FOUNTAIN HOUSE

Embedding Measures That Matter Into Mental Health Systems: A Lived Experience-Informed Measurement Framework for Serious Mental Illness & Guidance for Future Initiatives

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Key Terms

Language is a powerful tool. It can shape, broaden and focus our objectives as we tackle complex topics. By clearly defining key terms, we hope to enhance general knowledge about mental health and measurement, making it accessible to a variety of audiences. This includes those with lived experience, families, and communities of those most impacted by mental illness. In addition, through shared terminology, we also aim to clarify the scope of this current project and facilitate a shared understanding of our goals.

Care Teams – All human resources that support people living with serious mental illness. These professionals include, but are not limited to, psychiatrists, social workers, peers, staff of community-based organizations, Assertive Community Treatment (ACT) teams, and hospital workers. Care teams may provide therapy, psychosocial support, medication management, crisis response, or resources like housing or food. The term "care teams" was chosen in collaboration with people living with serious mental illness.

Clubhouse – A community-based, recovery-oriented space for people living with serious mental illness. Those that are part of the community are referred to as "members," as their engagement in the clubhouse is voluntary and not time limited. Clubhouses are a non-residential, supportive environment where members can engage in meaningful work, build relationships, and access educational and employment opportunities. They operate on a model of psychosocial rehabilitation and emphasize peer support, dignity and shared responsibility. For more information, visit fountainhouse.org.

Measurement-Based Care (MBC) – An approach that involves the use of standardized tools (i.e., measurements) to assess a patient's symptoms, functioning and treatment response. MBC techniques are used to inform and adapt treatment plans based on data.

Patient-Reported Outcome Measures (PROMs) – Indicators of change (progress, setbacks and other changes) as perceived and reported by people receiving health care and supportive services. In clubhouse settings, these are known as member-reported outcomes. We refer to these outcomes as both PROMs and self-reported outcomes, a term preferred by the people with lived experience with whom we worked, in this paper. Outcome measures differ from process measures (definition below) because they are the results of the services, rather than the steps to deliver the services.

People With Lived Experience – In this case, individuals living with serious mental illness. People with lived experience have expertise based on their experiences that leads to personal and translatable insights for work involving their care.

Person-Centered Care – A model of care that prioritizes the needs and values of individuals receiving treatment. It emphasizes collaboration between patients and care teams and involving patients in making decisions about their care plans.

Process Measure – A quantifiable measure used to assess the implementation and delivery of care services. Process measures track how well specific activities are carried out (e.g., frequency of follow-up appointments, use of standardized assessments) and help identify areas for improvement in care delivery systems. A good process measure tracks the implementation of a service or support that has a solid evidence base for producing desired outcomes.

Recovery and Wellness Journey – In this report, we use the terms "recovery" and "wellness journey" interchangeably. As aptly described by the Government of New South Wales, Australia, this is the non-linear process of "achieving an optimal state of personal, emotional, and social wellbeing" (NSW Health, n.d.).

Serious Mental Illness – Psychiatric disabilities that severely disrupt people's lives. The primary diagnoses typically include schizophrenia, schizoaffective disorder, bipolar disorder, and major depression, and can include others. Like other serious conditions, serious mental illness may have chronic impacts. It also can be managed in a way such that it no longer interferes with daily life, or the interference is minimal. Fountain House is aware that there are many different views about the semantics of serious mental illness among people with lived experience. When the Fountain House community engaged with members about how to refer to it in public conversation, consensus emerged to use the term serious mental illness even as some members prefer other terms. We defer to the collective views of our community of people with lived experience.

Social Drivers of Health (SDOH) – The non-medical factors that influence health outcomes (e.g., housing, education, food security, etc.).

Value-Based Payment (VBP) models – Methods of rewarding care teams based on the quality and cost-effectiveness of services. For example, within VBP models, care teams can be paid or reimbursed for improved outcomes due to the services provided, rather than for each service itself. Pay-for-performance is a type of VBP model.

About Fountain House

For over 75 years, Fountain House has been a beacon of hope and recovery for people living with serious mental illness. Through our direct service clubhouse programs in New York City and Los Angeles, as well as national policy, advocacy and research initiatives, we have transformed the lives of tens of thousands of people living with serious mental illness. Founded in 1948 in New York City, Fountain House originated the clubhouse model of community mental health that has been replicated more than 370 times in nearly 40 U.S. states and in 30 countries around the world.

Clubhouses are community-based places that support people living with serious mental illness through intentional community and shared work. Within each clubhouse, units — or teams of staff and members — contribute to meaningful work and the clubhouse's daily operations.

In 2020, with generous support from the Dauten Family Foundation, Fountain House established the Research, Analytics, Knowledge, and Evaluation (RAKE) department, a team that operates in partnership with people living with serious mental illness and expands the base of evidence supporting effective policies and practices as they relate to clubhouses and serious mental illness. To learn more about Fountain House and our research, visit **fountainhouse.org/research**.

Introduction

Despite increased focus and resources from the Centers for Medicare and Medicaid Services (CMS), state Medicaid programs, and employer-sponsored insurance providers to better integrate behavioral health with overall health care, a critical disconnect remains between commonly used measures and those identified by people with serious mental illness as most impactful to their recovery journeys. The metrics commonly used to evaluate behavioral health services often reflect what is easiest to measure — not what truly matters to individuals living with serious mental illness. This misalignment undermines the effectiveness of the system, leaving many of the most pressing needs of people with serious mental illness unmet.

As a result, the U.S. behavioral health system often falls short in supporting meaningful recovery and holistic well-being for and with those with serious mental illness. While a few countries have demonstrated some success in implementing meaningful measures (Kilbourne et al., 2018), there still remains an urgent need to redefine success in behavioral health through measures that reflect the lived experiences, priorities and recovery goals of those the system is meant to serve. In this paper, Fountain House shares a new measurement framework, informed by those with lived experience, to address this need as well as preliminary guidance for future implementation of the framework.

Fountain House's new measurement framework outlines measurement domains and constructs that were identified by people with lived experience as priorities in their serious mental illness recovery and supported by other key stakeholders. A diverse cross-section of providers and community-based organizations can collect these metrics to better reflect the needs of people with lived experience of serious mental illness, whose journeys are often non-linear and include interactions with a variety of care teams. The measurement framework is applicable to those with serious mental illness across psychiatric diagnoses. The research team has built on a foundation of existing important work, including the International Consortium for Health Outcomes Measurement (ICHOM), which has developed measurement frameworks specific to Depression/Anxiety (2017) and Psychotic Disorders (2022). Using the new measurement framework on a systems level can reduce fragmentation and guide public and private health systems, payers, and purchasers towards value-based care that rewards true value.

In addition to sharing a new, lived experience-informed measurement framework, Fountain House catalogs preliminary recommendations that the U.S. health care system can take to improve person-centered care for those with serious mental illness. The implementation guidance section starts with Fountain House's organizational experiences in collecting outcome data — from choosing outcome measures to reporting them to local government and training other clubhouses to collect similar data. Then, implementation guidance, based on our project findings, is shared as a starting point for integrating meaningful measures into care settings and payment programs. The guidance has considered the needs of large health plans, purchasers and providers — who generally want systemwide comparisons — and those of individuals who seek tailored care. Through this work, people with lived experience, care teams, system administrators, and policymakers can learn about key leverage points for adoption and an initial charting of a pathway that can support the feasible integration of the measurement framework into value-based payment (VBP) models.

Measurement-Based Care Context

Person-centered care and measurement-based care (MBC) are increasingly recognized as essential to improving the lives of those with serious mental illness (Green et al., 2014). Broadly, MBC has been shown to be effective, with Bonsel et al. (2024)'s recent review of 76 studies showing converging evidence that providing patient-reported outcome measure (PROM) feedback to patients improves communication, connection to care pathways, symptom identification, and outcomes. Such findings are further validated by Mass General Brigham's decade-long implementation study that found that when clinicians used patient-reported outcome data to tailor approaches to patient goals, both clinical results and patient satisfaction improved (Liu et al., 2024).

