

Increasing Measurement-Based Assessment and Care for People With Serious Mental Illness

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Executive Summary

Approximately one in 25 U.S. adults experiences a serious mental illness (SMI) each year. Many people with SMI take antipsychotic medications as a necessary part of their treatment. However, antipsychotics are associated with various adverse effects and medication-induced disorders. Tardive dyskinesia (TD) is one such disorder, characterized by uncontrollable and repetitive movements of the face, neck, arms and legs. Screening and routine monitoring for medication-induced disorders coupled with the use of antipsychotic medications greatly improves treatment outcomes for these patients.

Measurement-based care (MBC) is an important strategy to facilitate early screening, early intervention, mitigation of medication adverse effects and improved overall mental health outcomes for people with TD. In the case of TD, MBC provides an effective mechanism to detect early symptoms and develop and monitor a treatment plan, but it is only practiced by a fraction of mental health clinicians.

To increase the widespread adoption of MBC in the treatment of TD and mental illness more broadly, we must better understand both the barriers and facilitators to the adoption of MBC. This brief draws on the existing literature as well as key informant interviews to offer findings and policy recommendations to accelerate the adoption of MBC with the goal of improving health outcomes for individuals with TD and for all people with symptoms of mental illness.

Key Findings:

We identified four categories of primary barriers and facilitators—technical infrastructure, clinical operations, financing, and limited access to care and limited awareness of the impact of TD—that impede the adoption of MBC.

1. **Technical infrastructure** – In large part because it was left out of the HITECH Act of 2009, which invested in the infrastructure for healthcare information technology, the mental health system lacks the digital infrastructure to optimize MBC. Mental health data are often not integrated optimally into electronic systems and are not tailored in a way that enables real-time and informed decision-making for patient care.¹ Additionally, there are significant barriers to data integration to optimize and coordinate care.²
2. **Clinical operations** – While the value of implementing MBC is clear, its use can lead to increased time, effort and cost, making appropriate incorporation into clinical workflows, clear protocols, and careful change management key.
3. **Financing** – There are insufficient reimbursement and financial incentives to encourage clinicians and health systems to invest in MBC. For many common MBC measures, existing reimbursement options are not commensurate with the time required to

administer the tools, interpret the results, and develop integrative treatment and care plans. Value-based care may offer the most promising model for incentivizing MBC. Not only does it have potential to cover time for implementing MBC, but it provides additional incentives to improve patient outcomes.

- 4. Limited access to care and limited awareness** – People with SMI experience significant disparities in access to care, which are pronounced across racial, ethnic, geographic, and socioeconomic factors.^{3,4} Lack of health insurance, cost of care, mistrust of the mental health system, discrimination, stigma, and limited services in rural areas all contribute to these disparities. The lack of awareness of early symptoms of TD among both patients and their caregivers may lead to delayed identification of TD, reducing the likelihood of effective treatment to alleviate the symptoms of TD and impacting quality of life.

Policy Recommendations:

1. Federal lawmakers should increase funding for IT infrastructure to include behavioral health.
2. Mental health system leaders should invest in EHRs to optimize data collection and utilization.
3. Health systems and clinical teams should integrate MBC into clinical workflows.
4. Health systems should support behavioral health integration and/or coordination between specialty and primary care clinics.
5. Health systems and clinical teams should utilize evaluation and management time or complexity codes to enable adequate compensation for time spent on MBC.
6. The U.S. Preventive Services Task Force should declare TD screening and monitoring as a preventive service with a grade A or B recommendation for anyone taking anti-psychotic medications.
7. Public and private payors should provide adequate reimbursement for MBC and develop value-based care contracts for MBC.
8. Federal and state lawmakers should support flexible telehealth policy.
9. Clinical teams, professional associations and advocacy organizations should educate patients, families and community organizations on TD.
10. Providers should work to increase patient trust and engagement.

Introduction

One in five U.S. adults experiences a mental illness each year, and roughly one in 25 will experience a serious mental illness (SMI), commonly defined as a mental illness that substantially interferes with major life activities.⁵ Most mental health illnesses are not detected until eight to 10 years after symptoms emerge.⁶ Delayed care or a missed diagnosis can exacerbate an existing condition and lead to increased morbidity and mortality along with increased costs of care. Interventions are most effective at an early stage when symptoms are less severe and before they reach a crisis point.^{7,8}

Many people with SMI take antipsychotic medications as a necessary part of their treatment. However, antipsychotics are associated with various adverse effects and medication-induced disorders. Tardive dyskinesia (TD) is one such disorder that is characterized by uncontrollable and repetitive movements of the face, neck, arms, and legs.⁹ Not only does TD affect a substantial number of people who take antipsychotics, it is often permanent.¹⁰ Like with many mental health illnesses and medications, screening and routine monitoring for side effects associated with the use of antipsychotic medications (including TD) greatly improves treatment outcomes.

