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Use of the My Health Record (MyHR) by people with communication disability in Australia: a review to inform the design and direction of future research

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Abstract
Background. People with communication disability often struggle to convey their health information to multiple service providers, and are at increased risk of adverse health outcomes related to the poor exchange of health information.
Objective. The purpose of this article is to (a) review the literature informing future research on the Australian personally-controlled electronic health record, 'My Health Record' (MyHR), specifically to include people with communication disability and their family members or service providers, and (b) to propose a range of suitable methodologies that might be applied in research to inform training, policy, and practice in relation to supporting people with communication disability and their representatives to engage in using MyHR.
Method: The authors reviewed the literature and, with a cross-disciplinary perspective, considered ways to apply sociotechnical, inclusive research, and health informatics methodologies to research on MyHR use by adults with communication disability.
Research outcome(s).
This article outlines a range of research methods suitable for investigating the use of MyHR by people who have communication disability associated with a range of acquired or lifelong health conditions, and their family members or direct support workers.
Conclusion.
In planning the allocation of funds towards the health and wellbeing of adults with disability, both disability and health services must consider the supports needed for people with communication disability to use MyHR. There is an urgent need to focus

research efforts on MyHR in populations with communication disability, who struggle to communicate their health information across health and disability service providers. The design of studies and priorities for future research should be set in consultation with people with communication disability and their representatives.

Keywords (MeSH): Electronic Health Records**;** Communication; Health Communication; Personal Health Records**;** e-Health; Communication Disabilities; Disability; Research; Health Information Management; Methods; Health Equity

Supplementary keywords: Communication Disability; My Health Record; MyHR; Personally Controlled Electronic Health Records; PCEHR

Introduction
The World Health Organization's (WHO) World Report on Disability estimated that as many as 20% of the world's population have a disability (WHO, 2011). Furthermore, a vast array of health conditions are associated with impairments to body structures and function that impact upon communication (e.g., affecting the structures and functions of the brain, ear and hearing, eyes and vision, oral and articulatory structures, voice, respiratory system) and as such a high proportion of people with health conditions affecting those body structures and functions may have associated communication impairments impacting upon their activities and participation (WHO, ICF, 2001). According to the ICF (WHO, 2002: 2) disability is "an umbrella term for impairments, activity limitations and participation restrictions". In this article, we use the term 'communication disability' as an umbrella term for communication impairments, communication activity limitations, and restrictions in communicative participation. People with disabilities in Australia (18.9% of the population, an estimated 4.5M people) are supported by an estimated 2.6M carers (Australian Bureau of Statistics [ABS], 2013). People with chronic disabling health conditions, namely: acquired brain injury (e.g. stroke and traumatic brain injury), neurodegenerative disorders (e.g. Parkinson's disease, motor neuron disease), developmental disability, (e.g. cerebral palsy, intellectual disability, autism); who have severe or profound limitations in the core activities of communication mobility and self-care make up an estimated 5.8% (now ~1.4 million) of the Australian population (ABS, 2013) (now ~ 23.9M, ABS, 2016). In this group, 70% reported having four or more long-term health conditions (ABS, 2011), including several that affect communication (e.g., epilepsy, mental health conditions, and respiratory health conditions). People with developmental disabilities have particularly high rates of communication disability; up to 80% of people with cerebral palsy, intellectual disability, or autism have communication disability, including an estimated 25% being non-verbal (Access Economics, 2008).

People with communication disability also have higher rates of health service utilisation than the general population (Wallace and Beange, 2008; Young et al., 2007) and health service utilisations increase as this group experiences age-related illness or functional decline (Strauss et al., 2004). As a result of their impairments, people with communication disability often rely on family carers or paid carers for communication support to access health care (Balandin et al., 2007, Hemsley et al., 2008, Hemsley et al., 2013, Webber et al., 2010). They experience problems in care, including early discharge and readmission to hospital (Dinsmore 2011, Gibbs et al., 2008, Heaton et al., 1999, Hemsley et al 2013, Kelly et al 2015, Wallace and Beange

2008), and have a three-fold greater risk of patient safety incidents (Bartlett et al., 2008). In hospital and at home, poor health information exchange and follow-up leads to a cascade of errors and, at the most extreme, even premature death (Hemsley et al., 2015, NSW Ombudsman 2013, Scottish Government 2013).

