

# The Personally Controlled Electronic Health Record (PCEHR) for Adults with Severe Communication Impairments: Findings of Pilot Research

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**Abstract.** To date, there is little information in the literature to guide the provision of supports for using the Personally Controlled Electronic Health Record (PCEHR) in populations with severe communication impairments associated with a range of disabilities. In this paper we will (a) outline the rationale for use of PCEHR in these populations by providing an overview of relevant research to date, and (b) present results of three integrated pilot studies aiming to investigate the barriers to and facilitators for PCEHR use by people with severe communication impairments and their service providers. Finally, we will present directions for future research on use of PCEHR by people with severe communication impairments.

**Keywords.** PCEHR, severe communication impairment, disability supports

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## Introduction

An estimated 6.1% (~1.4M) of the Australian population have severe or profound limitations in the core activities of communication, mobility and/or self-care [1, 2]. People with severe communication impairments include those with acquired brain injury (e.g., stroke, traumatic brain injury) neurodegenerative disorders (e.g., Parkinson's disease) and developmental disabilities (e.g., cerebral palsy, intellectual disability, autism). In this heterogeneous group, 70% report having four or more long-term health conditions [3]; and up to 80%, have severe communication impairments, including 25% who are non-verbal [4]. They have significantly higher rates of health service utilisation than the general population [5,6] and health service utilisations increase as this group experiences age-related illness and functional decline [7]. This group often relies on family carers or paid carers for support to access health care [8-14]. They experience problems with early hospital discharge and unplanned readmission [6], have a three-fold increased risk of patient safety incidents in hospital [12,15] and are at risk of preventable harm and/or premature death related to poor communication [16 - 19]. There is now substantial evidence that problems with healthcare for patients with severe communication impairments relate to the inadequate exchange of health information [8-14,16]. These patients struggle to convey their health history and symptoms, and in healthcare episodes carers are unable to pass on all relevant health information in the limited time available [8-14, 16]. When admitted to hospital, people with severe communication impairments often take large folders of written information [12]. This information is rarely used by hospital staff who do not have time to 'sift through' a plethora of documents for information on medications, health history, and care planning [17]. Poor health information exchange and follow-up leads to a cascade of errors and, at the most extreme, premature death [19]. To date, there has been no attempt to evaluate ways to improve the exchange of health information for this vulnerable group of people.

The Personally Controlled Electronic Health Record (PCEHR) is "an electronic record for a patient that contains a summary of their health information from all their participating healthcare providers" [23]. It provides a timely means to rectify the problems associated with the poor exchange of healthcare information for people with severe communication impairments. Introduced in Australia in 2012, the main purpose of the PCEHR is to improve the quality, safety and efficiency of patient care [20-22]. Health benefits to individuals using PCEHR are expected to occur when: (a) patients and their healthcare providers are engaged in updating, uploading, sharing, and reading information in the record; (b) with regular use, the record builds up a picture of 'health events' for an individual; and (c) the information in PCEHR is referenced at critical points such as admission to hospital, discharge from hospital, and change of health or disability service providers [23]. Using PCEHR will increase patients' engagement in their own healthcare, potentially resulting in cost-benefits to the health system [24, 25]. Although the PCEHR presents an opportunity to improve health information exchange for people with severe communication impairment and associated poor health literacy [26], it also presents practical challenges for this group. Without appropriate support it is likely that people with severe communication impairment will be functionally excluded from this promising national e-health initiative [16, 27]. Disability and health services will need to support this population to use the PCEHR; but there is no evidence to guide them in how to do this. The proposed research will address this gap in knowledge.

## **1. Establishing the Rationale for PCEHR and Its Potential Benefits for People with Severe Communication Impairments**

In 2014 we were invited to conduct a metasynthesis review of research investigating the communication and care experiences of adults with severe communication impairments in hospital [14]. This revealed a strong rationale for shared health information to replace the ineffectual written folders patients/carers take to hospital, and the need to address substantial problems with care and safety. Our subsequent review of PCEHR literature in 2015 found only one study investigating the use of electronic medical records (not PCEHR) which related to making information about systems more accessible to adults with intellectual disabilities [16], a sub group of our target population. The National eHealth Transition Authority (NeHTA) publications have provided important information on the scale of use for PCEHR since its launch in July 2012. To date, 10,721 medical practitioners, 7,645 healthcare providers, and just over 2 million Australians have registered to use PCEHR [20, 23]. GP practices receive some support from Medicare Local e-health teams to use the system (in future, Primary Health Networks). However, we located no disability-specific information to guide disability and health services on the nature, configuration, or amount of support needed to implement PCEHR with any group, including people with severe communication impairments.

## **2. Pilot Studies on PCEHR for Adults with Severe Communication Impairments**

In 2014 we obtained ethical approval of the Human Research Ethics Committee at The University of Newcastle and the organisations assisting with recruitment, to conduct this research on use of the PCEHR with people who have severe communication impairments associated with a range of chronic disabling health conditions including: cerebral palsy, aphasia following stroke, intellectual disability, and traumatic brain injury. The aim of the studies was to investigate people's views and experiences of PCEHR, so as to identify barriers and facilitators to using PCEHR to inform future policy direction and future research.

