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Recommendations and Challenges of the Clinical Services Panel of the PhenX Early Psychosis Working Group

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Abstract

Coordinated Specialty Care (CSC) is a promising multi-element treatment for the care of individuals experiencing the onset of schizophrenia. The Community Mental Health Block Grant has increased federal support for CSC programs. In order to maximize the number of sites capable of science-to-service or service-to-science translations, NIMH funded the PhenX measures for Early Psychosis supplement to the PhenX Toolkit. The Early Psychosis Working Group included "Translational Research" and "Clinical Services" panels. The Clinical Services panel was charged with identifying low-burden and psychometrically sound measures for use in routine clinical settings. The 19 new clinical measures complement existing measures already in the Toolkit. Measures covered a range of domains including symptoms, social and occupational functioning, well-being, medication adherence and side effects, physical activity, and experience of shared decision making and person-centered care. Several challenges are also discussed. The review process underscored the challenges facing non-academic sites in collecting even low-burden assessments.

The last decade has seen the development of promising treatments for the care of individuals experiencing the onset of schizophrenia. International research as well as the National

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Institute of Mental Health (NIMH) sponsored Recovery After an Initial Schizophrenia Episode project have provided the foundational evidence for the effectiveness of coordinated specialty care (CSC). CSC includes evidenced-based psychopharmacological management with attention to general health, cognitive and behaviorally oriented individual or group psychotherapy, family support and education, and supported education and employment, case management and, more recently, peer support. The promise of CSC for promoting the recovery of individuals developing schizophrenia-related disorders has led to the expansion of federal funding for CSC programs through the federal Community Mental Health Block Grant program (1).

NIMH leadership recognized the research opportunities afforded by this expansion in CSC programs. However, the limited number of new programs with connections to academic centers underlined the need for novel strategies that could increase the number of sites capable of science-to-service or service-to-science translations (2). A common framework for data collection and reporting would strengthen connections within and between scientific and clinical service agencies.

This awareness drove NIMH to fund the PhenX measures for Early Psychosis supplement to the PhenX Toolkit. Faced with similar challenges in genomics research, the National Human Genome Research Institute established the PhenX (consensus measures for **Phen**otypes and e**X**posures) Toolkit to provide standard measures for use in genome-wide association studies. PhenX measures are selected by Working Groups of domain experts using an established consensus process (3). Working Groups select potential measures for the PhenX Toolkit based on criteria established by the PhenX Steering Committee (SC) identifying measures are 1) valid, reliable, with demonstrated utility; 2) low burden to participants and investigators; and 3) broadly applicable and generally acceptable. Outreach to the scientific community provides feedback to inform final deliberations and selection of measures and protocols. Measures selected by Working Groups are freely available to the biomedical research and clinical community through a Web-based resource, the PhenX Toolkit (https://www.phenxtoolkit.org).

PhenX measures for Early Psychosis included Clinical Service Delivery and Translational Research Panels. The Clinical Panel was charged with identifying measures with utility in routine clinical settings. The Clinical Panel included a diverse mix of members, including individuals with extensive community-based implementation experience as well as personal and/or family experience of psychosis. Recommendations from both panels were sent to the scientific and early psychosis clinical communities for review; stakeholder comments informed the final selection of measures.

The PhenX Early Psychosis Clinical Services Panel identified 19 measures for inclusion in the Toolkit (See online supplement)(4). These covered a range of domains including premorbid functioning, self-reported and rater-assessed symptoms, social and occupational functioning, well-being, personal recovery, medication adherence and side effects, physical activity, and experience of treatment with respect to shared decision making and recovery orientation. Family measures assessed family history of mental illness, family functioning, family burden and expressed emotion. The selected measures complement measures already

in the PhenX Toolkit such as use of alcohol, tobacco, and other substances, exposure to trauma and adversity, crime and delinquency, and anthropometrics.

The Clinical Services and Translational Research Panels also collectively recommended 6 measures as part of Supplemental Information that did not reach the threshold of adequate psychometric properties and/or ease of use of measures included in the collection (4,5).

Several issues arose in the development of the Clinical Services collection which pose challenges in reaching the goals of facilitating the service-to-science bridge that NIMH sought and ultimately in creating a learning health care system that allows data and outcome-based quality improvement.

Availability and Selection of Measures:

While multiple past PhenX Work Groups have selected common data elements for psychiatric disorders, the early psychosis clinical services panel was the first with the explicit charge of identifying measures with utility in routine clinical care. The group's initial work schematic identified a series of potential domains for exploration including both individual-level and program-level constructs of interest. Unsurprisingly, the availability of measures meeting criteria established by the PhenX SC varied substantially across domains, with far more measures available in more classical clinical domains (for instance, psychopathology) relative to broader psychosocial domains such as vocational achievement and social functioning.

