

# Randomized Trial of an Electronic Personal Health Record for Patients With Serious Mental Illnesses

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**Objective:** The authors evaluated the effect of an electronic personal health record on the quality of medical care in a community mental health setting.

**Method:** A total of 170 individuals with a serious mental disorder and a comorbid medical condition treated in a community mental health center were randomly assigned to either a personal health record or usual care. One-year outcomes assessed quality of medical care, patient activation, service use, and health-related quality of life.

**Results:** Patients used the personal health record a mean of 42.1 times during the 1-year intervention period. In the personal health record group, the total proportion of eligible preventive services received increased from 24% at baseline to 40% at the 12-month follow-up, whereas it declined in the usual care group, from 25% to 18%. In the subset

of patients with one or more cardiometabolic conditions (N=118), the total proportion of eligible services received improved by 2 percentage points in the personal health record group and declined by 11 percentage points in the usual care group, resulting in a significant difference in change between the two groups. There was an increase in the number of outpatient medical visits, which appeared to explain many of the significant differences in the quality of medical care.

**Conclusions:** Having a personal health record resulted in significantly improved quality of medical care and increased use of medical services among patients. Personal health records could provide a relatively low-cost scalable strategy for improving medical care for patients with comorbid medical and serious mental illnesses.

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Patients with serious mental illnesses are at risk for elevated rates of medical comorbidity and adverse health outcomes, including premature mortality (1). One of the most important factors contributing to these poor health outcomes is deficits in the quality of medical care (2, 3). At the patient level, symptoms of psychiatric illness, such as amotivation (4), cognitive limitations (5), and low health literacy (6, 7), make it challenging for people with serious mental illness to effectively manage their illnesses and obtain needed care. At the provider and system levels, patients with comorbid mental and general medical conditions typically receive care across multiple locations, leading to challenges in coordination of care between mental health and general medical providers (8).

Personal health records hold the potential to improve quality and outcomes of care by providing patients and providers timely access to key health information. Whereas electronic medical records are most commonly developed by individual provider organizations, electronic personal health records shift the ownership and locus of health information from being scattered across multiple providers to the patient (9, 10).

For patients with serious mental disorders, personal health records may be able to provide particular benefits for

improving care (11). Personal health records may help patients to better engage in care, facilitate communication across multiple providers, and provide a single record that follows patients across multiple settings. However, the same challenges that patients with mental disorders face in obtaining health services could also adversely affect their ability to use personal health records. To date, there has been almost no research testing the potential feasibility and benefits of personal health records to improve care for persons with mental disorders (12).

We report the results of a randomized trial testing the effects of a mental health personal health record in a sample of patients with serious mental illnesses and comorbid medical conditions. The results can help inform the use of this emerging technology in the care of people with mental disorders, as well as in other vulnerable populations.

## Method

### Overview

The project adapted an existing community-based personal health record to patients with serious mental illnesses. A 12-month randomized trial tested the effect of the record on the

This article is featured in this month's AJP **Audio**, is the subject of a **CME** course (p. 377), and is discussed in an **Editorial** by Drs. Fortney and Owen (p. 259)

FIGURE 1. My Health Record Screenshot

**My Health Record**  
You are In Charge of Your Health

Signed in: Jon Doe  
[My Registration](#)  
[Sign Out](#)

**John Doe**  
7/18/1963, 40 Years Old, Male

[Edit Johnnie's Registration](#) • [Printout Options](#)  
[Privacy Summary](#) • [Who's Accessed My Care Plan?](#)

Home **Care Team** About Me Diagnoses Next Steps Health Log Medications Allergies History Documents

**Important: Do not use your browser's back or forward buttons, as this may cause unusual results.**

**Emergency Contact** ([Help](#))  
Your Emergency Contact is the person you would like called first should you have an emergency. Your Backup Emergency Contact is the person you would like called if your primary Emergency Contact is unavailable.

Contact	Name	Phone Number	Alternate Phone Number
No Emergency Contact record. Please click "Add New" to add a new Emergency Contact.			

**Care Team Members** ([Help](#))  
Care Team Members are people and/or organizations who help you manage your health. Anyone who you feel has a role in your health care can be part of your Care Team.

