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**SUBMISSION TO SINGLE
QUALITY FRAMEWORK DRAFT
OPTIONS FOR ASSESSING
PERFORMANCE AGAINST AGED
CARE QUALITY STANDARDS**

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EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide input on the Department of Health's Single Aged Care Quality Framework - Options for Assessing Performance against Aged Care Quality Standards.

Overall, we welcome the approach towards a streamlined assessment processes across Aged care. We are encouraged by the Draft Quality Standards that will cover a broad range of services from entry level basic home support services to end-of-life care, and are pleased to note the strong focus on consumer outcomes throughout the assessment options as well as the draft standards.

The regulatory and compliance framework that supports the implementation of the quality standards will play a crucial role in determining the effectiveness of the entire single quality framework. The new draft Standards will influence standardisation of practice and will drive aged care service delivery towards a higher level of care quality. However, there remains a risk the standards may not widely adopted due to the relatively low qualification levels of the aged care workforce, fewer peer-learning opportunities, and the lack of guidelines to respond to complex conditions such as Dementia.

We are pleased to note that regardless of which quality assessment option is adopted, it is proposed that any new arrangement would be more inclusive of consumers and that there will be a greater focus on seeking the views of consumers about whether they experience safe, quality care and services that are consistent with their needs and preferences. We also applaud the intention to have better availability of information about the outcomes of the assessment to all consumers.

COMMENTS ON FEATURES PROPOSED TO BE COMMON TO ALL OPTIONS

A single set of aged care standards

As noted in our submission the consultation on Single Aged Care Quality Framework - Draft Aged Care Quality Standards, overall we welcome the approach towards a single set of standards for aged care services to replace the multiple current standards. These standards will cover a broad range of services from entry level basic home support services to end-of-life care, and we are very encouraged to note the strong focus on consumer outcomes. Alzheimer's Australia also advocates the importance of ensuring strong consumer and carer involvement not only in the development of quality standards, but also in all of the processes relating to their implementation.

However, we do note the remarkable absence of cognitive decline or dementia across the draft standards. This is very concerning given that the number of older Australians with dementia is growing exponentially, and the core business of both residential and home-based aged care services increasingly includes providing care to people with dementia.

Alzheimer's Australia remains positive about achieving greater consumer choice and flexible services that will be available to consumers under the ongoing reforms, and as demonstrated through these draft standards. For people with dementia and their families and carers, these objectives are particularly important given the progressive nature of the condition which requires responsive and individually tailored solutions from service providers that will evolve over time to remain aligned with the individual's situation. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported.

Alzheimer's Australia urges the Department to consider and include issues relating to the safety and quality of care for people with dementia through these draft standards. As the prevalence of dementia increases in our community, it is critical that all considerations of quality in aged care, including standards and assessment, must be fully inclusive of issues relating to dementia.

A wider range of methods for assessing performance against the aged care standards and for monitoring ongoing performance

This is a welcome move, as it has the potential to reduce regulatory burden on service providers and lower administrative costs that are normally passed onto consumers. Encouragement of pro-active self-assessment and reporting is also welcome move.

The current Accreditation Standards against which residential aged care providers are assessed have been heavily criticised by consumers. From the consumer perspective, the accreditation process creates excessive red tape which limits staff time for care of residents and at the same time is not effective in focusing on outcomes for residents.¹

Consumers have expressed concerns about the notification of visits and have indicated a preference for regular unannounced visits to check quality of care. Alzheimer's Australia

¹ *Caring for Older Australians*. Report No. 53, Final

Rendina, N., Brodaty, H., Draper, B., Peisah, C., & Bruque, E. (2009). Substitute consent for nursing home residents prescribed psychotropic medication. *International Journal of Geriatric Psychiatry*, 24(3), 226-231.

recommends that the primary approach of accreditation should be shifted to unannounced visits rather than planned visits.

Alzheimer's Australia also recommends that 10% of consumers should be interviewed across both home and residential aged care. Right now quality reviewers are required to conduct interviews with service users but do not specify the percentage of service users to be interviewed.

Alzheimer's Australia also recommends that the reach of the Community Visitors Scheme in residential care should be increased, to include a role for volunteers in quality monitoring, possibly as part of the accreditation process² - as currently occurs in the health sector through accreditation processes including those conducted by the Australian Council on Healthcare Standards care quality and compliance processes.

Continued use of data and intelligence to inform proportionate, risk-based assessment and monitoring

In recent times, consumers and advocacy groups have voiced their concerns regarding the structure of the Scheme. These have included the Scheme's focus on dispute resolution rather than consumer rights.³ Consumers are often unsure about how the Scheme, the Agency and the role of the Compliance section of the Department.