Measurement-based care (MBC) is an important strategy to facilitate early screening, early intervention, mitigation of medication adverse effects, and improved overall mental health outcomes. MBC involves systematically administering validated rating scales to assess the effectiveness of treatment and make adjustments as indicated to improve outcomes, supporting—*not replacing*—clinical judgement.¹¹ This type of routine, systematic monitoring of potential side effects of antipsychotics is recommended by international guidelines.¹² Importantly, MBC can provide an effective mechanism to identify TD earlier and develop and monitor a treatment plan.

Despite the benefits of MBC, most providers do not use it to screen and monitor for mental health illnesses or medication side effects.^{13,14} To increase the widespread adoption of MBC in the treatment of TD and mental illness more broadly, we must better understand barriers and facilitators to the adoption of MBC. This brief draws on the existing literature as well as eleven key informant interviews with healthcare executives, clinicians, payors, advocacy organization leaders, and community leaders to offer findings and policy recommendations to accelerate the adoption of MBC with the goal of improving health outcomes for individuals with TD and for all people with symptoms of mental illness. (*For more on our methods and approach, see Appendix A.*)

Background

More than eleven million U.S. adults live with serious mental illness (SMI).¹⁵ SMI most commonly encompasses diagnoses of psychotic disorders (e.g., schizophrenia), bipolar disorder, major depression with psychotic features, and treatment-resistant depression,¹⁶ and many patients with the SMI classification are thus prescribed antipsychotic medications.

Psychosis involves disrupted thoughts or perceptions in which a person may have difficulty recognizing what is real and what is not.¹⁷ The underlying etiologies of psychosis are complex and disparate, ranging from primary psychotic disorders and mood or substance use disorders to other neurologic and medical conditions (e.g., dementia). Other times, psychosis may be triggered by experiences such as trauma, stress, or childbirth.¹⁸ It is estimated that 15–100 people out of every 100,000 develop psychosis each year.¹⁹ The lifetime prevalence of primary psychotic disorders is approximately 3% of the U.S. population.²⁰ First episodes of psychosis typically occur between the late teens and early or mid-twenties, but people can experience initial psychotic episodes at any age.²¹

Higher rates of psychosis are associated with being part of a marginalized group, such as immigrants and individuals in ethnic minorities or non-heterosexual populations.²² Various social and environmental factors may contribute to these disparities.²³ For instance, marginalized and minoritized populations are more likely to experience discrimination and subsequent trauma that may contribute to the development of psychosis. They are also less likely to have access to early prevention or treatment interventions for health or mental health symptoms. Finally, these populations are more likely to be misdiagnosed regarding the underlying causes of psychosis. All of these factors can contribute to elevated rates of primary psychotic disorders.²⁴ In particular, Black patients are significantly more likely to be diagnosed with schizophrenia and related disorders than other racial and ethnic groups; however, this is due to societal (e.g. implicit bias and lack of cultural competency of the diagnosing clinician) rather than genetic reasons.²⁵

Antipsychotics and Their Side Effects

Treatment of psychosis is predicated on its underlying cause or etiology.²⁶ While psychosocial interventions are critical, treatment often also includes antipsychotic medications to mitigate or relieve symptoms such as delusions and hallucinations.²⁷ Antipsychotic medications are the primary treatment for schizophrenia and are commonly used to treat psychosis or agitation that occurs in the context of bipolar disorder, depression, and major neurocognitive disorders.²⁸ There are two categories of antipsychotic medications: first generation (typical) antipsychotics (FGAs), which primarily block dopamine receptors, and second generation (atypical) antipsychotics (SGAs), which block dopamine receptors while also interacting with

other receptors like serotonin.^{29,30} In most cases, the extent of dopamine blockage (i.e., D2 receptor antagonism) is greater for FGAs than SGA.

While antipsychotic medications can alleviate symptoms and reduce confusion or agitation caused by psychosis, they can have significant side effects. Side effects may include drowsiness, sedation, dry mouth, deleterious metabolic changes (e.g., weight gain), dizziness/hypotension, and abnormal movements.³¹ Of people taking antipsychotics, 10% develop diabetes, a risk that is 2-3 times higher than in the general population.³² SGAs, due to their more widespread interaction with non-dopamine receptors, carry an increased risk of sedation, hypotension, weight gain, and sexual dysfunction.³³ FGAs, due to their greater D2 receptor antagonism, are more commonly associated with side effects related to abnormal movements, including TD. However, all antipsychotic medications have the potential to cause TD.