In behavioral health and serious mental illness care specifically, MBC implementation challenges remain substantial despite strong evidence of improved outcomes compared to care as usual, with Lewis et al. (2019) finding that less than 20% of behavioral health practitioners routinely use PROMs. Traditional MBC in behavioral health has also primarily focused on symptom-based measures like the Patient Health Questionnaire-9 (PHQ-9) (Kroenke & Spitzer, 2002) and Generalized Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006), overlooking other recovery domains important to people with lived experience. As one person with lived experience noted in our investigation: "Rarely, if ever, do they go into the social aspect, which for me, personally, plays an outsized role in my own personal well-being." This narrow focus can perpetuate a system of measuring what is easy to measure rather than what truly matters.

Although progress within behavioral health and SDOH measurement is being made (Bright, 2024), cost-effectiveness and real-world implementation data for expanding MBC frameworks into domains prioritized by people with lived experience remains limited. Expanding VBP models that reward improvement in those outcomes is a compelling implementation pathway for MBC and outcome measurement in general.

Project Overview

The work represented in this paper is phase one of the Measures That Matter project. Phase one began in spring 2024 to build on prior measurement efforts related to serious mental illness. The research team identified project priorities, conducted a landscape assessment, facilitated more than 20 lived experience working groups and convened an advisory committee of approximately 20 key stakeholders in the field (that met 6 times over the next year). Based on this initial research, the team then conducted four focus groups and fielded a survey with individuals with lived experience of serious mental illness, both in a clubhouse setting and outside of a clubhouse setting, which generated 85 responses. The research team also held 14 key stakeholder interviews, including payers, providers, measurement experts, and other thought leaders, and collected additional feedback from stakeholders during each step of the project. More information about the processes, methods and takeaways from each of these steps can be found in the Appendix.

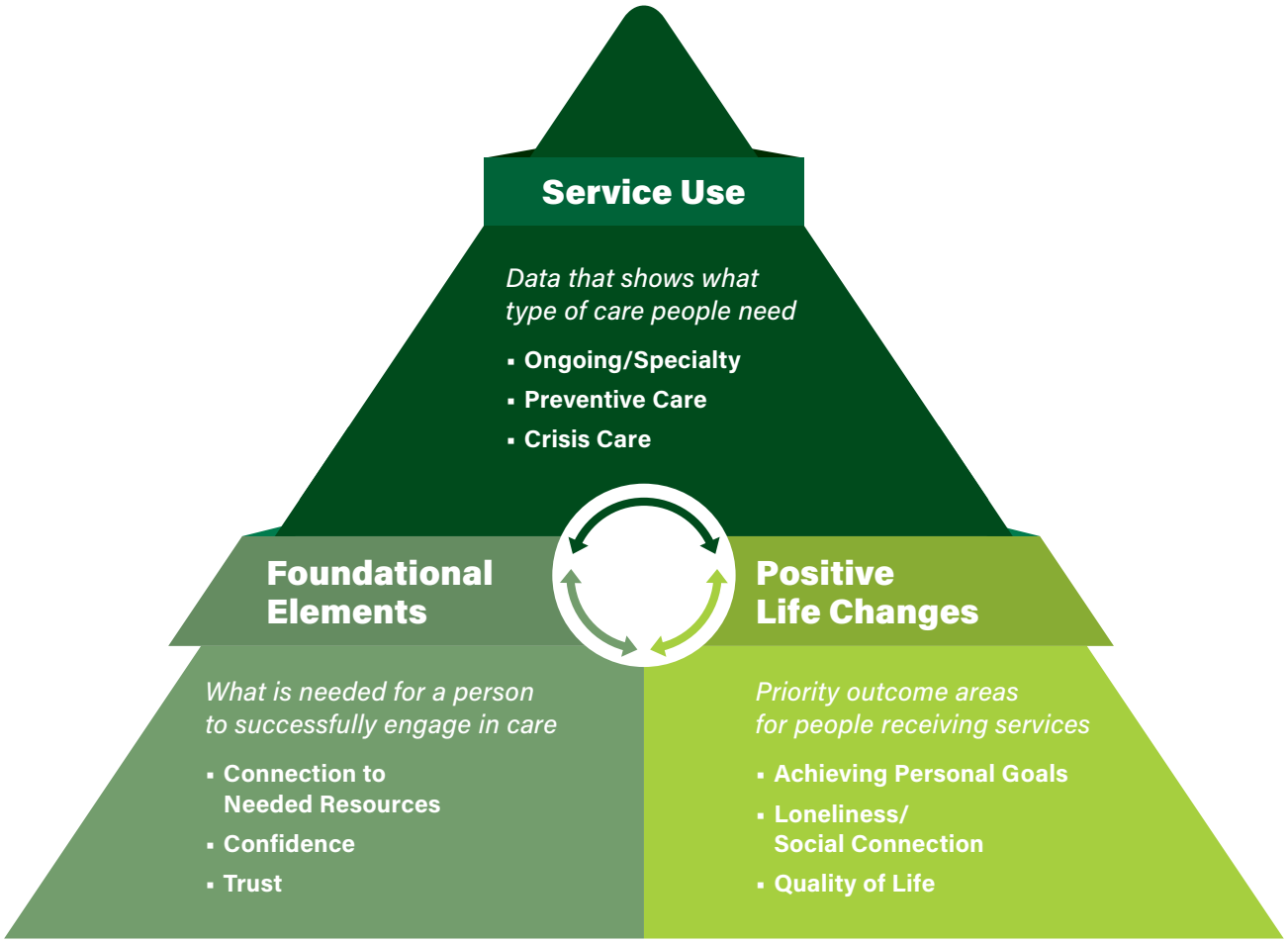
During later phases of the Measures That Matter project, the research team anticipates going into more detail about the specific measures to be utilized within the measurement framework. In addition, the team intends to dive deeper into how different care settings can best implement these measures into their systems and into broader payment programs. For example, a larger exploration of Artificial Intelligence (AI) tools that can facilitate measurement collection and integration into payment systems, as well as acceptability of these tools among those with lived experience, may be conducted.

Measurement Framework: Key Takeaways

After a year of exploration, the research team created a measurement framework for serious mental illness with three categories: (1) Foundational Elements; (2) Positive Life Changes; and (3) Service Use.

1. **Foundational Elements** make it possible for people to actively engage in a personal journey of recovery and wellness, including trust, self-confidence and connection to needed resources.
2. **Positive Life Changes** represent the impacts on people's real lived experience in terms of recovery and rehabilitation from the perspective of the person receiving care. They are the priority outcome areas for people receiving services. In the measurement world, they are often described as patient-reported outcome measures (PROMs), and clubhouses often refer to them as "member-reported outcomes." This framework encourages the measurement of self-reported outcomes regarding personal goal achievement, loneliness/social connection, and quality of life.
3. **Service Use** represents key utilization outcomes that indicate how someone with serious mental illness is engaging with mental health care services, such as those provided in hospitals, clinics or community-based settings. In general, the system should be striving to move care upstream because more effective engagement in preventive care (e.g., primary care and medication use) can often decrease the need for crisis care (e.g., hospitalization, emergency room visits and readmissions). In addition to preventive and crisis care, people with lived experience utilize ongoing outpatient and specialty care (e.g., therapy) as tools throughout their recovery.

Measurement Framework for Serious Mental Illness: Assessing the Impact of Care



Foundational Elements

People with lived experience emphasized that trust, connection to resources that promote the social drivers of health (SDOH) (e.g., stable housing, food security, employment, et al.) and self-confidence are what they need to actively engage in their recovery journey. These foundational elements should be assessed early on and reassessed periodically throughout a person's recovery journey.