There is now substantial evidence that problems with care for people with communication disability relate to the inadequate exchange of health information at the point of care (see Hemsley and Balandin 2014, Hemsley et al 2015a, Mastebroek et al 2014., Tuffrey-Wijne et al., 2014). Hospital patients with communication disability struggle to convey their health history and symptoms, and often carers are unaware or unable to pass on all relevant health information in the time available (Hemsley et al 2013, Hemsley and Balandin 2014, Tuffrey-Wijne et al., 2014). In attempts to address the problem of information exchange, people with severe communication disability often take written information about their health with them to hospital (Hemsley et al 2011, Webber et al 2010). This information is rarely used by hospital staff who do not have time to 'sift through' a large number of personally held documents for information on medications, health history, and care planning (Hemsley et al., 2012). To date, there has been no evaluation of attempts to improve the exchange of health information across multiple health settings for people with communication disability by the use of personally held electronic health record systems. As the national rollout of the National Disability Insurance Scheme (NDIS) supports a move from highly regulated Government to less well-regulated non-Government profit and non-profit disability organisations, an evaluation of the impact of using MyHR on improving the exchange of health information could inform funding of NDIS funded supports for people with communication disability, their families, and service providers to meaningfully engage with the MyHR system.

The Australian e-health record: My Health record
The Australian 'My Health Record' was launched in Australia in July 2012 as the Personally Controlled Electronic Health Record (PCEHR). The system is now named My Health Record (MyHR) (see the My Health Record Act, 2012, Australian Government, 2015). MyHR is an electronic record for a patient that contains a summary of a patient's health information from all their participating healthcare providers (NeHTA, 2016). It provides a timely means to rectify the problems associated with the poor exchange of health care information for people with severe communication disability. The main purpose of MyHR is to improve the quality, safety and efficiency of patient care (Pappas and Car 2011). By 30th June 2015, 7,773 healthcare providers, and just over 2.2 million Australians had registered to use MyHR (Commonwealth of Australia, 2015). Two trial sites for testing of systems surrounding an 'opt out' process of registration, one in New South Wales and one in Queensland, are underway (Australian Government, 2015) and will be evaluated in 2016. People with communication disability need to have the same opportunity for 'opting out' of MyHR as other people are afforded. The 'opt out' system is put forward as one way to increase population participation in MyHR. Health benefits to individuals using MyHR 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 MyHR is referenced at critical points such as admission to hospital, discharge from hospital, and change of health or disability service providers (Georgiou et al., 2013, Hordern et al., 2011). Using MyHR is expected to increase patients' engagement in their own health care, potentially

resulting in cost-benefits to the health system (Department of Health and Ageing, 2011, Hibbard et al., 2013). Despite the relatively low uptake in the general population, and the potential benefits to people with communication disability, in reviewing guidance to consumers or providers on using MyHR (see Australian Government Department of Health, n.d.) we could locate no disability-specific information to guide consumers or service providers on the nature, configuration, or amount of support needed to implement MyHR with people with communication disability.

Although the MyHR system presents an opportunity to improve health information exchange for all Australians, including people with communication difficulties and poor health literacy (Hill 2011), it also presents practical challenges for people with communication disability (Hemsley et al 2015b). Without appropriate support it is likely that people with communication disability will be functionally excluded from this promising national e-health initiative (see Van Dooren et al., 2013). Disability and health services will need to support people with communication disability to take up MyHR, but there is no evidence to guide them in how to do this. It is not known how people with communication disability will engage meaningfully to control who access their MyHR, nor (a) the configuration, types, timing, and amount of support needed for adults with communication disability to use MyHR, (b) factors affecting successful use of MyHR by people with communication disability, their families, support workers, and health service providers; (c) risks and benefits of MyHR use for people with communication disability; (d) people, teams, and processes needed to deliver supports for functional use of MyHR; or (e) costs and potential cost offsets of supporting the target population to use MyHR. People with a disability have rights under the United Nations Convention on the Rights of Persons with Disability (CRPD, 2006) to be included in using MyHR, and to be consulted and to have their views and preferences taken into account in decision about that use (e.g., the appointment of nominated or authorised representatives, and whether or not the record will be shared with health providers). Therefore, the aim of this paper is to review the literature relating to use of MyHR by people with communication disability in Australia, and propose various research methods that might be used in future research. Growth in research on the use of MyHR is urgently needed to inform new policies to support wellbeing and health through improved health information exchange for people with communication disability.