Tardive Dyskinesia

TD is a disorder characterized by uncontrollable and repetitive movements of the face, neck, arms, and legs. Afflicted individuals often experience substantial decreases in overall quality of life due to day-to-day activity impediment and social stigmatization.^{34,35} Importantly, TD is often permanent and usually does not go away with the cessation of medication.³⁶ The lifetime prevalence of TD in patients treated with antipsychotics is roughly between 15% and 40% with higher rates reported in older adults, women who are postmenopausal, individuals with previous brain injury or dementia, and African Americans.^{37,38} In addition, recent research has shown that people with TD have significantly higher utilization of health care and associated costs after diagnosis of TD compared to those without TD. Patients with TD have increased inpatient admissions, emergency room visits, and outpatient visits as well as longer hospital stays.³⁹

While roughly one-quarter of all patients receiving antipsychotics develop TD,⁴⁰ certain populations may be at increased risk for its development. In some studies, Black patients had nearly twice the rate of TD as white patients.⁴¹ This is at least in part due to the fact that Black patients are less likely than white patients to receive treatment adhering to recommended practices and, as a result, are more likely to be prescribed FGA medications at higher doses, both which are associated with greater risk of TD.^{42,43}

Additionally, older patients who are often prescribed antipsychotics for off-label uses (e.g., agitation, anxiety, or insomnia) are five times more likely to develop TD than younger patients.⁴⁴ Concerns about over-prescribing antipsychotic medications to older people (especially those in nursing homes) are frequently cited by policymakers and regulators at the state and federal levels. In response, the U.S. Congress and Department of Health and Human Services (HHS) have initiated several safety initiatives. Similar apprehensions are mainstays of policy discussions about older, lower-income patients, such as those who are dually eligible for

Medicare and Medicaid; studies have noted an increased risk of all-cause hospitalization, nursing home admission, and death in this group.^{45,46,47}

The number of people impacted by TD is likely to continue to grow: antipsychotics are increasingly prescribed, with the Agency for Healthcare Research and Quality (AHRQ) estimating that upwards of 6.1 million people in the U.S. had at least one antipsychotic prescribed in 2018, compared to 5.0 million in 2013.⁴⁸ The increase is likely due to the use of SGAs as adjunctive treatments for major depression, and off-label uses of these medications for anxiety, post-traumatic stress disorder, obsessive compulsive disorder, eating disorders, insomnia, and agitation, among others.^{49,50}

Prevention of TD is critically important because of the potential for significant impact on patients' quality of life, the risk of the condition becoming permanent, and the impact on health care utilization and cost. Because the use of antipsychotic medications is necessary for many patients,⁵¹ early identification and intervention increase the likelihood of effective treatment to alleviate the symptoms of TD and improve the quality of life for individuals living with TD.⁵²

Use of Measurement-Based Care for Early Intervention in Tardive Dyskinesia

MBC is defined as “enhanced precision and consistency in disease assessment, tracking, and treatment to achieve optimal outcomes.”⁵³ It involves systematically administering validated rating scales to assess the effectiveness of treatment and make adjustments as indicated, thereby supporting— *not replacing*—clinical judgement.^{54,55} MBC facilitates earlier detection, more timely treatment (less lag time), and improved outcomes for individuals with mental health illnesses.⁵⁶ Often, MBC involves patient-reported outcome measures (PROMS) that increase engagement and facilitate patients' engagement in treatment plans.

When used for screening and monitoring of TD, the American Psychiatric Association (APA) recommends assessment with a structured instrument, such as the Abnormal Involuntary Movement Scale (AIMS), once every six months at minimum for patients at high risk of TD, once every 12 months for other patients on antipsychotics, and when any new onset or exacerbation of preexisting movements is detected during a visit. Adherence to the APA recommendations helps to foster a comprehensive understanding between physicians and helps to ensure consistent implementation of the assessment tools.⁵⁷ MBC can also be used to assess the impact of TD on a patient's life, helping to inform the need, urgency, and best manner with which to treat TD. Beyond the AIMS, other instruments have been suggested or preliminarily tested for assessing TD and its impact, such as the modified Craniocervical Dystonia Questionnaire [mCDQ-24], the Tardive Dyskinesia Rating Scale [TDRS], and the Dyskinesia Identification System: Condensed User Scale [DISCU].

New tools offer promise in centering patients' needs and concerns in MBC for TD. The Impact-TD, assesses not just TD's physical impact but its social, psychological, recreational, vocational, and educational impacts as well.⁵⁸ Additionally, the Tardive Dyskinesia Impact Scale (TDIS) was recently developed and an initial study demonstrates its validity and reliability. Of note, the TDIS is the first patient-reported outcome measure (PROM) to assess the impact of TD.⁵⁹

In the case of TD, MBC can provide an effective mechanism to rapidly detect early symptoms and develop and monitor a treatment plan,⁶⁰ but it is only practiced by a fraction of mental health clinicians. In mental health care more broadly, uptake of MBC remains far below peer specialties in general health; less than 20% of mental health care providers report using MBC.^{61,62} The reasons for this lack of uptake are manifold—relevant barriers range from technological limitations to clinician reluctance. To promote the adoption of MBC in treatment of TD, it is necessary to understand general barriers and facilitators in the adoption of MBC plus the specific barriers to incorporating measurement of TD symptoms.^{63,64} Both are discussed next.

