



Consumers Health
Forum **OF** Australia

SUBMISSION

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. We welcome the opportunity to provide feedback to the Digital Health Strategy and are looking forward to continuing our ongoing work with the Agency.

This is a brief initial submission in response to the discussion paper released by the Agency in November 2016. We look forward to working with the Agency to involve consumers more and to progress and resolve the issues raised in this submission and by other consumers through the consultation process, such as through the focus groups we partnered with you to deliver in late January 2017.

We support the development of a digital health strategy for the entire health sector, one which is led by consumers but is executed by the entire health system. A comprehensive digital health strategy should provide a set of tools for consumers, clinicians and health service providers to work in partnership to have consumer –centred care. Central to this is empowering consumers to have more options for taking more responsibility for their own health.

The overall objective for the national digital health strategy should be framed simply and strategically, for example, “connected care, connected system”. A successful, forward-looking strategy needs to include several components including information, data and knowledge management; a prevention and patient self-management focus; measures and infrastructure to promote a better connected system and experience of care such as shared electronic records and secure messaging; and support for innovations in the delivery of clinical care and increasingly personalised medicine. In particular the strategy should prioritise:

- the roll out of a fully functioning comprehensive electronic health record with robust privacy controls .
- creating an environment for the development of and implementation of accredited on-line self-management tools and apps for smart phones and other smart devices across a range of conditions and needs;
- more widespread use of telehealth and telemedicine and related to this tools for remote monitoring for carers ; and
- training and education for consumers and health professional in how to use the tools and incentives put in place to encourage their adoption.

The strategy needs to address all these issues in a co-ordinated way. Whilst the electronic health record, *My Health Record*, is often seen as the most important part of the strategy, and for some consumers digital health is simply the record, there is no reason why the other parts of the strategy could not be pursued concurrently.

Issues

Electronic Health Records

We encourage the Agency to prioritise making the MyHealth record sharable and used by all health professionals and in all health settings. This fundamental step will have massive benefits to consumers who will be able to trust that their information is being adequately communicated and will not have to face the risk of medication and treatment errors occurring due to them losing a sheet of paper or not understanding the medical terminology being used by doctors.

We encourage the Agency to reflect on the many and varied attempts made in recent years to create an electronic health record and the impact that these false starts have had on consumer confidence in the tool. We recognise that there are good reasons that efforts to date have resulted in less than ideal outcomes – however from a consumer point of view these repeated attempts have been confusing and have increased levels of mistrust. Our work with consumers on this topic reflects this in their uncertain use of different terms for the record. They refer to ‘the PCHER/MyHealth record/electronic health record’ interchangeably. The disconnect between the agency’s perceived reality and consumer’s perceptions is shown in the phrasing used in the discussion paper. In principle both patients and healthcare professionals can gain immediate access to important health information on line. However, our discussions with consumers on this issue reveal that this is rarely the case.

We suggest that the Agency develops a strong public information campaign with realistic messaging and descriptions of what the Record can do. This campaign could concurrently work to develop digital health literacy through encouraging them to use both the Record and other eHealth technologies and giving them tools by which to do so.

As mentioned above, consumers still have to carry paper discharge summaries and referrals from one health service or doctor to another. They are expected to recall test results, names of specialists and other health information. Electronic links are the exception rather than the rule. This is a major source of frustration and difficulty for consumers, but one which the Agency can help address. We are able and willing to provide extra details and specific examples of these challenges to the Agency if it would assist your work.

Change management and co-production of the strategy

We support the co-production strategy that is being undertaken. However, we were disappointed that the early consultation didn’t involve consumers more intensively. We recognise the strong and positive attempts that are being made to involve consumers and the wider community in these later stages – however we would encourage the agency to continue to embrace consumers as one of the most key stakeholders. Consumer uptake of and

demand for digital health solutions will help accelerate change and adoption in the clinical community just as much as clinical stewardship will.

It is difficult to disagree with a national digital health strategy that aims for better connected care and a more integrated system. As with any ambitious agenda, the challenge invariably lies in getting the implementation right rather than setting the aspirations in the first place. The implementation of the national digital health strategy will require a deliberate, planned, step-wise change management strategy that acknowledges that across both the clinical and consumer community 'change readiness' and receptiveness to 'going digital' will vary. It will be as important to consult consumers and involve them in the co-design and oversight of the implementation plan as it has been to involve them in helping shape key themes for the strategy itself.

Responses to the questions for healthcare consumers, carers and families

The questions suggest that giving more access to health information will lead to improved health literacy, which is an incorrect assumption. We support the provision of adequate and appropriate information about digital health, however would caution the Agency against overwhelming consumers with information that they can't easily understand or are not motivated to engage with. Health literacy is a key issue for CHF and for health consumers. If people cannot find, understand and use health-related information and services, it is hard for them to make good decisions about their health. Health literacy can be improved in a number of ways. We suggest the Agency refers to the work of the Australian Commission for Safety and Quality in Health Care (the ACSQHC) (<https://www.safetyandquality.gov.au/publications/health-literacy-a-summary-for-executives-and-managers/>) and Deakin University's Ophelia project (<https://www.ophelia.net.au/about-health-literacy>) for consumer co-developed, reliable resources on the topic. The ACSQHC recommends that health literacy is included as a component in all levels of an organisation, such as in the Digital Health strategy.