Trust

Both those with lived experience of serious mental illness as well as care teams emphasized that trust serves as a foundation for receiving and giving support. Participants in focus groups agreed that without trust it is difficult to candidly discuss areas of concern, overcome challenges, and make meaningful life changes.

Trust within mental health care encompasses how well those receiving care feel they can communicate with their care teams, engage in open and honest feedback, and not be judged or discriminated against. Long-term relationships and low staff turnover can improve trust. The Association of American Medical Colleges Center for Health Justice has a toolkit developed to help providers build lasting trust with their community. They highlight the power of listening before acting, reflecting with humility, acting with intention and revisiting the topic of trust often (AAMC Center for Health Justice, 2021).

People with lived experience shared that mental health stigma can be a barrier to recovery, making them uncomfortable around care teams and even family and friends. As one participant shared, "I think [providers] think because we're mental patients, they think that some of us don't have the capacity to understand what we're talking about sometimes, and some do. So, I believe they kind of — not manipulate — but they misunderstand us, in a certain degree. So that's why I disagree [with] what they say sometimes." Trusting relationships between a care provider and the person receiving care can break down that stigmatizing barrier.

People with lived experience talked about cultural humility as an important part of how care teams can establish trusting relationships. Mental health professionals also need to understand that trusting people, perhaps especially providers, does not come easily for many people because of past negative experiences. Prior involvement in the legal system and other forms of institutionalization, in particular, are likely to make someone less open and trusting, including in how they describe their own progress and setbacks: "I just want to say, as someone who's been civilly committed, I always look at measures and [say], 'Could this be used against me in court?' So, I want to be really careful. I'm always thinking that way … you don't want to inadvertently create a measurement tool that could be used against somebody. How do you make sure it's used for somebody and never used against somebody?" Importantly, the trust providers build with people receiving care can lay the groundwork for people to engage as collaborators in care discussions, which can allow care teams to better understand what the person needs to move forward in their recovery.

Connection to Needed Resources

Both individuals living with serious mental illness and health care providers underscore the importance of meeting people's basic needs. People often described basic needs, such as acquiring stable housing and obtaining transportation to services, as essential components to being able to engage in care to further their recovery. One participant shared, "I'm just thinking that stability and security in your housing and the people you're around in your home is the most important thing next to taking medication for your mental health, because I used to live in an [unstable environment] and it just wasn't the right kind of situation. It really makes a difference."

In addition, people living with serious mental illness often face barriers to accessing basic health care resources. As one participant emphasized, "A lack of access to health care and having limited availability of mental health services and also a long waiting list or inadequate insurance coverage are some of the barriers and forms of discrimination that impacted my recovery." Ensuring that care teams — including care managers or clinicians — connect people with lived experience to essential services in a timely manner is critical to supporting recovery. Stakeholders and people with lived experience generally agreed that holding providers accountable for social outcomes (e.g., did someone get housing?) was an unreasonable expectation, but merely screening people regarding SDOH did not go far enough. In our key stakeholder interviews, providers shared that the reasonable compromise approach is holding them accountable for providing connections to resources that support those basic needs.

Self-Confidence

People with lived experience shared that self-confidence — in terms of their personal sense of agency, self-esteem and motivation — is vital in getting back on track after an acute mental health crisis. People highlighted the importance of self-efficacy, meaning confidence in one's ability to achieve their goals, as a crucial component to recovery. Self-efficacy was discussed in relation to awareness about someone's own mental health condition; developing self-efficacy helps individuals know what they need during a mental health crisis, what resources are available and how to navigate the system of mental health care. One focus group participant emphasized that over time, their growing sense of agency allows them to make more informed decisions about their treatment and helps them develop a better relationship with their providers: "Yeah, the way I was raised — and I went through the system — for many years the doctor always ordered me and ordered me, and I listened. Because I always say yes, and I went through stuff with the doctors that were no good. But then I found out it's okay to speak up. It's okay to disagree or talk about it. I found out in time that way." This reflection underscores how developing self-confidence and a sense of agency can empower individuals with serious mental illness to actively participate in their care and advocate for treatment approaches that align with their needs and goals.

Clubhouse members with lived experience explained that while recovery is often not a linear process, their confidence in navigating the behavioral health system and in knowing what they need to feel better generally increases over time. Although this is what the research team learned throughout working groups and focus groups, there can be exceptions to that trajectory: Those who lack supportive environments may find themselves staying the same or declining in terms of their self-efficacy. Factors like self-efficacy and agency were also described by people with lived experience as having a profound impact on long-term resiliency.

There are various different measures that capture the Foundational Elements identified, including trust, connection to needed resources and self-confidence. Below are some examples of validated measures within these categories.

Construct	Potential Measures
Trust	▪ Health care relationship trust scale (HCR) (Bova et al., 2006) ▪ Medical Mistrust Index (MMI) (LaVeist et al., 2009)
Connection to Needed Resources	▪ Camberwell Assessment of Need Short Appraisal Schedule – Patient (CANSAS-P) (Trauer et al., 2008)
Self-Confidence	▪ General Self Efficacy (GSE) (Schwarzer & Jerusalem, 1995) ▪ Patient Activation Measure for Mental Health (PAM-MH) (Green et al., 2010)

Positive Life Changes

The three self-reported outcome constructs within this category include: (1) loneliness/social connection; (2) quality of life; and (3) goal attainment.

Loneliness/Social Connection

People living with depression, bipolar disorder, schizophrenia and other serious mental illnesses are two to three times more likely to be lonely compared to people without a serious mental illness (Hajek et al, 2025). At the extreme, the gap is even larger: A 2023 study, for example, found that people with a serious mental illness of any type were nearly six times more likely to be "severely lonely" than the population at large — a prevalence rate of 41% compared with just 7% (Nagata et al. 2023). Moreover, the experience of being alone or feeling disconnected tends to intensify the symptoms of serious mental illness, creating a negative feedback loop (Teo et al., 2015).

Research conducted for this project suggests the dynamic is well understood by many people living with serious mental illness. People with lived experience reported that social support, connection and avoiding loneliness were critically important across all recovery stages. For example, one participant shared, "What I do find most important is I need some support and understanding — having a supportive network of family, friends or a therapist, and feeling understood and validated." Participants shared that they tend to isolate when they are not feeling well. They emphasized that social support was vital to their recovery and was a good indicator of their well-being at that given moment. In addition, some individuals with lived experience emphasized how different people need different types of social support to find meaning in their relationships. In this regard, measures of social support should be conversation starters to discover how to tailor support to meet a person's needs.

When reviewing an example social support measure, a participant highlighted the limitations of traditional well-being surveys, emphasizing the importance of social dimensions in mental illness recovery. They explained: "The surveys I was mentioning before are typically oriented around your own inner life … like, oh, 'Have you felt hopeless? Have you felt worthless?' Rarely, if ever, do they go into the social aspect, which for me, personally, plays an outsized role in my own personal well-being." This sentiment, echoed by many others with lived experience, underscores how social support plays a critical role in the recovery process. Family, friends and loved ones are often the first to know when someone with lived experience needs more support, so engaging them as part of a treatment plan — with the person receiving care's permission — can be helpful.

Quality of Life

Quality of life was consistently flagged as a key measure of recovery — both for short-term change and longer-term outcomes. Quality of life measures broadly indicate how well someone is living and functioning in their daily life, taking into account their physical health and emotional well-being. Quality of life measures encompass many aspects of well-being that individuals with lived experience of serious mental illness highlighted are important to them.

