

Dementia-Inclusive Communities Leadership Roundtable

OUTCOMES REPORT



About Standards Australia

Founded in 1922, Standards Australia is an independent, not-for-profit organisation, recognised by the Commonwealth Government as the peak non-government standards development body in Australia. It is charged by the Commonwealth Government to meet Australia's need for contemporary, internationally-aligned standards and related services. The work of Standards Australia enhances the nation's economic efficiency, international competitiveness and contributes to community demand for a safe and sustainable environment.

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Contact

If you have an interest or particular expertise in the subject of aging societies, Standards Australia would like to hear from you.

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This Report

This report outlines the discussion, outcomes and proposed next steps from the Dementia-Inclusive Communities Forum hosted by Standards Australia on 11 December 2018. It is intended to be used as a reference document following discussion on the day, to guide further engagement, and to help inform stakeholders of the future standards development opportunities for Australia and for any international participation in ISO/TC 314 Aging Societies and its work program around dementia-inclusive communities and aging workforces.

Introduction

As a result of increased life expectancy, 'aging societies' are emerging across the globe. And because of this change, countries are facing significant impacts on their national expenditure and challenges to their economic growth over the next few decades.

Australia is already seeing increased pressure on health and social services. It is expected that further impacts will be felt on medical and personal care needs, as well as challenging how we combat loneliness and isolation or sustain daily living tasks, financial management and personal security, through to how our citizens interface with increasing technology.

Today, we talk about people aging in the community. This not only requires functional inclusive communities, but an increase and diversity in primary care.

This societal change throws up challenges but also opportunities. It encourages us to identify how we can support people to effectively manage their own (or their family members') long term care, ensuring a high quality of life outside of institutionalised care.

It should spur us to move away from traditional models of support for our aged, and those with a disability, to look to more innovative and connected activities to drive change.

This is particularly important when, based on recent data:

- Nearly 3.7 million Australians (15% of the population) are aged 65 or over
- Half of population of older people have some degree of disability, even if three-quarters report good, very good or excellent health
- 1 in 3 older people were born in a non-English speaking country

Ensuring the support provided across the community also takes account of its cultural and linguistic diversity (CALD) is vital in providing people with the chance for a high quality of life as they age.

The proportion of older Australians participating in the labour force also more than doubled between 2000 and 2015 - from 6% to 13% - and this in itself poses different challenges for Australia and other international aging societies.

It is estimated that over 435,000 Australians are living with dementia and almost 1.5 million Australians (family members, friends and professional carers) are involved in their care. 300,000 of which are unpaid. In 2016, dementia became Australia's second leading cause of death and is estimated to cost Australia more than \$15 billion.

With more than 8.7 million Australians (or 22% of Australia's population) projected to be over the age of 65 by 2056, it's essential Australia face head on the challenges and the opportunities this shift represents.

Standards have a strong role to play as part of our 'enabling infrastructure' for this future.

(Australian Institute of Health & Welfare, Older Australia at a glance 2017)

Background

In July 2018, Australia became a participating member of the International Organisation Of Standardization (ISO) Standards Development Technical Committee ISO/TC 314 Ageing societies.

An Australian national Working Group (MB-009-11 Ageing workforce) was established to participate in the ISO/TC 314 Committee and promote the lifelong support and quality of life in aging populations.

Other topics such as universal design, accessibility, and technologies and systems for an aging society already have some level of standardisation and these have been developed by existing committees. There is, however, an opportunity to identify how these standards integrate and support whole communities – at a societal level, and not just the audiences they're currently developed for.

While the Committee has a broad scope, it has agreed on two priority areas:

1. ***Inclusive aging workforce***

- Provide generic guidance for an aging inclusive environment within the workforce. This would include recommendations to provide quality, meaningful work that empowers the workers of all ages to add value to an organisation.

2. ***Dementia inclusive communities***

- Provide a framework for dementia-inclusive communities, including principles and the considerations of inclusion, quality of life, built environments, special needs groups and stakeholder engagement. The aim is to promote further standards development and collaboration with service providers, standards developers and other interested parties.
- It is also expected at a later stage, the Committee will also give consideration to the development of standards to benefit other long term mental health conditions of a chronic or progressive nature.

In response to these developments, Standards Australia hosted a Dementia-Inclusive Communities Standards leadership roundtable on 11 December 2018. Attendees list is provided in Appendix A.

Roundtable Discussion

The leadership roundtable comprised of presentations from Standards Australia and guest speaker Anne Livingstone, Project Director, Global Community Resourcing. Ms Livingstone has also acted as Australia's representative for the dementia work stream at the first two meetings of ISO/TC 314.

These were followed by an open discussion facilitated by Catherine Dunkerley, Senior Stakeholder Engagement Manager at Standards Australia.

During the course of the roundtable, stakeholders shared their perspectives on dementia inclusive communities and aging societies in general. The following represents views expressed at the roundtable. They do not necessarily represent the collective views of all stakeholders active in this area.

Attendees voiced unanimous support for Australia's involvement in the development of standards around aging societies, particularly in relation to dementia-related activity. Standards are part of the solution that can support aging societies globally, providing a level of consistent guidance, developed through consensus that connects international communities.

Opportunities and considerations

- The Royal Commission into Aged Care Quality and Safety is to look at how Australia can best to deliver a range of aged care services including to those with disabilities; and to the increasing number of Australians living with dementia, paying particular attention to the importance of dementia care and its impact for the future of aged care services.