Key Findings: Barriers and Facilitators for MBC in Screening and Treatment of TD

Based on findings from the literature as well as our key informant interviews with healthcare executives, clinicians, payors, advocacy organization leaders, and community leaders, we outline three categories of primary barriers—technical infrastructure, clinical operations, and financing—that impede the adoption of MBC. Where possible, we highlight facilitators for MBC and solutions to overcome these barriers.

Technical Infrastructure

Health Information Technology Infrastructure

Behavioral health is lagging in health information technology (HIT) infrastructure. The [HITECH Act](#) of 2009 provided significant funding for the adoption of electronic health records (EHR) within physical health care settings, but it neglected to do the same for mental health and substance use disorder (SUD) settings. Without adequate funding to support critical operational changes, many mental health care systems struggle to create the necessary technological infrastructure to digitally collect mental health assessment data. Of the 1,059 inpatient psychiatric hospitals in the U.S., only 47% have adopted EHR technology.⁶⁵ There are similar challenges in the outpatient setting as EHR and HIT implementation may be cost prohibitive for many smaller clinics and private practices.

While technology is not required to use MBC, HIT greatly facilitates MBC implementation. Technology reduces the burden of administering and scoring measures while also making it easier to look at past scores and draw comparisons in real time, such as through automatic

graph generation. In the absence of electronic systems, practitioners and administrative staff have the burden of using paper forms to collect MBC assessment data, a practice that is labor intensive and does not readily allow clinicians to view of aggregate, population-level, or clinic-level data.⁶⁶

Integration Into EHR and User Interface

Even when electronic systems exist in mental health care organizations, MBC practices are often not integrated optimally into those systems. Often times, EHRs are not tailored for immediate data collection or streamlined analysis, a shortfall that hinders real-time and informed decision-making for patient care.⁶⁷ As one key informant noted, “Even though [her] clinic utilized EPIC, and it was possible to complete an AIMS measure in it, [the clinician] would not know where to look for AIMS scores from previous visits.”

Research has shown that the likelihood of clinicians checking scores and discussing data with patients drastically increases when that information is integrated into the EHR where a clinician already takes notes.⁶⁸ Further, the effectiveness and intuitiveness of the EHR user interface significantly impacts its acceptance by health care professionals.⁶⁹ In our interviews, organizations that prioritized MBC invested in supporting it through their EHR. For instance, one key informant from a behavioral health system focused on serious mental illness expressed the value of having the AIMS scale easily available in the EHR where providers can look back at previous scores; other assessment tools that are not as easily accessible do not end up being as impactful.

Another interviewee discussed how technological innovations let them customize data visualizations so that assessment responses can go directly in the medial record to be charted and graphed alongside treatment interventions. Others have even invested in deep learning technology, a type of artificial intelligence, to predict which patients are going to respond to a treatment, thereby allowing clinicians to adjust treatment plans accordingly from the start.

Need for Interoperability and Privacy

In many large health care settings, the data stored within the EHR, such as lab results, patient feedback, assessment scores, medical history, and other information, are coordinated and streamlined. However, outpatient and specialty mental health clinics frequently grapple with a lack of data integration, resulting in segmented patient information and potential care inconsistencies.⁷⁰ As noted by key informants, a barrier to optimal integration is the significant knowledge, time, and financial investment it takes to ensure that the correct tools are integrated properly and are accessible throughout a health care system or setting.

Additionally, some providers and patients may be concerned about breach of confidentiality if MBC data is collected outside of the EHR, especially for patient reported mental health data that can be collected outside of the clinic office, such as through online channels or a phone application. Ensuring the use of HIPPA and the Health Level 7 Standard, an international standard for medical record sharing between health compliant technologies, is critical to ensure privacy and facilitate trust^{71,72}

In the specific case of TD, advanced EHR and user interfaces are particularly useful because a clinician is not only focused on the aggregate score but also the changes in individual measures. Interoperability is also critical as patients with TD are likely to be seen by multiple health and mental health care providers to manage other antipsychotic side effects or co-morbidities.