MyHR and its potential benefits for people with communication disabilities
In 2014, a metasynthesis review of research investigating the communication and care experiences of adults with communication disability in hospital (Hemsley and Balandin 2014) revealed a strong need for shared health information to replace the ineffectual written folders patients/carers take to hospital to improve care quality. Subsequently, an integrative review of 27 studies relating to hospital patient safety and people with communication disability (Hemsley et al 2015a) reflected a need for increased use of written health information shared across service providers, to address substantial problems with healthcare safety. There is however very little research examining the implementation of new health information technologies to improve care quality or safety for patients with little or no speech in hospital. To date, we have located only two small studies including participants with communication difficulties investigating the use of electronic medical records: one exploring perceptions of MyHR use by adults with intellectual disability and their supporters (Van Dooren et al 2013) and another on perceptions of MyHR by people with communication disability

associated with a range of health conditions (Hemsley et al 2015b). Van Dooren et al., (2013) included four adults with intellectual disability, three mothers, and two direct support workers, in interviews revealing that people with intellectual disability and their supporters receive a large amount of information from different health providers, and that any use of MyHR would need to complement rather than add to their existing methods of managing their interactions with the health system and health information. In a pilot study testing integrated sociotechnical methods of research on MyHR, Hemsley et al., (2015) identified potential problems associated with MyHR use by adults with communication disability that might form barriers to MyHR implementation more broadly (Hemsley et al 2015b). The study included one case study observation and interview with an adult with cerebral palsy and severe communication disability, and interviews with 12 adults with various communication disability (associated with stroke, cerebral palsy, or brain injury). People with communication disability reported wanting to know more about MyHR but not having received information through disability service providers, and that they expected using MyHR would be of benefit in situations where they were talking with unfamiliar health providers. In two separate focus groups, paid carers and allied health professionals voiced broad support and positive expectations of benefit of MyHR for adults with communication disability. Despite seeing themselves as pivotal in advocating that their client's medical staff (in particular, the general practitioner) to read or use the client's MyHR system, direct support workers and allied health professionals described having no personal experience of using MyHR, and reported a range of misgivings about its use - mostly relating to lack of knowledge and experience (Hemsley et al 2015b). Given the pivotal part carers play in supporting health information exchange, their lack of clarity about their roles in relation to MyHR and their lack of experience in using the system poses a threat to its use and potentially impedes its benefit for people with communication disability. In the context of there being very little research on this field to date, it is not known whether MyHR use will lead to increased demands (e.g., of time, knowledge, information management) upon people with communication disability and their supporters, and, if so, whether these increased demands are balanced or outweighed by benefits to healthcare resulting from improved information exchange, or a reduction in effort to convey information at the point of health care (e.g., when admitted to hospital, when seeing a new healthcare provider).

In summary, the limited research to date that has included people with communication disability, their families, and disability support staff (Hemsley et al., 2015b; van Dooren et al., 2013) shows that MyHR is not yet integrated into policies on the use of paper health records in supported accommodation. People with communication disability are uncertain about how MyHR would integrate with their existing paper records in terms of duplication, or overlap. They perceive use of MyHR to be beneficial but are unsure whether MyHR 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 MyHR records integrate in the home so that implementation of MyHR is not problematic (Georgiou et al., 2007, Hordern et al 2011). It is vital to match the 'time cost' of using MyHR with evidence of 'time benefit' and 'health benefit'; the benefits of MyHR in reducing adverse events associated with poor information exchange may only be seen if time efficiency is evident.

We propose that an evidence-based framework of supports and guidance for patients with communication disability, carers and health providers is needed to

reduce or remove barriers to MyHR use so that its potential benefits can be fully realised. In these relatively early days of MyHR implementation, longitudinal research that is inclusive of people with a range of disability affecting communication (such as Participatory Action Research (Reason and Bradbury, 2008), mixed-methods research (e.g., using multiple data sources) analysed with constructivist grounded theory techniques (Charmaz 2014), and economic appraisal (Carter et al., 2008) are ideally suited to developing such a framework and guiding policy and practice in Information Communication Technology (ICT) implementation. Applying inclusive Participatory Action Research methods towards implementation of MyHR in supported accommodation settings might provide new information on ways that people within the disability service sector might influence uptake, use, and benefit of the MyHR system. The inclusion of people with communication disability on investigative teams, as participants, and on expert reference groups (Seale et al., 2015) is well justified in MyHR research, considering the lived experiences and insights into communication-related problems encountered in healthcare and on the feasibility of implementing strategies to improve participation in MyHR.