Establishing dementia-inclusive communities is an important way forward. This can be achieved by providing people living with dementia the communities they (and their carers) need; communities that are supportive of a high quality of life – one lived with meaning, purpose and value.

Attendees articulated that standards could help to provide organisations, businesses, community groups and individuals the information and tools to make the practical changes that will have a positive impact on these individuals and communities.

- There was broad agreement that while establishing 'dementia-inclusive' communities was a positive change, it was important where possible to ensure and support more 'human-friendly communities' that took account of universal design. This broader perspective would support dementia-inclusive communities but also take into account a larger range of community participants and support areas. It was agreed that any standards developed should recognise the importance and nuances of delivery through the engagement of indigenous, rural and remote communities.

Extensive discussion was had on the need to ensure any standards developed ensured cultural and linguistic diverse peoples and groups (CALD) along with broader multi-cultural considerations were core to the guidance provided.

- The concept of cognitive decline, and the trajectory from 'well-being' to 'diminished function' is considered to be an important inclusion in any future ISO/TC 314 dementia-related discussions and activity.
- Attendees also outlined the considerations of legal frameworks to support aging members of the community as essential to help sustain a level of 'daily living' activities and reduce elder abuse.

- All opportunities and considerations should be underpinned by the principle of ‘by the community for the community’. It was felt that ‘where communities are at the heart of decision making; where the ‘lived experiences’ of older members of the community were used to develop support mechanisms and feed back into the community; where local authorities, governments and/or commercial providers were not the main facilitators of change, then communities were more likely to be resilient and successful’.
- Consideration was given to the work Standards Australia had previously undertaken into the Silver Economy. The report ‘The Role of Standards and Innovation for Driving APEC’s Silver Economy’ was acknowledged and welcomed. It was unanimously agreed that further work could be done to update the mapping of all relevant aging societies’ standards (and other lower consensus publications) to the approved ISO/TC 314 agreed work program, not just to the ‘Silver Economy’ as previously undertaken.

Attendees also suggested that a gap analysis should be undertaken as part of the Stage Two of the APEC Silver Economy Program to map these to existing areas to domestic Policy. This would help Australia identify which areas of opportunity would be best suited to develop national standards, which could then be considered for international adoption.

- Economic sustainability of delivery across the state and federal health services – there is significant fragmentation and too many ‘silo views’ when seeking and receiving support for dementia. It is important that inclusive communities operate across the silos where all manner of support is easily identifiable and accessible.
- Within Australia it was recognised there is an opportunity to provide improved vocational and tertiary education on ‘Aging’ to ensure a future workforce with the understanding, skills and capabilities to deal with this growing area of the economy.

Leadership opportunities within ISO/TC 314

Attendees articulated the following areas as leadership opportunities for Australia within ISO/TC 314 due to our experience and expertise. These included:

- Mobilising communities – A range of stakeholders including Dementia Australia outlined their best practice examples but suggested these often weren't shared domestically, let alone internationally. Stakeholders will submit these examples to Anne Livingstone for submission to ISO/TC 314 for consideration/inclusion in its future work program.
- Place-making and place-makers – Driving critical infrastructure to ensure it is integrated and that those delivering it are engaged with and within the community. Transport for NSW provided an example regarding the positive impact of integrated transport.
- Aging in place - Balancing specialist care, mainstream health and community care, retirement communities and home care.
- Innovation in service provision and support – a number of case studies were discussed which referenced innovations not only in service provision but also in community building. These too will be detailed to Anne Livingstone for submission to ISO/TC 314 for consideration/inclusion in its future work program.

Examples included Home Fire Safety Check pilot (NSW) which helps identify the risk of community members at risk of 'falls'. This information is then used by support services to identify and provide additional areas of in-home support.

Beechworth, Kiama, Waverton as the positive and inclusive residential communities offered by Wintringham and Scalabrini.

Recommendations

The key recommendations from the leadership roundtable are outlined below. These have been captured to help inform the next steps progress.

- Establish a national Technical Committee to mirror ISO/TC 314 Ageing Societies.
- Australia should participate in the development of the new ISO standard 23623 - Ageing societies -- Framework for Dementia-inclusive communities to clarify and tighten the scope.
- Australia to be a leader and driving force in the development of standards that advance and support ageing societies, particularly the development of dementia inclusive communities.

Mirror committee representatives should ensure the committee considers the following themes within all ISO/TC 314 standards developed:

- Cognitive decline and functional ability capturing the trajectory from a person's well-being to diminished function
- Support of younger onset dementia, not only 'aged' activity
- Culturally and linguistically diverse peoples and groups (CALD)
- Guidance outlining activities should be driven 'by the community for the community'
- All Australian Standards projects relevant to ageing societies, where appropriate, should consider how the project supports 'inclusive communities'. This will ensure standards take a holistic account of ageing societies.

All relevant technical committees should consider the inclusion of a Universal Design facilitator to ensure the relevant technical skills are present within a Committee throughout the course of a project. The Victorian Government was given as a best practice example of UD facilitating with further information available online.

Participation is strongly encouraged by large employers and corporates who were invited but unable to attend the forum, along with federal and state-based health departments.

Appendix A – Forum Participants

Organisation
Australasian Association of Gerontology
Australian Academy of Technological Sciences and Engineering
Australian Aged Care Quality Commission
Centre for Universal Design Australia
Charles Sturt University
Fire and Rescue NSW
Consumers Federation of Australia
Dementia Australia
Department of Health (Australian Government)
Global Community Resourcing
Health Services Union
Medical Technology Association of Australia Ltd
Transport NSW
Samsung Australia
Sydney University, Centre for Rural Health