Clinical Operations

Incorporation Into Clinical Workflows and Culture

Increased time, effort, and cost are all barriers to provider adoption of MBC.⁷³ Incorporating MBC into existing workflows, including but not limited to EHRs, is critical for successful MBC implementation. The Interdepartmental Serious Mental Illness Coordinating Committee recommends using implementation planning guides to map out goals, codify processes, and revisit plans as needed.⁷⁴ As key informants shared, specific protocols, associated manuals, and targeted staff training support effective implementation of MBC. The manner in which MBC tools are integrated into the EHR should support these protocols.

The process of change in clinical settings can often be slow, and change management is important when adopting a new practice like MBC. A health system can facilitate MBC implementation with strong organizational leadership and buy in as well as by identifying champions who can ensure it remains a priority in routine practice.^{75,76} As expressed by key informants and in the literature, training staff on both the “how” and “why” of MBC (i.e., the benefit for patients and utility in medical decision-making) helps adoption. Creating clear protocols around frequency of use and how to access assessments in routine practice is helpful. As one key informant noted, setting up communities of practice is also helpful to establish new initiatives for MBC.

Need for Coordination With Primary Care Physicians

Individuals living with SMI often have multiple chronic conditions and may experience a number of side effects from their antipsychotic medications. Coordination of care between primary care providers and specialty care providers helps to avoid fragmentation of treatment efforts, thereby promoting safer and more effective care.⁷⁷ Ideally, individuals with SMI can receive “integrated care in settings equipped to diagnose and treat these complex and interrelated disorders.”⁷⁸

Financing

Insufficient Reimbursement and Financial Incentives

Many providers do not feel that they are appropriately compensated for the time and technology required to use MBC and may not always be aware of the best coding practice to ensure compensation for time spent on MBC. Reimbursement amounts need to be on par with the amount of time and effort dedicated to the work, whether through traditional fee-for-service or value-based care models. Further, value-based care models allow for the incorporation of patient outcomes and progress into the reimbursement and funding calculus.

Fee-for-Service Challenges

Many health systems do not provide adequate incentives, technology, or patient time for providers to collect quality- or outcome-focused measures, instead emphasizing volume-driven or productivity measures. Specific codes exist for some assessments used for MBC; however, reimbursement is payer dependent. Even when there is a distinct code, reimbursement is often insufficient.

For example, in 2010, the Affordable Care Act (ACA) began requiring insurers to reimburse for depression screening, but reimbursement offered by the billing codes is not commensurate with the time required to administer the tools, interpret the results, and develop integrative treatment and care plans. Moreover, ACA only allows for reimbursement one time each year, which allows for the screening but not continued monitoring involved in MBC.⁷⁹

In the case of TD, unlike depression, there is no specific reimbursement for most TD assessments (e.g. AIMS), which requires a skilled clinician to administer and is even more time-intensive than depression screening. However, health systems and clinical staff may be able to take advantage of evaluation and management codes to cover MBC and thus bill for complex cases or lengthy visits. In 2021 and 2023, The American Medical Association (AMA) updated billing codes and guidelines impacting the way prescribers can bill for outpatient and inpatient services respectively.^{80,81} With these changes, prescribers are reimbursed for their time spent with a patient *or* how complex the visit was. When a service fits within the criteria to use an evaluation and management code, health systems and clinical staff may be able to utilize these changes to enable appropriate compensation for the time it takes to assess TD.⁸²

Even when a prescriber's time is reimbursable, as expressed by key informants, TD assessment may exceed the time providers routinely receive to medically manage the psychopharmacology of patients with possible or ongoing TD. As expressed by key informants, this is particularly a challenge for providers at high-volume community-based mental health practices where patients with SMI often receive longitudinal care. In these cases, clinical practices can consider

developing clinical workflows to allow nurses or other clinical staff to assist with conducting the TD assessments, and thus, may minimize the amount of time a prescriber must use to complete the TD assessments. Additionally, the recently developed TDIS, the first patient-reported instrument that assesses the impact of TD, may offer a helpful supplement to clinician assessments, such as AIMS.

Value-Based Care

Even if the potential for reimbursement exists, there may still be insufficient incentives to implement MBC. There is increasing promise for MBC as health systems shift their focus from volume to value. In value-based care, rather than paying for the provision or volume of services, payors reimburse for clinical outcomes and/or the quality of care provided. MBC provides a clear pathway to measure and track relevant outcomes in such alternative payment contexts. At the same time, value-based care has a mechanism to cover costs associated with providing MBC.⁸³ For instance, a value-based contract could pay a provider a baseline amount for implementing MBC and an additional amount for improving patient outcomes at scale.

Patients with TD have significantly higher health care utilization and associated costs than those without TD.⁸⁴ Since early assessment and treatment could mitigate these costs, MBC for TD is ripe for value-based care payment methodologies. Introducing premium service categorizations for MBC-compliant health care providers could create a competitive advantage, driving other providers to adopt MBC in pursuit of similar recognition and associated financial benefits. Additionally, understanding the economic implications of treatment modalities can shed light on areas of inefficiency and provide insights into potential cost-saving measures.⁸⁵ With the right financial strategies, not only can MBC adoption be enhanced, but the overall economic burden on healthcare systems might be alleviated, leading to more sustainable and effective patient care.