Key measurement concepts not included in the toolkit are listed below:

Duration of untreated psychosis:

Duration of untreated psychosis (DUP) has emerged as a critical, potentially tractable, influence on both short and long-term functioning (6). Objective, reliable measurement of DUP poses multiple challenges, most stemming from the inherent difficulties involved in anchoring and dating initial psychosis and lack of consensus concerning definitions of entry into treatment (7). Debates with respect to the latter include whether initiation of antipsychotic pharmacotherapy is sufficient. Best practices developed to date include administration of lengthy semi-structured questionnaires with collateral validation, typically supervised by experienced senior clinicians or researchers.

Program-Level Measures:

While the clinical services panel selected one service satisfaction measure, and one measure of the perceived recovery orientation of the treating program, limitations of these measures (and others reviewed) include lack of specificity to the range of components of best practice coordinated specialty care (8), to team-based care models and to services designed to meet the sometimes unique needs of transition-aged youth and emerging adults. The work group was also unable to identify a sufficiently validated and cross-cutting fidelity metric, or set of objective programmatic or structural quality indicators. Key domains not adequately covered by the two measures selected including availability and quality of trauma-focused services,

cultural competency, and treatment for substance use disorders, suicidality, physical health needs.

Vocational outcomes:

Returning clients to full lives in the community is one of the express goals of CSC, elevating the importance of metrics focused on school/work functioning. In spite of this, the Clinical Services Panel was unable to locate any psychometrically validated measure of the *quality* of school/work involvement or related measures—for example, client satisfaction with work/school involvement, underemployment, or fit between current involvement and future vocational goals.

Clinician-Report versus Client or Family Self-Report:

Research has consistently found meaningful differences between client and clinician ratings or report of the same constructs (9–12); often it is not that either form of measurement is invalid or less reliable, but that they in fact capture different latent constructs, reflecting the perspective of the individual completing them and correlating with different variables of interest (13, 14). Some decisions as to which perspective to include hinged solely on availability (e.g. global clinician-rated role functioning versus client perception), while in other cases the panel included both (symptoms) or opted for one or the other based on panel consensus.

Measures Across the Age Range:

Many of the dimensions of importance in Early Psychosis care may have differential validity across the age range of individuals receiving services (15). Some of the selected measures have different versions for adults and children. For example, the Personal Well-being scale has different versions for children/adolescents and adults as does the Incarceration measure. In contrast, the Family Functioning scale was validated for use in individuals 12 years and older. In addition, specific domains that have been developed in the context of adult services, including standard operationalizations of 'recovery' may not neatly translate to early intervention services settings, Finally, multiple Toolkit measures have not specifically been tested in adolescents.

Challenges Related to Implementation in Non-Academic Clinics:

Clinical Services Panel and community feedback underscored the extent to which integrating even modest standard measurement practices would be advantageous not only for research, but for local quality improvement activities. This relates to time, training, as well as to the administrative structure needed to track and monitor data input and analyses. Clinicians and front-line staff in the US, for example, have often received only minimal training in research-oriented clinical measurement (16). Without appropriately trained staff to ensure the integrity of client-report measures, panel members expressed concerns about potential bias if, for example, program clinicians were directly administering (and collecting) client self-report for potentially sensitive constructs such as medication adherence or shared decision making. Notably, the ability of treating clinicians to administer the measures

without intensive training was an important selection criterion. Additional concerns centered on data quality assurance, including the potential for a high volume of missing data, a common challenge in community-based performance monitoring. The time and infrastructure necessary to complete assessments is often unavailable.

Even where an infrastructure is available, existing data collection/performance monitoring requirements also vary across states, with some programs mandated to utilize particular metrics or data collection systems, dictated by the state's central health authority, county or city governments or other funding entities. An individual CSC program may have little control over these mandates. In such contexts, the addition of PhenX measures might be perceived as adding little value and/or over-burdening programs.

Clinical utility of the measures hinges on timely reporting of individual patient or clinical-program level reports to the clinical providers, patients, and patient family member. Most clinical programs lack the infrastructure to develop reporting methods. A critical area for future research involves development of standard procedures that facilitate reporting methods such that the collected data has an opportunity to impact clinical decision-making.

Despite the challenges, the Early Psychosis Clinical Services Panel identified standard measures suitable for academic centers and routine clinical care. This panel sets an example for future science-to-service and service-to-science as well as quality improvement efforts. The participation of end users and individuals affected by illness likely influenced the inclusion of measures that are more person- and clinician-centered. Further, the effort highlight significant psychometric gaps, that suggest priorities for future measure development efforts. The process has also connected with the ongoing imperative to embrace measurement-based care as a foundation for achieving the triple aim of better health, better health care, and improved efficiency.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Disclosures and acknowledgments:

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