

Outcome Measure Harmonization and Data Infrastructure for Patient-Centered Outcomes Research in Depression: Final Report

Structured Abstract

Objective. The objective of this project was to demonstrate the feasibility and value of collecting harmonized depression outcome measures in the patient registry and health system settings, displaying the outcome measures to clinicians to support individual patient care and population health management, and using the resulting measures data to support patient-centered outcomes research (PCOR).

Methods. The harmonized depression outcome measures selected for this project were response, remission, recurrence, suicide ideation and behavior, adverse effects of treatment, and death from suicide. The measures were calculated in the PRIME Registry, sponsored by the American Board of Family Medicine, and PsychPRO, sponsored by the American Psychiatric Association, and displayed on the registry dashboards for the participating pilot sites. At the conclusion of the data collection period (March 2020-March 2021), registry data were analyzed to describe implementation of measurement-based care and outcomes in the primary care and behavioral health care settings. To calculate and display the measures in the health system setting, a Substitutable Medical Apps, Reusable Technology (SMART) on Fast Healthcare Interoperability Resource (FHIR) application was developed and deployed at Baystate Health. Finally a stakeholder panel was convened to develop a prioritized research agenda for PCOR in depression and to provide feedback on the development of a data use and governance toolkit.

Results. Calculation of the harmonized outcome measures within the PRIME Registry and PsychPRO was feasible, but technical and operational barriers needed to be overcome to ensure that relevant data were available and that the measures were meaningful to clinicians. Analysis of the registry data demonstrated that the harmonized outcome measures can be used to support PCOR across care settings and data sources. In the health system setting, this project demonstrated that it is technically and operationally feasible to use an open-source app to calculate and display the outcome measures in the clinician's workflow. Finally, this project produced tools and resources to support future implementations of harmonized measures and use of the resulting data for research, including a prioritized research agenda and data use and governance toolkit.

Conclusion. Standardization of outcome measures across patient registries and routine clinical care is an important step toward creating robust, national-level data infrastructure that could serve as the foundation for learning health systems, quality improvement initiatives, and research. This project demonstrated that it is feasible to calculate the harmonized outcome measures for depression in two patient registries and a health system setting, display the results to clinicians to support individual patient management and population health, and use the outcome measures data to support research. This project also assessed the value and burden of capturing the measures in different care settings and created standards-based tools and other resources to support future implementations of harmonized outcome measures in depression and other clinical areas. The findings and lessons learned from this project should serve as a roadmap to guide future implementations of harmonized outcome measures in depression and other clinical areas.

Note: Full report is forthcoming.