estimates, health services evaluations, outcomes research and economic analyses which can provide a robust basis for change[17] in primary care practice.

Incontinence and follow-ups for post-prostate cancer treatment are considered a low priority in primary care practice. A survey of Canadian GPs found 26% of respondents 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.[1] This can translate in poor identification and resulting continence care practice. In a local context, a survey by the Foundation of Australian GPs found a concerning proportion believe incontinence is a normal part of ageing and that all children who experience bedwetting will be continent by age ten[18] which is not supported by evidence. Anecdotal evidence suggests that doctors do not follow up consistently with men following prostate cancer treatment, which often results in incontinence[19-22], leaving many to find their own support networks. Anecdotal evidence also indicates that alerts should be built into the system for Prostate Specific Antigen tests if the individual is on active surveillance as 25% of affected men are not attending their follow-ups.

Primary health care staff, including general practitioners, nurses, midwives and allied health professionals, have all been shown to be unlikely to be adequately prepared in their education and/or training to provide effective continence care.[4-7] eCDS systems developed to prompt primary health professionals to enquire, address and monitor relevant health outcomes, including continence-specific measures, can lead to better measures for accountability and care management.

In line with this, the Foundation recommends inclusion of alerts for continence-specific and post-prostate cancer treatment enquiries and assessments when one or more risk related factors are recorded in primary care settings.

With only a few continence-specific indicators existing as part of guidelines addressing urinary and faecal incontinence in the primary care sector, there is still considerable work to be done to ensure they are routinely reported as part of the Primary Health Network, the Australian Institute for Health and Welfare or other datasets. The following guidelines on continence-related issues provide an indication of relevant measures that can be utilised to better understand continence care in primary care eCDS systems:

- The Royal Australian College of General Practitioners (RACGP) *Red book* focuses on urinary incontinence for the general population and includes indicators related to history taking, diagnosis and treatment (including referral).[23]
- The RACGP *Silver book* focuses on urinary and faecal incontinence-specific indicators for older Australians including on reviewing medication and ruling out potentially reversible factors in addition to those mentioned in the *Red book*.[24]
- The Royal Children's Hospital Melbourne *Urinary Incontinence – Daytime wetting* guidelines promote measures related to history taking, diagnosis and treatment.[25]

- HealthDirect, a public facing health promotion website, provides information for self-assessment, treatment options and self-management tips.[26]
- The National Institute for Health and Care Excellence (NICE) guidelines on *Urinary incontinence and pelvic organ prolapse in women: management* provide indicators on history taking, diagnosis, treatment and management.[27]
- The British Journal of Urinary Incontinence (BJUI) *Guideline of Guidelines: urinary incontinence in women* recommends history taking, indicators for specific types of urinary incontinence, associated characteristics and a stepwise treatment approach starting from conservative to more complex or invasive approaches.[28]

While the above indicators exist, no publicly available reporting exists which is inadequate and needs to be addressed.

The Foundation recommends for the BJUI indicators outlined above as the baseline set to be incorporated within the eCDS system, and also expanded to all demographics including by gender, age groups and for all types of incontinence (urinary and/or faecal). In addition to the key measures of history taking, diagnosis and treatment (including referral) as listed, health outcomes and whether the issue of incontinence was raised by the health professional or consumer should form the core continence-specific indicators in primary care settings in Australia.

The Foundation calls for the following recommendations to be implemented:

- **Incorporating continence-specific indicators into general practice data, including history taking, diagnosis, treatment, health outcomes and how the issue was raised, and recording them in eCDS systems.**
- **Inclusion of alerts for continence-specific assessments and post-prostate cancer treatment in eCDS systems when one or more related risk factors are recorded in primary care.**

eCDS early prevention, consultation and system planning responses for continence care

Inclusion of appropriate, evidence-based indicators will lead to an expansion in information and data collection reflective of Australian health priorities and facilitate better care practices. Specifically, this can lead to early identification and preventive actions for continence-related issues that might otherwise lead to worse outcomes. For example, incontinence compounded with unsafe and ineffective continence care in aged care can also result in urinary tract infections[29,30], pressure injuries[31,32], falls[33,34], avoidable emergency department admissions[35], function decline[36] and death.[37] A 2009 report found experience of faecal or urinary incontinence increased the risk of being recommended for residential care by 86% and 39% respectively.[38] Further, where continence-related health assessments such as completion of bowel cancer screening kits, or when a key risk-related factor is recorded like pregnancy, diabetes or obesity, eCDS systems should guide continence-related health enquiries and support early management and treatment processes. eCDS systems should capture a large volume of data so that accurate measurements of patient health outcomes and quality of general practice care are available and can be cross-analysed.[39] In so doing, it can lead to a transformation of primary care practice, assessments conducted, and offering of supports or referrals based on contemporary evidence.