In one focus group, participants discussed key indicators of feeling better after a mental health crisis. Many emphasized improvements in physical well-being as a meaningful sign of progress: "I think I know if I'm feeling well, because I feel it physically. Like for me before I got the right support I needed for my mental illness, I got headaches and stuff, and I felt like physically tired. And I can tell that I'm feeling better now, because I feel physically a lot better." This underscores the importance of incorporating quality of life measures into assessments of recovery, as the measure reflects the multidimensional aspects of well-being that people with lived experience identify as significant markers of improvement.

Goal Attainment

People with lived experience frequently brought up how tailored support based on their goals would be helpful or had been helpful in their own wellness journeys. Personal goals included a range of items. Some examples are listed below:

- Obtaining employment
- Overcoming personal fears or phobias
- Exercising more
- Pursuing an education or completing educational goals
- Spending more time outside of their house
- Socializing with others more

Goal attainment was identified as particularly important given that a person's goals may change throughout their recovery. One participant, for example, highlighted how their goals evolved as they began to feel better: "Thanks to a lot of different resources and people, I'm mainly recovered, and I'm kind of trying to [become] more high functioning like I was before. I'm trying to get a full-time job again, and I'm trying to be more financially independent again … that's how my needs have changed, because originally, I was trying to get more basic services like medication and therapy." Measuring goal attainment is a way to encourage care and service providers to help people identify and achieve the life changes that are important to them at that time.

Construct	Measures
Social Support & Connection/Loneliness	▪ UCLA-3 Loneliness Scale (Russell, 1996) ▪ Social Provisions Scale (Cutrona & Russell, 1987)
Quality of Life	▪ World Health Organization Disability Assessment Schedule (WHODAS 2.0) (Ustün et al., 2010) ▪ RAND Health-Related Quality of Life 12-item Short Form Survey (SF-12) (Ware et al., 1995) ▪ Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (Endicott et al., 1993)
Goal Attainment	▪ NCQA Goal Attainment Scaling (GAS) (Gorby, 2023)

Service Use

Service use measures describe people's utilization of health care services. These measures provide insight into how people with lived experience move through systems of care, ideally using upstream care (e.g., preventive care) that reduces the need for crisis care (e.g., hospitalizations and ER visits).

Crisis Care

For people with lived experience of serious mental illness, avoiding hospitalization reflects a desire for stability and autonomy. Hospitalizations and the symptoms that lead to them can be distressing, disorienting and traumatic. While receiving crisis support is sometimes necessary, people with serious mental illness want to feel well, stay connected to their communities and manage their health. Key stakeholders — including providers, measurement experts and payers — also highly value reducing hospitalizations and emergency room (ER) visits, both because avoiding crises improves the health care experiences of those with serious mental illness and because of the large impacts on cost of care. It is much more expensive to care for someone in an emergency than it is to prevent an emergency.

Preventive Care

People with lived experience highlighted the importance of including measures of service use for preventive services — including attendance at clubhouses, primary care visits and physical health screenings. This data can be collected at an administrative level.

Ongoing/Specialty Care

It is important to note that many people with lived experience of serious mental illness use ongoing health care services to receive therapy or care for other chronic physical health conditions.

Construct	Measures
Acute Care	▪ Hospitalizations ▪ Emergency Room visits ▪ Readmissions
Preventive	▪ Attendance at community-based settings ▪ Completion of time-limited mental health program ▪ Primary care physician check-ups and visits ▪ Medication adherence ▪ Self-reported engagement in psychosocial rehabilitation
Ongoing/Specialty Care	▪ Ongoing therapy ▪ Care for chronic physical health condition(s) ▪ Objective physical health measures (e.g., A1C results for diabetes management)

Discussion

This project investigated how people with lived experience, clinicians, care teams, measurement experts, payers and purchasers perceive and prioritize measurements related to serious mental illness recovery and SDOH to ultimately create a measurement framework. The process for developing this framework was iterative and included ongoing feedback from people with lived experience and the advisory committee. Overall, the framework received positive feedback. For example, one advisory committee member shared that "What I like about this measurement framework is that I think it can appeal to clinicians. It can appeal to what clinicians want to do [like talk about goals and build trust], as opposed to just a measure about symptoms."

Advisory committee members further highlighted that clinicians want to know about how their patients assess their quality of life and loneliness, so collecting the data makes sense as long as it can be provided to clinicians in a usable way. The measurement framework reveals new dimensions of well-being that warrant measurement, validates existing frameworks and contributes to the field's understanding of how measurement priorities can vary throughout individuals' serious mental illness recovery trajectories. In addition, it has expanded awareness of the measurement field among those with lived experience.

As mentioned, in the second phase of this project, the research team plans to choose specific measures and provide more in-depth guidance for implementation. In the meantime, the team has started to outline what future implementation initiatives can look like and where they can occur below. First, an example from Fountain House is presented, and then opportunities for integrating the framework into other VBP models throughout the U.S. are discussed.

Future Implementation Initiatives

Implementation of Measures at Fountain House

In 2018, a group of staff and members established a working group to discuss the collection and usage of outcome metrics at Fountain House in Hell's Kitchen, New York City. A staff member with research expertise initially curated a list of available measures and the group met to review and consider different measures. When talking with the working group, they identified items that they really cared about in the community. They decided to focus less on individual experiences and more on what it would be like for our clubhouse to ask these questions, as they wanted to make sure the questions were in alignment with the clubhouse model.

With additional input from senior leadership, the group came up with three main constructs consistent with the current Measures That Matter project. The ideas that were most important to them were having social connections, being able to carry out daily activities, and — given our strengths-based model — leading a fulfilling, purposeful life with achievements one could be proud of. The group looked at individual validated measures and talked about the instrument's length, wording, breadth of use and alignment with community values. To match these ideas and preferences, Fountain House started collecting measures of loneliness (UCLA-3), quality of life (Q-LES-Q) and the brief inventory of thriving (BIT) in 2019. The measures were collected on peoples' applications to join the clubhouse and yearly after that.

At this point in time, the biggest focus of the group was building the capacity to collect pre-post measures in the clubhouse.

For years, Fountain House has continued to collect these metrics (although there were pandemic-related data collection issues) and has even brought them to other clubhouse locations. Some barriers that the organization came across included the following:

1. The thriving scale had extreme ceiling and floor effects, which resulted in a clustering of responses at the highest and lowest ends of the scale. This pattern limited Fountain House's ability to detect meaningful changes over time, raising concerns of the measure's validity, sensitivity and responsiveness of the measurement. This experience reinforced the importance of piloting measures before widespread implementation.
2. Fountain House had to create positions and workflows to ensure that data was collected accurately and consistently.

In 2024, Fountain House released a report about our community loneliness outcomes based on pre and post data. Of those surveyed, 73% joined the clubhouse with high levels of loneliness. These findings validate existing data that demonstrates a much higher rate of loneliness among those with serious mental illness compared to the general population (Nagata et al., 2023; Heron et al., 2022). The report found that more than half of those who felt high loneliness upon joining the clubhouse felt less lonely at follow-up and 22% were no longer categorized in the highest loneliness level (Usman et al., 2024). The quality of life measure demonstrated similar findings in terms of data collection and improvement (data to be published later in 2025).

This experience proved instructive for future measurement activities in two critical ways. First, community-based organizations can feasibly collect, report and track PROMs. Second, pre-post changes in PROMs suggest community-based organizations can impact performance on these PROMs and therefore they can be useful as tools for quality improvement and accountability purposes.

In 2025, Fountain House uses its measurement approach to report outcomes to New York City (NYC). The NYC Clubhouse Contract includes 13 clubhouses that are all now reporting measures of loneliness, quality of life and self-efficacy to the Department of Health and Mental Hygiene. These measures are collected when someone joins a clubhouse, at their 6-month membership mark, and yearly following that. Fountain House is building out a larger data-sharing network that goes beyond New York City to collect these data in a standardized way in clubhouses across 11 states.