Apts.	Name	Contact	Role/Description	Access Level	Comments	Action
	John Doe	Johndoe@gmail.com	Patient	Fully Edit		<a href="#">EDIT</a>
	Jane Doe	janedoe3@gmail.com	Spouse	View Only		<a href="#">EDIT</a> <a href="#">DELETE</a>
	Robert Smith	drrob@grady.org	Physician	Fully Edit		<a href="#">EDIT</a> <a href="#">DELETE</a>
	Jennifer Johnson	jjohnson11@grady.org	Nurse	Fully Edit		<a href="#">EDIT</a> <a href="#">DELETE</a>

quality of medical care received in an urban community mental health center.

### Intervention

My Health Record is an adaptation of the Shared Care Plan, a community-based personal health record developed by providers and by patients with chronic medical conditions to self-manage their illnesses and interact with the health system (13). The core features consist of personal details; diagnoses; goals and action steps; health indicators, including fields for blood pressure and cholesterol and glucose levels; medications and allergies; hospital visits; immunizations; and health and family health history. Prompts remind patients about routine preventive services.

To adapt the health record to the needs of patients with serious mental disorders, a series of focus groups consisting of mental health consumers (two groups), mental health providers (one group), and primary care providers (one group) presented the personal health record and identified potential modifications that were needed for this population. Based on the findings, the following changes were made: 1) rewriting all elements of the personal health record to a sixth-grade reading level to address limited health literacy in the population (7); 2) adding a section establishing mental health and health goals to help patients overcome amotivation and improve patient engagement with self-management and medical care; 3) adding

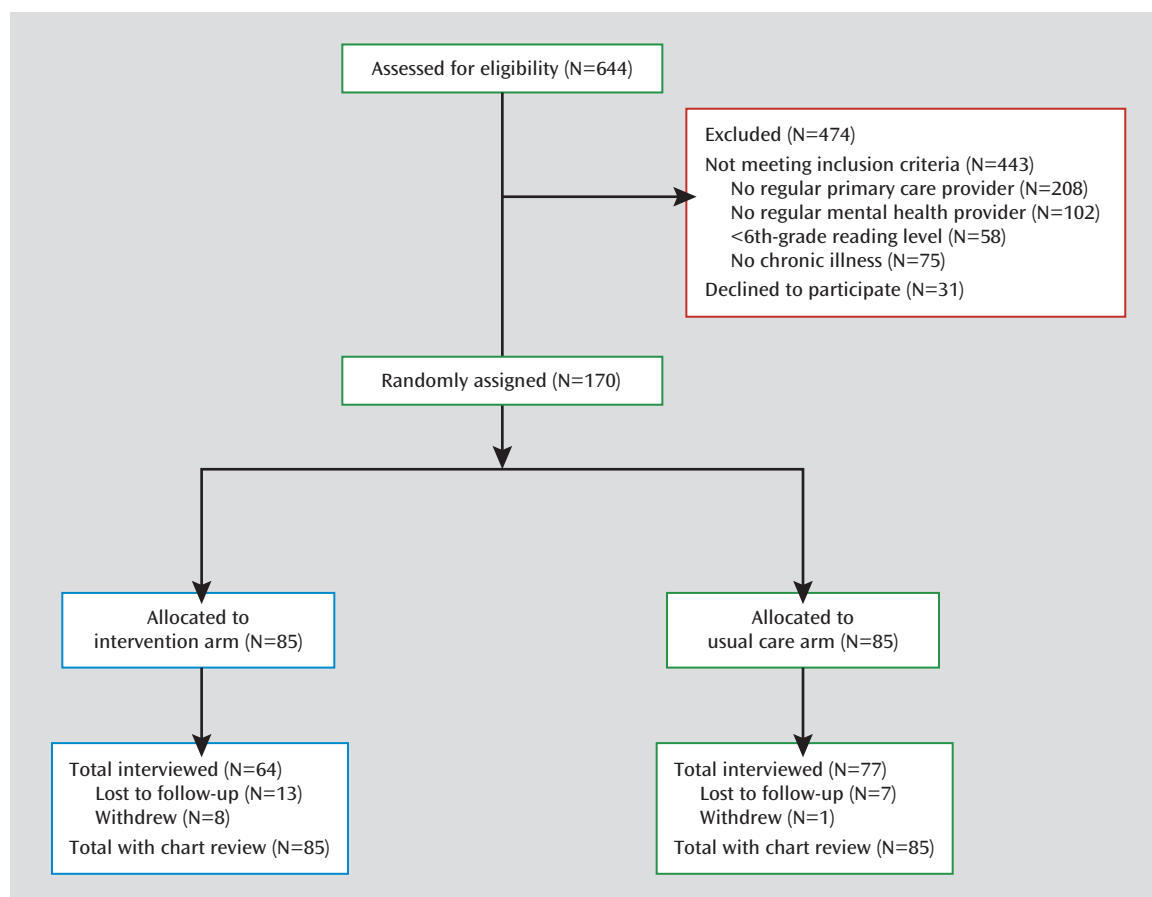
a mental health advanced directive section addressing patient preferences for mental health care in cases in which the patient is unable to make mental health decisions (14); and 4) providing contact information about resources, including grocery stores, YMCAs, and safety net health providers in the patients' neighborhoods. A screenshot of the My Health Record web interface is presented in Figure 1.

