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Australian Institute of Health and Welfare

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Australian Institute of Health and Welfare

Productivity Commission Submission

Inquiry into the Economic Impacts of Mental Ill-Health

April 2019

Introduction

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to participate in the Productivity Commission's inquiry into the role of improving mental health in Australia to support economic participation and enhance productivity and economic growth.

The AIHW is a national independent statutory agency established under the *Australian Institute of Health and Welfare Act 1987 (Cth)* (AIHW Act). The AIHW's purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians. The AIHW does not generally engage in evaluation or compliance activities.

The AIHW currently performs the following key roles in the context of the health and welfare of Australians:

a. the development and collection of comprehensive data, including making this accessible to others;
b. analysing and reporting on data (from national data collections that the AIHW has custody of, as well as other credible data sources);
c. developing and improving performance indicators and targets for national agreements;
d. providing data linkage services that have been approved by the AIHW's Ethics Committee; and
e. the development and maintenance of national metadata standards, housed in the AIHW's Metadata Online Repository (METeOR).

The AIHW Act enables the release of information for public benefit while protecting the identity of individuals and organisations and ensuring that data providers can be confident that the AIHW will adhere to data supply terms and conditions. As a statistics and information agency, the AIHW relies on strong data governance arrangements to retain the trust of our many data providers, data recipients and other stakeholders.

AIHW's Mental Health Information Activities

The AIHW has a long history of curating, analysing and reporting national mental health information. AIHW's Mental Health and Palliative Care Unit (MHPCU), a multidisciplinary team of 17 people, leads AIHW's mental health information activities and currently undertakes the following activities:

a. Data curation, analysis and reporting of mental health-related expenditure and activity from the following datasets:
    - Admitted Patient Care National Minimum Data Set (APC NMDS).
    - National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD).
    - Mental Health Establishments National Minimum Data Set (MHE NMDS).
    - Community Mental Health Care National Minimum Data Set (CMHC NMDS).
    - Residential Mental Health Care National Minimum Data Set (RMHC NMDS).

- National Seclusion and Restraint National Best Endeavours Data Set (SECREST NBEDS).
- Medicare Benefits Schedule dataset (MBS).
- Pharmaceutical Benefits Scheme dataset (PBS).
- Disability Services National Minimum Data Set (Disability Services NMDS).
- Specialist Homelessness Services (SHS) data collection.
- Your Experience of Service (YES) survey dataset (currently only 3 jurisdictions).
- Development, supply and reporting of key national performance indicators, including the Fifth National Mental Health and Suicide Prevention Plan, the *Key Performance Indicators for Australian Public Mental Health Services* and National Healthcare Agreement mental health-specific indicators.

b. Authoring and publication of our online *Mental Health Services in Australia* (MHSiA) website and its companion hard copy *Mental Health Services: In Brief* publication.

c. Transitioning of the National Mental Health Service Planning Framework (NMHSPF), a national population-based model that enables estimates of the resources required for mental health services for any selected population region in Australia, from a Microsoft Excel tool to an interactive, online platform.

d. Provision of secretariat support for three Australian Health Minister Advisory Council (AHMAC) mental health committees: Mental Health Information Strategy Standing Committee (MHISSC), National Mental Health Performance Subcommittee and National Mental Health Dataset Subcommittee (NMHDS SC).

e. Participation in AIHW's burden of disease study (AIHW 2016) which analysed the impact of nearly 200 diseases and injuries in terms of living with illness (non-fatal burden) and premature death (fatal burden). It established that *Mental and behavioural disorders* were the largest contributor (23.6%) of the non-fatal burden of disease in Australia.

Importance of Mental Health to Australians

The importance of mental health to Australians both collectively and individually is undeniable. As former Prime Minister Turnbull observed in December 2015: *"We are recognising what we know to be true, which is that our greatest assets are all of you, are all of us – 24 million Australians – and we know that mental illness is the single largest debilitation of working age people, the single largest diminution of the wealth, the mental wealth of our nation."*

A considerable proportion of the Australian population will experience a mental illness at some time in their life whilst many others may experience mental health issues which can cause them distress and affect both their personal and working lives. The AIHW believes that access to effective, appropriate and high quality mental health care is of increasing importance given Australia's growing and ageing population.