Implementation Guidance

When implementing measure collection in various care settings, key challenges include the burden being placed on care teams to collect data as well as buy-in of service users, providers and payers. To be effective, a new measurement framework must minimize this burden and embed measurement into care delivery in a way that enhances, rather than hinders, the relationship between the person receiving care and their provider. For example, by capturing a person's levels of trust with health care, connection to resources, and preventive care utilization, care teams can adjust treatment plans, promote holistic care, and tailor treatment for those who need it most. To avoid overburdening providers, the capabilities and priorities of each type of provider — whether clinical, community-based or emergency care — need to be considered, and measure collection must be implemented incrementally.

In this following section, the research team expands on these types of challenges and proposes strategies to ameliorate them.

Exploring Different Implementation Models

Several key considerations have guided the current assessment of different implementation strategies. First, an effective implementation strategy must balance comprehensiveness with feasibility, seeking to capture the full picture of recovery through the measures that matter while not creating unsustainable data collection burdens. Second, systems need to balance how accountability structures create shared responsibility across providers for measurement and outcomes while also recognizing that different providers provide varied contributions to the outcomes tied to specific measures. Third, implementation must be achievable within existing service networks and resource constraints while also expanding those networks to ensure that the requisite services most relevant to the outcomes being measured are integrated and have pathways towards service connection.

For example, implementation models that are integrated and focused on SDOH have provided meaningful insights into effective coordination across multiple providers, such as Accountable Communities for Health (ACH) models (Heeren et al). (2022) found that ACH models successfully brought together health care providers, social services and community partners to address SDOH needs through data sharing and resource sharing collaborations. However, such models still faced barriers in effective data capture, building capacity in community-based organizations and achieving alignment around what outcomes measures related to SDOH needs should be prioritized and were feasible to capture (Mittman et al., 2022). Building on these insights, the research team aims to inform implementation strategies that not only reflect the measurement priorities of people with lived experience but also are feasible across a variety of care settings. The research team intends to develop this implementation guidance in future phases of our work on the Measures That Matter project, which is anticipated to dive deeper into specific ways to strike these balances while implementing these measures.

Using the Measurement Framework: Moving Towards Accountability Across Care Settings

While the measurement framework identified constructs and measures that were prioritized by the people with lived experience, this implementation guidance explores how these measures could be applied across the variety of services that play a role in supporting recovery for people with serious mental illness. Previous measurement efforts have typically explored single-sector accountability for multi-sector care needs or considered community-based support services as adjuncts to clinical care. However, people with serious mental illness receive support from a diverse range of services that often require coordination across clinical and non-clinical providers, including community-based organizations, peer support services and social service programs.

Phase two of the Measures That Matter project intends to further explore how to extend measurement and accountability across different care settings through different implementation approaches, such as stepwise and cross-sector implementation strategies that acknowledge the varying readiness of measures, the different capabilities of various providers and organizations, and the types of services they focus on. This is especially important in considering the fuller integration of community-based social support services, given how many of the constructs within the measurement framework directly relate to service domains they provide.

The project also found that the different measures prioritized by our engaged stakeholder groups likely differ in terms of implementation readiness. Some measures, like the UCLA-3 Loneliness Scale and utilization tracking, are brief, well-validated, and have clear pathways to action if the appropriate services are available. Other tools, like Goal Attainment Scaling and quality of life measures, have strong evidence bases, but require training, workflow adaptation, and (in the case of quality of life) selection among multiple versions for specific use with serious mental illness communities. Most of the PROMs identified have been psychometrically validated. However, they have rarely been used as performance measures in the U.S., which will require some real-world testing — some of which is already taking place in 2025 — and/or incorporation of lessons learned from other countries that have used PROMs in this way. Lastly, constructs and readiness measures like trust and self-confidence require further selection and development of validated measurements suitable for cross-sector use. Payers and purchasers can begin to introduce some of these measures into VBP models and payment programs now and conduct additional feasibility testing on the others at the same time.

Technology and Reducing Administrative Burden

The current system does not make it easy to measure the things that matter most to people receiving care; clinicians are often overwhelmed by large caseloads and administrative tasks that detract from direct care. In key stakeholder interviews, direct service providers emphasized the importance of succinctness in the measurement framework, as it takes time and skill to collect metrics. People with lived experience of serious mental illness shared that they sometimes also feel burdened by filling out surveys, especially without knowing how they would be used to help them in their recovery. In addition to narrowing down measures to the most prominent constructs and recommending implementation based on provider-specific supports, the research team also provides strategies to streamline data collection, analysis and usage:

1. **Using Artificial Intelligence (AI)** – AI technology continues to grow rapidly and is already starting to be utilized in health settings. Although the technology is still being built, there is a potential (near) future wherein AI could support the implementation of measures in care settings by minimizing data collection burden on providers and the people they serve. For example, AI could passively record answers when care teams and people with serious mental illness discuss their needs using validated instrument questions in the conversation. AI would then be able to score that individual and report on their outcomes in ways that automatically embed into existing information systems. Overall, the use of AI could significantly impact the feasibility of the measurement framework. As mentioned in a key stakeholder interview with a provider, "The advent of generative AI makes this now feasible in new ways — you can collect a huge amount of data that gets standardized and quickly tabulated in real time without anyone having to fill out a form."

   Further research is needed to test this method's ability to produce psychometrically valid results. People with lived experience recommended overall that AI should be used as a tool and not as a replacement for human interpretation and interaction. This is in alignment with the American Medical Association term "augmented intelligence," which emphasizes how the tool can assist — rather than replace — human intelligence (American Medical Association, 2025). People with lived experience were open to the idea of AI being used in care settings to improve efficiency and help with notetaking, provided that its use and data security was explained by the provider beforehand. Further engagement with people with lived experience and technologists will be required to clarify what needs to be done to create conditions for success.

   Effective implementation of AI depends not only on collection but on its meaningful use in clinical care. AI tools can streamline data collection behind the scenes — automatically gathering necessary information from electronic records or pre-visit surveys — so that providers can spend more time building a relationship and addressing patient concerns directly. This shift could foster a more patient-centered experience and potentially improve retention in treatment. AI-powered data visualization tools can transform raw data into visual insights for both patients and providers. These tools support shared decision-making by highlighting areas for discussion and tracking progress. When data is presented in a clear, accessible format, it becomes a resource to help align care with patient goals. To ensure relevance and usability, data visualization tools should be developed in partnership with communities and clinicians, incorporating feedback on what information is most valuable and how it should be presented.

2. **Multi-modal data collection** – In key stakeholder interviews, a few mentioned that it would be valuable to offer many avenues for data capture. For example, options could include phone applications, QR codes, interviews, patient portals and printed forms. People receiving care have varying levels of digital literacy and preferences that would influence how they would like to respond to questions on validated measures. Reminders in someone's preferred mode of communication were also discussed as a helpful practice.

3. **Integration into existing electronic health records (EHRs) and workflows** – An assessment of existing technology features and capabilities can be the first step to integrating measures into EHRs. Furthermore, workflows need to be established to make it as easy as possible for clinicians to enter information and for the information to be accessed by those who need it.

These recommendations provide starting points and opportunities to make the right thing the easy thing to do. Ultimately, enhancing technology solutions has the potential to enhance automation and improve efficiency in care settings. Reducing administrative burden and aligning incentives with meaningful outcomes can create a system that provides more effective care for people with serious mental illness.