Because of low levels of digital literacy, a 4-hour computer literacy training curriculum was provided to all patients in the personal health record arm to enable them to effectively use the computer and the personal health record.

Data from the personal health record were stored on an encrypted server, and passwords were required to log in. Clients were able to access the personal health record data with protected passwords from any computer with an Internet connection. Additionally, they were allowed to designate health partners (including physicians, other providers, and friends and/or family), who could obtain access to the personal health record, and to identify the fields that health partners could access. For those without access to a computer, a workstation was provided at the mental health clinic.

A study staff member was available to patients to help orient them to the use of the personal health record and to enter and retrieve data during the first 6 months of the intervention. An initial 1-hour visit orienting patients to the personal health record was followed by 30-minute follow-up visits as needed.

FIGURE 2. Study CONSORT Diagram



On average, patients had 14.8 support visits ( $SD=5.53$ ), for a total of approximately 8 hours of support time during the study period.

After entering the initial data, clients were encouraged to access the personal health record at least every other week. Each patient printed out a wallet-sized card that provided an overview of his or her medical history, laboratory workup, and medications. Before each medical appointment, patients also printed out a detailed, full-size printout for their providers.

### Recruitment and Randomization

Patients with schizophrenia, schizoaffective disorder, bipolar disorder, major depression, or posttraumatic stress disorder and one or more chronic medical condition confirmed through chart review were eligible to participate. Patients were also required to have a primary care provider and to have a minimum of a sixth-grade reading level to ensure full participation in the project. Individuals were recruited through clinician referral or community mental health center waiting room screening or self-referred through recruitment flyers or word-of-mouth. Participants assigned to the usual care group continued to receive medical and mental health care as usual in the community and returned for follow-up interviews but were not provided a personal health record. After complete description of the study to the participants, written informed consent was obtained.

### Outcome Assessment

Interviews and reviews of all medical and mental health charts were conducted at baseline and the 12-month follow-up. Quality

and service use indicators were assessed through review of all medical and mental health charts; patient activation and health-related quality of life were assessed through patient interviews.

The primary study outcome was quality of medical care, which included 1) quality of preventive services and 2) quality of cardiometabolic care in the subset of individuals with cardiometabolic conditions. Quality of preventive services measures were obtained from the U.S. Preventive Services Task Force guidelines (15). These include four measures of physical examination, eight screening measures, seven vaccination measures, eight education measures, two measures of preventive services for men, and five preventive services measures for women. A score for each domain was calculated as the total number of preventive services for which an individual was eligible that were received by the individual. An aggregate score was developed as the total number of services across all domains for which an individual was eligible that were received by the individual.

Quality indicators for cardiometabolic risk factors were used as a second outcome measure because of the relatively high prevalence, clinical burden, and availability of indicators for this group of conditions. For the subset of individuals with these conditions ( $N=118$ ), indicators were developed using the RAND Community Quality Index (16–18). Cardiometabolic measures included 11 indicators for hypertension, seven measures for diabetes, and six measures for hyperlipidemia. As with preventive services, a score for each group of cardiometabolic indicators was calculated as the total number of services for which an individual was eligible that were received by

TABLE 1. Demographic and Clinical Characteristics of the Study Sample<sup>a</sup>

