



People With Disability ACT
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People With Disabilities ACT – Submission to Senate Standing Committee on Community Affairs

Inquiry and Report into My Health Record

6 September 2018



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Who we are

People With Disabilities ACT (PWD ACT) is a not-for-profit consumer systemic advocacy organisation which represents the interests of people with disabilities in the ACT. PWD ACT works to improve access to all amenities and to all formats of information and activities of the community. PWD ACT is a peak body which seeks to inform the community about disability issues.

We welcome to opportunity to make this submission, based on the experiences of people with disabilities in ACT.

Background

While the challenges of accessing suitable, timely and adequately informed healthcare is a challenge for all Australians, people with disabilities record worse healthcare access and outcomes. Research conducted by Australian Institute of Health & Welfare (2017) found that:

- 30% of people with disabilities who saw a medical specialist waited longer than they felt was acceptable to get the appointment;
- 17% of people with disabilities who saw three or more different health professionals for the same health condition reported there were issues caused by lack of communication among different health professionals; and
- 17% of people with disabilities who had experienced discrimination in the last 12 months reported the source of that discrimination as health staff (GP, nurse, hospital staff).

All three of these statistics, and more, saw people with disabilities achieve worse healthcare outcomes than people without disabilities. The concept of My Health Record (MHR) has the potential to address some of the challenges of accessing, managing, controlling and appropriately disseminating healthcare information that people with disabilities have traditionally faced.

a. the expected benefits of the My Health Record system;

People With Disabilities ACT accepts that the fundamental idea of My Health Record, as was the case with the Personally Controlled Electronic Health Record (PCEHR), is a beneficial one: to collate healthcare information into a more easily accessible, manageable and consumer-controlled portal. Research and experience tells us that people with disabilities too often live with the consequences of inconsistent communication processes and information



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management systems from a range of healthcare providers. We also understand the potential research and population health benefits of such a rich picture of health across Australia.

One concern that People With Disabilities ACT had with all iterations of the Personally Controlled Electronic Health Record and My Health Record was accessibility: for example, MyGov and the My Health Record portal are inaccessible to screen readers for people with a visual impairment, meaning the ongoing benefits of the system are essentially out-of-reach for these people. Both MyGov and My Health Record portals have little-to-no accessibility for people with physical disabilities (e.g. limited hand movement).

Recommendation 1: that the MyGov and My Health Record portals are urgently updated to meet Web Accessibility standards.

b. privacy and security, including concerns regarding:

- i. the vulnerability of the system to unauthorised access,**
- ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and**
- iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;**

Our most significant concerns in this area are the opportunities for further discrimination to occur against people with disabilities, based on third party access to healthcare information through My Health Record. This may include health insurers, government agencies, law enforcement and researchers that otherwise a person may not give informed, explicit consent to accessing their information.

While details about who and what agencies and organisations would be able to access information contained in MHR have been confused, varying and sporadic, there have been consistent concerns about how information collected today will be used in the future. There is no way of telling what policy trends will eventuate and develop in the future that third party access to healthcare records will affect.

People with disabilities report higher rates of discrimination from healthcare professionals than people without disabilities (AIHW, 2017) and we are concerned that any potential access by a third party in the future would see an increase in these incidences, as well as discrimination by other non-healthcare agencies. We also note our understanding that a low rate of implementation of My Health Record connectivity across healthcare providers in ACT will lead to a significant delay in seeing the full benefits of functionality, meaning the risks of



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third party access won't be offset by the benefits of a fully functioning system. Healthcare providers require their clinical records systems to interact with My Health Record, and until there is functionality to do this across the healthcare sector in ACT then information going into the system will remain sporadic and scattered.

the Government's administration of the My Health Record system roll-out, including:

- iv. **the public information campaign, and**
- v. **the prevalence of 'informed consent' amongst users;**

There currently seems to be no function planned for on-the-ground support for people without regular access to a computer or internet. We know that people with disabilities face systemic barriers to public computer and internet access, and that people with disabilities have lower rates of internet access at home than those without disabilities (2012, ABS Survey of Disability, Ageing and Carers). We have members who are not registered with MyGov yet have expressed interest in accessing the benefits of MHR. With no initial or ongoing support to access the system, they are likely to simply opt out over the phone, meaning the full benefit of the system for that individual and the Australian community overall will not be realised.

As well as the lack of MHR rollout support for people with disabilities in ACT, we have also witnessed a lack of contextualised and accessible information about MHR that is suitable for people with disabilities. This extends to:

- basic information about the system, it's risks and benefits;
- requirements to access the system; and
- support for people with disabilities to access the system, use the system and make an informed decision to stay in or opt out.

Information that was presented to the public was inaccessible, or on platforms that are not accessible to all people with a disability (such as Facebook).

An additional concern is the lack of support for people with cognitive impairments to make an informed decision to stay in or opt out. We are not aware of any accessible support or resources created by the Digital Health Agency (or its partners) that supports people with cognitive impairment to make an informed choice about the management of their healthcare information through My Health Record. We produced some basic resources (available on our website, <https://www.pwdact.org.au/>) as part of a wider project we are undertaking on disability and health, but there are lots of organisations in ACT that would be able to assist with individual support if they were funded for it. While primary healthcare providers are in



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an ideal position to do this, to get most impact it needs to be done in collaboration with established consumer bodies.

Recommendation 2: that ongoing, individual, face-to-face support for people to better understand and access My Health Record is funded through local sector organisations.

Recommendation 3: that any individualised support for people with disabilities accurately reflects the needs of people with disabilities to make an informed decision about using the system. This should include accessible processes to opt out of the system for people with disabilities in ACT.

Recommendation 4: that a more thorough public information campaign, across a number of accessible mediums and platforms, is funded to ensure information about the system reaches all members of the community.

Summary of recommendations

Recommendation 1: that the MyGov and My Health Record portals are urgently updated to meet Web Accessibility standards.

Recommendation 2: that ongoing, individual, face-to-face support for people to better understand and access My Health Record is funded through local sector organisations.

Recommendation 3: that any individualised support for people with disabilities accurately reflects the needs of people with disabilities to make an informed decision about using the system. This should include accessible processes to opt out of the system for people with disabilities in ACT.

Recommendation 4: that a more thorough public information campaign, across a number of accessible mediums and platforms, is funded to ensure information about the system reaches all members of the community.