Continence Foundation of Australia

Aged Care Data Strategy Consultation

September 2022

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Introduction:

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the consultation on the development of the Aged Care Data Strategy being undertaken by the Australian Institute of Health and Welfare (AIHW) in conjunction with the Australian Department of Health and Aged Care.

The Foundation supports this development and sees it as an important step to ensuring people are at the centre of the aged care system and the services they receive. Importantly, we see this as an overdue opportunity to recognise the significant impact of incontinence on older Australians receiving care and support, and the benefits that can be gained from comprehensive data collection on its prevalence, management, treatment, research, and outcomes for consumers.

The Continence Foundation of Australia is the peak body for promoting continence (bladder and bowel control) health. The expertise of the Foundation is in education, awareness, advice information, advocacy, continence service provision, and more importantly, experience of putting people at the centre of program design, 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 disability.

The Foundation's Submission

In February 2022 AIHW released a discussion paper on future data needs in aged care. We endorse the Institute's view that:

Existing data are neither comprehensive nor able to answer many important questions relating to the aged care system. Current data about the aged care system are fragmented and lack common data definitions. As a result, these data do not enable a person-centred view of pathways and outcomes within aged care (as well as across health and other support systems) and there are notable data gaps (such as detailed information on workforce, regular assessment of care needs, quality of life and quality of care). The key recommendation arising from the Royal Commission was to put people at the centre of aged care. In the context of aged care data, this will require targeted actions for aged care data improvement to provide timely and comprehensive information that is responsive to the needs of the different participants and stakeholders in the aged care system.[1]

We also support the findings outlined in the AIHW's summary of responses to the issues paper:

Thematically, the largest gaps in the current data relate to information that goes to the experience of aged care – such as updated information on what care people need (beyond initial assessment), what care they receive (beyond broad program descriptor), from whom (workforce), how this care relates to their assessed needs, how people experience aged care and the outcomes and quality of their care.[2]

It is the Foundation's position that Current and contemporary data on incontinence and its management in residential aged care is lacking, with reports on the costs of managing incontinence in the aged care sector now a decade old. This is despite research on the impact of incontinence showing it has significant negative effect on the quality of life of older people, including physical and mental health.

We endorse the approach outlined for the Aged Care Data Strategy and seek urgent attention to the lack of data on incontinence to ensure improved quality of life, support and care for older people receiving aged care services.

The Vision, Purpose and Guiding Principles

The Foundation supports the approach outlined for the Aged Care Data Strategy, and the stated intention that the Strategy will better support:

- people to make informed choices about aged care
- services and providers to improve their provision of safe, high-quality, and dignified care.

In particular, we welcome that the Strategy will be underpinned by guiding principles, as suggested in the Information Paper for this consultation.

- **Putting older Australians at the centre of aged care**
  It is essential that all aspects of the reformed aged care system are committed to this principle, to achieve the vision outlined by the Aged Care Royal Commission.

  The Foundation supports the principle of putting older Australians at the centre of aged care and practices this approach in our continence work as demonstrated through our consumer involvement and clinical governance processes. We see people with incontinence as citizens with a voice and dignity, not as objects of care and treatment alone. We incorporate codesign as a principle in developing programmatic work with communities to address the community needs from their perspective.

  As noted in the issues paper by AIHW *Exploring future data and information needs for aged care*, we agree that from a person-centred view there are several limitations with how data is collected currently.[1] The Foundation recognises that a person-centric data design is much more complex and requires a conceptual and innovative approach. It is often focused on administrative and clinical management and does not have the provision for recording other needs of the person. The datasets must have provision to record the voice and the person's experience along the pathway. It must cater to recording the experience in terms of barriers, specific circumstances, prior experiences, personal risks such as the risk of homelessness or abuse, and circumstances that can impact their care and treatment. More significantly, capturing the perspective and outcomes the person wants to see in the pathway. These are often discussed during consultations but do not form part of data capture as datasets in the system and should form part of the minimum datasets.
- **Data that meets the needs of participants and stakeholders including consumers, providers (including aged care workers), governments and researchers**
  Data should serve all stakeholders, and not be a box-ticking process, to meet funding requirements or other obligations.