Characteristic	Study Arm				Analysis p
	Personal Health Record (N=85)		Usual Care (N=85)		
	Mean	SD	Mean	SD	
Age (years)	49.3	7.1	49.3	8.1	0.98
Income (monthly [U.S. dollars])	554.8	379.4	607.9	448.6	0.41
Number of medical comorbidities	2.3	1.5	2.3	1.3	0.74
	N	%	N	%	p
Male	43	50.6	41	48.2	0.76
Race/ethnicity					
White	13	15.3	8	9.4	0.24
Black	68	80	74	87.1	0.21
Hispanic	0	0	2	2.4	0.15
Single	45	54.2	38	44.7	0.21
Stable housing	66	79.5	71	83.5	0.50
Stable employment	41	49.4	52	61.2	0.12
Disability	23	27.1	26	30.6	0.61
Medical diagnosis					
Asthma	19	22.4	21	24.7	0.72
Osteoarthritis	29	34.1	17	20	0.03
Chronic obstructive pulmonary disease	8	9.4	10	11.8	0.61
Coronary artery disease	10	11.8	8	9.4	0.61
HIV	2	2.4	7	8.2	0.08
Hepatitis	15	17.7	19	22.4	0.44
Active tuberculosis	3	3.5	2	2.4	0.65
Cardiometabolic conditions	58	68.2	60	70.6	0.74
Diabetes	20	23.5	22	25.9	0.72
Hyperlipidemia	36	42.4	28	32.9	0.21
Hypertension	55	64.7	57	67.1	0.75
Mental diagnosis					
Schizophrenia	21	24.7	26	30.6	0.39
Bipolar disorder	14	16.5	6	7.1	0.06
Depression	40	47.1	41	48.2	0.89
Substance use disorder	2	2.4	7	8.2	0.09
Other mental illness	4	4.7	1	1.2	0.17

<sup>a</sup> For continuous variables, a t test was used, and a chi-square test was used for dichotomous variables.

the individual. An aggregate cardiometabolic quality score was developed as the total number of services across all domains for which an individual was eligible that were received by the individual.

Secondary outcomes included 1) health services use, including mental and medical inpatient, outpatient, and emergency department use; 2) patient activation, as measured by the Patient Activation Measure (19), a 22-item measure of patient skills and confidence in self-management behaviors; and 3) health-related quality of life, using the physical and mental component summary measures of the Medical Outcomes Study 36-Item Short-Form Health Survey (20).

### Data Analysis

All analyses were conducted as intent-to-treat. General linear analyses were conducted using the SAS PROC GLM (SAS Institute, Cary, N.C.) procedure to model change in each outcome as a function of being in the personal health record group compared with the usual care group. For dichotomous outcomes, the baseline value was included as a covariate in the regression predicting the measure at the follow-up interview. For continuous outcomes, changes in scores between baseline and follow-up were specified as dependent variables. Two-tailed tests of significance were used for all analyses.

## Results

### Study Flow, Participant Characteristics, and Use of the Personal Health Record

Of a total of 644 individuals screened, 170 were eligible and randomly assigned; the most common reasons that patients were screened but not enrolled were 1) lack of a regular primary care (N=208) or mental health (N=102) provider and 2) lack of a comorbid chronic medical illness (N=75) (Figure 2). All individuals in the personal health record and usual care groups had complete baseline and 12-month chart data available for the primary quality outcomes; a total of 141 (82.9%) had 12-month interviews.

All demographic and clinical parameters were balanced between the intervention and usual care groups (Table 1). The mean age of participants was 49.3 years (SD=7.62). One-half (49.4%) of the participants in the sample were men, and a majority (83.5%) were African American. Most participants were poor, with a mean annual income in the sample of \$6,966 (SD=\$4,985.13). On average, participants