Building Capacity and Buy-In

Implementing a more person-centered approach to care in serious mental illness requires strategic, phased action and broad stakeholder engagement. Buy-in from providers, payers, people receiving care and policymakers is essential to create sustainable measurement infrastructure that can fundamentally change outcomes. Below are strategies for building capacity and buy-in:

1. **Using measurement for collaboration and trust-building** – The measurement framework first and foremost impacts those with lived experience of serious mental illness. In working groups and focus groups, people with lived experience wanted to learn more about the value of measurement to both them and their care teams. They wanted to avoid instances wherein a validated measure is collected and not referenced or discussed. For example, people with lived experience emphasized that filling out a quality-of-life survey could prompt a conversation with their care teams about a topic that is important to them that may not come up naturally in a standard visit. These conversations could lead to more collaborative problem solving or goal setting. As highlighted by a provider and health care entrepreneur, "One of the things I have learned is the reason most people drop out of care is their first meeting is all about getting stuff the provider needs to get reimbursed. It's not about getting what [the patient] needs. The process of the patient-reported outcome isn't just to measure an outcome; it's the key to engaging someone on the front end."

   Centering the first encounter on the client's needs through tools like patient-reported outcomes (PROMs) can transform it from a transactional exchange into a meaningful engagement that builds trust and encourages continued care.

2. **Learning and Training** – Learning about MBC practice can promote buy-in for care teams by demonstrating that PROMs can support and inform treatment planning. It can be rewarding for care teams to see the value of their interventions through measurable data. In addition, by learning more about the foundational elements that impact someone with serious mental illness, care teams can focus on addressing the barriers that may be present.

Beyond promoting individual conversations with those with lived experience and potentially demonstrating improvements, PROMs can also be aggregated to reveal trends in the broader community and identify areas for improvement. For example, if a community-based organization finds that trust has decreased over time, steps could be taken to gather further information. The community could assess staff turnover rate, cultural humility and qualitative feedback from people being supported by the practice. This insight could help practitioners refine their support, interventions and practices. For implementation to be successful, practitioners will need dedicated time to complete trainings, collect data, and review analyses or dashboards. They will also need ongoing technical and analytical support.

3. **Early Adopters and Empowerment** – Highlighting data champions or early adopters within the entity and training others on measure implementation can support adoption (Lewis et al., 2019). As highlighted from a provider in a key stakeholder interview, it is important to ensure provider buy-in by creating an incentive-based approach and not one that is based on penalties for certain outcomes: "I tried to enact some value-based care, and there is a lot of resistance. People were very worried that if clients were filling out outcome measures, they would be held accountable, and it would somehow reflect badly on them. I think we need to somehow shift this narrative. It's not about judging providers; it's about getting the best care possible for a client and understanding their needs." Shifting the narrative means reframing outcomes measurement as a tool for empowerment and improvement — not punishment — so providers and clients can work together toward better care.
4. **Demonstrate Cost-Effectiveness** – Payers also expressed a keen interest in efforts to shift towards MBC to improve outcomes and lower the cost of care. In a key stakeholder interview with a provider that works directly with payers, they emphasized, "It is critical to realize that payers are wanting to do this as well. Their frustration is they see their cost going up without evidence that all these people are getting any [better]. They are the ones pushing for measurement-based care, so in some ways you are pushing on an open door." To strengthen payer engagement, it's essential to align measurement efforts with their goals by demonstrating how outcomes data reduce uncertainty around spending and support the effort towards lowering overall health care spending.

Key Leverage Points

The research team has identified several key leverage points for application of the framework to key initiatives throughout the U.S. The listed leverage points include both large-scale systems — where policymakers, committees and health departments have jurisdiction — as well as small-scale systems where individual organizations or providers can take leadership on implementation.

There is currently a need for measuring outcomes among those with serious mental illness and a strong interest in using those outcomes to assess performance. It is important to focus on outcomes for people with serious mental illness to address disparities, complex needs and discrepancies in quality of care throughout the behavioral health system.

Examples of Current Leverage Points 2025

Entity Name	Description of Opportunity
Centers for Medicare & Medicaid Services (CMS)	When CMS released the CY 2025 Physician Fee Schedule, it included a specific request for information (RFI) about technology solutions to advance patient-centered care and improve health outcomes. Several organizations, including the Alliance for Person-Centered Care, have used the opportunity to drive CMS toward greater use of PROMs (Leavitt Center for Alliances, 2024). More focused attention on PROMs in behavioral health services, specifically those supporting people with serious mental illness, could increase focus on the measures that matter from providers and plans serving significant Medicare populations (Centers for Medicare & Medicaid Services, 2024).
Center for Medicare & Medicaid Innovation (CMMI)	CMMI has selected four states (New York, Michigan, South Carolina and Oklahoma) as demonstration sites for the Innovation in Behavioral Health (IBH) model. IBH will test a new VBP model for people with moderate to severe mental illness that establishes behavioral health community-based organizations as accountable for the outcomes of Medicare and Medicaid beneficiaries. CMMI has stated that it intends to include PROMs in assessing performance as part of holding providers accountable in this VBP model (Centers for Medicare & Medicaid Services, 2024).
Legislative Activity	Bills have been released by both Republicans and Democrats in Congress calling for more widespread collection of PROMs, specifically in the area of loneliness. The "Improving Measurements for Loneliness and Isolation Act" (introduced by Rep. Mike Flood, R-NE, and Rep. Ami Bera, D-CA, in February 2025) calls on HHS to convene a working group of experts to provide recommendations on standardizing loneliness measurement. A similar bill was introduced in 2023 by Flood and Rep. David Trone, D-MD, and Senator Pete Ricketts, R-NE, introduced a companion bill in the Senate (U.S. Congress, 2025).

Entity Name	Description of Opportunity
California	California is transforming its mental health and substance use disorder system to better support those with serious mental illness through new funding mechanisms, including a Medicaid 1115 waiver. That waiver specifically highlights the need to measure quality of life, and the state's Department of Health Care Services has convened a quality committee to make recommendations about the specific measures that should be used (California Department of Health Care Services, 2024).
New York City	New York City now requires all contracted city clubhouses to report on three PROMs (loneliness, quality of life and self-efficacy) as well as other measures that matter (such as crisis care and social outcomes). This offers an opportunity to provide a real-world feasibility test of how to drive accountability for the measures that matter to people with serious mental illness (New York City Department of Health and Mental Hygiene, 2023).
Certified Community Behavioral Health Clinics (CCBHCs)	Certified Community Behavioral Health Clinics (CCBHCs) exist nationally to deliver behavioral health care. These clinics blend mental health, substance use and physical health care in a single point of access. Future performance measurement could promote collection of measures that matter to those being served by CCBHCs (New York State Office of Mental Health, n.d.).

Other Opportunities

There are several opportunities to strengthen measurement capacity and implementation across different stakeholder groups. Community-based organizations (CBOs) are motivated to demonstrate impact and improve outcomes yet often have underutilized potential for collecting outcomes data. With technical assistance, they can build the infrastructure needed to support this work. Care teams benefit from understanding what matters to patients, which fosters buy-in to accountability. Training is essential to help providers see how measurement can enhance care quality. Additionally, people with lived experience of serious mental illness can become advocates for their own care by engaging with the measures being collected and discussing them with their care teams. Learning from peers who have navigated acute mental health episodes can also provide reassurance and guidance. Additionally, peers with lived experience can serve as data champions and assist in collecting data.

Moving Towards Value-Based Care

Examples

As implementation models mature and demonstrate feasibility, the ultimate goal is creating payment systems that reward outcomes that matter to people with serious mental illness. Transforming payment models can incentivize person-centered care and has the potential to contribute to cost savings in the long run (Khalili, 2024). Below are two examples of approaches that have transformed payment models.

Program	Method
Quality Improvement Program – New Jersey (QIP-NJ)	The Quality Improvement Program in New Jersey (QIP-NJ) is a pay-for-performance program for acute care hospitals. They planned a phased-in approach and gap-to-goal methodology for meeting performance metrics (Public Consulting Group, 2025). Within this methodology, the hospitals aim to improve their outcomes by small percentages each year based on their initial baseline performance (New Jersey Department of Health, 2024).
Maryland Total Cost of Care (TCOC) Model	This model includes an Outcome-Based Credits system that rewards hospitals for preventing or delaying diabetes onset (Health Services Cost Review Commission, n.d.).

