A randomized study of the personal health record in the public health setting

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Outline

Main Points

Background

Provide a brief glimpse of the system

What is the data telling us?

What worked and what did not work

Future activities
Main Points

The study design is acceptable
Patients will enroll in a RCT
Investigators remain blinded to the data
Patients have some challenges such as maintaining their online identity
How to reconcile research data and clinical care remains an issue
We will unlikely reach our target full enrollment
Background

• PHRs are becoming more common
• PHR functionality is a criteria for EMR certification under Meaningful Use criteria
• PHR use by persons in public health settings is desired by patients and clinicians
  – Information exchange (lab data)
  – Scheduling appointments
  – Reminders (appointments, medications)
  – Communication (immunizations, concerns)
Do vs. know

Transformative technology

Hypothetical growth with knowledge and resources

Incentives for the process
Pay for results
Empower Consumers

Real world
Goal of the project

Our central hypothesis is that a secure PHR that combines meaningful information, web-based tools for support and reminders for patients will provide a substantial opportunity to promote self-management and will lead to improved health outcomes.

To test our hypothesis we are performing a randomized controlled study to evaluate the biologic outcomes between persons randomly assigned to full use PHR compared with persons assigned to deferred access.
The future is already here, it's just not evenly distributed

William Gibson
The Economist 2003
About the Study

• 600 patients followed for one year
• Half are randomized to full access of their online PHR and half randomized to receive ONLY surveys in the PHR without health information
• Patients are incentivized by receiving Starbucks gift cards as well as entries into a monthly groceries drawing worth $60
• Enrollment period from 6/24/09 to 6/1/10
Welcome!

Dear myHERO user:

Welcome to myHERO and the AHRQ study. We want to thank you again for agreeing to participate in this exciting study! Now that you have successfully registered, you will be able to see your health information as well as a section where you will complete all of your surveys for the research study.

Over the next year, you will see 3 groups of surveys available in the My Surveys tab. The first group of 9 surveys is available now, another group will be available in 6 months and a final group in 12 months. We’ll send you an email when the 6 and 12 month surveys are ready for you to take. For completing each group of surveys, you will get a $5.00 gift card to a local restaurant and for completing each individual survey, you will be entered into a monthly grocery drawing worth $65.00. Each survey will have an expiration date, shown in the survey list. You may save a survey you are working on and return later to finish it, but you must complete it before the expiration date.

The myHERO web page has many tools that we hope you find helpful. Under the tab that says My Health Record, you can see your allergies, blood pressure (that you record), conditions, glucose levels (that you record), lab results, medications, weight (that you record) and notes. This information is updated any time your provider changes your medical record. It is important to know that there will be a two week delay of your Lab results. For the Meds section, you will see a list of your current meds and med pictures if available. You can find more information about a medication by clicking on the medication name. Under Conditions, you will find your current diagnoses with links to more information (if available).
Welcome!

Dear myHERO user:

Welcome to myHERO and the AHRQ study. We want to thank you again for agreeing to participate in this exciting study! We hope that you will find the myHERO surveys to be very useful! Now that you have successfully registered, you will have two months to complete the first group of your surveys.

Over the next year, you will see 3 groups of surveys available in the My Surveys tab. The first group of 9 surveys are available now, another group will be available in 6 months and a final group in 12 months. We'll send you an email when the 6 and 12 month surveys are ready for you to take. For completing each group of surveys, you will get a $5.00 gift card to a local restaurant and for completing each individual survey, you will be entered into a monthly grocery drawing worth $65.00. Each survey will have an expiration date, shown in the survey list. You may save a survey you are working on and return later to finish it, but you must complete it before the expiration date.

Thank you for your interest in this study, we hope you will have a positive experience with myHERO. If you have any problems with the myHERO site, you can email us at myhero@ucsf.edu.