TABLE 2. Quality of Preventive and Cardiometabolic Care

Variable	Study Arm				Analysis		
	Personal Health Record		Usual Care				
	Mean	SD	Mean	SD	F	df	p <sup>a</sup>
<b>Quality of preventive services</b>							
Physical examination					12.78	169	0.0005
Baseline	0.53	0.18	0.55	0.14			
12-Month interview	0.55	0.13	0.46	0.21			
Screening					5.76	169	0.02
Baseline	0.29	0.13	0.33	0.16			
12-Month interview	0.21	0.16	0.18	0.15			
Vaccination					20.13	169	<0.0001
Baseline	0.08	0.12	0.08	0.13			
12-Month interview	0.19	0.2	0.06	0.09			
Education					153.82	168	<0.0001
Baseline	0.17	0.16	0.17	0.16			
12-Month interview	0.73	0.34	0.15	0.16			
Preventive care for women					0.19	85	0.66
Baseline	0.32	0.37	0.27	0.33			
12-Month interview	0.27	0.31	0.27	0.3			
Preventive care for men					0.4	83	0.53
Baseline	0.16	0.28	0.15	0.23			
12-Month interview	0.14	0.27	0.09	0.19			
Total percentage of eligible services received <sup>b</sup>					99.35	169	<0.0001
Baseline	0.24	0.1	0.25	0.1			
12-Month interview	0.4	0.14	0.18	0.11			
<b>Quality of cardiometabolic services</b>							
Hypertension					9.98	169	0.002
Baseline	0.73	0.24	0.78	0.2			
12-Month interview	0.78	0.19	0.7	0.3			
Hyperlipidemia					0.04	34	0.85
Baseline	0.87	0.34	0.92	0.28			
12-Month interview	0.71	0.46	0.86	0.35			
Diabetes					3.02	36	0.09
Baseline	0.42	0.25	0.58	0.25			
12-Month interview	0.54	0.22	0.51	0.27			
Total percentage of eligible services received <sup>b</sup>					9.39	169	0.003
Baseline	0.73	0.24	0.78	0.2			
12-Month interview	0.75	0.2	0.67	0.31			

<sup>a</sup> The data represent the values for group type (personal health record compared with usual care), the key independent variable of interest, without adjusting for the number of outpatient medical visits.

<sup>b</sup> The data indicate the proportion of services for which a participant was eligible and obtained.

had a mean of 2.3 comorbid medical conditions; the most common mental health conditions were major depression (47.6%) and schizophrenia (27.6%). A total of 118 patients (65.6% of the sample) had one or more cardiometabolic conditions.

Based on data from the personal health record web server, participants used the personal health record a mean of 42.1 (SD=55.0) times during the 1-year intervention period.

#### Effects on Quality of Medical Care

The total proportion of eligible preventive services received increased in the personal health record group (from 24% at baseline to 40% at the 12-month follow-up,

compared with a decline in the usual care group from 25% to 18%), resulting in a significant difference in change between the personal health record and usual care groups ( $p<0.001$ ) (Table 2). Compared with the usual care group, the personal health record group had significantly greater improvements in rates of physical examination ( $p<0.001$ ), screening ( $p=0.02$ ), vaccination ( $p<0.001$ ), and education ( $p<0.001$ ). The overall rate of preventive service use in the personal health record and usual care groups is presented in Figure 3.

In the sample of patients with cardiometabolic conditions ( $N=118$ ), the total proportion of eligible cardiometabolic services received improved by 2 percentage points in the personal health record group but declined

by 11 percentage points in the usual care group, resulting in a significant difference in change between the two groups ( $p=0.003$ ) (Table 2). In the personal health record arm, there was a significantly greater improvement in care for hypertension ( $p=0.002$ ) but not for diabetes or hyperlipidemia.

### Effects on Secondary Outcomes

Participants in the personal health record group had a significant increase in the number of outpatient medical visits compared with those in the usual care group (mean increase: 14.9 [SD=10.71] compared with 0.5 [SD=11.15],  $p<0.001$ ) (Table 3). There were no significant changes in other measures of inpatient, outpatient, or emergency department services.

Both groups exhibited small improvements in patient activation, physical health-related quality of life, and mental health-related quality of life; however, none of these changes differed significantly between the two groups (Table 3).