A mixed-methods approach (Creswell 2009) is also appropriate to apply to analyses of data in building the evidence-base for use of MyHR by people with communication disability. Multiple case analyses would allow blending experiential reports (focus groups, narrative interviews) (Krueger and Casey 2008; Reissman 2008) with observations and metrics (MyHR; hospital medical records; patient safety databases) and include the views of experts in expert consensus panels. Matching of data from multiple sources, including experiential, observational, and PCEHR data on multiple cases, matched by medical record number with safety incidents logged in a patient safety incident database, would form an innovative extension of methodologies. These multiple data sources analysed using constructivist grounded theory approaches (Charmaz 2014) would lay the foundation for future quantitative designs for measuring specific aspects of PCEHR use or benefit for particular populations.

Sociotechnical data

Research investigating human use of an ICT solution in health information management demands a sociotechnical approach. Sociotechnical research enables both the technology and the human supports needed to use the ICT to be uncovered - vital in a population who rely on assistive technology and human supports for access to e-health technologies (Georgiou et al 2007, Whetton and Georgiou 2010, Westbrook et al 2007). The Committee on Patient Safety and Health Information Technology Board on Health Services from the Institute of Medicine (Committee 2011) underscored the complexity of health ICT systems along with the many risks associated with poor design or faulty implementation strategies (Georgiou et al 2007, Whetton and Georgiou 2010). The committee noted that human elements must be considered in the design and implementation phases of new health ICT systems to maximise benefits and reduce unintended adverse consequences (Georgiou et al 2013, Greenhalgh et al 2010, King et al 2010). Sociotechnical perspectives consider health care settings as open systems in which people interact with technology within the environment (Georgiou et al 2007, Whetton and Georgiou 2010).

Qualitative data

Qualitative and mixed methods research designs are important foundational studies in exploring the human experience and social forces that might impact MyHR use (see

Garrety et al., 2014). Data on the experiences of people with communication disability and their supporters as they start to use MyHR would shine a light on the guidance and supports needed for registration and use of MyHR at home, including its first integration with paper records (Fitzpatrick 2000; Georgiou et al 2013). Researchers and policy makers could attend to ways in which organisations, individuals, carers, and people with communication disability approach the 'sifting' process to transfer and integrate written health from their hard copy paper files (Fitzpatrick 2000) and computer storage folders to a MyHR system of record keeping. This would yield important information on barriers and facilitators for *both* the person with communication disability along with carers and health providers, to engage with MyHR. Diverse methodologies including focus groups (Krueger and Casey 2008), narrative interviews (Reissman 2008), observations (Creswell 2009), could be used to yield information on the following topics (a) perceptions of information and support needs for start-up and use of MyHR, (b) person identified as responsible for consent identified, including relationship and process; (c) experiences of carers/family members/healthcare providers in using MyHR; and (d) supports, assistance, adaptive equipment and time involved in encapsulating health histories for documents to be uploaded to MyHR.

Longitudinal data
Longitudinal data on MyHR use could be gathered to determine: (a) MyHR patterns of use, benefits obtained, and barriers or enablers to use; (b) resources used in relation to MyHR use (time, money, personnel, adaptive equipment, consultation, supports or guides); and (c) the inclusion or exclusion of the person with a disability from engagement with MyHR activities. Inclusion of sociotechnical observations at home might yield data on any issues relating to access and the inclusion or exclusion of the person with communication disability from the process of using MyHR. Other matched data sources might provide important triangulating insights and relevant details alongside MyHR data. Using medical record numbers to match a person's MyHR data with information retrieved from patient safety incident databases, and from hospital medical records, can to add information on patient safety incidents, hospital admissions data, discharge summary data, and any references to the use of MyHR at admission or discharge from hospital. A comparison of data from the different sources would be useful to determine the completeness and consistency of health information across data types. Such a comparison will show 'gaps' in data quality between the hospital record and MyHR. For example, if an allergy is documented in the medical record, it would be possible to detect if it is in: the pharmacy database connected within MyHR, the Shared Health Summary, the Personal Health Note on the consumer side of the record, and on the hospital discharge summary uploaded to MyHR.