Take a Survey now!
### My Surveys

<table>
<thead>
<tr>
<th>Survey Name</th>
<th>Status</th>
<th>Expires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet and Health</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>Well Being</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>How I Feel</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>The Mood Screener</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>Medications Survey</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>About My Provider</td>
<td>New!</td>
<td></td>
</tr>
<tr>
<td>About Me</td>
<td>50% Complete</td>
<td>4/07/2011</td>
</tr>
<tr>
<td>My Annual Health Survey</td>
<td>92% Complete</td>
<td>4/07/2011</td>
</tr>
<tr>
<td>Satisfaction with MyHERO</td>
<td>New!</td>
<td></td>
</tr>
</tbody>
</table>

Thank you for completing these surveys. You are participating in a one-of-a-kind study! All of your answers are private and will not affect your care at Ward 86. Please answer the questions the best you can. You may skip questions you do not want to answer.

You can always stop a survey in the middle and finish it later. Once you have finished a survey, it will disappear from your surveys list.

myHERO Study Consent Document
My Health Record

- **Allergies**
  - View Your Allergies

- **Blood Pressure**
  - Record your blood pressure

- **Conditions**
  - View your conditions

- **Glucose**
  - Record your glucose level

- **Labs**
  - View your CD4, Viral Load and other test results

- **Meds**
My Health Record - Meds

View My Meds
See a list and photos of your current medications

Update My Meds List
Let your provider know which meds you are not taking

Report Side Effects
Let your provider know of any side effects you are having

My Current Medications

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose and Formulation</th>
<th>Photo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albuterol inhalation solution</td>
<td>0.5 percent nebulization, 3 every four to six hours, as needed</td>
<td>No Image on File</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>25 mg tablet, 1 at bedtime</td>
<td>No Image on File</td>
</tr>
<tr>
<td>Atorvastatin</td>
<td></td>
<td>No Image on File</td>
</tr>
<tr>
<td>Atripla (Emtricitabine/Tenofovir/Efavirenz)</td>
<td>200/300/60 mg tablet, 1 at bedtime</td>
<td>No Image on File</td>
</tr>
<tr>
<td>Norvir (ritonavir)</td>
<td>100 mg capsule, 1 daily</td>
<td></td>
</tr>
<tr>
<td>Truvada (Emtricitabine/Tenofovir)</td>
<td>200/300 mg tablet, 1 daily</td>
<td></td>
</tr>
<tr>
<td>Ziagen (abacavir sulfate 300mg)</td>
<td>300 mg tablet, 1 twice daily</td>
<td></td>
</tr>
</tbody>
</table>

The information displayed above is the most current that we have on file. If this information is not correct, please tell your provider so we can update your record.
### My Current Medications

<table>
<thead>
<tr>
<th>Medication</th>
<th>Photo</th>
<th>Remove</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albuterol inhalation solution</td>
<td>No Image on File</td>
<td>Waiting on provider update</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>No Image on File</td>
<td>Waiting on provider update</td>
</tr>
<tr>
<td>Atorvastatin</td>
<td>No Image on File</td>
<td>Waiting on provider update</td>
</tr>
<tr>
<td>Atripla (Emtricitabine/Tenofovir/Efavirenz)</td>
<td>No Image on File</td>
<td>Remove</td>
</tr>
<tr>
<td>Norvir (ritonavir)</td>
<td>Remove</td>
<td></td>
</tr>
<tr>
<td>Truvada (Emtricitabine/Tenofovir)</td>
<td>Remove</td>
<td></td>
</tr>
<tr>
<td>Zidovudin (abacavir sulfate 300mg)</td>
<td>Remove</td>
<td></td>
</tr>
</tbody>
</table>
My Survey - Medication

This is your medication list from your doctor. Please answer YES if you take the med (or sometimes take the med) and NO if you don’t.

<table>
<thead>
<tr>
<th>My Current Medications</th>
<th>Photo</th>
<th>Do you take this Med?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atenolol 25 mg tablet, 1 daily</td>
<td>No Image on File</td>
<td>○ Yes ○ No</td>
</tr>
</tbody>
</table>

Do you take any other medications? If yes, please list: (example: medication x, medication y, ...)