Limited Access to Care and Limited Awareness

Limited Access To Care

While access to care is an issue across mental health systems, access is a particularly important challenge with TD due to the significant impact of early identification on long-term treatment outcomes. Almost 35% of adults and 42% of young adults with SMI do not receive mental health treatment in a given year, and disparities in access to quality care are pronounced across racial, ethnic, geographic, and socioeconomic factors.^{86,87} Research clearly demonstrates that, the longer treatment is delayed, the worse the outcomes. The consequences of these unmet needs are dire—SMI is associated with high rates of homelessness, increased criminal justice involvement, and extremely low rates of employment.⁸⁸

Cost and Insurance Coverage Challenges

According to a 2015 report by the Substance Abuse and Mental Health Services Administration (SAMHSA) on disparities in mental health services, adults with SMI who reported an unmet need for services cited the primary reason as cost or insufficient coverage by a health benefit plan.⁸⁹ Indeed, mental health service utilization is significantly lower for adults with SMI who do not have insurance than those that do.⁹⁰ As described by one key informant who works in both private and public settings, providers in public settings often have less time with their patients and may have less of an opportunity to use MBC, particularly for TD. While their patients may benefit most from MBC to ensure their continuity of care, they may be least likely to receive it.

Mistrust of Mental Health System and Stigma

Individuals with SMI may be reluctant or resistant to seek care as well. Distrust of care providers and experiences of racism in the healthcare system contribute to this reluctance.⁹¹ In fact, adults with SMI who reported an unmet need for services cited prejudice and discrimination as more significant factors in not obtaining care than either a low perceived need for care or not thinking services would be helpful.⁹² It is imperative that issues of discrimination in the diagnosis and treatment of psychosis and in the crisis care system be addressed.

At times, cultural norms and stigma may play a role in delayed treatment. Stigma, especially around mental health symptoms and needs, has a profound impact on people's willingness to seek professional help and/or familial support in seeking care. Clinicians and community organizations working with people with SMI should be aware of cultural nuances and provide patient-centered care that is responsive to the cultural and spiritual needs of individuals.⁹³

Increased Challenges in Rural Areas

Mental health workforce shortages are greatest in poorer and rural counties. This can lead to challenges such as long wait times for appointments and higher use of acute care services. Telehealth is viewed as a mechanism to address mental health workforce shortages, especially in rural areas.⁹⁴ In fact, a recent study found that telemental health services increased mental health visits by Medicare patients with SMI by 13%.⁹⁵

The assessment of TD is best conducted by a trained clinician during in-person visits, as a full-body view of the patient is preferred to optimize evaluation accuracy and reliability. In this regard, telehealth cannot serve as a complete replacement for in-person care, though a recent qualitative study provided insights from experts on the benefits of virtual TD assessment (especially during the COVID-19 pandemic), such as fewer missed appointments, reduced time/cost, and easier access to family/caregiver feedback.⁹⁶ The same study, however, also recognized other pressing challenges associated with virtual TD assessment, such as technology barriers and the inability to conduct comprehensive neurological examinations. Therefore, it

emphasized the importance of in-person assessments, recommending an in-person TD assessment within the six months before the first virtual visit and at least one in-person assessment every six months thereafter. The American Psychiatric Association does not comment specifically on the merits of virtual versus in-person evaluation, but clearly recommends screening for TD with a structured assessment at least every six months for patients at high risk (or at any time if there is new onset or exacerbation of existing movements) and every 12 months for all patients.

Limited Awareness of Symptoms

Nearly half of all patients with TD are not aware of their symptoms and may not report their movements due to lack of understanding about the underlying cause, decreased cognitive awareness due to their SMI, or because of the varying intensity of TD symptoms themselves.⁹⁷ Family members or other people who regularly interact with a person with TD can often more readily observe symptoms of TD than the patient. As one key informant pointed out, a patient's family member may be the first one to identify symptoms of TD and/or notify a health care provider. Community organizations such as Clubhouses or faith-based settings that have staff or volunteers who spend significant amount of time with individuals with SMI may also be well suited to identify when someone shows signs of TD. Educating family, caregivers, and community organizations could help enhance early identification of TD at scale.⁹⁸

Key Recommendations

Despite the many barriers to the use of MBC and associated data collection, recognition of its effectiveness is increasing.⁹⁹ In this section, we offer recommendations for addressing barriers to MBC implementation and optimizing the process. These recommendations are aimed at enhancing the IT infrastructure that underpins MBC for people with SMI, streamlining health care processes, and ultimately improving patient outcomes.