Potential data sources in MyHR
The data contained in a participant's MyHR is important as being categorical evidence of MyHR use and an archived record (Coiera 2015) that reflects the person's - and their healthcare providers' - timing and use of MyHR. As such, research need not be solely reliant upon views of MyHR experiences or attitudes towards MyHR, although this is also important information since attitudes and experiences influence behaviour in use of e-health technologies (Sorensen et al., 2012, Squiers et al., 2012). MyHR usage and content data, gathered with appropriate informed consent, can be used to triangulate, verify, expand upon, and be compared with other data sources.

Notification SMS alerts - sent to participants or their Authorised Representative(s) whenever a person (e.g., participant, carer, health provider) has accessed their MyHR - could be included as research data on the date and type of use, to see *who* entered the person's record and *when* this occurred. This could be checked against the audit log to determine *what* was done in the record at the time. Quarterly data capture would detect changes in document versions, how often new Shared Health Summaries or Event Summaries are uploaded, what has changed within them, and the number of different authors. MyHR usage data can matched to other data sources (e.g., every three months) specifically: Health Event Summary, Shared Health Summary (SHS), Discharge Summaries and Prescribe/dispense notifications, and also information stored on the 'consumer' side of the record, the Personal Health Note, and Custodian of the Advanced Care Directives. The contents of the Personal Health Note are also of importance in person-centred MyHR research, in that only the person can upload and view their Personal Health Note, and the information is not seen by any health providers with online access to the person's MyHR. It is only available to the health provider if the person provides a printed copy, or if the health provider is viewing the person's computer screen when that person is logged in MyHR. It would also be important to note whether there is a named custodian of the Advance Care Directive in MyHR system for each participant, and broader research on Advance Care Directives might benefit by the inclusion of MyHR data.

Health economic analysis
Economic evaluation is designed to answer one or both of two questions: (i) should an option for change be introduced (value for money or 'allocative efficiency' question); and (ii) if so, how best to design or implement it (the 'technical efficiency' question). Early studies in this area might need to focus on the efficiency question - not whether MyHR should be introduced or not, but rather 'how best' to provide MyHR for this vulnerable group. Indeed, the concept of 'how best' to implement MyHR has a range of dimensions, including equity of access for a special needs group, efficiency, affordability, and acceptability to stakeholders. While any early focus of the economic evaluation of MyHR in a heterogeneous group such as people with communication disability from a range of health conditions might be on technical efficiency, it is important the economic results are interpreted in the context of these broader considerations. A range of techniques can be used to analyse potential economic impacts, including: (a) Cost benefit analysis (CBA) to assess the potential cost savings (e.g., if $ value of adverse events/hospital admissions avoided > $ cost of the intervention); (b) Consequence analysis (CCA) to place the cost effectiveness ratios (ICERs) in the context of the full range of information collected in the study; and, (c) Filter analysis as used in the assessing cost effectiveness (ACE) studies to capture policy and implementation issues (such as 'acceptability to stakeholders', 'equity impacts', 'feasibility of implementation' and 'quality of the evidence base') (Carter et al., 2008).

While the need for modelled cost utility analysis (CUA) with 'cost per QALY' outcomes will also be considered as research progresses, it is unlikely to be required in early stages given the technical efficiency focus. Economic methods need to be chosen to provide useful information on potential cost-effectiveness for decision-makers, supported by comprehensive sensitivity and uncertainty analyses. Qualitative research, case studies, and data collection activities detailed in this paper will define the need for action and the intervention to meet that need. Costing of the intervention could then follow conventional 'pathway analysis' techniques with specification of

events, probabilities, and unit costs. Health economics research on disability and use of MyHR is necessarily multi-layered, covering 'government/agency as 3rd party funder', 'health sector', 'health provider', and 'participant /carers'. The information collected from observations, interviews, and MyHR records, together with expert judgement, might facilitate modelling of 'current practice' for the target population, together with scenarios for uptake of access and associated outcomes. Then, potential for cost offsets could be examined, modelled off case studies and best available data on avoidance of adverse events. Depending on the findings of early stage research, a number of 'current practice' and 'intervention pathways' may be constructed and analysed as both paired and weighted average comparisons using a range of economic methods.

