

30 January 2017

Dr Monica Trujillo
Chief Clinical Information Officer,
Australian Digital Health Agency
Emailed to: yoursay@digitalhealth.gov.au

Dear Dr Trujillo,

RE: The National Digital Health Strategy Consultation

Thank you for the opportunity to comment on the Digital Health Agency's consultation on a National Digital Health Strategy. Alzheimer's Australia is particularly pleased to note the Agency's aim to co-produce a strategy with extensive community and stakeholder consultations.

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. Dementia is the second leading cause of death in Australia and will continue to have an increasing impact on the health system. Dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP.¹ An effective and responsive digital health system is therefore of critical importance, both to the people living with dementia, their families and carers who navigate the health system, and to the broader health sector that needs to provide increasingly coordinated and cost-effective services.

A well-functioning digital health system is also an integral element of the ongoing changes across the ageing and disability sectors, with large scale reforms aimed at implementing Consumer Directed Care (CDC). These reforms aim to provide consumers with greater control over their own health and wellbeing, including who will deliver their services. As such, the corresponding roll-out of a consumer controlled electronic health record system is important in supporting consumers to make informed choices.

A strategic focus on navigation, access and the appropriateness of digital technologies for people living with dementia, their families and carers is vital if a national digital health strategy is to be successful. While the terms of reference for this consultation are broad, Alzheimer's Australia offers below some key observations for your consideration.

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

Opt out model of My Health Record

The My Health Record (MHR) holds large potential for people living with dementia, their families and carers, including:

- 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.
- Better access by health care professionals and service providers to advance care plans. These plans outline an individual's care wishes when they no longer have legal capacity to make decisions about their care.

In order to maximise these benefits, Alzheimer's Australia recommends consideration of an opt-out participation model for the My Health Record, rather than an opt-in model.

People living with dementia admitted to hospital, for example, experience poorer clinical outcomes, longer lengths of stay as well as a higher likelihood for readmission compared to people without dementia, at a high cost to the health care system.² Automatic access to a functional, inclusive model of the electronic health record system would facilitate appropriate and accurate medical and health records and reduce some of the confusion and distress that people with dementia often face in clinical and hospital settings.

An opt-out electronic health record system would ensure that the full benefits of an eHealth record are available to people living with dementia, their families and carers, who may not otherwise be aware of these benefits and explicitly choose to sign on.

Considering the unique needs of people living with dementia

Consumer experience of the access, navigation and technological aspects of aged care reform has been mixed, especially around usage and functionality of the My Aged Care website.

Feedback from older consumers 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 found the many links to information and services very confusing. Some consumers reported it took hours of navigating the website to find the information relevant to them.

² Australian Commission on Safety and Quality in Health Care (2013). *Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review*. Sydney: ACSQHC.

Consumers have thus recommended a more consumer-friendly approach to the My Aged Care website – and any other health-related website. Instead of having to sift through all the information on the website, for example, consumers suggested a more direct approach be implemented in which simple questions are used to guide consumers to the relevant information.

Alzheimer's Australia's recommendation to the Agency would therefore be to provide detailed and accurate information to people living with dementia, families and carers so they are able to make informed decisions about the use of health records. Communication about MHRs 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.

Enabling access for all consumers

As mentioned above, not all people living with dementia, their families or carers have access to the internet. People with dementia may also need additional support to access and make changes to their MHR, including in residential aged care facilities. As such, the option of easily printing out the record and other important digital resources also needs to be available.

Supporting the role of carers and substitute decision makers

The vast majority of people living with dementia living in the community (91%) rely on an informal carer to support them. More than one in five (22%) rely solely on informal care and do not access any formal care services. There are a significant number of Australians providing informal unpaid care to people living with dementia, and most of these carers are the spouse or adult child of the person with dementia.³

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 digital health records if they are the substitute decision maker or if the person living with dementia decides that they want them to access/change or make decisions regarding the MHR.

In considering the afore-proposed opt-out model, the system design needs to facilitate support for people with moderate to advanced dementia to opt-out. For example, if the person no longer has legal decision making capacity, their power of attorney or substitute decision maker needs to have the ability to opt out of the system on their behalf.

³ Brooks D, Ross C, Beattie D for Alzheimer's Australia (2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, pp. 7-8.

Privacy and Security risks to vulnerable consumers

Appropriate measures should be in place to ensure that people with dementia are not vulnerable to privacy and security breaches and that they are appropriately supported in the use of their MHR.

Advanced Care Plans and their integration into a Digital Health Strategy

Advanced Care Plans and Directives need to be prioritised as a key issue for any future digital health strategy. The ability for health services to access a consumer's directives around their own healthcare are the most significant feature of the eHealth record, and while we are pleased to note that this functionality has been included on the MHR, the uptake has been disappointing (only 12,254 Advance Care Directive Custodian Reports and 693 Advance Care Planning Documents as on 15 January 2017).

For consumers living with dementia, this is an important issue. Consumers need continuous access to their advance care plan and the functionality to change it at any time, especially for diseases like dementia that change markedly throughout the disease trajectory. Carers, close family and/or nominees also need to have access to the advance care plan if the person with the terminal illness cannot access/change or make decisions regarding the advance care plan.

A digital health strategy – and the incorporation of advanced care plans/directives – also needs to be ably supported by health professionals.

A robust and flexible digital health strategy

Overall, Alzheimer's Australia is optimistic that a carefully conceived, well-implemented digital health strategy will improve the quality of care provided to people living with dementia within and across the healthcare sectors. A focus on system/record access and navigation is vital, while digital technologies must be adaptable and user-friendly.

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

Yours sincerely,

Maree McCabe
Interim Chief Executive Officer
Alzheimer's Australia