Consumers have also raised the potential conflict of interest inherent in the current; at present, the Federal Government funds, creates policy and regulates the sector. This has resulted in questions regarding the reliability and effectiveness of the Scheme and the need for an independent watchdog to increase transparency and accountability.

Although consumers have the option to lodge a complaint confidentially, many consumers are still hesitant to contact the Scheme due to a fear of reprisal or retribution for complaining about an RAC provider. This has been reiterated by consumers and advocacy groups on multiple occasions and is considered to be the main barrier in lodging a complaint.

In addition many consumers may not be aware of the Scheme and its role. A benchmark survey conducted into awareness of the scheme and associated reforms was conducted from August to October 2011.⁴ The results revealed a high level of awareness of the Scheme amongst care managers and to a lesser extent care staff, however, only one in three care recipients and one in four friends or family members were aware of the Scheme.⁵

There are also concerns from consumers about adequate access to the Scheme for residents. In 2011-12 care recipients accounted for just 10.7 per cent of complaints to the Scheme with the majority coming from care provider staff, care recipients' representatives and family members. The majority of complaints made to the Scheme are done via telephone and private access to a telephone may be an issue for some residents at an RAC

² Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

³ Barnett, M. & Hayes, R. (2010). Not seen and not heard: protecting elder human rights in aged care. *University of Western Sydney Law Review*, 14. Retrieved from <http://www.questia.com/library/journal/1G1-262691573/not-seen-and-not-heard-protecting-elder-human-rights>

⁴ Australian National Audit Office. (2012). The Auditor General Audit Report No. 10 2012-13 Managing aged care complaints. Retrieved from <http://www.anao.gov.au/~media/Files/Auditper cent20Reports/2012per cent202013/Auditper cent20Reportper cent2010/Reportper cent20No10.pdf>

⁵ Ibid.

facility and for those consumers experiencing isolation, lodging a complaint through a willing staff member or volunteer visiting the facility may be their only option.

The responsiveness of the current system has also been called into question. The timeframes for resolution of complaints are variable and dependent upon the nature of the complaint, however, an average of 20 days for an early resolution and up to 3 months for complaints that require investigation have been reported. There are concerns that delays up to 3 months may mean that care recipients are receiving poor quality care until the matter can be resolved.⁶

Consumer Views on Complaint Scheme

“During my complaints process, my father and I have been continuously subjected to lies and unprofessional behaviours by the aged-care facility including verbal excuses for their behaviour that contradict the documented evidence (including emails) supplied to the Complaints Scheme. The Scheme has not commented on these lies and untruths. While I appreciate that the Scheme is constrained by legislation, it’s important that people in the community continue their battle to improve what I perceive to be a system that has failed our elderly and is in desperate need of change. Within about one month of lodging each of my complaints with the Aged Care Complaints Scheme my father has been forced to lie in his own faeces: three complaints and three times this has occurred.’ I have been shocked by the Aged Care Complaints Scheme’s failure to recognise breaches to the Residents’ Charter of Rights and Responsibilities.”

Alzheimer’s Australia therefore recommends that changes are concurrently made to the Complaint Scheme to ensure that complaints which relate to medications, use of restraint or assault are handled within three days to ensure the safety of residents. Further work should be done to increase awareness amongst consumers about the role of the Scheme.

Greater consumer involvement in the assessment process

Partnering with consumers is a critical element of ensuring safety and quality in healthcare. Aged care organisations need to develop partnerships with *all* consumers, including people with dementia and their carers.

Greater involvement of consumers in the assessment process therefore needs to be inclusive of carers in the case of people with dementia or other cognitive impairments. There is significant anecdotal evidence that improving communication with carers, as advocates for patients and as participants in care planning, has beneficial effects on patient experience and outcomes, and can contribute to quality care⁷.

Alzheimer’s Australia also recommends that the development of new criterion on health literacy and health information to support consumer involvement, which should aim to ensure everyone involved in the partnership can give, receive, interpret and act on information in an effective way.

⁶ Op. Cit. ANAO 2012

⁷ Alzheimer’s Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, pp 12-13.

Often people with dementia and their carers have difficulty navigating the aged care system and related health and care systems. Aged care organisations need to consider providing care co-ordinators or navigators – such as an advocate or social worker who has education and training to work with people with dementia – specifically to assist people with dementia and their carers. The quality assessment process should also address this need.

Alzheimer's Australia also recommends that the reach of the Community Visitors Scheme in residential care should be increased, to include a role for volunteers in quality monitoring, possibly as part of the accreditation process⁸ - as currently occurs in the health sector through accreditation processes including those conducted by the Australian Council on Healthcare Standards care quality and compliance processes.

