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## VALUE-BASED MENTAL HEALTH SERVICES FOR YOUTH AND FAMILIES: THE ROLE OF PATIENT-REPORTED OUTCOME MEASURES IN YOUTH MENTAL HEALTH SERVICES

Megan Mungunzul Amarbayan, Travis Carpenter, Michèle L. Hébert, Maria Santana and Jennifer Zwicker

### SUMMARY

In Alberta, the responsibility for youth mental-health is shared among three separate government ministries, compounding the challenge of determining the value of services delivered, especially from the youth's own perspective. As a result, Alberta's ability to measure service quality at the systems level is limited. Yet, given the short-term and long-term effects of poor mental health on youth, families, and society, there are clinical, moral, and economic imperatives for ensuring that all services provided are of the highest value possible.

Currently, Alberta is limited to estimating value mainly through quantitative measures focused on the cost of service delivery. However, value-based health-care services are measured as quality or outcomes for persons receiving health services in relation to the costs of delivering those services. One approach is to measure outcomes of youth receiving mental-health services from their own perspective to achieve value-based measurement of youth mental-health services.

Patient-reported outcome measures (PROMs) are questionnaires filled out by the persons receiving mental-health services themselves, and assess their self-reported health and well-being. PROMs have been shown to be important in evaluating the value of health-care services both at the individual and systems level.

At the individual level, PROMs allow patients and health-care providers to track progress over time. At the systems level, PROMs data can be compiled to evaluate trends between different sites or different health-care services or treatments over time, to help improve quality. Policy-makers can use these comparisons to help pinpoint which services offer the most value.

Given resource constraints, implementing PROMs province-wide in Alberta can improve the value of youth mental-health services at a time when they have become a matter of great urgency. Improving the quality and outcomes for youth and their families in the short term will deliver positive socioeconomic impacts in the future.

## POLICY ISSUE

Healthy emotional and social development in youth — those who are 15 to 24 years of age — lays the foundation for mental-health throughout the life course and builds resilience (MHCC n.d., 11). Yet, in Canada, 10 to 20 per cent of youth may develop mental-health concerns (CIHI 2019). Relative to any other age groups, youth have a higher probability of developing mental illness (MHCC, n.d., 11). Youth mental-health concerns underpin both short- and long-term adverse impacts over the lifespan for the individual, on the individual's family and, on a larger scale, on social and economic costs (Kutcher, Hampton, and Wilson 2010; Kessler et al. 2005). On an individual level, reduced resiliency associated with youth mental-health concerns can increase the risk of suicide in adulthood, hospitalizations and hindered relationships with family and other loved ones (Weissman 1999; Malla et al. 2018).

Significant socioeconomic impacts of mental-health concerns can persist into adulthood and affect families. Mental-health concerns are correlated with a higher incidence of incompleteness of high school or post-secondary education, and subsequent employment and income loss (Breslau et al. 2008; Patel et al. 2007). Mental-health concerns are also associated with significant economic losses due to parents needing to take time off from work to care for their child. For example, Ontario alone reported \$421 million per year in lost wages by parents who took time off work to care for their children (Jeffords 2019). The costs of adult mental-health concerns (most of which manifests in youth) in the Canadian economy totals \$50 billion each year, including \$42.3 billion in health and social care, along with \$6.4 billion in unplanned absences from work, based on 2011 statistics (MHCC, n.d., 1).

To address these individual and broader societal impacts, ensuring access to appropriate youth mental-health services is essential. The value of mental-health services is measured by service outcomes relative to the cost (Porter 2010). However, service delivery must be continuously assessed to determine the value of current and future youth mental-health services, ensuring that they are ultimately meeting the needs of youth and families. While we have a sense of service costs, Alberta's ability to measure service quality is currently limited. Patient-reported outcomes are one value-based approach that could be used to assess quality (Hostetter and Klein, n.d.). Given the relative scarcity of youth mental-health services in the context of a sharply increasing demand, there are clinical, moral and economic imperatives for ensuring that all services provided are of the highest value (CIHI 2019).

