



**dementia
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The new voice of Alzheimer's Australia

Australian Digital Health Agency: Digital Medicines Program Blueprint

A response from Dementia Australia

March 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 436,000 Australians living with dementia and the estimated 1.4 million Australians involved in their care.

Dementia Australia works with people living with dementia, families, carers, all governments, and other key stakeholders to ensure that people impacted by dementia are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with people impacted by dementia means that we are an important advocate and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

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



Why is medicine safety a concern for people with dementia?

Dementia Australia welcomes the opportunity to comment on the Digital Health Agency's consultation on the Medicines Safety strategic priority and supports the strategic aim of improving safety functions around medication usage and management.

Currently, 80% of people with dementia, living in residential aged care are receiving medications to manage the behavioural and psychological symptoms of dementia (BPSD). We anticipate that many outside of residential care also receive medication for BPSD and/or comorbid illnesses. As recently highlighted in the Royal Commission into Aged Care, there is a growing concern around the overuse of medications across the aged care sector, and in particular the inappropriate use of anti-psychotic medication.

Therefore, a well-functioning medicine safety strategy is an integral part of the ongoing changes across the ageing and disability sector. These reforms aim to provide consumers with greater control over their own health and wellbeing and greater assurances that medications are given appropriately and in the best interest of consumers to support their reablement.

Our previous letter dated 30 January 2017 highlighted a number of potential benefits from adopting a digital health record system for people living with dementia, their families and carers. Many of those potential benefits can be reiterated here for the Agency's Medicine Safety Blueprint proposals. They include:

- Helping health care professionals and service providers share accurate and up to date information about a person with dementia, which can support them to provide appropriate dementia care.
- Improving coordination of care between primary, acute, community and residential care sectors resulting in overall better quality care.
- Enabling improved medication, treatment and allergy management and thereby reducing adverse reactions.

However, in order for the Medicine Safety strategy to be successful Dementia Australia strongly recommends a broad strategic focus on navigation, access and the appropriateness of new digital technologies and platforms for people living with dementia, their families and carers.

In developing the blueprint for the Medicine Strategy we also suggest considering the following recommendations.

Recommendations

1. Consider the unique needs of people living with dementia

Experience of people with dementia, their families and carers of the access and navigation of digital health technology has been mixed, especially around usage and functionality of the My Aged Care website and My Health Record.

Feedback from individuals on the My Health Record and My Aged Care websites has focused primarily on access and navigation barriers: they either had no access to the internet, did not have the skills necessary to navigate the website effectively, or found it too difficult to find the information that they needed. People living with dementia as well as their families and carers also found the many links to information and services very confusing. Some people reported it took hours of navigating the website to find the information relevant to them.

Feedback received by Dementia Australia recommends a more consumer-friendly approach to health-related websites. For example, instead of sifting through large amounts of information on the website, a more direct approach could be implemented in which simple questions are used to guide individuals to the relevant information. There is also great importance placed on information being written in plain English and avoiding jargon which can be hard to interpret – this will be especially important to note when using medical terminology.

Dementia Australia's recommendation to the Agency would therefore be to provide detailed and accurate information to people living with dementia, families and carers on the newly proposed medicine programs, how they may benefit consumers and how to navigate them. Communication about the medical safety programs should be easily accessible to people living with dementia and in a form that they can understand. Information delivery methods that extend beyond electronic means should also be considered: for example, during GP consultations, in clearly written letters or in community information sessions that include sessions in residential aged care facilities.

2. Enable access for all consumers

Not all people living with dementia, their families or carers have access to the internet – this is especially true of remote and rural populations. Equally, people from culturally and linguistically diverse communities may require information to be translated and adjusted to appropriately suit their culture and language. People with dementia may also need additional support to access and navigate the proposed programs, such as instructions on how to use electronic prescriptions and how to access information on their medications. As such, the option of *easily* printing out the medication and prescription records and other important digital resources also needs to be available.

3. Support the role of carers and substitute decision makers

The majority of people living with dementia live in the community (approximately 70%), and a significant portion (approximately 20%) live alone. Many of these individuals (91%) rely on support from an informal carer, such as a friend or family member. More than one in five (22%) rely solely on informal care and do not access any formal care services, and most of these carers are the spouse or child of the person with dementia.¹

This significant role needs to be recognised and supported within any digital health strategy and it is strongly recommended that the Agency builds pathways to support carers, who often act as advocates for their loved one, either formally as a substitute decision maker, or informally. The responsibility for medical decision making increasingly falls on carers, many of whom who feel ill-equipped or under-informed (even with an advance care plan in place). Thus provisions need to be made so that carers, close family and/or nominees can have access to information on medications and prescriptions.

