



Submission

National Mental Health and Suicide Prevention Information Priorities

7 June 2019

Orygen, The National Centre of Excellence in Youth Mental Health (Orygen) welcomes the opportunity to provide feedback on the draft National Mental Health and Suicide Prevention Information Priorities (3rd Edition).

About Orygen

Orygen is the world's leading research and knowledge translation organisation focusing on mental ill-health in young people. At Orygen, our leadership and staff work to deliver cutting-edge research, policy development, innovative clinical services, and evidence-based training and education to ensure that there is continuous improvement in the treatments and care provided to young people experiencing mental ill-health.

Orygen has provided comment on actions identified in the draft National Mental Health and Suicide Prevention Information Priorities document (Priorities document) related to the organisations fields of research and practice. The submission identifies opportunities to strengthen the focus, direction and potential of the draft Priorities document.

Promoting personalised care and support

Measurement and data collection in the mental health sector has historically focused on evaluating service delivery. This focus has resulted in the development and implementation of measurement tools that are generally not patient-centred. While the type of data collected has broadened from an output focus to include people's experiences of a service and an emerging focus on outcomes, the original focus on service evaluation presents a barrier to the development of patient-centred data collection. The draft Priorities document identifies extending the function of national data collections from primarily descriptive (reporting) to be outcomes-focused (improvement) as a key challenge of mental health information over the next decade.

Consecutive national mental health plans have identified gaps in data collection and the need to include outcome measures, but with minimal progress being achieved. The opportunity to set in train tangible processes exists in the development of the draft Priorities document. If this opportunity is missed, the potential for outcome measurement to improve health and life outcomes for young people will be delayed another ten years.

Embed consumer and carer voices

Implement consumer and carer experience surveys

Implementation of the Your Experience of Service (YES) survey in all state and territory specialised mental health services is also an action identified in the Fifth National Mental Health and Suicide Prevention Plan. There is a lack of consistency, however, in existing measures collected across state and territory specialised mental health services due to concessions made to individual jurisdictions. Implementation of the YES survey should be sensitive to the barriers arising from making concessions to states and territories that will potentially limit the capacity to collect nationally consistent data.

The acceptability of the survey format for young people may be a barrier to implementation. The YES survey requires adaptation to acknowledge different experience of child and adolescent consumers. The potential for a shorter version of the YES for young people should be considered.

The acceptability of the YES survey would also benefit from review for relevance by diverse groups of young people. Working groups should include: Aboriginal and Torres Strait Islanders, multicultural populations and LGBTQI young people. The co-design of a youth version of the survey within these groups would increase acceptability of the survey. Consideration could also be given to developing an alternate carer version where young people do not complete a survey.

Clarification is required on which services fall within the NGO category in the action to encourage NGO services to implement the YES survey. Ideally, the voice of young people should consistently be heard in all of their experiences of mental health help-seeking across the service continuum. This may be challenging, however, where services have already implemented a service satisfaction survey and may be unwilling to adopt or change to the YES survey. Consideration needs to be given to providing supports and incentives to NGO services to implement the YES survey and to incorporate data in quality improvement activities.

Orygen, agrees that a version of the carer experience survey should be developed that is suitable for young people (aged 12-24 years). Young people experience and use services in different ways to adults. Surveys should reflect their unique level of satisfaction, means and modes of engaging services. Development of a carer experience survey that is appropriate and acceptable to young people should be undertaken through a co-design process.

Data/information to support consumer and carer engagement, participation and leadership

The draft Priorities document confuses shared decision-making and overall consumer and caregiver involvement (i.e. participation and engagement, "leadership"). Shared decision-making is a form of involvement that occurs at the individual level (i.e. the last step in the provision of evidence-based care by a treating clinician). Consumer and caregiver involvement that involves "leadership" would refer to engagement and participation activities. Examples of this are: including consumer and carer representatives on boards/committees/working groups; co-design activities for the purpose of designing services and service development initiatives; and priority setting activities with consumers and carers to determine focus areas.

The proposed activities identified in the draft Priorities document will not deliver on the promises of either shared decision-making or consumer/carer involvement and leadership. Many of the action points are passive and barely adequate in nature (e.g. collecting experience survey data). To ensure shared decision-making occurs requires the development of a suite of evidence-based translational resources and materials (e.g. evidence summaries, decision aids) and client and carer activation resources (e.g. public awareness campaigns of questions to ask to facilitate shared decision-making - see www.askshareknow.com.au as an example). To support implementation will require workforce training in shared decision-making behaviours.

The draft Priorities document refers to collecting information to inform shared decision-making but does not sufficiently describe this information. Shared decision-making involves the communication of relevant and available treatment options plus evidence-based information about the potential harms and benefits of each treatment option. It is not clear how the data collection proposed in the draft Priorities document would contribute to that process.