Technological Infrastructure

1. Federal lawmakers should increase funding for IT infrastructure.

Behavioral health was largely left out of the Health Information Technology for Economic and Clinical Health (HITECH) Act, which helped the rest of the healthcare system build its IT infrastructure over the last few decades. Consequently, behavioral health IT infrastructure and funding significantly lags behind physical health. Federal lawmakers should address this unjustified discrepancy by extending long-overdue funding for EHRs and related technologies to behavioral health providers.

A bipartisan, bicameral effort to remedy this concern is underway with the introduction of the Behavioral Health Information Technology (BHIT) Coordination Act (S2688/H.R. 5116). The BHIT Coordination Act would extend funding for EHRs and related technologies to behavioral health

providers. Ensuring that behavioral health providers have access to effective and user-friendly EHRs as proposed in the legislation would improve reliable data collection and the ways data can be used to inform and improve patient care.¹⁰⁰ Interoperability between systems to allow for care coordination between hospitals, specialty care, and primary care is key to maximizing the potential of EHRs to support care of people with SMI.

2. Mental health system leaders should invest in EHRs to optimize data collection and utilization.

The effective use of MBC is greatly facilitated by seamless integration into an EHR in a way that supports clinical workflows. Health systems should invest in EHR integration to allow for easy data collection and enable clinicians to readily view historical data in real time. Healthcare systems should work towards enabling interoperability so that data can be easily shared and securely accessed across different platforms and care settings.^{101, 102}

Clinical Operations

3. Health systems and clinical teams should integrate MBC into clinical workflows.

Health systems and/or clinical teams should implement existing clinical practice guidelines for MBC. These should delineate when and how clinicians should use MBC instruments with patients who have SMI for TD and other behavioral health assessments in a manner that supports clinical workflows and minimizes burden on providers.

4. Health systems should support behavioral health integration and/or coordination between specialty and primary care clinics.

Health systems should support the implementation of integrated care whenever possible. Clinical teams and health systems should prioritize coordination of care between mental and physical health providers (e.g., primary care providers) through information sharing and other mechanisms.

5. Health systems and clinical teams should utilize evaluation and management time or complexity codes to enable adequate compensation for time spent on MBC.

Health systems and clinical teams should take into account recent CPT code and guideline changings for evaluation and management services that enable prescribers to bill for either time or complexity of medical decision making to support appropriate compensation for the time and effort it takes to implement MBC, especially time intensive TD assessments. Health systems and payers should provide education to clinical teams and billing professionals to make sure teams understand these new guidelines and when they are applicable to ensure the best coding practice is implemented.

Financing

6. The U.S. Preventative Tasks Force should declare TD screening and monitoring as a preventive service with a grade A or B recommendation for anyone taking anti-psychotic medications.

Preventative services are required to be covered by private insurers and Medicaid under the Affordable Care Act Sections 2713 and 4106, respectively.¹⁰³ Including TD screening and monitoring as a preventive service would encourage prescribers to include TD screening along with other routine screenings for on-going clients, such as screening for suicidal thoughts and thoughts of harm to self and others.

7. Public and private payors should provide adequate reimbursement for MBC and develop value-based care contracts for MBC.

Reimbursement should incentivize high-value care and be on par with the amount of time and effort required to do this work effectively, whether through traditional fee-for-service or value-based care models. While evaluation and management codes may provide compensation for prescriber's time conducting MBC, it does not cover all providers (e.g. psychologists) or situations. Value-based care models may offer the opportunity for additional compensation in cases where clinicians or practices demonstrate improvements in process of care (e.g., frequency of follow-up visits) or clinical outcomes (e.g., improvement in symptoms or functional status). In doing so, these models can align incentives to ensure that increased compensation is directly tied to better care. Of note, it is important that these mechanisms be implemented in a way that does not place undue burden on providers and ensures requirements are clear and actionable.

Further, the Centers for Medicare & Medicaid Services (CMS) and other payors should consider specific coding with reimbursement for implementing an evidence-based TD assessment in accordance with the American Psychiatric Association's recommendation (every 12 months for patients taking antipsychotics; every 6 months for patients at high risk for TD). CMS set forth a goal to have 100% of original Medicare beneficiaries and the majority of Medicaid beneficiaries in accountable care relationships, a type of value-based care, by 2030.¹⁰⁴ Payors should embrace this shift to value-based care in behavioral health care by incentivizing the use of MBC and/or specific value-based payment mechanisms, such as payment bundles, to cover treatment for people with psychotic disorders, such as [Coordinated Specialty Care for Early Psychosis](#).

