

**SUBMISSION TO PCEHR
REVIEW PANEL**

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Where things stand

PCEHRs have considerable but currently untapped capacity to lead to better health and more cost effective health care for people with intellectual disability -

1. PCEHRs have great potential benefit for people who have impaired capacity to recall and give a history to a health professional.
2. There are approximately 1,000,000 such people in Australia - with intellectual disability (approximately 300,000), dementia, other cognitive impairments and mental illnesses. Members of these groups commonly have poor access to health services and poor health outcomes; this is the case for people with intellectual disability who face 'stark health inequalities' (National Health and Hospitals Reform Commission, Interim Report page 55, Final Report, page 82).
3. The balance of this submission focuses on people with intellectual disability. However, the situation is similar for other people with impaired capacity.
4. People with intellectual disability will commonly need support to exercise 'personal control' over their records. In many cases, this will extend to needing a substitute decision maker to make decisions about the records.

5. Until a clear, practical and user friendly substitute decision making system was in place, it would have been impractical to promote take up of PCEHRs in the intellectual disability sector.
6. The PCEHR Act section 6 created a framework for an 'authorised representative' to make substitute decisions for people unable to make their own PCEHR decisions.
7. With major input from us, in June 2013, the then Department of Health and Ageing resolved policies to give effect to the authorised representative system:
 - *Authorised representatives for the purpose of the PCEHR Act.*
 - *Disputes amongst authorised representatives*
 - *Obligations of authorised representative or nominated representative to act in the best interests of consumers.*
8. Research by Queensland Centre for Intellectual and Developmental Disability indicates that people with intellectual disability and their families are positive about the potential of PCEHRs, but have limited understanding about how to register and use records.
9. There remain necessary steps to underpin take-up of PCEHRs in the intellectual disability sector:

What still needs to happen

1. Produce a package of website and pamphlet material on the authorised representative system including material accessible to people with intellectual disability and their families.
2. Remove a legislative impediment to public guardians around Australia (called Public Guardians, Public Advocates etc in different jurisdictions) being authorised representatives due to their not having a healthcare identifier (section 6(6))
3. Design and implement a strategic plan to promote take-up. This plan should include the following ingredients:
 - a. Strategies for promotion of take-up aimed at key players:
 - People with intellectual disability and their families.
 - GPs and other health professionals.
 - Disability service providers.
 - b. Liaison with the National Disability Insurance Agency - there is clear scope for a win-win-win result from collaboration between the PCEHR system and the NDIA:
 - Better health for people with disability leading to
 - Lower health care costs and
 - Lower disability support costs.

We would be happy to input to design of such a plan which is in line with one of the Recommendations from the National Roundtable on the Mental Health of People with Intellectual Disability which we organised with high level input from health, education and disability agencies around Australia and professional colleges.