To ensure consumer and caregiver involvement occurs, strategies and actions are needed that develop and sustain consumer and caregiver roles within and across the mental health sector, including to inform the breadth of strategies and actions in the draft Priorities document. Proposed actions need to adhere to core principles of meaningful engagement. To develop leadership within these roles, career pathways are needed for consumer and carer representatives that build on their expertise and skills sets.

Inform service delivery

Identify information and undertake actions to support personalised care at the point of delivery

A historical focus on service-related data collection and analysis in the mental health sector has meant the information needs of clinicians, young people and carers have long been overlooked. Clinicians require information that has clinical utility. Information needs to support the therapeutic relationship and inform treatment decisions. Measuring functionality will provide information that can benefit clinicians and young people, and help inform shared decision-making in choosing the treatment course.

For young people and carers, the opportunity to assess their experience and health outcomes can give them a voice in a clinical setting. Involving young people in assessing their own recovery can provide insights into what is important to them, enabling self-defined recovery to be a consideration. Implementation and data collection needs to be acceptable and appropriate for young people.

The role of the My Health Record, electronic records and young people's concerns around confidentiality and data security need to be balanced in relation to availability of personal health data/information. From the age of 14 years, young people need to be fully informed and their rights and responsibilities in relation to their My Health Record. Clinicians and services should routinely check in with a young person about their permissions and preferences relating to the management of electronic records.

Measure what matters

Focus on outcomes

National policies have largely focused on implementing outcome measures for auditing purposes. This focus has meant that less attention has been paid to the clinical utility of measurements, presenting a policy challenge in expanding the application of outcome measurements as a clinical tool for the benefit of clinicians and young people. The impact of illness and interventions on a young person's wellbeing are not as easily measured as the number of service contacts or service quality and, therefore, require investment in developing and implementing validated tools for this purpose. Data collection by practitioners, young people and families/support people will provide different perspectives on outcomes.

The experiences of young people and what they consider to be meaningful outcomes needs to be considered in investigating ways to measure and report on outcomes that matter to them. The use of idiographic measures (e.g. goals) should be investigated. Patient reported outcome measures will reflect a young person's self-perceptions. People's mental health fluctuates and experiences of mental ill-health can be episodic. These factors will influence a young person's responses to

questions about their mental ill-health asked in an outcome measurement tool. A specific youth-focused outcome measure is required that is sensitive to clinically significant change, meaningful to young people and suitable for routine use to provide feedback to clinicians and young people. The development of such a tool needs to be sufficiently flexible to enable clinical utility and acceptability (for young people) while also ensuring data will align with nationally consistent datasets.

Information development to support improvements in medication safety

Medication is a component of treatment in specialist mental health inpatient units and in community clinical settings (including primary care and specialist settings). Admission to hospital due to mental ill-health will include a medication review and consideration of changes to dose or the medication being used. While a young person or their family will likely be able to provide information about medication currently being taken, knowledge of past prescriptions may not be immediately recalled. This is important information if a switch in prescribed medication is being considered. The possibility that a young person will have had contact with multiple primary care and mental health services and practitioners may be a barrier to identifying this information. Digital hospital pharmaceutical systems and patient health records would help with identifying this information.

The development of performance metrics on medication safety for primary care would be useful. Australian General Practice Accreditation Limited accreditation standards and a range of self-assessment tools are available for auditing medication safety. Auditing of general practitioners (GPs) prescribing safety could be used to analyse prescribing concordance with evidence-based practice.

Expanding the evidence base

The draft Priorities document identified an objective to extend data reporting beyond public mental health services to include non-government organisations, private sector providers and primary health care. Component datasets required to provide a more comprehensive national dataset exist. Policy leadership is required to extend data reporting identified in the draft Priorities document.

Evidence is the cornerstone of effective mental health service delivery, treatment design and clinical practice. Data collection and analysis is integral to research, service and program development and evaluation.

Improve self-harm and suicide prevention data

Develop mechanisms for monitoring and reporting of suicide attempts

Orygen agrees that reporting on national data for suicide attempts and fatal suicide behaviour should be established. The potential of 'real time' data needs to be included as part of this action.

There are challenges to establishing such reporting that the final Priorities document should address. There is a need to:

- harmonise datasets between states and territories
- engage service providers (i.e. emergency departments, PHNs and first responders) ensure data collection system also meets service needs
- identify resources required for the smooth operation of the system
- ensure data collection is beneficial for services and will be an enabler of implementation.

Developing a suite of indicators relating to suicide attempts and deaths from suicide while under care and immediately after care requires a clearer definition of 'under care'. For example, does this include the criminal justice system? Clarification is also required on whether this action relates to suicide only or does it include suicide attempts. In addition to developing a suite of indicators, a further action should be included to translate knowledge gained from these data into best practice

service guidelines or other suicide prevention actions, such as limiting access to means of suicide for people 'under care'.

