Submission:

**The future of Digital Health in Australia –
Consultation to develop a National Digital
Health Strategy**

January 2017

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Introduction

Carers Australia welcomes the opportunity to provide comments to the Australian Digital Health Agency (the Agency) in response to the Discussion Paper on *A consultation with the Australian community to co-produce the National Digital Health Strategy* and to assist with the Agency's consideration of digital health reform.

Carers Australia acknowledges the genuine interest in suitable and sustainable reform that this Discussion Paper projects. We further acknowledge the genuine interest of the Agency in engaging stakeholders through this process, and thank the Agency for having an extended consultation and submission period.

Carers Australia agrees with the statement in the Discussion Paper that there is nothing more important than our health and the health of those we care about, and that digital health reform will lead to people having more choice and control of their health and healthcare needs.

Carers Australia would like to acknowledge the clear references to carers, in the discussion paper, as key stakeholders of the health system. Carers have a legitimate interest in health system reform for the people they care for as well as how it will affect their own daily lives.

The workload of caring can make contribute significantly to the deteriorating health and wellbeing of carers themselves. It is widely recognised that carers tend to neglect their own health because so much of their focus is on the person they are caring for. We hope that a new Digital Health Strategy can go some way to alleviating this issue.

Carers are also high users of health and healthcare services both as a carer and in their own right; and bring a unique set of variables, barriers, experience and opportunities to the digital health reform space. Carers Australia looks forward to working with the Agency to advance our recommendations for reform.

Summary of Recommendations

Recommendation 1: Targeted outreach and communication to promote the value and benefit of digital health.

Recommendation 2: Enhanced rollout of electronic tracking of patients and real time data on provider timing.

Recommendation 3: Enhanced digital platform to facilitate service mapping and referrals; placing client choice and control at the forefront.

Recommendation 4: Develop online functionality to assist client engagement with health and healthcare services.

Recommendation 5: Develop and implement an integrated digital health platform or digital health records clearing house.

Recommendation 6: Amend My Health Record to allow an individual to identify as a carer, and provide relevant accompanying information.

Recommendation 7: Scope and host a health and healthcare innovation hack on one key identified long-term and short-term priority.

Recommendation 8: Digital literacy training for end users and specially targeted training for carers on using digital health services.

Recommendation 9: Investigate the option for a data chargeback scheme to mitigate the household cost of data when accessing digital health interventions.

Being in Control of your Healthcare

What does this mean to carers and the people they provide care for?

A fully integrated digital health strategy should allow easy portability of client history from one provider to another, where the client is truly the owner of their own health data.

This will allow a seamless transfer of client data across government, non-government and private providers (where appropriate). For example, a fully integrated digital health platform should assist a person's primary health care provider to access case notes, directions and other material that has been recorded by an allied health practitioner, NDIS or Aged Care provider and vice versa. This would mitigate any unintended conflict between treatment regimens, and promote a fully holistic care record.

Carers Australia would support a robust digital health strategy which allows carers and the people they provide care for more opportunities related to choice and control over health and healthcare services.

By being able to choose health and healthcare providers on merit, instead of having to worry about where your records are situated, will promote healthy competition amongst providers, but also allow carers and the people they provide care for to feel, and be, more in control of their health and healthcare needs.

The Digital Health Strategy must include outreach through a variety of communication channels to promote the value and importance of using the tools available not just rely on healthcare professionals alone.

> **Recommendation 1: Targeted outreach and communication to promote the value and benefit of digital health.**

Digital Technologies - Health and Wellbeing

How could digital technologies change the experiences of carers and the people they provide care for in managing their health and the way they interact with the healthcare system?

As mentioned earlier, the portability of health information will make it easier for individuals to change health or healthcare service provider, based on their needs. For example, carers and others have reported that they continue to visit their doctor even if they move away and a new doctor is closer – because the doctor has all their history.

Digital health of course, goes beyond data and My Health Record. As mentioned in your consultation video, St Stephen's Hospital in Hervey Bay Queensland has designed a very innovative electronic tracking board which allows someone to track the progress of their family member or friend through their procedure.[1]

There is value to rolling out a similar scheme across all hospitals; this would be particularly beneficial to carers who can track the progress of the person they provide care for without the need to ask health service staff for advice. There would also be merit to rolling out access through a secure website or app; allowing a carer (or indeed any family member or friend of a patient) the ability to track their loved one from home, work or whilst travelling to and from the hospital or healthcare centre.