Access and Awareness

8. Federal and state lawmakers should support flexible telehealth policy.

Telehealth is increasingly recognized as a strategy to reduce barriers to treatment, particularly for people living in rural areas or otherwise underserved areas.¹⁰⁵ The Center for Medicaid and

CHIP Services should encourage states (1) to continue the telehealth advancements made during the COVID-19 public health emergency that extended access to care and (2) to ensure continuity of care under the current telehealth flexibilities.¹⁰⁶

At the same time, the expansion of telehealth resources should not be implemented in an inflexible, one-size-fits-all manner that hinders or discourages the use of in-person care where needed. Policymakers should be particularly careful not to allow telehealth expansion and reimbursement to be used to discriminate against in-person treatment, particularly in instances where physical exams are critical for screening, diagnosis, or care. For example, the American Psychiatric Association recommends regular physical screening for individuals at high risk of TD to ensure early detection of even minor changes in movement. Telehealth expansion should be additive and not used to impede efforts to provide such care or as an excuse to add barriers to in-person examinations and care.

9. Clinical teams, professional associations, and advocacy organizations should educate patients, families, and community organizations on TD.

Identifying TD early is critical to mitigating its impact. Symptoms of TD are often more readily observable by family members or other people who regularly interact with the person with TD than to the patient themselves. Accordingly, educating patients, family caregivers, and leaders/members of faith-based settings or other community organizations (e.g., Clubhouses) could enhance the early identification of TD.¹⁰⁷ Clinical teams—including physicians, nurses, community health workers, and peers—can all help to educate patients and family members about the signs and impact of TD. Advocacy organizations, such as National Alliance on Mental Illness or National Organization for Tardive Dyskinesia, can also help to educate patients, families, community organizations, faith-communities, and peer recovery organizations.

10. Providers should work to increase patient trust and engagement.

People of color, particularly Blacks, living with SMI are likely to have experienced negative interactions including prejudice and discrimination within the health care delivery system. Given the role and impact of bias in the development, diagnosis, and treatment of psychotic disorders, it is important that providers work to mitigate bias. As a starting point, we must work to eliminate differential prescribing practices that disproportionately impact Black people and contribute substantially to mental health outcome disparities.

Clinicians and mental health advocates should be aware of patients' potential negative experiences with the medical system and work toward gaining patient trust. Providers should be aware of cultural nuance and work towards patient-centered care that is responsive to the cultural and spiritual needs of individuals.¹⁰⁸

Additionally, efforts should be made to ensure the cultural sensitivity and relevance of measures. Tools should be provided in multiple languages.¹⁰⁹ Engaging providers and patients in the selection of measures is important. Measures related to client goal setting and tracking may be more acceptable to both providers and patients than standardized measures, though the evidence for MBC is limited to standardized measures.¹¹⁰ As some key informants pointed out, integrating measures that focus on quality of life and functional status (e.g. IMPACT assessment), rather than just symptom reduction, aligns with the philosophy of patient-centered care.

Conclusion

Despite substantial evidence showing that MBC leads to improved mental health outcomes, there continues to be resistance to its implementation among clinicians, lack of awareness among patients and families, and poor support of the practice from payors and health systems. For patients who have SMI and experience early or emerging symptoms of TD, a delay in diagnosis may lead to an often-irreversible worsening of the condition. Lawmakers and policy makers can accelerate the adoption of strategies that facilitate MBC outlined in this paper, such as increasing funding for electronic health records within outpatient and specialty mental health centers, supporting flexible telehealth policies, enhancing reimbursement for MBC codes, and promoting education for families and community members on early TD signs and symptoms. Future research should promote the relationship between MBC and artificial intelligence (AI) as a tool to help clinicians leverage MBC data to improve patient health outcomes (a practice already underway in many health systems). Additionally, future research should continue to focus on identifying culturally relevant, validated assessments that can be used in MBC. Ultimately, accelerating the adoption of MBC for SMI and other mental health conditions will lead to improved quality of care, mental and physical health, and, ultimately, quality of life for those with mental illness and reduced costs for effective care.

Appendix A: Methods and Approach

In the initial phase of this project, the Meadows Institute executed an environmental scan, reviewing existing literature and relevant policies to identify potential barriers and opportunities in advancing measurement-based care for people with SMI. Based on these initial findings, we identified a range of key informants with specific expertise, experience, and roles within their respective organizations. These national and international experts represented the following types of stakeholder groups:

- Psychiatrists (from public, private, and academic settings)
- Informatics professionals with specific focus areas, such as electronic health record (EHR) integration
- EHR integration experts
- National advocacy organizations
- Community organizations
- Clinicians, administrators, and payors
- Health plan or insurance representatives
- MBC experts

We conducted twelve semi-structured stakeholder interviews and analyzed the results to identify key barriers and facilitators to measurement-based care and develop recommendations.

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