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National Mental Health Commission

## **Response to public consultation – Development of a Framework for Secondary Use of My Health Record System Data**

The National Mental Health Commission (the Commission) appreciates the opportunity to provide a submission to this public consultation. The Commission broadly supports the proposals provided in the Development of a Framework for Secondary Use of My Health Record Data public consultation paper.

### About the National Mental Health Commission

The Commission provides cross sectoral leadership on policy, programs, services, and systems that support better mental health, and social and emotional wellbeing in Australia. There are three main strands to the Commission's work: monitoring and reporting on Australia's mental health and suicide prevention systems, providing independent advice to government and the community, and acting as a catalyst for change.

In 2012, the Commission developed its *Contributing Life Framework* which acknowledges that a fulfilling life requires more than just access to health care services. It means that people living with mental ill health can expect the same rights, opportunities, and health as the wider community. In 2014, the Commission completed a national review of mental health programs and services, providing 25 recommendations across nine strategic directions in *The Contributing Lives, Thriving Communities Report (the 2014 Report)*.

### Secondary use of My Health Record System Data

1. Support for the 'opt-out' My Health Record mechanism and integrated care.

The development of a framework for secondary use of My Health Record system data has been driven by growing demand for health data resources in conjunction with the forthcoming introduction in 2018 of the revised 'opt-out' model of e-health records in Australia. In the 2014 Report, the Commission endorsed such a model, in conjunction with Integrated Care Pathways (ICPs) for mental health, for the provision of a seamless journey through the mental health system<sup>1</sup>. This approach is based on the underpinning philosophy that people living with mental ill health should be able to 'provide once' in relation to their health history, and that this single record should be 'used often' by treating health practitioners. The Commission also identified people with high needs in relation to mental health as a priority group for ICPs, ideally facilitated by use of an e-health record i.e. one continuous system, one care plan, and one digital platform. The employment of a single e-health record also gives public sector, community managed organisations, and private providers, a vehicle to enable a whole-of-person approach to the care and support of people with complex health needs.

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<sup>1</sup> The National Mental Health Commission. The National Review of Mental Health Programmes and Services, Sydney NHMC, 2014





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2. Support for secondary data uses in relation to health service provision.

Potential secondary uses of data held in the My Health Record system have been identified as: policy analysis, health services program development and improvement, quality and safety measurement, and other broader public health applications. The Commission supports these proposed uses of the primary clinical data collected at patient level and aggregated at population or system level. There is potential for this data to be used as indicators of system performance for mental health, describing integration of care pathways, appropriate deployment of stepped care models, and monitoring of co-existing physical morbidity and treatment thereof. The latter is of particular importance given the high rates of undiagnosed/late diagnosed and poorly treated physical health complications noting that four out of every five people living with mental ill health have a co-existing physical illness and people living with severe mental illness are likely to die between 14 and 23 years earlier than the general population<sup>2</sup>.

In terms of service evaluation and quality improvement, the secondary use of data has the potential to assist service providers to improve clinical pathways, inform decision makers about the downstream results of funding allocation, or contribute to planning for the new regionally based clinical commissioning under the auspices of the Primary Health Networks.

Regardless of the application, the Commission notes that any and all potential secondary use of data will require validated, systematic methods to assess data quality at the point of extraction from the database, and its application in relation to the respective standards for quality, safety, or clinical appropriateness. The necessity of validating the quality and external validity of the data is directly connected to its utility as a data source for secondary use related to health.

3. Support for secondary data use for cross-sectoral applications.

The Commission's *Contributing Life Framework* consists of five domains including 'something meaningful to do, 'connections with friends, family, culture and community', 'feeling safe, stable and secure', 'effective support, care and treatment', and 'thriving, not just surviving'. These domains reflect the inter-related social and structural factors which promote mental health and wellbeing. The Commission's approach acknowledges that data from outside the health system may be equally vital in measuring outcomes for people living with mental ill health. This data includes, but is not limited to: housing, education, employment, disability, and the quality of interpersonal relationships. Cross sectoral application of data should therefore be considered in construction of the Framework for Secondary Use of My Health Record data, with suitable avenues for data linkage identified and potential non-health related use of data made clear to individual record holders at the point of record activation, in association with advice about the 'opt-out' functionality.

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<sup>2</sup> National Mental Health Commission. *Equally Well Consensus Statement: Improving the physical health and wellbeing of people living with mental illness in Australia*. Sydney NMHC, 2016





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4. Potential use of secondary data for monitoring outcomes of research and pilot interventions.

Various types of research could be applied to My Health Record cohorts<sup>3</sup>, from analysis of baseline health information e.g. clustering of health behaviours and association with physical and psychological status, linkage with social determinants of health e.g. age of retirement and health status, and almost unlimited potential for sub-studies e.g. selection of a particular demographic from the aggregated data set in order to conduct intensive interrogation of information relevant to specific research questions such as use of Category B or C medications in pregnancy and associated rates of miscarriage, premature birth or other peri-natal complications.

As highlighted in Chapter 3 of the consultation paper, secondary use of clinical data also has capacity to provide an extended Clinical Trial environment, with tracking of real world outcomes for consumers treated with drugs or devices that have only been trialled initially within a narrow therapeutic range of indications and/or in unrepresentative populations. The scale of the My Health Record population data set also provides the opportunity to detect and explore the significance of rare events in relation to interventions and service provision. For example, the My Health Record data set could be used to undertake longitudinal follow up of the regional suicide prevention trial being rolled out at 12 sites nationally<sup>4</sup> to understand the impact of this mental health reform initiative. Such longitudinal studies are usually financially demanding and risk being abandoned if the original funding body ceases to support the work over time, as research and funding priorities change. Use of My Health Record data circumvents many of these constraints, as data is already collected for alternative purposes and is intended to be enriched over time, with no additional data capture from investigators required.