Phased-In Approach

Systems that have moved towards value-based care typically do so in a stepwise manner, known as a phased-in approach. This allows for learning and system adjustment that improves implementation. Below are recommendations for moving towards value-based care based on prior and current work in this field:

1. **Increase awareness and buy-in** – The first step in moving towards VBP is buy-in of people with lived experience of serious mental illness and their care teams. As mentioned earlier, buy-in can be supported by emphasizing improved treatment plans and person-centered care for those with serious mental illness. In addition, those with lived experience of serious mental illness should be involved in the planning processes of measure collection.
2. **Build capacity and infrastructure** – Building capacity and infrastructure can include training on systems, building workflows and acquiring necessary technologies for implementation. Care teams will want to start small pilots to see whether their workflows can be improved. These initial pilots can focus on insight and learning, rather than jumping to payment incentives or penalties.

3. **Pay for collection** – Many payers start out by paying for collection. For example, local, state or federal agencies may provide incentives initially for reporting data and transition over time to paying based on relative or normative performance levels. By incentivizing data collection, systems will be able to have baseline information that performance can be based on. This helps address health disparities between different systems, wherein one population could theoretically start off in poorer health than another. In addition, data sharing networks among integrated care settings may be important to set up to understand aggregate data as well as how individuals move through systems of care.
4. **Set up pay-for-performance mechanisms** – Offering bonuses for collecting PROMs improves feasibility and workflows around collection. It also allows payers to build data baselines that can be used to test performance measurement approaches using PROMs. This offers natural environment testing that can help payers and providers construct workable pay-for-performance programs that tie dollars to achievement of outcomes that matter to people with lived experience of serious mental illness. For example, PROMs can be turned into performance-based measures using baseline data and numerator/denominator calculations.
5. **Hold care teams and health plans accountable for serious mental illness outcomes** – With this testing in place, systems can develop technical specifications for the performance measures that can be used to ensure objective, systematic approaches to outcome comparisons. Care teams need to be held accountable for the important serious mental illness outcomes, especially those that have large health impacts. If smoking cessation is widely accepted as a core responsibility of the U.S. health system, why isn't addressing loneliness — which has health effects comparable to smoking 15 cigarettes a day (Holt-Lunstad, Robles, & Sbarra, 2017) — treated with the same urgency? Although meeting accountability goals can be difficult, health systems need to do better for people with serious mental illness, who often face low-quality, fragmented care.

In the future, a tailored toolkit can be created for different types of audiences including care teams, technology companies and payers/purchasers. For example, measurement leaders can work with care teams to address feasibility barriers in the collection, analysis and reporting of the data. In addition, sharing what technologies need refinement and development or what payment transformation systems need to be established can tangibly move the system towards implementation of the measurement framework. In phase two of Measures That Matter, Fountain House intends to create a guide for different audiences to utilize the measurement framework in their settings. Additionally, more learning and fieldwork can inform the stepwise manner in which the measurement framework can be implemented in the future.

Lived experience feedback and perspectives will be valuable going forward to lead to more actionable solutions and promote equity. People with lived experience can improve the quality of research and, with training, reliably contribute as researchers (Hancock et al., 2012). Future work should aim towards broadening understanding of outcome measurement among people with lived experience of serious mental illness. This can lead to people with serious mental illness becoming ambassadors for outcome measurement and advocating more for what truly matters in care. For example, people with serious mental illness can advise on quality improvement teams, contribute as researchers to gain insight and train providers on what person-centered care or cultural humility looks like. With proper training, support and compensation, people with lived experience will be vital in measure implementation in the future.

Appendix: Creating a Measurement Framework: Research Processes, Methods and Findings

Initial Landscape Assessment

The research team conducted a landscape assessment designed to catalog what relevant measures currently exist, which of them are in use, and how, if at all, those measures are being used to assess and tailor heath care and ancillary services for people living with serious mental illness. The team started with a PubMed search to review peer-reviewed and scholarly articles related to serious mental illness, PROMs and SDOH. Then, the search expanded to white papers and other sources from entities such as the National Committee for Quality Assurance (NCQA), the Kennedy Forum, the Agency for Healthcare Research and Quality (AHRQ), and the International Consortium for Health Outcomes Measurement (ICHOM). The landscape assessment continued to expand throughout the duration of the project.

The research team found that many PROMs have been developed to assess serious mental illness recovery and SDOH needs. While most symptom scales are diagnosis-specific, the Modified Colorado Symptom Index (MCSI) stood out as a reliable and valid self-reported measure of psychological symptoms (Conrad et al., 2004). Several broad metrics of recovery were also available, including the Recovery Assessment Scale (RAS) (Felix et al., 2024), the Self-Reflection and Insight Scale (SRIS) (Silvia et al., 2023) and the Questionnaire about the Processes of Recovery (QPR) (Felix et al., 2024). SDOH could be assessed by the Protocol for Responding to and Assessing Patients' Risks and Experiences (PRAPARE) Tool (National Association of Community Health Centers, n.d.), or the patient-rated version of the Camberwell Assessment of Need Short Appraisal Scale (CANSAS-P) (Trauer et al., 2008). Specific constructs that came up in our landscape assessment included functioning, loneliness, and self-efficacy, which can be measured by the World Health Organization Disability Assessment Schedule (WHODAS 2.0) (Ustün et al., 2010), UCLA 3-Item Loneliness Scale (UCLA-3) (Hughes et al., 2004) and Problem-Solving Inventory (PSI) (Heppner et al., 2004), respectively.

Lastly, many available measures focused on multiple constructs, such as the Health-Related Quality of Life brief scale (SF-12) (RAND Corporation, n.d.), the PROMIS Global Physical and Mental Health measure (Global01) (Hays et al., 2017) and the Patient-Reported Experience Measure for Improving Quality of Care in Mental Health (PREMIUM-CE) (Fernandes et al., 2024). With this familiarization of the landscape of available measures, the team was then able to research how they were being collected and used in the mental health landscape.

Measures are collected and used by several different entities, including Medicaid providers, Medicare providers, certified community behavioral health clinics (CCBHCs), federally qualified health centers (FQHCs) and the Veterans Health Administration. While most measures collected were process measures, some were PROMs. Certain PROMs are more widely used than others due to their brevity, non-proprietary status, payer requirements/ incentives, or because of how long they've been in circulation.

Symptom scales such as the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder Screener (GAD-7) seem to be collected more frequently than other measures related to serious mental illness recovery.

Although many entities have established their commitment to moving towards value-based care, there is not widespread implementation of these measures for performance purposes. Two examples of systems that have started to implement measures to assess performance include the following:

1. In the Merit-Based Incentive Payment System (MIPS) for Mental/Behavioral Health and Psychiatry, PROMs are included for serious mental illness recovery and social roles (Centers for Medicare & Medicaid Services, 2024).
2. In the Quality Improvement Program – New Jersey (QIP-NJ), acute care hospitals can earn incentive payments for quality measures that show improvements in connections to behavioral health services and reductions in potentially preventable utilization for the behavioral health population (Public Consulting Group, 2025).

Fountain House Working Groups

Over the course of three months, the research team conducted 20 working groups, both in-person and virtually, with Fountain House members. In these groups, the research team covered a wide range of topics and facilitated a combination of co-learning and co-creating activities. The working group membership varied week by week and captured a wide variety of perspectives among members.

Throughout the 20 sessions, the working group engaged in a series of collaborative activities aimed at aligning our goals, refining our methodologies and ensuring lived experience voices in each step of the research design process. The working groups started with various teach-ins around understanding the project goals, VBP, and accountability, which helped improve alignment on project goals and community understanding of the influence measurement has in the mental health care system.

