



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Legal Advocacy for vulnerable people with Disability

14 September 2018

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Committee,

My Health Record System Inquiry

Queensland Advocacy Incorporated (**QAI**) thanks the Senate Standing Committees on Community Affairs (**Committee**) for the opportunity to have input into the inquiry on the My Health Record System.

We **attach**:

- My Health Records Fact Sheet, published by QAI;
- My Health Record Privacy Control Tips, published by QAI.

QAI is an independent, community-based systems and individual advocacy organisation and a community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for almost a decade, highly in-demand individual advocacy through our individual advocacy services – the Human Rights Legal Service, the Mental Health Legal Service and the Justice Support Program and more recently the National Disability Insurance Scheme Appeals Support Program.

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

QAI's position

QAI has monitored and considered the development of the My Health Record system, as it is a system that has the potential to impact – in both positive and negative ways – on the lives of a number of our clients, particularly those with mental illness and intellectual and cognitive disability.

Both the issues for consideration and the potential impact on these two groups are distinct (although for many clients there will be overlap). We note that many people live with both intellectual or cognitive disability and mental illness.

For clients with mental illness, there are potentially concerns associated with the availability of their health information and a desire to safeguard information that may be considered potentially stigmatising.

For clients with intellectual or cognitive disability, there are concerns about capacity to understand and express their preference in terms of 'opting out', the accessibility of information and concerns about communication of relevant information in the event that paper-based records are ultimately superseded.

We note the importance of ensuring that all people are aware of their rights and have the ability, including any requisite support, to exercise those rights should circumstances change.

QAI submits that it is important that consideration be given to the following issues:

- How will the My Health Records system ensure that people's views, wishes and preferences are collected and recorded?
- How will the government use the data that is collected from My Health Records and for what purpose will the information be used? Is there any independent oversight to protect patient anonymity and privacy?
- How will the system be maintained and populated? There may be an assumption that individuals will have regular contact with healthcare services or will upload changes to the health themselves.

We emphasise that our rationale in expressing caution with aspects of the My Health Records system is not to hamper progress, but rather to highlight the minority perspectives of those who have been marginalised in the paper age, in the hope that this disadvantage will not be perpetuated further by advancing technology.

The expected benefits of the My Health Record system

To assist our clients to understand the pros and cons of the My Health Records System, QAI has developed the following fact sheet:

- My Health Records Fact Sheet.

We provide this fact sheet for the Committee's consideration, as it provides a succinct summary of our views of the pros and cons of the system.

Additionally, we note that access to information must benefit the individual as well as the community as a whole. We note that the individual has the greater risk in that their personal and sensitive information may be subject to data breaches. The loss of such data may result in further victimisation and discrimination of individuals already marginalised in the community. At the same time, access to information is clearly a benefit to people with disabilities. If individuals are able to have their views, wishes and preferences recorded accurately and in a timely manner it is hoped that their future care will be undertaken in a person centred manner.

The decision to shift from opt-in to opt-out

We note that there are concerns associated with the shift from an opt-in to an opt-out system. These concerns are particularly pronounced for many of our clients, particularly those who:

- have an intellectual or cognitive impairment that impacts on their capacity to access, understand and respond to relevant information;
- for reasons which may be related to their impairment, their financial vulnerability, or other circumstances, have limited or no access to technology to access relevant information and log their preference to opt-out of their scheme (should that be their preference).

The opt out model is a tacit yes which does not provide sufficient clarity in terms of what has been agreed to, the extent of what has been agreed to and how a person can regain the control of that information. The approach is problematic as it undermines the principle that consent should be freely given and unencumbered by any coercion.

The timeframe for the opt-out option is also problematic in that in the time that a person with a disability is given the opportunity to effect their decision to opt out, data and information about them may have already been accessed and processed in a myriad of different ways. The effective control of their information has been lost further compounding their disenfranchisement

Privacy and security concerns

To assist our clients to understand relevant privacy considerations, QAI has developed the following fact sheet:

- My Health Record Privacy Control Tips.

We provide this fact sheet for the Committee's consideration, as it provides a succinct summary of relevant privacy and security concerns and tips.

QAI submits that education is needed to allow people to protect their My Health Record data. This education must be delivered in a way that targets groups that are unlikely to be 'tech natives' and as such would require education that is directly applicable for individuals to protect their data or get assistance to protect their data.

In the event of data being disseminated by way of act or omission, QAI submits that there should be a sufficient redress option that may operate in a tortious manner. It is hoped that this redress would provide sufficient relief to compensate the victim for their injuries, losses, and pain/suffering.

Other matters

QAI does not wish to comment on the other issues raised in this inquiry.

Conclusion

QAI thanks the Committee for the opportunity to make this submission.

We would be happy to provide further information upon request.

Yours Faithfully,

A handwritten signature in black ink, appearing to read "Michelle O'Flynn". The signature is written in a cursive, flowing style.

Michelle O'Flynn
Director