As a national statistical agency, AIHW's submission will focus on the Institute's experience in creating, analysing and reporting national mental health information and statistics that informs decisions and improves the health and welfare of all Australians.

National Mental Health Information

Australia has had a relatively long history of collecting and publishing national mental health information and statistics. Under the National Mental Health Strategy, which effectively commenced in 1992, there have been five National Mental Health Plans, with their associated data monitoring and reporting activities. Consequently, the mental health sector is relatively rich in terms of the data that it collects and reports at the national level when compared with other Australian health and welfare sectors. However, the mental health sector's information activities necessarily reflect Australia's federated model of funding and delivery of the health and welfare sectors, and is fragmented. Consequently, there is no single 'unified information system' with consistent definitions and structure which policymakers and researchers can use to assess whether programs and support services are 'making a difference' and effectively supporting Australians living with mental ill health or experiencing mental health issues.

Rather, the current Australian mental health information landscape has evolved over time, and in 2019 is a mix of Australian and state and territory government administrative data, a purpose-built national outcomes collection and survey data, supplemented by academic studies and evaluations commissioned for specific purposes. The sector has also been able to draw on four mental health National Minimum Data Sets (NMDS) brought together by the AIHW (Admitted Patient, Mental Health Establishment, Community Mental Health Care and Residential Mental Health Care) to guide its decision making. This matrix of mental health information has served the sector well over the years and is more advanced than most other health and welfare sectors. However, there are gaps in measurement and reporting in the mental health sector, which prevents Australia from comprehensively monitoring and reporting on programs and initiatives aimed at making a difference to peoples' lives, and determining whether desirable outcomes are being achieved. One of the challenges is that the data are not routinely integrated which makes it difficult to observe patterns of service use across sectors.

As previously noted, Australia's mental health information system is fragmented and reflects our federal system of government. Australia's Fifth National Mental Health Plan commits all governments to working together to achieve integration in planning and service delivery at a regional level. Should this aim be achieved then it will be easier to monitor a consumer's journey through the health and welfare system and the myriad of potential support providers and evaluate the effectiveness of their respective interventions. A significant challenge though, from a data perspective, will be the reality that information support systems are expensive to design, implement and maintain and often have long lead times from conception to implementation.

Outcome Measurement

A key issue that the mental health sector, and the health and welfare sector more generally, has been grappling with in recent years is outcome measurement i.e. how do we assess whether an intervention has made a difference or make more informed decisions about scarce resource allocation. In an ideal world we would be able to access information from the consumer or individual, a significant other, the clinician/provider and/or observe the impact of an intervention or mental health-related program. The reality is that outcome measures in the Australian context consist primarily of clinician rated measures (Health of the Nation Outcome Scales [HoNOS]) in the National Outcomes and Casemix Collection (NOCC) managed by the Australian Mental Health Outcomes and Classification Network

(AMHOCN) on behalf of the Australian Government. However, clinician measures alone are not considered sufficient by many stakeholders who advocate that a spectrum of measures, including patient-rated outcome measures and measures of recovery that are meaningful to both consumers and clinicians, should be available to better asses the effectiveness of mental health services.

Peasgood et al. 2019 recently explored the opinions of a sample of UK decision makers on the relevance of wellbeing and subjective wellbeing for resource allocation decisions and concluded that there is a need for improved consideration of broader quality-of-life outcomes than used at present. They also identified a reluctance to rely only on self-reported happiness or life satisfaction measures. AIHW is of the view that there needs to be further discussion about what outcome and recovery measures we need to use to give Australian decision makers the information they need to make informed decisions about efficiently allocating scarce resources to achieve better outcomes for mental health consumers and society more generally.

Data linkage can also assist in the assessment of outcomes. Some outcomes are not observed or cannot be observed while a program is operating as they require generational change. Early childhood education is a good example — some of main benefits of early childhood education are not apparent until participants are teenagers. It can be possible to observe the subsequent impact of programs and policies through data linkage. The Chicago Longitudinal Study has demonstrated the impact of early childhood education by linking existing administrative data. A similar approach would be possible for mental health as high quality early intervention may result in better employment and education outcomes in due course. Through data linkage, it would be possible to assess whether particular types of assistance have a positive impact on key outcomes such as employment compared to a control group.