Youth mental health in Alberta is a shared responsibility between the ministries of Health, Community and Social Services, and Education (Zwicker 2020). Thus, cross-ministry strategy is needed to guide service delivery. Since 2017, the Alberta government has biannually updated the Valuing Mental Health strategy document, to address the mental health needs of "priority populations," one of which is youth and families (Alberta. Health 2019, 4). This report outlines the various policies intended to address youth mental-health concerns. Still, it does not detail approaches for assessing the value, or more specifically the outcomes, of the policies and services. Notably, the cross-ministry responsibility for youth mental-health services presents challenges in

evaluating the value of these services from youth perspectives, as well as for health-care providers, health-care systems and policy-makers. Equally as important is the type of measurement and assessment of youth mental-health services.

## **PURPOSE**

The purpose of this communicate is to describe how the usage of patient-reported outcome measures (PROMs) in youth mental-health services in Alberta could be incorporated as an approach to provide an assessment of value for policy-makers.

## **MEASURING VALUE IN HEALTH-CARE SERVICES**

Value-based approaches to health-care delivery incorporate concepts of quality or outcomes for persons receiving health services in relation to the cost of delivering those services, rather than focusing on the total amount of investment in a service (Gilmore et al. 2019; Teisberg, Wallace, and O’Hara 2020; Porter 2010). Value-based care refers to “whether it (care) is done safely and efficiently but also whether it is right for this person, in this time and in this setting — and whether this is the best use of funding, all things considered” (Gilmore et al. 2019). Value would increase if the outcomes for persons receiving the service improve while maintaining constant costs, or by lowering costs of services for equivalent outcomes. Value focuses not just on a single service but rather all types of care that are received by the person (such as primary, acute and/or emergency care) and the longitudinal change in outcomes that are most impactful for the overall well-being of that individual (Porter 2010).

Value-based approaches to youth mental-health services have great potential to reduce the health and social costs later in adulthood (Wong, Perrin, and McClellan 2018). However, in Alberta, assessing the value of youth mental-health services cannot solely be captured through the currently used measurements, such as emergency department visits and mental health rehospitalizations, which largely focus on cost of services used (Malla et al. 2018; Gill et al. 2017; Alberta. Health 2020). One approach is to measure outcomes of youth receiving mental-health services from their own perspective, using PROMs, to achieve value-based measurement of youth mental-health services.

## **PATIENT-REPORTED OUTCOME MEASURES (PROMS)**

PROMs are self-reported questionnaires that assess the person’s health and well-being from the person’s own perspective (CIHI 2015; OECD 2017; APERSU 2020). PROMs may be administered to assess changes in health status due to a decline in functioning as a result of an illness or other influences on well-being, or to measure any changes resulting from health services (CIHI 2015; APERSU 2020). There are both general and disease-specific measurements (CIHI 2015; APERSU 2020). General PROMs assess overall well-being, while disease-specific measurements measure more specific aspects of health and well-being related to a particular diagnosis or disease. Appropriate

usage of both general and disease-specific instruments allows for the systematic measurement and tracking of health status over time.

The collection of PROMs data has been shown to be important in evaluating the value of health-care services for stakeholders, both at an individual and systems level (APERSU 2020). At the individual level, periodic administration of PROMs can indicate self-reported patient progress, and provide this feedback to the patient’s family, clinicians and other health-care providers (APERSU 2020; Australian Commission on Safety and Quality in Health Care, n.d.). PROMs foster a collaborative relationship between patients and providers about patient health status, and they allow both patients and providers to track patient progress over time.

At the systems level, PROMs data can be compiled to evaluate data trends between various sites or between different health-care services, and to provide comparisons between services or treatments for quality-improvement purposes. Similarly, PROMs data can be compared over time to assess the relative quality or outcomes of health-care services, facilitating comparisons between disparate interventions with varying effectiveness in alleviating symptoms or improving health and well-being. For policy-makers, these kinds of comparisons can be facilitated by PROMs, helping pinpoint which services have the most value.

