Submission to
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Electronic Health Records and Healthcare Identifiers
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Never Stand Still | Medicine | Department of Developmental Disability Neuropsychiatry

A Response to the Legislation Discussion Paper:

Electronic Health Records and Healthcare Identifiers

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Introduction and Background

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Australia supports the mental health needs of individuals with an intellectual disability (ID) through education and training of health and disability professionals and by conducting research with a particular focus on the mental health of people with an ID. 3DN's vision is to work with people with an ID, their carers and families, to achieve the highest attainable standard of mental health and wellbeing. 3DN is led by UNSW's inaugural Chair of Intellectual Disability Mental Health, Professor Julian Trollor, who is supported by a dedicated team of researchers, project and administrative staff. Professor Trollor has over 20 years of clinical experience in the management of people with an ID and complex health and mental health problems. He has had extensive experience with a range of disability service providers and professionals, and has led or contributed to numerous legislative, policy and service reviews in the disability arena. More information about 3DN and the work of the Chair IDMH can be found on our website: http://3dn.unsw.edu.au/

A significant minority (about 2%) of Australia's population have an ID[1]. People with an ID experience very poor physical health and mental health compared to the general population. The prevalence of mental disorders is at least two to three times higher in people with an ID compared to the general population[2]. Many people with an ID experience a high degree of complexity and an atypical profile and presentation of mental disorders[3], thus requiring a high level of psychiatric expertise, and coordinated approaches between services.

3DN commends the Department of Health on the proposed changes to the personally controlled electronic health record (PCEHR) and the Healthcare Identifiers (HI) Service to increase the number of individuals and healthcare providers participating in the PCEHR system and to increase the clinical utility and usability of the system.

Key PCEHR issues for people with an ID and their carers
The increased morbidity of people with an ID is compounded by difficulty accessing health and mental health services and an impoverished service system characterised by poor cross-sector coordination and poor preparedness of staff to meet mental health support needs. A cross-portfolio approach to improving health and mental health outcomes for people with an ID is greatly needed. In this context, it is important that data from the National Disability Insurance Scheme (NDIS) is able to be linked to the PCEHR. This will ensure that

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1 Australian Institute of Health and Welfare (2003). Disability Prevalence and Trends. AIHW Cat. No. DIS 34. Canberra: AIHW.
2 Cooper, S-A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. The British Journal of Psychiatry, 190(1), 27-35.
3 Fuller, C.G. and D.A. Sabatino, Diagnosis and treatment considerations with comorbid developmentally disabled populations. Journal of Clinical Psychology, 1998. 54(1): p. 1-10

de-identified data can be used to examine health outcomes in people with an ID (using the NDIS identification of ID, linked to health records), and to examine the impact of health supports on disability service provision and vice versa. This is critical if we are to improve the health status of people with an ID.

Researchers at 3DN currently undertake a large data linkage project where health, disability and other administrative datasets are linked to establish, relative to the general population, the epidemiology of mental and physical illness, the service pathways and costs, and patterns of mortality in people with ID (see: https://3dn.unsw.edu.au/project/intellectual-disability-mental-health-idmh-data-linkage-project). Once State-based disability services cease to collect and administer minimum data sets, the capacity to examine such outcomes will be lost unless specific capacity for such linkage is built in to NDIS and PCEHR data systems. We strongly recommend that data linkage capacities between health, disability and other administrative datasets (such as NDIS and PCEHR data) are enhanced, to ensure the routine and public reporting of health outcomes data for people with an ID, and to allow further research similar to that illustrated above. Doing so is an essential step to improving physical and mental health outcomes for Australians with an ID.

Participation

Many people with an ID may not have the understanding, information or support to consider what access controls they want to set. It is important to support and include people with an ID and their families in the decision making process. We recommend that comprehensive and nuanced information will be provided for any authorised representatives on the benefits and risks of the participation arrangements for individuals. This information should also be available in easy read versions for people with an ID.

Further, we propose that a mechanism is articulated by which an appointed (public) guardian is enabled to be an authorised representative for people with an ID so that the opt-out option is available for people with limited or no capacity to make decisions who are represented by a public guardian. Failure to take this step risks exclusion of some individuals with ID from an opt-out option.

Governance

The new eHealth organisation ACeH (Australian Commission for Electronic Health) will be governed by a skills-based board supported by a number of advisory committees with appropriate technical expertise and representation from jurisdictions and the sector. We recommend that the skills-based board and advisory committees include experts in the area of ID, and develops a mechanism for direct consultation with people with ID so that the needs and rights of people with an ID are being met.

Privacy and security

A strong strategy to protect privacy has been proposed. The PCEHR system provides access control mechanisms that enable registered individuals to set controls for their PCEHR if they wish to do so. However, people with an ID may not be able to make these choices with ease or fully understand the implications of these choices. We therefore recommend the development of a clear process for supporting people with an ID to engage with all access control mechanisms.

Summary of Recommendations

We recommend:

- That at least one of the trials of different participation models for the PCEHR system include a focus on people with an ID
- Inclusion of ID experts in skills-based board and advisory committees of ACeH, and development of a mechanism for the ACeH to consult directly with people with an ID
- The design and legislation of PCEHR should allow for linkage between NDIS and PCEHR, and develop a mechanism for annualised publication of outcomes (health and disability) for people with an ID
- Provision of comprehensive and nuanced information for any authorised representatives on the benefits and risks of the participation arrangements for individuals as well as easy read versions of this information for people with an ID
- That officially appointed 'public guardians' be enabled to be an authorised representative for people with an ID so that the opt-out option is available for people with ID who are represented by appointed guardians
- The development of a clear process that allows people with an ID to engage with all access control mechanisms

We appreciate the opportunity to inform the development of legislative changes and welcome the opportunity to be further involved. Please contact Professor Julian Trollor by email j.trollor@unsw.edu.au or by phone on (02) 9931 9160, should you require further information.

Sincerely,

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