Mental Health Information Development

AIHW notes that, from its inception, Australia's Mental Health Strategy has included a program of mental health information development to establish a mental health information culture to support the Strategy. The national approach adopted has been instrumental in delivering the contemporary mental health information landscape with some notable achievements, including a national mental health consumer experience of care measure (Your Experience of Service [YES]) and a national restrictive practice data collection.

AIHW has recently been engaged by the Australian Government Department of Health, in conjunction with AHMAC's Mental Health Principal Committee (MHPC) and its Mental Health Information Strategy Standing Committee (MHISSC), to author a Third Edition of the National Mental Health and Suicide Prevention Information Priorities (3NMHSPIP). Work is well advanced on the Third Edition which will articulate the kind of mental health information landscape that Australia aspires to over the next ten years: personalised, comprehensive and connected. AIHW anticipates that, once the 3NMHISPP is agreed by AMHAC, it will work with MHISSC and other stakeholders to further develop Australia's mental health information systems to support the identified initiatives.

What is missing from the picture?

Despite the relative richness of the Australian mental health information landscape, AIHW perceives that there are opportunities in the mental health sector for more comprehensive mental health data to flow more swiftly to the national level, particularly in areas where there has been substantial investment e.g. Better Access, headspace and NDIS. In addition,

there are known data gaps in a number of areas which should be filled as a matter of priority to give a more comprehensive view of the sector's activity and the mental health-related support being given to Australians:

- **General Practitioners.** The mental health-related Medicare Benefits Schedule (MBS) items are currently the only source of national data on mental health-related services provided by GPs. Not all mental health-related GP encounters are billed using mental health-specific MBS items—so these items are an underestimate of total mental health-related GP activity, which a recent Royal Australian College of General Practitioners (RACGP) survey suggests is in the top three reasons for a patient's visit.
- **Primary Health Networks.** Data on the activity of Primary Health Networks—collected under the Department of Health's Primary Mental Health Care Minimum Data Set—are anticipated to be available for reporting in 2018–19.
- **National Disability Insurance Scheme.** It is estimated that 64,000 Australians with a psychosocial disability will meet the criteria to access the NDIS. However, data on the supports accessed under the NDIS by people with psychosocial disability are not currently available for reporting.
- **Mental Health NGOs.** There is currently no nationally consistent data on the workforce or activities of mental health non-government organisations (NGOs) to inform policy, practice and planning of their activities. This is a notable data gap as NGOs play an important role in providing non-clinical mental health-related services to people living with mental illness, their families and carers. Information about numbers of peer and consumer workers employed in the sector and their activity is currently unavailable.
- **Specific Demographic Groups.** Information on the mental health support needs and subsequent support provided to a number of specific sections of Australian society: Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse people, Lesbian Gay Bisexual Transgender and Intersex (LGBTI) people, people with experience of suicide, refugees and victims of traumatic crime is not currently available for national reporting purposes.
- **Prevalence of Mental Illness.** Given the passage of time since the last adult survey of mental health using a diagnostic instrument was conducted in 2007, consideration should be given to identifying a cost-effective method to update the prevalence information on Australian adults and Aboriginal and Torres Strait Islander Australians.
- **Suicide prevention data.** Information on suicide deaths and attempts is need by a range of stakeholders so that they can more effectively target their suicide prevention activities.

AIHW's NIHSI

The AIHW is working with the Australian Government Department of Health and state and territory health authorities to create the National Integrated Health Services Information (NIHSI) Analysis Asset (AA). The NIHSI AA will contain de-identified data from 2010–11 onwards on admitted patient care services (in public and private hospitals where available), emergency department services and outpatient services in public hospitals for all participating states and territories, along with Medicare Benefits Schedule data, Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data,

Residential Aged Care data and National Deaths Index data. The incorporation of data into the NIHSI AA will be staged and will be dependent on timing of receipt of the required data.

The creation of the NIHSI AA provides an opportunity to link existing mental health data sets with other pertinent health and welfare datasets and should be considered as a priority.