Indicators that are not developed in accordance with appropriate expertise from relevant stakeholders stands to become ineffective and translate into added health and time costs. Current schemes such as the Medicare Benefits Scheme and the Pharmaceutical Benefits Scheme both provide good national coverage and high quality data but they often lack detail important for research such as prescribed dosage which is useful to underpin responsive and evidence-based care provision.[17,40] In line with this, introduction of continence-specific indicators should be developed in line with stakeholder feedback for inclusion that covers history taking, diagnosis, treatment, and health outcomes to enable holistic care provision to take place. This will enable time and cost efficiencies to be facilitated as well. The Foundation is in a key position to be able to facilitate these consultations due to its existing expertise and health professional and consumer stakeholder base.

High quality, longitudinal data can shape system reform that focuses on system planning, identifying and addressing gaps as well as promote health professional education and training. The eCDS system can highlight where incidence of continence-related issues are high and subsequently influence change targeted at addressing need. It can lead to analysis and transformation of history taking, diagnosis, treatment, and health outcomes in primary care. The Foundation can facilitate these at a national level through existing training and resources to address gaps in primary care practice, resources, training courses for primary health professionals and access to the National Continence Helpline. Expanding on this, these can be supported through funding, recruitment of qualified and experienced professionals such as Nurse Continence Specialists or lead to changes in existing foundational education, training and professional development courses so that continence care in the long-term can match level of need.

The Foundation makes the following recommendation to support robust development of eCDS systems:

- **Developing appropriate continence-specific indicators in consultation with relevant stakeholders and, with consideration of existing clinical indicators, for inclusion into eCDS systems**

Systematic reform has to be based on more than introduction of an eCDS

Electronic Clinical Decision Support systems form only one part of the primary care system that has to be addressed to in order to develop a holistic, person-centric approach. While it can support enquiry, diagnosis, facilitate treatment and health outcomes, there are still inherent gaps to be addressed across the primary care system. For instance, once incontinence is deemed a risk factor, assessment using a valid, reliable and responsive tool is essential. The Foundation supports the use of an internationally validated tool like the International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form (ICIQ-UI SF)© 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 in a sensitive manner.[41-44] These tools should be incorporated into eCDS systems to allow for efficient diagnosis and recording of in-depth and relevant data.

Further, to address the broader scope of the issue, key measures of success as outlined in national strategies must be implemented. The National Women's Health Strategy outlines an aim to establish specialist primary care services for incontinence and for the de-stigmatisation of incontinence alongside improved service access for women.[45] The Foundation advocates for the expansion of this key measure to include everyone affected by incontinence, across the life course, as part of this strategy. Furthermore, the inclusion of incontinence in the the National Stigma and Discrimination Reduction Strategy to ensure the potential harms from incontinence at a primary care and societal level are reduced is also necessary. Together, these can translate into national and local efficiencies that provide benefit in terms of health, cost and socioeconomic outcomes.

These considerations should be incorporated into any future development operation for eCDS systems so the primary care sector and eCDS systems form a mutually beneficial symbiosis for the betterment of primary care consumers.

The Foundation makes the following recommendations in light of this evidence:

- Continence-specific assessments and plans of care should be included in eCDS systems when one or more related risk factors are recorded in primary health care.

In consideration of the evidence outlined, the Foundation calls for the following recommendations to be implemented as part of this consultation:

- **Incorporating continence-specific indicators into general practice data, including history taking, diagnosis, treatment, health outcomes and how the issue was raised, and recording them in eCDS systems.**
- **Inclusion of alerts for continence-specific assessments and post-prostate cancer treatment in eCDS systems when one or more related risk factors are recorded in primary care.**
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