### Mediation Analysis

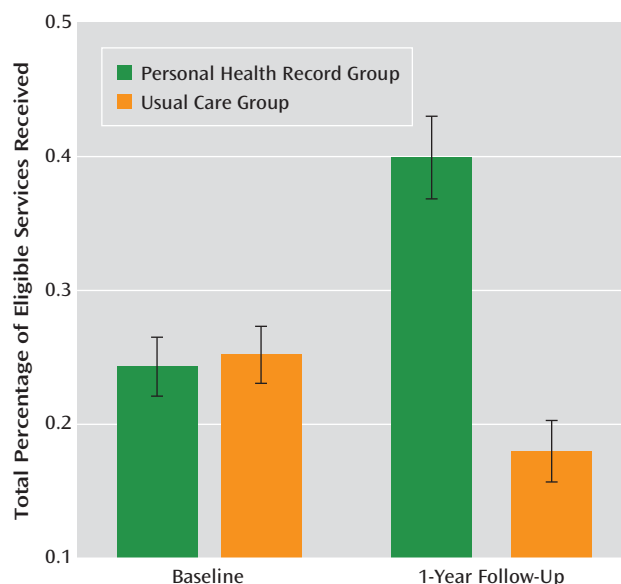
To explore whether the number of visits might explain a portion of the effect on quality measures, an exploratory mediation analysis was conducted examining whether controlling for the number of outpatient medical visits attenuated the association between the intervention and the quality scores. After adjusting for outpatient use of services, only education and total number of preventive services remained significant ( $p<0.001$ ). The magnitudes of differences in preventive services changes and cardiometabolic care changes between the personal health record and usual care groups all decreased substantially, except for preventive services for women, preventive services for men, and quality of hyperlipidemia treatment (Table 4).

## Discussion

In a sample of patients with serious mental illnesses and comorbid medical conditions, having a personal health record was associated with improved quality of preventive care and cardiometabolic care, as well as increased use of general medical services. There were no evident benefits regarding patient activation, quality of life, or other measures of service use.

An increasing number of studies have found that personal health records can improve rates of routine preventive services in general medical populations (21, 22). Our study demonstrated that a poor and complex population of people with serious mental illnesses can derive similar benefits from these new technologies. In contrast to most personal health records, which are developed as extensions of electronic health records, the community-based personal health record in this study made it possible for patients to include information from multiple providers,

**FIGURE 3. Personal Health Record and Rate of Receipt of Indicated Preventive Care Services**



a high priority for populations whose care may be scattered across multiple organizations.

While the study showed that implementing such programs is feasible, particularly for this population, they need to be implemented with adequate support. In this study, computer training helped address deficits in computer literacy, and technical assistance was important in helping patients enter data and access their personal health record. As with other health technology interventions, implementation studies are needed to identify which training and technical assistance approaches can most efficiently allow patients to reap the benefits (23).

What allowed patients with a personal health record to obtain higher quality of medical care? Analyses suggested that greater rates of medical utilization in the personal health record group appeared to be an important driver of higher quality of preventive and cardiometabolic services. Underuse of medical services commonly underlies quality deficits in this population (2); increasing patients' use of services, in turn, may help foster improved quality of care.

Several limitations to this study should be noted. The study was conducted in a single, urban community mental health center. Further work is needed to establish generalizability to other mental health settings. Second, the study was only conducted among the subset of patients with a regular mental health and medical provider. For populations without a regular source of care, addressing access barriers may be needed before implementing interventions such as personal health records, in which the goal is to improve quality and engagement in treatment. Finally, reflecting the state of technology at the time the study was conducted, the web-based personal health record relied on participants to enter all data and access the record through



TABLE 3. Service Use, Patient Activation, and Health-Related Quality of Life

Variable	Study Arm				Analysis		
	Personal Health Record		Usual Care				
	N	%	N	%	F	df	p <sup>a</sup>
<b>Services use (dichotomous)</b>							
Inpatient mental health hospitalization					1.03	168	0.16
Baseline	1	1.2	1	1.2			
12-Month interview	0	0	2	2.4			
Emergency department mental health visit					3.68	168	0.68
Baseline	23	27.1	14	16.5			
12-Month interview	10	11.8	7	8.3			
Inpatient medical hospitalization					3.01	168	0.68
Baseline	3	3.5	4	4.7			
12-Month interview	10	11.8	12	14.3			
Emergency department medical visit					3.6	168	0.85
Baseline	50	58.8	41	48.2			
12-Month interview	39	45.9	38	45.2			
	Mean	SD	Mean	SD	F	df	p <sup>a</sup>
<b>Services use (continuous)</b>							
Number of outpatient mental health visits					2.65	168	0.11
Baseline	12.1	8.1	11.4	8.1			
12-Month interview	21.5	23.8	15.4	21.9			
Number of outpatient medical visits					73.36	168	<0.0001
Baseline	12.2	9.8	13.1	14.3			
12-Month interview	27.1	11.5	13.7	12.2			
Patient activation measure (100 possible score)					0.02	138	0.90
Baseline	56.1	14.3	55.6	14.4			
12-Month interview	58.9	12.5	59.2	15.7			
Medical Outcomes Study 36-Item Short-Form Health Survey composite indices							
Physical component measure					0.85	139	0.36
Baseline	33.4	11.2	32.7	9.2			
12-Month interview	33.4	9.7	33.6	8.9			
Mental component measure					0.64	139	0.42
Baseline	33.4	10.9	33.8	11.1			
12-Month interview	34.6	10.9	36.2	11.3			