In other sessions, the working group helped co-create research materials, including the focus group guide, lived-experience survey and key stakeholder interview guide. The working group made significant edits to draft materials to ensure clarity and added questions to reflect the interests of those with lived experience. The working group's process also highlighted the importance of defining key terms like "recovery" and "mental health episode," and ultimately influenced how the research team used the terms in further materials. The working group discussions ultimately led to a greater understanding of these definitions, as well as a visualization of factors that influence recovery, which was presented in later discussions and focus groups.

Throughout the 20 working group sessions and meetings with various Fountain House groups, such as the Women's Group and Advocacy Committee, the research team had many discussions around what matters to members in the Fountain House community when it comes to their recovery journeys. The research team consistently heard themes of goal setting, mental health literacy, coordination of care, trust and strong social relationships as key factors in recovery.

Defining Recovery

When the working group began to talk about what measures matter most in recovery, people with lived experience said that different factors matter depending on where someone is within their recovery. With consensus that recovery does not follow a linear, stage-by-stage path, the lived experience working group came up with a framework for thinking about recovery or wellness journeys in terms of two factors: (1) feelings of wellness and (2) awareness. In terms of wellness, members of the group described the chronic nature of serious mental illness, sharing that environmental, social and biological factors can lead to fluctuating symptoms. Depending on how well someone is feeling and the factors that are contributing to their symptoms, different items matter. They also described that their awareness of their diagnosis, coping mechanisms, medication and resources impacts what they would need most from their care teams.

For example, a measure that could best assess recovery for someone who is experiencing a mental health emergency for the first time may be about their management of medications and side effects. For someone who has experienced mental health emergencies before, and perhaps already understands their medications and side effects, social connection may be more important.

This framework helped the working group define recovery and influenced the research team's view of how different measures can be most important at different times.

Advisory Committee

Throughout the duration of this project, the research team convened an advisory committee of key stakeholders and experts across many sectors in the measurement and behavioral health spaces. The committee included representatives from large payers (such as Humana and Centene), providers (psychiatrists, psychologists, primary care), measurement experts (representatives from ICHOM, Leavitt partners, NCQA, and CMMI), mental health advocates, and individuals with lived experience of serious mental illness.

In the bi-monthly advisory committee sessions, the team gathered direct feedback about the project; given the wide range of perspectives on the committee, there were fruitful discussions about the issue of measurement from various vantage points. The research team also had additional individual meetings with advisory committee members to dive further into their specific areas of expertise.

Lived-Experience Focus Groups and Survey

Using the guides created in the working groups, the research team, including people with lived experience of serious mental illness, conducted four lived experience interviews with 33 participants total. Around half of the participants were members of clubhouses, while half were people with serious mental illness who were not clubhouse members. The majority of participants shared that they had been involved in the criminal justice system — defined by whether someone had been arrested, participated in a diversion program, gone to court or been incarcerated — and that substance use had impacted their serious mental illness recovery.

The research team designed the focus groups to be iterative and become more specific over time. The four focus groups addressed different topics:

1. The first focus group aimed to learn more about what matters most in moving recovery forward for people with serious mental illness. The research team also asked about barriers to recovery. This helped the research team create a list of prioritized measurement constructs.
2. In the second focus group, people with lived experience matched measurement constructs to recovery phases, in terms of the two factors described above: (1) feelings of wellness and (2) awareness. Researchers shared and explained a visual that guided the discussion and process.
3. In the third focus group, the researchers asked participants about their experiences completing measures in care settings, how those measures can or should be used, and about accountability of care teams. People with lived experience were shown a measure of social support as an example to talk about, since social support was viewed as highly important in previous groups.
4. In the fourth focus group, the researchers asked similar questions as in the third focus group. Since trust was discussed as a pre-requisite to engaging in care and measurement, the group viewed an example measure of trust after talking about measurement in care settings in general.

The discussions in each focus group strongly informed the constructs the researchers chose for the measurement framework, as demonstrated by the lived experience quotes within the construct explanations. Some of the recommendations for implementation were also informed by these focus groups, in which the research team heard about the importance of concise measures that lead to collaborative conversations with care teams.

To reach a broader group of people, the research team also fielded a survey that generated responses from 85 people in 21 states, encompassing people with lived experience of serious mental illness — with and without experience in a clubhouse. Participants were recruited through convenience sampling, which was non-random and self-selecting, rather than as a representative sample. In the survey, social support and connection were emphasized as one of the most necessary conditions across all points in time throughout recovery.

Basic needs, like housing and food security, and access to community-based supports were also highly important to the survey respondents throughout their wellness journeys. Quality of life was seen as a meaningful measure of recovery, with about 80% of respondents sharing that it was highly important. Financial insecurity and low self-confidence were chosen as the top barriers to recovery. Overall, many participants indicated that they were focused on getting better or being more independent as their goals. Survey findings were interpreted in conjunction with the focus group findings and working group conversations to inform the measurement framework.

After conducting the lived experience survey, lived experience focus groups and key stakeholder interviews, the research team met regularly to discuss emerging takeaways. Feedback on takeaways was then gathered from those with lived experience, staff of Fountain House, members of the advisory committee and other key stakeholders. The feedback from all helped the research team refine both the framework itself and the accessibility of the language used to describe measurement domains and constructs.

Key Stakeholder Takeaways

General Overview

In addition to many informal conversations with experts, we conducted 14 semi-structured interviews with providers, payers, policymakers, researchers, leaders of community-based organizations, measurement experts and other experts in the field. Each provided insight into key measurement constructs as well as strategies, challenges and opportunities for implementing a measurement framework in different care settings.

We presented the initial measurement framework findings during each interview, and many stakeholders validated the constructs we identified as reflective of their own experiences of what is important to measure in serious mental illness care. Stakeholders discussed current issues in the health care system, focusing on the inadequacy of process measures in improving the quality of care for individuals with serious mental illness. Many placed an emphasis on creating better incentives for providers and integrating simpler, more relevant measures. Stakeholders highlighted the importance of accountability in care in order to ensure that what gets measured gets done.

Social Drivers of Health

SDOH, (e.g., access to housing, food, transportation and financial security) were identified as significant obstacles in recovery for those with serious mental illness. Stakeholders called for improved measurement tools to be integrated into clinician visits that assess barriers patients face in addressing their basic needs and accessing care. While all stakeholders agreed that clinical providers should not be held accountable for the outcomes of SDOH needs, it is important they are accountable for facilitating connections to outside resources that could address key needs.

Implementation Considerations

While many stakeholders affirmed the framework, including in the advisory committee, they emphasized the potential challenges to implementation and provided insight into how to increase stakeholder buy-in. Effective implementation requires robust support systems and technology integration; various stakeholders emphasized that if measure collections significantly increase work for clinicians, it will be very difficult for them to follow through on collecting them. They suggested integrating measures into existing workflows and Electronic Health Record (EHR) systems. Generative Artificial Intelligence (AI) could play a role in improving efficiency in measurement collection and reducing provider burden. Through passive capture of measures, AI may be able to score individuals receiving care on various domains, such as social support/loneliness, quality of life, and goal attainment, without the need to facilitate formal survey collection. Therefore, AI has the potential to significantly ease administrative burden for providers.

Stakeholders also discussed the importance of stakeholder engagement and buy-in with the measures outlined in the framework; we heard from providers, people with lived experience and payers whose engagement is all required to allow for measurement to successfully shift outcomes. People with lived experience expressed that measurement should feel useful and empowering, and they want to be able to see how their responses inform care. Care teams, including providers, highlighted that they are more likely to embrace PROMs when they see how the data can inform treatment, demonstrate their impact, and support better outcomes. Payers and broader health system organizations, additionally, need to see that the outcomes being measured can impact cost of care and reduce emergency care utilization. Stakeholders outlined strategies for ensuring buy-in across these different players.

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