- **Safeguarding trust, privacy, and security**
  In line with putting older Australians at the centre of aged care, trust, privacy, and security is essential, for ethical purposes but also to foster confidence amongst older people, their carers, and the workforce, that their views and experiences will be confidential while contributing to improved outcomes.
- **Share data once, and use it often**
  In our submissions to the Royal Commission, the Foundation supported a standardised data collection program designed on the principle of 'collect once, use many times'. We are aware the Department of Health collects large amounts of aged care data and supports requirements for all data collected to be accessible, up-to-date, reliable, consistent, transparent and of high quality.
- **Data that supports evaluating the performance of the aged care system and supporting future improvements**
  Evaluating the performance requires ongoing monitoring of data against a set of indicators. A person-centric dataset must capture the outcomes and quality of life the individual and the community is looking for so these can form part of the indicators for outcomes focussed evaluations. The Foundation maintains that data should be for the purpose of improving the quality of services, evaluating support and care provided, and benchmarking best practice.
- **Leveraging existing data assets and capabilities**
  The Foundation also recommended in our submission to the Aged Care Royal Commission, that the aged care minimum dataset include continence data items and linkages to other data sets currently managed by the AIHW, such as the 2013 Incontinence Report, and by the Australian Bureau of Statistics, such as the Survey of Disability, Ageing and Carers.
- **Data that continually improves**
  The Foundation supports the notion that evaluation and monitoring of data collection processes, priorities and benefits should be undertaken on a continuous and planned basis.

The Continence Foundation of Australia endorses the guiding principles as outlined in the Information Paper and suggests their inclusion and application involve input from consumers, carers, advocacy organisations as a priority.

Given the significant impact of incontinence on the quality of life for older people in care, and the potential benefits to be gained from improving management, treatment and support for people experiencing incontinence, the Foundation suggests that addressing the lack of data on this issue will should be a priority under the Aged Care Data Strategy.

Areas for urgent attention

Incontinence continues to be largely unrecognised but significant health burden on older Australians and is a significant factor in admission to residential aged care. Previous Australian data has shown that incontinence is one of the top three critical factors in admission to residential aged care, particularly to receive high level care.[3] The most up to date publicly available data on condition related-risk factors influencing recommendations for admission into residential aged care found both urinary and faecal incontinence to be in the top four condition-related risk factors in influencing recommendations to residential care (39% and 86% increase in risk respectively) alongside confusion and dementia.[4]

Evidence shows that the prevalence of incontinence increases quickly with time spent in residential aged care. A study of people admitted for the first time to residential aged care

services in the United States found that the prevalence of urinary incontinence at two weeks was 37% but increased to 43.8% after one year.[5] A Swiss study found that the prevalence of urinary incontinence in women increased from 32% at admission to 42% at six months and 49% at 12 months.[6] For men, the prevalence increased from 45% at admission to 48% at six months and 57% at 12 months.6 Although no studies can be located for faecal incontinence, it is likely that the prevalence of faecal incontinence in residential aged care also increases over time. The impact that incontinence can have is significant as both urinary and faecal incontinence have been shown to be associated with lower quality of life including physical and mental health.[7,8]

In the Interim Report: Neglect released by the Royal Commission into Aged Care Quality and Safety, poor continence management was listed as one of the 'major quality and safety issues' in aged care.[9] The report also stated that: *It is shameful that such a list can be produced in 21st century Australia.*

In the last quarter of 2018/2019, formal complaints to the Aged Care Quality and Safety Commission showed that for residential aged care continence management ranked in the top five most common issues subject to complaint.[10]

Given the Aged Care Royal Commission has found many examples of substandard care, specifically for continence and incontinence needs[11] it is imperative that improvements are introduced urgently to address this area of care and support. Data collection on the incidence, management, treatment and outcomes for people experiencing incontinence will be important in achieving this.

Data Gaps

Current and contemporary data on incontinence and its management in residential aged care is lacking, with reports on the costs of managing incontinence in the aged care sector now a decade old.

There have been substantive changes within the residential aged care sector since reports on the costs of managing incontinence were published a decade ago, with multiple reviews, and reforms to regulation and standards of care being introduced. The past decade has also seen changes in public expectations about standards of care, including continence care, changes to the composition of the aged care workforce, and changes in the characteristics and health care requirements of residents living in aged care homes.

Whilst international research shows that incontinence has a significant impact on the needs of residents of aged care facilities, the lack of contemporary data prevents policymakers providing accurate projections on the cost estimates of incontinence within residential aged care.

Key Issues related to Incontinence:

- **Incontinence-Associated Dermatitis (IAD)**

The prevalence of IAD in nursing homes is between 3.1% – 6.5%.[12] The majority of this data is drawn from a US study. Faecal incontinence (FI) is the strongest predictor of IAD however this research is mainly around the physical impacts of IAD, and data is lacking on the psychosocial impacts of IAD on aged care residents' QoL.