## **PROMS USAGE IN ALBERTA**

Currently, there is no province-wide policy for implementation and collection of PROMs data for health-care services (APERSU 2020). Alberta Health, Alberta Health Services (AHS) and the Health Quality Council of Alberta (HQCA) have jointly agreed to utilize and implement the widely used general PROM known as “EQ-5D” for health-care services, such as in primary health care. The EQ-5D is also being incorporated into the new province-wide Connect Care electronic medical-record system in Alberta. The EQ-5D implementation is an example of how PROMs data can be used to better understand individual and system-level impacts. A person receiving rehabilitation services at a community rehabilitation program through AHS can fill out the EQ-5D. The person’s responses can be reviewed by a health-care provider, instigating discussion about how to address any symptoms that the person may be experiencing. This data can also be aggregated to assess the impact of the service, for development of quality-improvement initiatives, and for policy-makers to more effectively allocate resources to best improve outcomes for patients. While there is a youth version of the EQ-5D, it is not specific to, nor likely to be adequately suitable for youth mental-health concerns. Hence, similar collaborative initiatives between stakeholders for the usage of PROMs are absent in youth mental-health services in Alberta.

## **PROMS DATA AND VALUE IN YOUTH MENTAL-HEALTH SERVICES**

AHS has professed the importance of “value (and) measuring outcomes — especially those that matter to patients — is imperative” (APERSU 2020, 7). Now is the time

to extend this imperative to youth mental-health services. Major projects currently underway in Alberta, representing the cross-ministry collaboration, likely represent opportunities for action that should not be missed (Alberta 2017). In the city of Calgary, the Centre for Child and Adolescent Mental Health, expected to open in fall 2021, is meant to deliver essential services for youth in the community (Valleau 2019). Since 2018, the Alberta government, building on priorities of providing community-based services for youth, has provided mental-health services in schools as a part of a prevention-first strategy (Alberta. Health 2019; Alberta 2017). Measuring the value of these services through PROMs is necessary to provide policy-makers with critical information on the effectiveness and quality of these services to the youth and families they are responsible to.

One way to assess the value of youth mental-health services is through the collection of PROMs by mental-health service providers. In the United Kingdom, the Child Outcomes Research Consortium (CORC) is an example of an effort that aims to improve the quality of youth mental-health services through PROMs data (Fleming et al. 2016; CORC 2021). CORC is a group of mental health-care providers, researchers, managers and funders of the National Health Service in England (Fleming et al. 2016). The PROMs data compiled from 2011 to 2015 on youth who received mental-health services from NHS and non-NHS institutions show improved outcomes for youth receiving mental-health services (CORC 2016).

Important lessons can be gained from looking at models like CORC. First, CORC was faced with challenges with collecting PROMs on a widespread scale (CORC 2016, 29). It lacked the necessary electronic infrastructure to collect and integrate data from the various service providers. Alberta does have some advantages in common health internet technology infrastructure, such as the new Connect Care system. Still, a cross-ministry mandate and commitment are required to facilitate greater integration of Ministry of Health data with data from the Ministry of Community and Social Services and the Ministry of Education, which are also provisioning youth mental-health services (Zwicker 2020). Second, CORC experienced challenges with electronic infrastructure being burdensome to providers with respect to data entry and organization (CORC 2016). This finding suggests a careful implementation strategy, in collaboration with providers, can help facilitate the success of such a system in Alberta. Third, there is a lack of consensus on which PROMs are most suited specifically for youth mental-health services, mainly because most of the literature on PROMs are based on adult populations, and there is a comparative paucity of data on youth populations (Barbic et al. 2019; Fleming et al. 2016; CORC 2016). CORC acknowledges that to increase the accuracy of the PROMs data in youth mental-health services, there must be more research and prospective validation of these measures to generate the needed consensus on which measurements are most suitable for detecting meaningful changes in youth mental health (CORC 2016). These learnings are important considerations for the adoption of a similar system in Alberta.

