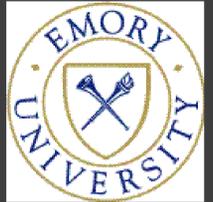




# An Electronic Personal Health Record for Mental Health Consumers

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## BACKGROUND

Electronic Personal Health Records (PHRs) hold promise in reshaping healthcare. PHRs shift the ownership and locus of health records from being scattered across multiple providers to the patient. Given the complex health needs and the fragmentation of care for persons with serious mental illnesses, these individuals could derive particular benefit from a PHR. This study is the first to test PHRs this population.

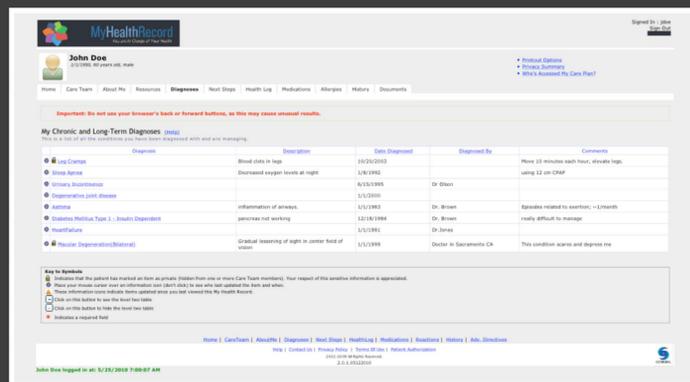
## ADAPTING THE SHARED CARE PLAN

Qualitative methods were used to incorporate input from mental health consumers, mental health clinicians, and primary care providers to adapt the PHR to the specific needs of our population. Based on the focus groups, enhancements to the Shared Care Plan included:

- Mental health advanced directives
- Links to community resources
- Personal mental health goals
- Option of adding a “Health Partner”

Other lessons from focus groups:

- Access to computers is less of a barrier than anticipated (70% report having access).
- Clinicians indicated health information that would be useful for them (e.g., related to psychiatric diagnosis)



## TACKLING LOW COMPUTER LITERACY

- Low digital literacy for about 50% of consumers.
- Community resources too burdensome on consumers.
- Graduate research assistant provided each client with individualized assessment and learning-style adjusted training.
- For low-literacy consumers, digital proficiency was reached after an average of four 1-hour training sessions.
- Computer training classes increase retention of consumers with low computer literacy.
- Computer training provides added incentive for participation.

## INTERVENTION

We developed and are testing a PHR for persons with serious mental illnesses and one or more comorbid medical condition (My Health Record).

- 12-month randomized trial of My Health Record vs. Usual Care for patients with serious mental illnesses with one or more chronic medical condition (n=170).
- Setting: Urban public-sector mental health clinic.
- Participants receive a manualized computer skills assessment and basic computer skills training before setting up their PHR.

Outcomes include:

- Quality of medical care
- Coordination of medical care
- Service use
- Health-related quality of life
- Patient activation
- Recovery
- Mental and medical health status

Evaluations are being conducted at baseline and 12-months via interviews and medical/psychiatric chart review.



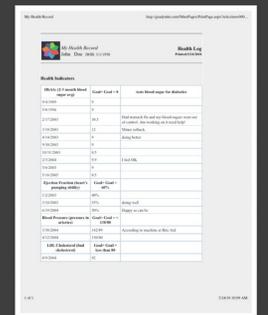
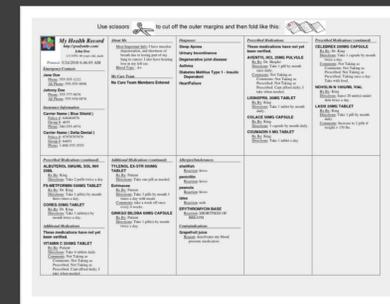
## IMPLEMENTING THE SHARED CARE PLAN

The patient is the primary driver behind maintaining the PHR

- The nurse specialist only gathers and verifies initial labs.
- The primary role of nurse specialist is to help the consumer identify the treatment data that is the most essential, obtain it from their medical records, and enter it into their PHR.
- Patient Activation Measure (PAM) is used as a tool to drive intervention approach.
- After 6 months, patients “graduate” to maintaining and shaping record themselves.

## DATA OUTPUT

After inputting their medical history with the assistance of the nurse, patients can print out wallet cards that provide a quick overview or detailed print-outs. In addition to summaries of their medical histories, My Health Record also helps patients establish and keep track of personal health goals including but not limited to: number of depressed days, number of cigarettes smoked, blood pressure, and glucose monitoring.



## BASELINE PATIENT CHARACTERISTICS

Demographics: N = 170 (Case: 85, Control: 85)	%	Primary Psychiatric Diagnosis	%	Chronic Medical Conditions	%
Female	51%	Major Depression	38%	Hypertension	63%
African American	81%	Schizophrenia	29%	Hyperlipidemia	34%
Single, Never Married	49%	Bipolar	11%	Diabetes	25%
Receiving Disability	29%	PTSD	4%	Osteoarthritis	25%
Stable Housing	81%	Other	17%	Asthma	22%
Stable Income	55%	Co-Occurring Substance Abuse	35%	Hepatitis (any)	19%
Have Primary Care	98%	Currently substance abusing	5%	CAD	11%
Mean Age (years)	49	More than one diagnosis	32%	COPD	9%
Mean Monthly Income (\$)	614.17			HIV	5%
				Active TB	3%
				More than one condition	64%

## EARLY IMPRESSIONS

- **Access to computers** less of a barrier than anticipated
- **Low digital literacy:** Significant portion of participants; but can be successfully addressed with basic computer training.
- **Usefulness for coordination of medical care** less than anticipated
- **Interactions with clinicians:** PHR print-outs help consumer take charge
- **Overcoming initial reluctance by clinicians:** improved interactions with “activated” consumers and access to hard-to-obtain health information.
- **“Activated” consumers** take over directing their own health care.

Free-standing, community-developed PHRs can be an empowerment tool for consumers