### *2.1. A Sociotechnical Case Study (Observation) of Home Health Record Use*

This sociotechnical case study of a young adult (aged under 25) with severe cerebral palsy and severe communication impairments involved an interview, an observation of her use and access to her own health records at home, and an examination of her home health informatics (storage method and document types). She used a wheelchair for mobility and having no speech used a speech-generating device to communicate, by use of a wheelchair mounted switching system. Her health information was stored loosely at home as hard copy documents in an expandable file, and in soft copy on her personal computer in the 'documents' folder or on 'email'. She required full assistance from a carer to access the health documents in the expandable file (i.e., retrieval from under her desk, open, search through, find). In contrast, she accessed the computer and Internet independently using assistive technologies, and could retrieve information that health professionals had sent to her by email. However, her health information was not stored or organised systematically; there was some ad-hoc duplication between electronic and hard copy information; and no cross-referencing. This case study

suggested that the PCEHR could benefit individuals with severe communication impairments, but that a range of supports may be needed to (a) organise and prepare information for upload to the PCEHR in a systematic way [28], and (b) integrate hard and soft copy documents (on the home computer) with documents in the PCEHR.

## *2.2. Survey of Adults with Severe Communication Impairments on Use of PCEHR*

In 2014, we surveyed 12 adults with diverse severe communication impairments (after stroke, cerebral palsy, brain injury) about using PCEHR, including 9 by face-to-face interviews and three by online survey. All participants lacked confidence communicating with unfamiliar healthcare providers and thought the PCEHR would help them by improved 'storing' and 'sharing' of health information that was important to them. Only one of the 12 had registered for PCEHR and all wanted further information from disability service providers. This suggests that supports are needed for this group to commence PCEHR use and upload documents. The participant who had registered for PCEHR considered it had been beneficial and all participants expected to benefit by using PCEHR. As one said: *"It is so tiring to continually explain my history and progress. Every meeting with a new health professional requires a lot of work for them to understand."* Further information is needed to determine whether the investment of time and effort by people with severe communication impairments and their supporters in using PCEHR will see improved health information exchange when people with these disabilities meet with health professionals [6,9-13].

## *2.3. Focus Groups Discuss the PCEHR*

In 2015, we held two focus groups to discuss barriers to and facilitators for PCEHR in people with severe communication impairments. Each focus group was 1 hour long and held at each participant's workplace. The groups were audiotaped and transcribed verbatim with identifying information removed, and analysed for content themes. Participants in our pilot study were care workers in supported accommodation ( $n = 9$ ) and allied health clinicians ( $n = 5$ ) supporting adults with severe communication impairments. Further focus groups are underway in March 2015 to capture other key stakeholder groups (parents, medical staff, nurses). Overall, the focus group discussions reflected that direct support workers and allied health professionals have a keen interest in PCEHR, perceiving it to be "wonderful", and "a huge benefit" to people with severe communication impairments. However, despite seeing themselves as pivotal in prompting GPs to use their clients' PCEHRs, they had no personal experience of using PCEHR themselves. For example, they were unclear about who would give consent to opt in or out of PCEHR when a client lacked capacity, and about who gave consent for uploading new documents (e.g., a Shared Health Summary). Allied health professionals were also unsure how use of the PCEHR would facilitate collaborative engagement across the disciplines and saw the role of GP as pivotal in this regard. They also acknowledged that PCEHR might support improved health information exchange for people with disabilities who see new healthcare providers in busy GP practices.

### **3. Directions for Future Research**

As governments seek to predict costs relating to the physical wellbeing of adults with disabilities, the allocation of funding for carers and disability and health services to support people with severe communication impairments in using PCEHR has been overlooked. The findings of these pilot studies are timely, as from 2016, the demand for effective exchange of health information will increase as disability service provision in Australia transitions from highly regulated government to non-government providers through individual funding packages within the National Disability Insurance Scheme (NDIS). Disability support worker time will be tied to provision of funds for support in the home. There is an urgent ethical imperative to focus research efforts on PCEHR use in populations with severe communication impairments who have a three-fold increased risk of adverse events, and are at risk of being excluded from use of the PCEHR system unless there are adequate supports from disability service providers and carers. Further research is needed to inform policies and practices that will help to ensure the inclusion of people with many types of disabilities in one of Australia's most significant national public health ICT initiatives. This information is urgently needed as new policies and updated legislation for PCEHR are formed, to ensure that 'adoption' is followed by use and not by the 'abandonment' or dis-use associated with problems either with the process, people involved, or the PCEHR technology.

Further research is needed to determine the configuration, types, timing, and amount of support needed for adults with severe communication impairments to use the PCEHR, by investigating: (a) Factors affecting successful use of PCEHR by people with severe communication impairments, their families, support workers, and health service providers; (b) Risks and benefits of PCEHR use for people with severe communication impairments; (c) People, teams, and processes needed to deliver supports for functional use of PCEHR; (d) Costs and potential cost offsets of supporting the target population to use PCEHR; and (e) An exploratory economic appraisal that draws together findings of (a)-(d) to model potential cost-effectiveness.

### **4. Conclusion**

In conclusion, the results of our three pilot studies show that PCEHR usage is not yet integrated into organisational policies in supported accommodation settings. People with severe communication impairments, direct support workers, and allied health clinicians are uncertain about how PCEHR integrates with existing paper records in terms of duplication, overlap, or replacement. They perceive use of PCEHR to be beneficial but are unsure whether PCEHR use will replace the large amount of written material in folders taken to appointments for patients with complex conditions. Consequently, it is essential to understand how both paper and PCEHR records integrate in the home so that implementation of PCEHR is not problematic [28]. Participants in our pilot studies were unsure whether healthcare providers would invest the extra time required to use PCEHR with patients who, because of their communication impairments already require long consultations. They feared they would be refused access to GP practices for this reason. Thus, it is vital to match the 'time cost' of using PCEHR with evidence of 'time benefit' and 'health benefit'; the benefits of PCEHR in reducing adverse events associated with poor information exchange may only be seen if time efficiency is evident. Given the pivotal part carers

play in supporting information exchange, their lack of clarity about their roles in relation to PCEHR poses a threat to its use and potentially impedes its long term benefit.

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