An Electronic Personal Health Record
for Mental Health Consumers

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Organization: Emory University
Mechanism: RFA: HS08-002: Ambulatory Safety and Quality Program: Improving Management of Individuals with Complex Healthcare Needs Through Health Information Technology (MCP)
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Project Period: September 2008 – September 2011
AHRQ Funding Amount: $1,199,379
Summary Status as of: December 2010

Target Population: Adults, Mental Health/Depression

Summary: Poor quality of care may be an important risk factor for accelerated rates of morbidity in people with serious mental disorders. Electronic personal health records (PHRs) can shift the ownership and locus of health records and make them less likely to be scattered across multiple providers and more likely to be longitudinal and patient-centered. Due to the complex health care needs and fragmentation of care faced by individuals with mental health disorders, these patients may benefit from the use of PHRs. However, currently available PHRs typically lack mental health-related modules. To address this gap, the project team adapted an existing PHR to better meet the needs of patients with serious mental illness and one or more co-morbid medical conditions. The investigators are evaluating the impact of this modified mental health PHR (MH-PHR) in a 12-month, randomized controlled trial. During the first 6 months of the intervention phase, a clinical care nurse helps patients access and maintain use of the MH-PHR; during the second 6 months, patients continue use without support. A control group receives education materials about health and self-management. The investigators will evaluate the impact of the MH-PHR on patient self-activation and provider effectiveness in managing chronic disease by conducting chart reviews and interviews with patients. Originally, the mental health module was developed in an older version of an established PHR, the Shared Care Plan; however, the software was not functioning correctly and the module moved to Microsoft HealthVault.

Specific Aims:
• Develop a MH-PHR for mental health consumers. (Achieved)
• Implement a randomized trial of the MH-PHR. (Ongoing)
• Evaluate impact of the MH-PHR. (Ongoing)
• Disseminate results. (Upcoming)

2010 Activities: The primary activities in 2010 were recruitment for the randomized controlled trial and data collection. Initially, some participant attrition occurred as a result of the computer literacy skills required for patients to use the MH-PHR. Investigators devised two approaches to increase recruitment and retention. First, at the time of screening and enrollment, patients are given more detailed information about the computer skills required for the study, and investigators explain the
resources that are available. This helps to ensure that participants know what is expected of them. Second, investigators hired a nursing student who was trained as a computer literacy coach. Each participant is assessed for computer literacy and receives as much help as requested to use the MH-PHR effectively.

By August 2010, the team ended recruitment after enrolling 170 participants, exceeding the enrollment goal of 150 patients. In fall 2010, the first participants completed the 12 month study period; the last participants will not complete the study period until fall 2011. While the study has a low overall attrition rate, there has been a group of participants that has not been actively engaged in the intervention and using the PHR. Researchers conducted focus groups with both engaged and non-engaged participants to investigate reasons for engaging or not engaging. Their findings revealed that some people were not engaging mainly because they did not see the value of using the PHR.

The project team has done several presentations highlighting the project, including at the Tenth Annual Behavioral Health Information Management Conference and Exposition in California and the Agency for Healthcare Research and Quality (AHRQ) Health Information Technology Grantee and Contractor Meeting in June 2010. The project director also participated in “Patient Recruitment: Challenges, Trends and Best Practices”, a joint AHRQ Technical Assistance Webinar on strategies for patient recruitment in April 2010.

Grantee’s Most Recent Self-Reported Quarterly Status (as of December 2010): Project progress is completely on track and the project budget is somewhat underspent.

Preliminary Impact and Findings: The project does not have any findings to date.

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use