<sup>a</sup> The data represent the values for group type (personal health record compared with usual care), the key independent variable of interest.

TABLE 4. Quality of Preventive and Cardiometabolic Care (Mediation Analysis)

Quality of Care	Prediction of Service Change Between Baseline and Follow-Up Interview			
	Without Adjustment for the Number of Outpatient Medical Visits		With Adjustment for the Number of Outpatient Medical Visits	
	Coefficient <sup>a</sup>	p <sup>b</sup>	Coefficient <sup>a</sup>	p <sup>b</sup>
<b>Preventive services</b>				
Physical examination	0.118	0.0005	0.021	0.58
Screening	0.071	0.02	0.037	0.30
Vaccination	0.128	<0.0001	0.038	0.24
Education	0.587	<0.0001	0.441	<0.0001
Preventive care for women	0.043	0.66	−0.065	0.58
Preventive care for men	0.038	0.53	0.060	0.42
Total percentage of eligible services received <sup>c</sup>	0.228	<0.0001	0.140	<0.0001
<b>Cardiometabolic services</b>				
Hypertension	0.129	0.002	0.074	0.12
Hyperlipidemia	−0.033	0.85	−0.194	0.28
Diabetes	0.152	0.09	0.119	0.29
Total percentage of eligible services received <sup>c</sup>	0.127	0.003	0.082	0.09

<sup>a</sup> The data represent the coefficient of group type (personal health record compared with usual care).

<sup>b</sup> The values for group type are presented.

<sup>c</sup> The data indicate the proportion of services for which a participant was eligible and obtained.

## Patient Perspective

“Ms. J” is a 58-year-old African American woman with a history of schizophrenia, diabetes, and hypertension who participated in the personal health record arm of the study. She received her mental health care from a community mental health center and her medical care from a federally qualified health center in the neighborhood. She often left her appointments feeling overwhelmed and uncertain as to how to manage her health. She did not own a computer but had some experience in using e-mail and the web and was able to access a computer from the public library.

During the study, she accessed the personal health record on average once per week, using it to update her medications and health goals. She brought a printout of her personal health record to each of her medical and mental

health appointments and began attending her primary care physician visits more regularly. At her 12-month chart review, her receipt of needed cardiovascular services increased from 40% to 75%; her mean blood pressure improved from 159/90 mmHg to 130/81 mmHg, and her fasting blood glucose levels went from 90 mg/dL to 78 mg/dL.

At her final interview, the patient described her experience with the record as follows: “My Health Record helped me understand my health conditions and helps me keep track of my weight and my blood pressure. I gave printed copies of my personal health record to all my providers, and this has made me more confident when talking to them. I feel better prepared and more organized now when I meet with my doctors.”

desktop computers. Exchange of health information across providers (24), along with patient portals (25), will increasingly make it possible to directly synchronize with clinical and laboratory data, reducing patient burden and increasing utility of personal health records as tools for coordinating care. The increasing ubiquity of smartphones may further increase the ability of patients to access health records and communicate with providers whenever and wherever the need arises (26, 27). Further research is needed to examine the benefits of these new technologies in improving care.

This study demonstrated that personal health records hold potential to improve the quality of care among individuals with serious mental illnesses treated in public mental health settings. More generally, personal health records point to the promise of new health technologies for improving care in vulnerable populations who have traditionally not been included in developing the interventions or in evaluating their effectiveness. As these technologies are developed and disseminated in the coming years, it will be essential to ensure that they are available to, as well as tested in, patients with serious mental illnesses and other disadvantaged populations.

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