Orygen agrees with the need to establish a national system for timely collection and communication of suicide and self-harm data. The final Priorities document needs to address challenges to achieving such a system to enable this action to be realised. In establishing a national system it is important to:

- avoid duplication of efforts through close collaboration with existing national systems for suicide data collection and dissemination
- define 'communication' and relevant audiences, recognising diverse needs (e.g. general public, researchers, clinicians, policy makers, funding bodies, NGOs)
- define 'timely'; for example, there are challenges related to the complexity of the coronial procedures.

Better understand the nature of follow-up care that is provided after a suicide attempt has occurred

In implementing the collection of data to understand models of follow-up care after a suicide attempt, the scope and definition of 'models of follow-up' need to be clearly identified as these will be related to the sources of relevant data (e.g. emergency departments, GPs, mental health system, applications and web-based interventions).

Linked-data sets need to include suicide risk factors that can be monitored following a suicide attempt, including high risk periods for a subsequent attempt. The selection of outcomes will influence the datasets that can be used or need to be developed, and will differ for different subpopulations groups of young people after a suicide attempt.

Develop the datasets and methods to support suicide prevention trials and the monitoring of suicide prevention efforts

Orygen agrees with actions identified to enable this strategy. The final Priorities document should reflect the importance of meeting the needs and matching resources of diverse stakeholders involved in the process of data collection and dissemination in developing common processes.

Monitor the physical health of Australians with mental illness

People experiencing mental ill-health are more likely to have low or sedentary levels of exercise and experience higher rates of physical ill-health than the rest of the population, dying up to three decades earlier. Risk of poor physical health outcomes accumulates from the earliest stages of mental ill-health. The side effects of some medication can also contribute to poor physical and sexual health outcomes for young people.

Monitoring the health of young people experiencing mental ill-health needs to encompass not only their mental health, but also their physical and sexual health. This responsibility begins in primary care and extends to mental health services. Although there is some overlap in the wider health needs of young people with different forms of mental ill-health, the potential health effects are shaped by the type of illness, severity and treatment options.

Training in the monitoring and treatment of physical and sexual health is required for all disciplines working in public, private and non-government mental health services.

Enhance planning for services

Improve data on prevalence of mental health conditions

A lack of prevalence data continues to be a major barrier to planning mental health services for young people. This barrier is especially evident for vulnerable subpopulations, such as Aboriginal and

Torres Strait Islanders, the LGBTQI community and migrant and refugee populations. A stated reluctance by the Department of Health to fund a third National Mental Health and Wellbeing survey¹ highlights the need for targeted surveys to improve prevalence data among young people for whom early interventions hold the greatest potential of achieving lifelong benefits. As a demographic category in which early interventions can be most appropriate and effective, a focus on improving prevalence data for 12-24 years olds is justified.

The use of predictive models can enhance the value of prevalence data. The data needs of predictive models should be considered in the design of prevalence surveys.

Further develop the tools that underpin mental health planning and funding

Further development of the Australian Mental Health Care Classification (cost data) and the National Mental Health Service Planning Framework (regional planning) would inform mental health planning and funding. Orygen supports the strengthening of the youth mental health component of the National Mental Health Service Planning Framework. The incorporation of predictive models has the potential to enhance service planning. Orygen is currently two predictive models; readyforwhatsnext data synthesis and simulation software suite, and the Youth Mental Health Epi Application.

Improve availability of information across the full range of government funded mental health services

Improve data relating to primary mental health care

There are shortcomings in the measures used and data collected through current minimum datasets. Outcome measures need to be improved. For example, the use of the K10 is insufficient. Aspects of young people's health and wellbeing such as social functioning need to be measured. Service providers and young people should be included in discussions about what items to include and remove from minimum datasets.

The utility of data and outcome measures needs to inform the choice of outcome measures. Services (including Primary Health Networks, non-government organisations) need to be engaged to identify what data would be useful. Services need to be able to see how data collection will support local service delivery. Ensuring the utility of data for services and clinicians would remove some of the barriers to implementation. Other barriers (e.g. time, technology) need to be addressed to better enable data entry.

Bringing it all together

Coordinated implementation of outcome measures and data collection will require policy commitment and national leadership. The purpose of collecting data differs for service funders and providers, clinicians and young people. To realise the potential of bringing together various datasets will require all parties to see the benefits.

Improve public reporting and transparency

Publish more timely and locally-relevant data

Quarterly reporting for the national minimum datasets, including a 14-24 year old category is required to enable timelier service responses. Consideration should be given to mechanisms that can be implemented at a national level to ensure that data is supplied. For example, including data supply in commissioning contracts entered into by Primary Health Networks.

¹ Community Affairs Legislation Committee, Estimates, 24 October 2018.