Health literacy can be improved through co-producing any information with consumers, preferably from a wide variety of backgrounds and situations. While we recognise that this process can be time and resource intensive it is one that results in fit for purpose, more usable products and information.

Of particular concern to the Agency should be the 'digital divide'. Digital health consumers should not be treated as one homogeneous group in the services offered or the way they are offered. Australians who live in regional and remote Australia have considerably less access to the internet than their city counterparts, which directly impacts on how they can access health care. The AMA has highlighted this issue in their recent position statement on the topic – CHF supports the concerns raised in this statement (<https://ama.com.au/position-statement/better-access-high-speed-broadband-rural-and-remote-health-care-2016>). Consumer's ages also impact on their use of digital health resources. While there are exceptions to this, younger Australians are more likely to be early adopters and more

technologically savvy than their older counterparts. Older Australians experience greater barriers to using digital health resources as part of their care. The notion of digital inclusion and how to promote digital inclusion is very important. According to work undertaken by the Centre for Social Impact in 2016, Australia's digital inclusion index is on the rise but it is still quite low with some groups very digitally excluded.

Consumers have expressed to us that they would like to access their health information in ways that are secure and private but also on a platform that is easy to use. Depending on their background and level of health literacy what this means in practice varies considerably. Some consumers would prefer not to have anything stored electronically, and for this reason we support the maintenance of non-electronic mechanisms. Other consumers would like to have control over and knowledge about where and how this information is stored –for these consumers we suggest that the how and why of storage is built into the above information campaign. A final group of consumers are trusting of the government and are happy to have their records stored as the government deems fit.

Privacy and ownership of health records is a related and complex area which we strongly suggest the Agency conducts specific consultation on. Broadly, consumers hold a wide variety of views on the subject. For some consumers, total control and being able to write into their records is an essential part of having ownership of their records. Other consumers believe that only trained health professionals should be able to input into the record, but feel they should be able to see what is on there. The majority of consumers we have spoken to about the subject feel strongly that at the very minimum they should be able to see the contents of the record and ask their health professionals to amend this information if needed.

Many consumers also feel that they are not being consulted as to where and how their data is being stored. One consumer has said to us:

I have been writing and lobbying in this area for some years. As someone with a disability, I increasingly take the view that too much of my personal information is on-line with Centrelink and other agencies. While I am obliged to use some of these environments, governments are increasingly cost-shifting both access to information and even sometimes the holding of information to third parties like NGOs. As a consumer with chronic conditions, I have never felt like I have ever really been asked whether these outcomes were desirable, nor that my dissatisfaction was something government wanted to hear.

This consumer raises the importance of communicating to consumers not only what information is being collected and stored, but how it is being collected and stored. As shown last year by the ABS, consumers feel that there is a real risk that their data is not being stored safely and that, despite the best assurances of the government, that it might be captured and used by organisations they have not explicitly agreed to sharing it with. The very personal nature of health data adds weight to this concern, as stigma and discrimination against people with certain medical conditions (e.g. severe mental illness) does exist, and having medical records being able to be accessed may have prejudicial outcomes against consumers.

Consideration should also be given to who will have control over which information is shared with whom, particularly in cases where the health consumer may lack capacity for decision making. As the digital health record process proceeds changes may be required to legislation around mental health treatment orders and powers of attorney to ensure that uniformity and consistency exists around health information sharing and consent thereof.

The use of digital devices, accessing health information through them and self-monitoring with them does not seem to be a priority of health consumers at this stage. While some consumers have expressed that they would like to be able to access information in this way, it is largely framed as a 'nice to have'. There is strong recognition, however, that health is lagging behind the modernisation and digitisation that has occurred in other sectors such as banking, travel and telecommunications and hence an expectation that a national digital health strategy will – and should – set out a blueprint for health to catch up. As the Record progresses and the fundamental limitations are surpassed this broader agenda will become an issue worthy of more attention. The majority of consumers we are in contact with have experienced difficulty navigating the health system. This is particularly true of consumers who have chronic or co-occurring illnesses. Some of the biggest pain points we see in this area are:

- Links between primary and specialist care
- Links between hospital and primary care

Issues raised with CHF by consumers about Digital Health

As part of selecting consumers for the focus groups held in partnership with the Agency in January 2017, we heard about a wide range of issues of importance to consumers. These issues include those discussed above, and:

- The needs of specific age groups – particularly young people and seniors
- Working with health professionals to educate them about digital health and taking measures to ensure that they cooperate with digital health efforts
- Ensuring digital health innovations are easy and convenient for consumers to access
- Interoperability – specifically the use of consistent platforms across all health systems, ensuring all health professionals can access and maintain the MyHealth record and the development of a patient portal within public hospitals.
- Developing strategies to allow for adequate levels of informed consent to be provided before the record is accessed, particularly in emergency situations
- The use of telemedicine to improve rural and regional health outcomes, such as through monitoring through skype like services.
- The use of electronic health data for research purposes
- Support for consumers, families/carers and clinicians:
 - To make the most of digital health, social and mental health tools to improve outcomes - This includes using programmes, such as smartphone apps, to keep track of medications, symptoms, outcomes and to manage overall health as part of an integrated mental health service.
 - The behaviour, social, legal and technical challenges digital health may bring from a community viewpoint.
 - The support of carers in Australia, through digital health means
 - Ensuring that digital health resources are simple and easy to understand but not patronizing.