4. Ensure digital processes have clarity on the role responsibilities in medicine management

A common concern raised by individuals with dementia, their families and carers are the inconsistencies in record keeping and clinical governance – especially for residents living in aged care facilities. Unclear clinical governance structures and poor record keeping often creates for poor communication between GPs, locum GPs, aged care staff and families in relation to the personal, clinical and medical care of someone with dementia. In practice, this often leaves people with dementia, their families and carers in doubt about the appropriateness and effectiveness of medication that is being administered.

Underpinning this issue, is a lack of clarity around the roles of and responsibilities of aged care staff and medical practitioners, as they relate to the personal care, clinical care and medical care of a resident with dementia.

Therefore, in developing a digital solution that seeks to improve medication management, the Agency need to make sure that all roles and responsibilities are clearly articulated, and communication channels between medical and care staff are effective. Also, that clear clinical governance structures are embedded into the digital processes, to enforce the roles and responsibilities.

Feedback on blueprint actions:

Electronic prescriptions

- Given the navigational and access challenges raised in response to My Health Record, Dementia Australia recommends the electronic prescriptions program provide clear communication and offer additional support (i.e. helpline services) for people wishing to use an electronic prescription.

¹ Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW, 2012 Cat. no. AGE 70.

- Information on the merits to using electronic prescriptions – for example, reducing the need to rely on paperwork, and simplifying the process of obtaining medication – should be made clear and communicated throughout the aged care sector, in addition to clear instructions on how to navigate and use the system.
- As stated above, information dissemination should not rely on electronic methods, but utilise community groups, residential care providers and carer networks.

Best medicines list

- Having a central source which holds prescription and dispense records has potential to benefit people with dementia, their families and carers – providing the information is easily accessible and communicated clearly.
- In particular people with dementia may find it helpful, and may be more engaged with this program if the best medicines function included prompts and alerts to remind them to collect regular medications. An alert function may also be a useful for carers and family members, who are often responsible for medications.

Medicine information for consumers

- Most people living with dementia live in the community (70%) and therefore rely on their carers for a number of everyday activities, such as preparing and taking medication. Easing access to information on medications is therefore an important initiative for people living with dementia, and their families and carers.
- Information on recommended dosages, instructions for taking medication and potential side effects or reactions should also be made available under the medicine information.
- A measure for success in this program may be the ability for consumers, their families and carers to access accurate information they need regarding their medication. Also, the level of confidence consumers have in understanding their medication.

Medicine decision support tools

- Medication management is often a concern for people living with dementia. As previously mentioned, there is increasing concern around over prescribing of medications, particularly those used to manage BPSD. Dementia Australia advocates for better regulation around prescribing medications, and wants to see a significant reduction in medication being used as a first response to BPSD. Improvements also need to be made to medications monitoring procedures, to ensure individuals are not taking inappropriate medications that no longer effective or reflect their reablement needs.
- The *medicine decision tool* has potential to play an important part in improving individuals' safety around medication, by improving the regularity of medication reviews and improving decision making regarding prescriptions. Thus driving improvement to the number of people with dementia who currently receive inappropriate medications.
- For this program to be effective, provisions need to be in place to ensure guidelines on prescriptions and decision making are followed and the support tools are utilised by all prescribers.

Enhance incident reporting capabilities

- As mentioned above, medication management and monitoring for adverse reactions to medication is vital to ensuring people with dementia are receiving the best possible treatments. Due to the complex nature of dementia, there are a variety of conditions, both psychological and physiological, which can be comorbid with dementia. This sometimes results in the experience of adverse side effects due to medication interactions.
- The digital solution to incident reporting, in the event of an adverse reaction, may assist in creating a more joined up approach between health providers to ensure people with dementia are not being prescribed medication which is ineffective or may cause harm.

National Allergy Strategy

- Dementia Australia supports the national allergy strategy, which will assist in the prevention of allergic reactions to medications.
- Memory loss is a typical symptom people with dementia experience. For some, this may include difficulty recalling medical information – such as allergies – and thus a joined up method for prescribers and health providers to be aware of such allergies is important.

Conclusion

Overall, with the provisions mentioned throughout this submission, Dementia Australia is optimistic that the medicine safety strategy will improve the quality of care provided to people living with dementia within and across the healthcare sectors. However, we must stress that a focus on clear communication, access and navigation is vital, while digital technologies must be adaptable and user-friendly for people with dementia.

We look forward to continuing to provide input to this work.