Better information about the outcomes of the assessment

It has also been noted by consumers that the Accreditation process is a blunt instrument as the vast majority of RAC providers (nearly 95 per cent as of 30 June 2012) pass the accreditation process with no changes required. The Agency reports whether the facility met each of the expected outcomes but does not provide more nuanced information and this makes it difficult for consumers to ascertain whether the provider is delivering high quality care or just passing the minimum standards for accreditation.

Alzheimer's Australia recommends consideration of a more nuanced approach to Accreditation which would include whether a facility has met or exceeded the expected outcomes and may assist in the comparison across RAC facilities resulting in greater transparency in relation to quality for consumers.

We are very pleased to note from the consumer workshops on the subject that the Quality Agency is working with consumers, organisations and aged care specialists to develop and test a set of structured consumer interview questions for use as part of the site audit, which will be a standard feature across all options. Consumers have highlighted the need for similar information on all services on which to make informed decisions.

Complementary processes for dealing with complaints or non-compliance

A firm commitment should be made to develop and implement a consumer experience survey. While indicators can, and should be, chosen and promoted on the basis that they measure both clinical care and quality of life much more needs to be done to understand the consumer experience and views of the services they receive.

The National Safety and Quality Health Service (NSQHS) Standards provides an example on how this can be built into the draft standards. The focus in the NSQHS Standards on consumer involvement and data collection has led the states to release data on patient experiences surveys. For example, most states have publically available reports of patient experience data from specific patient groups and provides comparisons across hospitals.

It would be such a step forward in terms of transparency to have a national consumer experience survey of all Government funded aged care services which was released

⁸ Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

publically on an annual basis, and Alzheimer's Australia looks forward to working with the Aged Care Agency to progress work in this area.

COMMENTS ON THE THREE PROPOSED OPTIONS

In assessing the options, Alzheimer's Australia has made some comments against each option as below.

Option 1: Quality Assessment process based on care setting (based on status quo)

The Alzheimer's Australia Dementia Advisory Committee supports this Option. This is mainly due to the implicit recognition that residential care by its very nature is higher risk, and needs a distinct monitory and compliance framework to safeguard consumers. This would mean ongoing distinct processes that is accreditation, which would apply to organisations delivering residential care and short term restorative care in residential aged care settings, and quality reviews, which would apply to organisations delivering care in the home and community setting.

Option 2: Single risk-based assessment process applicable to all aged care settings

Alzheimer's Australia is supportive of this option as it provides the opportunity to scale the assessment to the individual organisation based on the services provided. Consultation sessions held by the Department indicate that risks assessment would take into consideration the impacts of any failure to the consumer.

For example an assessment would consider the scope and nature of services being delivered, such as whether the service is delivering clinical care, personal care or non-personal care, and the level of responsibility that the service has for the consumer, such as whether the service delivers 24 hour care or low frequency or low intensity care.

Consideration would also be given to the performance of the organisation and its services and its compliance history with the aged care standards and other aged care requirements, and whether the organisation has been accredited through other relevant schemes.

Alzheimer's Australia is broadly supportive of this approach, however we would like to ensure that unannounced calls to monitor compliance remain an integral part of assessing all services, irrespective of their risk profile.

Option 3: Safety and quality declaration by organisations providing low-risk services readily available to the broader population (can be combined with Option 1 or 2)

The third option outlined is aimed at organisations delivering low risk services that are available to the broader population, and would involve such organisations to complete a safety and quality declaration. This option could apply to services such as gardening services and community transport.

Alzheimer's Australia does not support this option, either on its own merits or in combination with Option 1 or 2. The main assumption that this option makes is that all consumers already have access to low risk, appropriate services. This is not true, especially for people with dementia and their carers, who often face many barriers in accessing mainstream services.

People with dementia will always need to be supported by mainstream services. However, it must be recognised that although dementia is a core part of aged care, it is not enough to rely on the provision of mainstream services to adequately provide for the needs of people with dementia. Instead there must be an approach that combines building capacity in mainstream services to provide quality care for people with dementia, along with the integration of specialist dementia services to support mainstream services where required.

CONCLUSION

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, quality care for people with dementia must be core business for the aged care system, including both home-based care and residential care. Assessment and Compliance of quality standards however will form the real crux of how effectively they can be adapted. We trust that the matters raised in this submission will be of assistance to the Department of Health in the further development of quality system for aged care that ensures the best outcomes for all consumers and carers.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information.

Alzheimer's Australia is a member of Alzheimer's Disease International, the umbrella organisation of Alzheimer's associations across the world.

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation forums and advisory groups. We are involved in other key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.