Much of the research using mental health data currently relies on self-report methodologies or the utilisation of linked datasets. The Commission has historically engaged in a number of data linkage projects, most recently integrating Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) with Mental Health Services, Census and Mortality data to further understand the complex relationship between physical and mental health in Australia<sup>5</sup>.

A serious challenge to such data linkage work in the mental health sector is the inability to accurately map Commonwealth data about MBS and the PBS utilisation, to data collected by state and territory governments and the non-government sector about occasions of mental health service provided in local hospital networks or community settings. The secondary use of My Health Record data will a better understanding of the mental health services provided in Australia and strengthen our ability to monitor and report on the outcomes for consumers.

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<sup>3</sup> Examples have been informed by work associated with the Sax Institute's 45 and Up study.

<https://www.saxinstitute.org.au/our-work/45-up-study/research-underway/> Accessed 13 November 2017.

<sup>4</sup> [Minister for Health. Media Release. Major suicide prevention trial extended to four more regions. 6 February 2017.](#)

<sup>5</sup> Australian Bureau of Statistics (ABS), Mortality of People Using Mental Health Services and Prescription Medications, ABS Catalogue: 4329.0.00.006, ABS: 2011





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5. Governance mechanisms to ensure that privacy and security of data is protected and use is appropriate to the purposes of collection.

In many OECD countries, Commissioning authorities, non-profit academic researchers, and eligible government users are permitted to access national health data provided that the purpose of access is ethical, lawful, and beneficent for the population from whom the data is derived. Given the capacity for re-identification of individuals based on unique identifying features e.g. diagnoses of low prevalence combined with age and postcode, this risk must be mitigated through both legislation and through security and privacy policies which have suitably harsh penalties for breaches of these standards. The Commission is encouraged to see consideration of pre-existing models and processes for managing secure data access including through existing accredited integrating authorities, but would not wish for protocols to be excessively onerous which may discourage quality and innovative research, and appropriate commissioning of services relative to clinical need.

The Commission would further raise the issue of data access by the insurance industry including providers of superannuation, life, and health insurance. All three streams of insurance could be considered to have a vested interest in disclosures in relation to policyholder health status, especially in relation to mental health, given that there have been increasing claims related to mental health conditions<sup>6</sup> and recent reforms have been announced in relation to private health insurance and mental health<sup>7</sup>. The data that will potentially be captured and aggregated from the reformed My Health Record may also have value in relation to calculation of premiums for insurance products. The prospect of providing public data to private, commercial interests is addressed in the consultation paper and the Commission would counsel similar cautions in the Australia context, given previous experiences in the United Kingdom (UK) with the care.data program failure, and the admission by the Health and Social Care Information Centre that pseudonymised (but re-identifiable) coded hospital records were provided to the insurance industry, which were later fed into actuarial analyses to inform life insurance premiums<sup>8</sup>. This risk is even more acute in Australia, given the much larger proportion of health service delivery in the private sector with associated private insurance arrangements, in comparison to the UK.

6. Engagement and communication with community, and informed consent for secondary use of data.

The Commission notes the extensive public consultation process being undertaken via workshops, online survey, and webinars in association with the development of the Framework, and the dedicated webinar to be hosted by the Consumers Health Forum, with capacity for input via live questions. This avenue, earmarked for input and information sharing with the community, and likely consumers and carers with lived experience, is of prime importance to ensure that the Framework reflects a truly informed discussion with those who will inevitably own an e-health record, even for a short period.

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<sup>6</sup> Actuaries Institute. Mental Health and Insurance. Green Paper. August 2017.

<sup>7</sup> [Australian Government. Department of Health. Private health insurance reforms: Supporting mental health. 16 October 2017](#)

<sup>8</sup> [Triggle, N. Medical records rules broken, NHS admits. BBC Health News. 24 February 2014.](#)





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Sound understanding of the implications of making e-health record data available is at the heart of community acceptability of secondary use of personal health information, with the failure of care.data in the UK clearly linked to poor communication about intent, safeguards and conditions of data use by secondary parties<sup>9</sup>. The Commission recommends that serious consideration be given to ensuring communication material is tailored to different audiences and to varying levels of (health) literacy.

7. Importance of evaluation to validate use of My Health Record data for secondary purposes.

The use of an 'opt-out' mechanism to mitigate low uptake of the previously badged 'personally controlled e-health record' has the potential, but not the guarantee of introducing a novel, high yield data set in Australia. The utility of this data, especially in the context of secondary use, should be validated with an evaluation mechanism designed prospectively and implemented in conjunction with the new 'opt out' arrangements from 2018 forward. This review mechanism should capture metrics from the baseline use of data currently available under the remit of 'health', and track the outcomes, including published research, changes to quality and safety measures, and level of integration (including capacity for data linkage) across parallel data sets held at jurisdictional and Commonwealth levels.

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Thank you for the opportunity to provide comment on the proposed development of a Framework for Secondary Use of My Health Record System Data. The Commission would be pleased to discuss the above points in more detail, if it may assist in completing the final version and informing the future implementation of the Framework.

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<sup>9</sup> [Baldwin, C. NHS England admits failure to explain benefits of care.data. 24 February 2014.](#)