Productivity Commission Questions on Monitoring and Reporting Outcomes

Are decision-making forums for mental health receiving high quality and timely information on which to base strategic decisions?

As previously noted, AIHW is of the view that Australia's national mental health landscape is relatively data rich compared with other health and welfare sectors due to the strong leadership provided via the AHMAC mental health committees over the life of the National Mental Health Strategy. However, it relies heavily on state and territory administrative health data sets which are necessarily designed to facilitate and monitor the provision of services to mental health consumers rather than to evaluate and assess the outcomes of specific interventions and associated mental health-related programs. Thus administrative health data sets have universal coverage, are data rich and systematic. However, they also have known jurisdictional differences in data elements, coding criteria and database storage.

The known limitations inherent to administrative data sets can make data extraction, linkage and merging of different mental health data sets challenging in the absence of a nationally agreed linkage methodology (Mazzali et al. 2016). The multiplicity of data sets also means that Data Custodian responsibilities are dispersed across a variety of organisations and individuals which can significantly impact on the timeliness of data flows. That said, there are international examples where administrative data are used very effectively to monitor system performance and improve clinical care. For example, Statistics Sweden and the Swedish National Board of Health and Welfare collect individual level data for all Swedish residents using a 10-digit personal identity number (PIN) which enables comprehensive linkage of their population and health data registers.

As previously discussed in the section "What is missing from the picture", there are a number of key parts of the health and welfare sector for which there is very limited information about the support being provided to Australians experiencing mental ill health and mental health issues. The existing administrative data sets could also be further refined to enhance their utility i.e. better identifiers, more comprehensive information about interventions and consumer outcomes. AIHW is of the view that these deficiencies should be systematically addressed by Australian governments, through existing AHMAC committees and processes, in order to provide health and welfare sector decision makers (Health ministers, Primary Health Networks, state and territory departments and agencies – such as Local Hospital Districts, Local Hospital Networks) with the comprehensive, high quality data they need to assess whether Australians with mental health issues are getting the necessary treatment and support that they need to lead contributing lives.

Does Australia have adequate monitoring and reporting processes to assure compliance with national standards and international obligations?

The monitoring of the various standards in the sector is typically subject to state and territory legislation or the subject of discrete funder contractual obligations with individual mental health service providers. Some national reporting of progress made by a specialised mental health service unit in implementing the national standards for mental health services by or at 30 June is undertaken through the MHE NMDS. However, units can be accredited against a number of national standards and work is underway to clarify the reporting of relevant standards via the MHE NMDS. A more fundamental review of the monitoring and reporting of relevant national standards would be required to establish whether the current system is 'adequate'. If the current system of monitoring and reporting were to be considered deficient then appropriate targeted, remedial action would be required.

Is there sufficient independence given to monitoring, reporting and analysing the performance of mental health services?

Establishing the independence and efficacy of the monitoring and reporting of the performance of Australian mental health services is difficult due to the fragmented way in which services are delivered across the Australian health and welfare sector by multiple providers with unique, tailored reporting requirements. A substantial number of health and welfare stakeholders report on their mental health-related activities: government departments, mental health commissions, corporate and individual service providers and academic institutions. At the national level, no single entity currently has the responsibility or authority to analyse, monitor and report on performance of mental health services across the health and welfare sector at the national level. AIHW's online *Mental Health Services in Australia* report, funded by the Australian Government Department of Health, is an omnibus report which brings together a wide range of data from across the health and welfare sector in a 'one-stop shop' format. Other national mental health reporting entities include:

- Productivity Commission – *Report on Government Services.*
- National Mental Health Commission – *Monitoring Mental Health and Suicide Prevention Reform: National Report* and *Fifth National Mental Health and Suicide Prevention Plan Progress Report.*
- The Australian Commission on Safety and Quality - *Australian Atlas of Healthcare Variation*
- The Australian Private Hospital Association - *Private Psychiatric Hospitals Data Reporting and Analysis Service Report*

Consideration could be given to rationalising the multitude of mental health-related reporting activities in the interests of creating a simpler, authoritative system.

Which agency or agencies are best placed to administer measurement and reporting of outcomes?

As per our previous comments, measurement of mental health outcomes can be vexed due to the use of a range of measures and the multiplicity of funders in Australia who place differing reporting requirements on service providers.