The importance of youth mental-health services and growing urgency in this time of increasing clinical need, combined with the potential to better assess the value of these services when resources are constrained, suggest the usage of PROMs in Alberta

could be a necessary step forward. To maximize quality and outcomes in youth mental-health services, policy initiatives are needed to enhance collaborations and at least initiate PROMs data collection, like what has been attempted with CORC in the U.K. Once operational, widespread collection and aggregation of PROMs data can serve as a useful catalyst for generating more thoughtful and informed integration between the current mix of services provisioned under the ministries of Health, Community and Social Services, and Education. In this way, we can help ensure that policy-makers have the tools to help guarantee that youth mental-health services are based on increased value, verifiably improving outcomes and optimally enhancing the overall well-being of young Albertans.

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## About the Authors

**Megan Mungunzul Amarbayan** is a recent graduate of the Master of Public Policy Program, class of 2020. She has previously obtained a Bachelor of Science, majoring in Biology and minoring in Sociology in 2019. This communique is an extension of her capstone, which dealt with the evaluation of youth mental health services with person-centered measurements. This research was supported by the Carpenter Medical Corporation Health Policy Studentship.

**Travis Carpenter** is an Assistant Professor at the University of Toronto and a general internist at Unity Health Toronto (St. Joseph's Health Centre). He completed his medical degree at the University of Alberta, residency and fellowship at the University of Toronto, and his graduate degree in public health at the Harvard Chan School. Dr. Carpenter currently serves as faculty with the Temerty Faculty of Medicine in Toronto, focusing on health quality and health policy.

**Dr. Michèle L. Hébert** is an Eyes High Postdoctoral Fellow at the University of Calgary, School of Public Policy and Faculty of Social Work, and founder of Buds in Bloom, child/family federal non-profit organization. Her research and grass-roots initiatives for children with neurodisability and families aim to improve cross-system and cross-sectoral partnerships – child and family wellness drive her work. Through her work, she promotes wellbeing, quality of life and mental health, and helps shape guidelines and policy supportive of timely, seamless, inclusive, culturally sensitive, personalized and cost-effective access.

**Dr. Maria J. Santana** is a health services researcher, patient and family-centred care scientist, an Assistant Professor in the departments of Pediatrics and Community Health Sciences at the University of Calgary. Dr. Santana has received training in clinical pharmacy, public health, and clinical epidemiology. Her research focuses in patient and family-centred outcome research and the methods to advance person-centred care and patient-oriented research. She is the Provincial Lead Patient Engagement ABSPORu.

**Dr. Jennifer Zwicker** is the Director of Health Policy at the School of Public Policy, an assistant professor in the Faculty of Kinesiology, University of Calgary, Canada Research Chair (II) in Disability Policy for Children and Youth and the Deputy Scientific Officer for Kids Brain Health Network. With broad interests in the impact of health and social policy on health outcomes, Dr. Zwicker's research program assesses interventions and informs policy around allocation of funding, services, and supports for youth with disabilities and their families.

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Ron Kneebone and Margarita Wilkins | June 2021

### GENDER DISPARITIES IN THE LABOUR MARKET? EXAMINING THE COVID-19 PANDEMIC IN ALBERTA

[https://www.policyschool.ca/wp-content/uploads/2021/06/TEG88\\_Gender-Disparities-Labour-Market\\_Baker-et-al.pdf](https://www.policyschool.ca/wp-content/uploads/2021/06/TEG88_Gender-Disparities-Labour-Market_Baker-et-al.pdf)  
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### SOCIAL POLICY TRENDS: HOME ALONE

<https://www.policyschool.ca/wp-content/uploads/2021/06/SPT-JUNE-Kneebone.pdf>  
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### ALBERTA'S KEY CHALLENGES AND OPPORTUNITIES

[https://www.policyschool.ca/wp-content/uploads/2021/06/AF16\\_AB-Key-Challenges\\_Smith.pdf](https://www.policyschool.ca/wp-content/uploads/2021/06/AF16_AB-Key-Challenges_Smith.pdf)  
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