This system could be extended even further and be rolled out across general practices, allied healthcare services and even residential aged care facilities. This would allow patients, carers and family or friends real time data on if their doctor or healthcare provider is running on time, how long waiting times are and so on. This would provide greater transparency to the operations of the provider, but also increase personal and economic productivity through reductions in the time people spend needlessly waiting at a health or healthcare provider's offices.

> **Recommendation 2: Enhanced rollout of electronic tracking or patients and real time data on provider timing.**

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[1] http://ststephenshospital.com.au/patients-and-visitors/arriving/track-a-surgery's-progress

Health Professionals

What gets in the way of health professionals being able to connect, communicate, and co-ordinate with the right people?

Currently health professionals are expected to refer their clients to other providers as the need arises; often clients are referred to providers that have an official or unofficial business relationship (such as a memorandum of understanding, contract or shared ownerships) with the referring health professional or their overarching organisation; or that the referred organisation is the most well-known or is the only provider available. In essence, there is inadequate or no service mapping, or the one that does exist is not presented in a usable fashion, meaning patients (and their carers) have little or no say on their health or healthcare journey.

Many health professionals have an aversion to adopting digital technology. This is more apparent with senior or experienced health professionals or independent practices. Whilst Carers Australia does acknowledge that some medical professionals have adopted such technology, it is still not being used to its full potential. Technology at the patient interface is usually limited to watching a flat screen television in the waiting room, and making a payment at an EFT/HICAPS terminal.

This is often coupled with health professionals having inadequate or dated technology for practice management. Carers and other individuals have reported that health practitioners spend too much time fiddling with software, printers and scanners during consultation or treatment sessions. Several have reported that health practitioners have reverted to hand writing notes, referrals and scripts because it's simply easier than fighting the digital system or learning how to use the tools.

It would also appear that there is often limited time that medical professionals do, or can, allocate to communication and co-ordination; rather the bulk of their time is spent on face to face consultations or treatments with patients.

What do health professionals need to do to be able to effectively connect, communicate and co-ordinate with the right people?

Health professionals need to set aside time to learn, or be instructed in, the most appropriate technological innovations and interventions for their particular practice and how these innovations and interventions can improve the client interface. This not only needs to be technology that is right for the business model, but is also user friendly and enhances the client experience.

An online system that fully maps services, supports and other referral pathways needs to be developed; however this platform must also include the ability for the client to choose their provider, not simply a provider that has an agreement with the health professional. The platform must increase the choice, control and decision making ability of individuals; therefore the platform must have a mechanism for checking client satisfaction.

> **Recommendation 3: Enhanced digital platform to facilitate service mapping and referrals; placing client choice and control at the forefront.**

Consideration must also be given to how individuals, their carers and family might interact with health and healthcare providers through technology; how a consultation could occur via telepresence; what portable platforms can facilitate treatment; does a person really need to visit their health professional's office for a simple script refill.

> **Recommendation 4: Develop online functionality to assist client engagement with health and healthcare services.**

Organisational Priorities and Digital Health

Digital health and/or e-health priority reform areas – long term

A fully integrated digital health platform needs to be developed; this system must have client choice and control at the forefront.

The system must be able to interact with, or centralise, data that can be accessed by an individual's health or healthcare provider, and must be able to interact or centralise with other government systems such as NDIS, Aged Care or other health record systems. This will allow the individual to fully own their healthcare data, but also provide heath and healthcare providers with comprehensive data on their clients.

Until this is met, a simple digital records clearing house could also facilitate information flow; this may simply be met by developing a single sign-in portal allowing health, healthcare providers and individuals the opportunity to easily access their records through a central portal.

Recommendation 5: Develop and implement an integrated digital health platform or digital health records clearing house.

Once the system is fully operational and working well, it would make some sense to set it up as an opt-out feature of medical record keeping; health and healthcare providers and their clients would both have to agree to an alternate method of record keeping. This should nudge parties into to using the system, which will, in theory, provide greater access to information and promote more choice and control for the client.

Digital health and/or e-health priority reform areas – short term

As part of the 2015 *Electronic Health Record Legislation Consultation*, Carers Australia recommended that My Health Record be amended to allow an individual to identify if they have a carer. The Department of Health accepted this recommendation and the system was amended accordingly. Feedback from carers and the people they provide care for has been positive towards this improvement.