Kilbourne et al. 2018 describe the field of mental health quality improvement as a 'team sport' requiring coordination and buy-in from a range of stakeholders including funders, providers, consumers and systems. This is an apt description for Australia's federated mental health landscape, which also requires buy-in from a multitude of stakeholders, if outcome measurement is to be universal, systematic and effective and improve the quality of mental health care provided to Australians with mental health issues.

AIHW's experience with outcome measures in both the health and welfare sectors suggest that the success of outcome measurement is largely determined by the clinical utility of the measurement being undertaken and extent to which it resonates with consumers/patients rather than who is doing the measurement. Consequently, no single entity in the mental health sector is likely to have a mortgage on outcome measurement in the sector. Rather, any changes to the existing system to redress any perceived inadequacies should be team based, scientific, systematic and resonate with clinicians and consumers alike.

Obvious candidates to take the lead at the national level in any changed 'system' include the Australian Government Department of Health, National Mental Health Commission, AMHCON, Productivity Commission, Australian Commission on Safety and Quality in Health Care and the AIHW.

What does improved participation, productivity and economic growth mean for consumers and carers? What outcomes should be measured and reported on?

As mentioned previously, the issue of outcome measurement has been the subject of robust discussion in the mental health sector for a number of years. In particular, the sector has been concerned about the extent to which it is able to measure a person's clinical and personal recovery and how it can improve outcome measurement e.g. participation, work and study. AIHW is of the view that the National Mental Health Commission's concept of a Contributing Life has merit and could be used to guide further enhancement of existing outcome measurement in the mental health sector. In addition, AIHW makes the following observations:

- Australia has a long-standing program of outcome monitoring through public mental health services. However, there is a need to expand outcome measurement to cover private office-based care (GPs (who deliver the bulk of care), psychiatrists, psychologists), and NGO providers.
- Consumer-rated outcomes are a key component of outcomes measures, in line with consumer's dictum of 'nothing about us without us'. Work is underway through the MHISSC to develop a nationally consistent measure of consumer-rated outcomes.
- Data on broader outcomes around social participation (housing, employment, community participation) are only available from large national surveys run by the ABS, which are unlikely to include the people for whom monitoring is most needed (people with low prevalence, high impact conditions). Data on housing, employment, and other

measures of recovery should be collected on people in touch with specialised services, either public or private.
- Work is underway to develop a version of Living in the Community Questionnaire that could be used to survey the population under care. There is likely to be buy-in from states and territories to implement it but mechanisms are needed to deliver the survey through the private sector and collate data nationally.

What approaches to monitoring and reporting are implemented internationally? What can Australia learn from developments in other countries?

AIHW has had the opportunity to participate in a number of international mental health benchmarking exercises through the World Health Organization (WHO) and International Initiative for Mental Health Leadership (IIMHL), a collaboration of nine countries: Australia, England, Canada, the Netherlands, New Zealand, Republic of Ireland, Scotland, USA and Sweden. AIHW's observation is that the mental health challenges facing other countries are not dissimilar to our own, though the models of care can be markedly different between countries which makes international benchmarking challenging. AIHW's additional observations include:

- Australia is leading the way in some aspects of monitoring and reporting e.g. National Outcome and Casemix Collection and national restrictive practice data collection.
- Australia's reporting reflects inherent structural barriers in our health system: relatively strong reporting of state and territory services but more limited reporting for other sectors e.g. primary care, office-based care.
- Australia shares similar challenges with most other western countries in measuring and reporting on mental health interventions, the use and efficacy of psychotropic medication and broader outcome measurement.

To what extent is currently collected information used to improve service efficiency and effectiveness?

Anecdotal evidence suggests that the currently collected mental health information is used by mental health service managers and policymakers to guide their service improvement activities. AIHW, in conjunction with MHISSC, is the project lead for Action 25 under the Fifth National Mental Health and Suicide Prevention Plan – *'Governments will ensure service delivery systems monitor safety and quality of their services and make information on service quality performance public'*. This will provide additional information on the extent to which Commonwealth and state and territory-funded services avail themselves of currently collected mental health information to guide their activities.

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