Setting priorities for MyHR research

We have outlined a range of research methodologies that might be applied towards investigating MyHR use by people who have communication disability. Including people with a range of different communication disability in the design and conduct of future studies on MyHR is important. However, we have not outlined research priorities for people with a communication disability or any population with a disability. It is important that priorities for future research are set in consultation with people with communication disability who have a good understanding of the issues confronting them in attempting to share their health information with their multiple service providers. Future research needs to take into account which populations stand to benefit more by knowledge of the barriers and enablers to using the system - such as by their age (e.g., adolescents and young adults with a disability moving to adult services; older people with declining function or health), their health conditions (e.g., also have multiple health providers, or chronic health conditions), their reliance upon other people for support (e.g., have higher support needs), or which populations with a disability might be excluded by lack of support (e.g., those who live alone or lack adequate disability or family supports) and people with a disability who are not eligible for NDIS funding, including those with mild, temporary, or fluctuating communication impairments (e.g., associated with mental health conditions). Research attention could also be directed at the changing moral order of MyHR (Garrety et al., 2014) and its relation to and influence upon a shift of health services towards 'person-centred care' and 'supported decision-making', consistent with the UNCRPD (2006) and The Australian Law Reform Commission report on Equality, Capacity and Disability in Commonwealth laws (2014).

Ethical and Legal Issues in MyHR Research

The privacy, security, and confidentiality of health records is of central concern in disability and health services, and in health research. While it is beyond the scope of this paper to outline all of the legal considerations (see Gajanayake et al., 2012) and ethical issues impacting on implementation of MyHR in Australia (see Fry et al., 2014, Pearce and Bainbridge 2014, Spriggs et al., 2012), researchers need to be familiar with the complex "web of overlapping and inconsistent provisions" (Gajanayake, 2012, p. 17) in relation to privacy laws at National, State, and Territory level, that require agencies and organisations to "take reasonable steps to secure personal information." (p. 17). In applying legal and ethical considerations to MyHR research with people who have communication disability, appropriate informed

consent procedures would need to be in place for people with communication disability to individually authorise the use of their own MyHR data for research. Each participant (or legal guardian), and his or her Authorised Representative for MyHR access, need to be engaged in the informed consent process for the researcher to access to the contents of Shared Health Summary, Health Event Summary, and the Audit Log of the person's MyHR, and other documents in the system, for descriptive and categorical data. Informed consent is vital and, in order to protect the person's privacy and confidentiality of their health information, only de-identified data should be reported in such a way that any combination of data would not identify the person or their carers to people who know them or other parties. The participant and legal guardian/Authorised Representative would also need to be consulted in the de-identification of data prior to analysis to ensure clearance of materials published. Any expert consensus panels need only have access to de-identified case and MyHR data. A further protection to privacy and confidentiality would be reporting only de-identified group results in the public domain, and not providing all information on any one case in its entirety.

Conclusion
As governments seek to predict costs relating to the physical wellbeing of adults with disability, the allocation of funding for carers and disability and health services to support people with communication disability in using MyHR has been overlooked. Research on use of MyHR is urgently needed: by 2018, 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 framework of the NDIS. Disability support worker time will be tied to provision of funds for support in the home, and individual funding packages will need to factor in resources needed for use of ICT at home - including ICT related to health information management such as MyHR.

People with communication disability are a diverse and heterogeneous population. The authors would like to encourage researchers across disciplines to gather and combine research evidence across populations of people with diverse communication disability to inform an evidence-based framework for MyHR use by people with communication disability, elucidating (a) patterns of use, support, and a taxonomy of outcomes for MyHR use across the lifespan; (b) policies, practices, training, and decision aids for people with communication disability and their families and service providers, to facilitate use and benefit of MyHR; and (c) a schedule of costs for supports to use MyHR, to guide future funding allocation and planning in disability and health services. These outcomes will clearly identify the people, teams, processes, and funds necessary to deliver the supports required to enable the participation of people with severe and profound communication disability in the national MyHR initiative. A schedule of costs relating to use of MyHR, detailing suggested recommendations for supports and their associated costs, would enable funds to be allocated appropriately to support use of this important health infrastructure.

There is an urgent ethical imperative to focus research efforts on MyHR use in populations with communication disability who have a three-fold increased risk for adverse events, and are at risk of being excluded from use of MyHR system unless there are adequate funded supports from disability service providers and carers. The results of research on MyHR that includes people with communication disability will

inform policies and practices that will help to ensure the inclusion of people with disability in one of Australia's most significant national public health ICT initiatives. This information is urgently needed as new policies and updated legislation for MyHR 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 technology itself. The early outcomes of research on MyHR in populations with communication disability may assist non-government services in taking up their responsibilities to support the health of people with disability across Australia.

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