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Done, Submit Survey
Provider Role

- For each patient that have agreed to take part in the study, the clinician is asked to complete a single survey at baseline, 6 months, and 12 months (based on when the patient first registered)
- Clinicians have 4 months to complete the survey
- Study team sends weekly emails with the names of newly registered patients
Study participants-patients and clinicians

336 Patients have consented for the study
  – 2 deceased patients
  – 8 withdrawn (reasons recorded)

59% of patients have taken one or more baseline surveys (N=254)
61% completion of baseline (N=199)
45% completion of R2 surveys (N=38)

149 Provider surveys completed 46% PCPs have taken 1 or more surveys (N=18)
AHRQ Enrollment Numbers (Day)

$y = -0.0158x + 4.1398$

Day Number

# Patients Enrolled

Number of Patients Enrolled (by day)

Linear (Number of Patients Enrolled (by day))

$y = -0.0158x + 4.1398$
CD4 levels on log scale, by Collection time
(dark colors are patients' levels; pale colors are Arm means)
How do we perform follow-up?

Email sent every other week

Phone call* every week
  – Cannot leave messages
  – Set up “appointments” for patients to get back into their email/myHERO account:
    • Many have forgotten their username and/or email account information
    • 11 email changes (create new email address in the database)

*Major issue: phone numbers are inaccurate
Recent changes to improve follow-up

CHR approved advertising video for patient waiting room

Can give PHR username over the phone

Observing a better survey completion rate (even though it is taking a longer time) in the clinic!
Observations from Recruitment

• Patients who are “full” users are very excited about seeing their personal health information.
  – “This is the coolest thing I have ever seen”
  – “This is truly amazing”

• Deferred users are not thrilled with their assignment but there is no differential drop-out rates
Computer Skills

• 3 types of users:
  – Computers are completely foreign
  – Somewhat familiar with a computer
  – Completely comfortable with a computer

❖ Challenges: We can only teach so much in one sitting
❖ Opportunities: We are providing resources and some basic skills that can jump start their skill building
Accessibility Issues

• Font Size—we made the Font Bigger
• Radio Button Size—increased the size
• Mouse Use
• “Next Page” vs. “Submit”—now “DONE”
• User names and passwords
  – Patients now write these down
  – New tool to reset passwords online
What worked and what did not

- Patients will use the PHR survey system.
- Patients want accurate data
- Patients are receiving appropriate care especially related to ART.
- Good responses are common
- Problems of sample
- Consider differences between PHR users and non-users.
Future Data Collection

1. Do you have a computer at home?
2. Do you have your own email address?
3. How many times a week do you check their email? Never, daily, few times per week, weekly, monthly
4. Where do you use a computer? Home, library, clinic, school, friend/relative, other
5. Do you ask for assistance when you are using a computer?
Patient Name:___________________________________________________________

- Helped patient reset Email

- Helped patient reset myHERO username

- Helped patient reset myHERO password

- Patient took --______ surveys

- Patient picked up coupon -

- Spent ______(min) with Patient

Notes:______________________________________________________________
Future work

• Allow patients to change data.
• Record data in the database when patients change their data.
• Automate reconciliation processes
  – Simple confirmation
  – Clinician confirmation
• R18 at AHRQ for
  – Integration CES information
  – Integration and understanding of how to change treatment guidelines
• R01 at NIDA for integration of NIDAMED tool
• Improve access via cellular technology
Main Points

The study design is acceptable
Patients will enroll in a RCT
Investigators remain blinded to the data
Patients have some challenges such as maintaining their online identity
How to reconcile research data and clinical care remains an issue
We will unlikely reach our target full enrollment
Good ideas are not adopted automatically. They must be driven into practice with courageous patience.

Admiral Rickover
Demonstration

https://myhero.sfdph.org