Improved routine data publishing has the potential to enable the development of responsive service systems. The routine publishing of all data at sub-jurisdictional levels (while ensuring the privacy of individuals) needs to be dynamic and linked to response mechanisms. For example, in relation to suicide and self-harm, published data also needs to include data from multiple agencies including state coroners, police, ambulance and hospital emergency departments. This system should be linked to an evidence-based and strategically coordinated immediate response delivered at community level.

Improve national reporting to allow services to benchmark against like services

The capacity of services to commit to supplying data to support benchmarking could be problematic in youth mental health where age groups vary (e.g. 0-18; 12-25; 15-24 years). Barriers stemming from differences in age categories can be overcome through data disaggregation. Resources are needed to implement or modify collection to provide disaggregated data.

The development of a methodology for grouping like mental health services needs to include demography and geography. Such a methodology will be best enabled through the implementation of a national reporting standard developed across services to minimise underreporting and/or duplication of reporting across agencies and sectors.

Make reporting more meaningful to consumers

Development of an indicator set that includes the whole mental health system and that monitors key points of the patient journey needs a definition of the mental health system that includes a broader workforce and services. A specific indicator set for young people 12-24 years should be co-designed with people who use services as well as those who will use the data.

Expand the user base of mental health information

Strengthen engagement with specific communities to ascertain data needs

In general, mental health data collection in Australia does not adequately or appropriately collect data for subpopulations of young people that recognises their diversity. National datasets need to be routinely reviewed and updated to reflect best practice in regard to personal identification and appropriate data collection methodologies. Creating relationships with relevant national bodies would enable this process.

Adaptation of measures to a local context or specific population, including dimensions relevant to subpopulations, will better enable implementation. Where adaptation is made to enable implementation of measurement tools should be tested and validated prior to implementation.

Connect the data

Develop better information on the integration of mental health care and specialist care, and on the integration between Australian Government and state/territory funded services

Linked datasets provide an opportunity to broaden outcome measures for young people throughout the mental health services journey. Linking data has the potential to measure outcomes such as a return to education or employment following mental health treatment. In England, the concept of a unique identifier to link records across health, education and social care to improve the value of data and information for working with young people has been suggested.

This approach relies on a data link being found and the availability and appropriateness of existing data. More importantly, this approach is dependent upon data sharing. Making data available, within careful parameters, has been pursued in the United Kingdom to enable improvements in state funded health systems. Existing barriers to data sharing between government departments and agencies, and across jurisdictions and between mental health services, would need to be addressed if the potential of data matching and linking was to be implemented in Australia.

In partnership with headspace National Youth Mental Health Foundation (headspace), Orygen is developing a National Youth Mental Health Report Card based on identifying existing data collections from which a broad dataset will be compiled to form a detailed picture of a young person's mental health and wellbeing and to track changes.

Investigate the use of connected data to improve services for people living with mental illness

Connecting existing data to produce more detailed datasets has the potential to improve data quality and breadth, which could inform service improvements in the mental health and interconnected sectors. For example, measuring social and economic participation would enhance outcome measures for young people who have received treatment.

On their own, larger datasets will not improve services. Technical infrastructure is required to enable data analysis and predictive modelling to improve services. For example, the creation of 'synthetic' populations based on available data (a dataset whose joint distribution of variables is reflective of reality, but does not use real individuals and personal data) to be used in health care simulation models. This technical capacity would expand the scope and ambition of mental health care simulations to answer a wider set of questions (including predicted response to alternative system design configurations – something that cannot be answered by analytic work on historic data).

Orygen and headspace are working on two projects that connect data for youth mental health services. The Youth Change and Outcome Measure project has tested the validity of an extended list of items drawn from a number of existing evidence-based measures. The next stage of development will identify a practicable number of items for everyday use in a clinical setting with young people. A single National Youth Mental Health Report Card is also under development (mentioned above).

Use data linkage to gain new insights from self-harm and suicide prevention data

The use of linked datasets to better understand health service utilisation prior to self-harm and suicide should also include fatal suicide behaviour. Investigation of the potential role for large linked datasets for factors associated with a high risk of suicide must ensure that variables which provide information on the risk and protective factors are included in datasets, including risk and protective factors specifically for young people and subpopulations.

Harness findings of research and data analysis to inform policy, service planning and clinical service delivery

The development of mechanisms for utilising translational and applied research to inform data analytics and improvements to data collections to improve clinical service delivery would be enhanced through the use of simulation based analysis of what we expect would happen under alternative policy, service planning and clinical service delivery approaches.

Orygen supports the use of data analytics to develop more targeted performance indicators. For example, quantifying the health related quality of life that was predicted to be generated by a proposed policy, service delivery model or therapeutic intervention and how such gains are distributed throughout the population (i.e. are there differences based on diagnosis, sex/gender, socioeconomic status, etc.) would inform service and workforce planning.

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