The Foundation welcomes the inclusion of IAD in the National Aged Care Mandatory Quality Indicator Program from April 2023.

- **Falls**

Evidence suggests that there is a significant association between urinary incontinence (UI) and falls in older adults and the general population.[13] However, there is little research on the impact of incontinence on falls within residential aged care facilities. Like IAD, there are no known studies on the impact of incontinence related falls on the psychosocial wellbeing of aged care residents.

- **Functional decline**

Evidence on the impact of incontinence demonstrates that incontinence is associated with a decline in daily activities, however it is based on international data, and focuses on UI in women who reside in the community.[14]

- **Psychosocial impacts of incontinence:**

The psychosocial impact of incontinence is mainly focused on UI, again from international research. An American study found that residents with UI had a lower quality of life than those without.[15] Data on the psychosocial impacts of bowel symptoms, especially on aged care residents, is limited. However, one study found that faecal incontinence has a strong impact on quality of life, and that women with FI were particularly at risk of experiencing anxiety and depression.[7] There is also evidence to suggest that constipation may have adverse effects on quality of life, including physical functioning and mental health.[16]

- **Costs associated with managing incontinence:**

There is no national dataset on the prevalence of bladder and bowel symptoms or their management in residential aged care, and little is known about rates or consequences of incontinence in residential aged care homes. This affects the ability to evaluate the effectiveness of current approaches to prevent, reduce or manage incontinence.

There are no current and contemporary costing models for incontinence and its management in Australian residential aged care settings. The most recent costing estimates are at least a decade old. A 2013 AIHW report used data from 2008-2009 which estimated expenditure in residential aged care settings to be $1.3 billion.[17] Costs associated with constipation management in Australian residential aged care settings have not been previously modelled.

- **Cost drivers of incontinence in aged care settings:**

Data on staff costs, which relate to the amount of time spent by direct-care staff on continence management, is limited and outdated. The most recent (known) report on staffing costs is from 2006 and references studies that are now approximately 20 years old.[18]

Data on productivity loss is also lacking. The most recent data is from the Deloitte Access Economics report in 2010 and relates to the loss of earnings for informal carers of incontinence in the community. However, there is no data on the scale or costs of earnings lost for informal carers of residents in aged care homes.[18]

There is no current data on the burden of incontinence on residents in residential aged care homes.

Proposed Quality Indicators (QI)

The Continence Foundation supports the expansion of the National Aged Care Mandatory Quality Indicator Program to include more comprehensive indicators for the existing domains of pressure injuries, physical restraints as well as new domains of falls, and we welcome the introduction of IAD into the QIs from April 2023.

However, there is a need to specify the development of measurable QIs which will detect unsafe ineffective and undignified continence care. Indicators for quality continence care

should include measurements of the extent of UI and FI and be linked to QIs for pressure injury, falls, nutrition, physical restraint and polypharmacy.

The Foundation strongly recommends the following quality indicators also be incorporated into reporting:

- percent of residents with worsening urinary incontinence,
- percent of residents with worsening bowel incontinence and residents with faecal impaction on most recent assessment, in line with a recent University of Queensland report on quality benchmarking in aged care.[19]

Doing so would translate to transparent and measured performance supported by policies and processes that drive organisational improvement which can be communicated readily to the public.

Other impacts due to lack of data on incontinence:

- Data that does not capture highly prevalent conditions such as incontinence may exacerbate the gap between need and service provision.
- Lack of central electronic registry which results in inconsistent continence care.
- The lack of data on the increase in prevalence of incontinence in Australian residential aged care facilities (RACFs) means it is also difficult to determine the role that RACF practices play in the increased prevalence of UI and FI, and what is attributable to a natural decline in health.

Conclusion

The Foundation welcomes the development of an Aged Care Data Strategy, and we support the approach outlined for the Strategy. We see it as an important step in reforming the aged care system to have older people at its centre, and to ensure that data identifies and contributes to improvement in how people experience aged care and the outcomes and quality of their care.

Given the significant impact of incontinence on the quality of life for older people in care, and the potential benefits to be gained from improving management, treatment and support for people experiencing incontinence, the Foundation suggests that addressing the lack of data on this issue will should be a priority under the Aged Care Data Strategy.

We look forward to the next steps in the development of the Aged Care Data Strategy, and to working with the Government and providers on ensuring it achieves its vision and application of its principles.

References

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