However, there has been concern that My Health Record does not allow an individual to identify if they are a carer – that is, if they provide care for someone. It is important for My Health Record to identify this, and allow health practitioners to identify if the person they are treating has dependents or is providing care – this would be extremely important in critical healthcare situations where the care recipient is non-verbal.

It would be best if the system allowed the individual to identify that they are a carer, and provide the name and contact details for the person they provide care for, but also an alternate care provider in the event of an emergency.

Whilst this may be technically complex, it may be beneficial to have the ability to digitally link the profiles of carers and the person they provide care for. This will remove any ambiguity around the relationship, and make it easy to identify the relationship, and access relevant contact information, and mean that only one record need be updated to reflect the relationship.

> **Recommendation 6: Amend My Health Record to allow an individual to identify as a carer, and provide relevant accompanying information.**

Data and Innovation in Healthcare

What are the barriers or obstacles to innovation in healthcare?

The barriers and obstacles to innovation in healthcare are the same or similar to the general obstacles and barriers that exist across the Australian innovation ecosystem – traditionally government and the bureaucracy have been risk adverse, and only targeting limited innovations that are delivered by large national or multinational entities.

Whilst the Government's Innovation and Science Agenda has gone some way to promoting smaller entrepreneurial ventures and social innovations, there is still a parcel of work that needs to be done to assist the interaction between entrepreneurial ventures, social enterprises and delivering a marketable product. This could be assisted by a health and healthcare innovation hack, summit or TEDx style forum where all sectors could come together to tackle specific issues, in a specific time, with specified funding committed.

Recommendation 7: Scope and host a health and healthcare innovation hack on one key identified long-term and short-term priority.

Digital literacy and access is also a significant barrier that needs to be addressed; both in terms of technical ability to access the internet and other digital platforms, but also having the financial means to do so.

The Australian Digital Inclusion Index[2] shows that poorer people, older people, Indigenous people and people with a disability have levels of digital exclusion that is significantly above the national average. The Survey of Disability, Ageing and Carers indicates that a large number of carers are of the aforementioned cohorts.[3] Additionally, surveys undertaken by State and Territory carer associations reinforce the broad findings of the Australian Digital Inclusion Index in relation to carers. The Tasmanian Council of the Ageing's recent research project found that only 40% of the over 600 people surveyed used a digital platform to access information. This

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[2] http://digitalinclusionindex.org.au/
[3] http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

decreased with age, with only 12% of 60-74 year olds and 6% of 75-84 olds;[4] and a startling 77% of carers for the elderly had not used My Age Care.[5]

Options for resolving this barrier could include digital literacy training for end users, but also targeted training for carers. The training should include all functionality for accessing and using digital health services.

> **Recommendation 8: Digital literacy training for end users and specially targeted training for carers on using digital health services.**

The cost of data services through telecommunications providers may also be prohibitively expensive; at the very least it becomes an added expense that low income or disadvantaged households can not afford. Consideration should be given to investigating an innovative chargeback approach to using data in the digital health space, weather that be charged back to the Provider, Digital Health Agency, Department of Health, Department of Human Services or become a Medicare line item would warrant further consultation. However, the data service being charged back to a Commonwealth entity would give the Government a clear statistical source for measuring the update of digital health interventions.

> **Recommendation 9: Investigate the option for a data chargeback scheme to mitigate the household cost of data when accessing digital health interventions.**

Priorities in respect of innovation and healthcare – long term.

As mentioned earlier, the development and national rollout of an enhanced patient tracking system, similar to that of St Stephen's Hospital in Hervey Bay Queensland would be a good long term venture to improving the client, carer, family and friend experience at a health or healthcare facility. Similarly, as mentioned earlier the development and implement of an integrated digital health platform or digital health records clearing house would also go a long way to alleviating any data management issues faced by health and healthcare practitioners and alleviate the need for clients or their carers to fill out repetitive paperwork.

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4 Council of the Ageing Tasmania (2015) *Finding Out – Supporting older people to access the right information at the right time*
5 Carers South Australia, Our Carers Our World, 2015, http://carers-sa.asn.au/Assets/Files/Carers%20SA%20Carers%20Survey%202015%20Summary%20Oct%202015.pdf