A National Web Conference on Effective Design and Use of Patient Portals and Their Impact on Patient-Centered Care

Presented by:
Ruth Masterson Creber, Ph.D., M.Sc., RN
Courtney Lyles, Ph.D.
Jessica Ancker, Ph.D., M.P.H.

Moderated by:
Chris Dymek, Ed.D.
Agency for Healthcare Research and Quality
March 23, 2017
Agenda

• Welcome and Introductions
• Presentations
• Q&A Session With Presenters
• Instructions for Obtaining CME Credits

Note: After today’s Webinar, a copy of the slides will be emailed to all participants.
AHRQ’s Mission

To produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.
AHRQ invests in research and evidence to understand how to make health care safer and improve quality.

AHRQ creates materials to teach and train health care systems and professionals to catalyze improvements in care.

AHRQ generates measures and data used to track and improve performance and evaluate progress of the U.S. health system.
The following presenters and moderator have no financial interests to disclose:

- Ruth Masterson Creber, Ph.D., M.Sc., RN
- Courtney Lyles, Ph.D.
- Jessica Ancker, Ph.D., M.P.H.
- Chris Dymek, Ed.D.

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- At any time during the presentation, type your question into the “Q&A” section of your WebEx Q&A panel.
- Please address your questions to “All Panelists” in the drop-down menu.
- Select “Send” to submit your question to the moderator.
- Questions will be read aloud by the moderator.
Learning Objectives

At the conclusion of this activity, the participant will be able to do the following:

1. Describe an inpatient personal health record (PHR) portal designed for sharing information between patients and their care teams and methods for assessing its impact on patient engagement and satisfaction with their care.

2. Identify barriers and facilitators related to the use of a patient portal among diverse diabetes patients.

3. Describe the impact of systemic redesigns to match patient portals to patient needs for information and action.
Expansion of Online Patient Portals in the United States

Courtney R. Lyles, Ph.D.

Courtney.Lyles@ucsf.edu

Assistant Professor

Division of General Internal Medicine at Zuckerberg San Francisco General Hospital

UCSF Center for Vulnerable Populations
Patient-Facing Technology in Health Care

Range in health technologies:

- Mobile phone apps
- Connected devices (e.g., Fitbit)
- Patient Web sites
- Electronic health records (EHRs)

Integration with health care systems/data
Online Patient Portals

Patient access (via secure Web site) to portions of the EHR:

- Visit summaries
- Immunizations/allergies
- Lab test results
- Secure messaging with providers
- Viewing/making appointments
Example Feature: Lab Results

| Patient: | FRANCIS ZZZCOE |
| DOB:     | 07/10/1960     |
| Address: | 101 GROVE ST., SAN JOSE, CA 95128 |
| Phone:   | 415-555-8888   |
| Ordered Date: | 11/19/2012 |

Assessments: GLUCOSE, Fasting (gray)

<table>
<thead>
<tr>
<th>Name</th>
<th>Value</th>
<th>Reference Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>GLUCOSE,FASTING</td>
<td>100</td>
<td>(70-99) mg/dL</td>
</tr>
<tr>
<td>ADA CLASSIFICATION OF DIABETES MELLITUS:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORMAL FASTING GLUCOSE -- &lt;100 MG/DL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IMPAIRED FASTING GLUCOSE (IFG) -- 100-125</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROVISIONAL DIAGNOSIS OF DIABETES -- &gt;125</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Result: Normal
Received Date: 11/19/2012

Notes:
Rapid EHR/Portal Spread Across Vast Majority of U.S. Health Care Systems

- Driven by financial incentives (Meaningful Use→over $30 billion)
  - Includes targeted portal metrics

Figure 1: Percent of non-Federal acute care hospitals with adoption of at least a Basic EHR with notes system and possession of a certified EHR: 2008-2014

~50% offering portals

NOTES: Basic EHR adoption requires the EHR system to have a set of EHR functions defined in Table A1. A certified EHR is EHR technology that meets the technological capability, functionality, and security requirements adopted by the Department of Health and Human Services. Possession means that the hospital has a legal agreement with the EHR vendor, but is not equivalent to adoption.

*Significantly different from previous year (p < 0.05).

SOURCE: ONC/American Hospital Association (AHA), AHA Annual Survey Information Technology Supplement
Importantly, Portals Are Patient Centered

- High interest in portal functionality nationally:

Optum Institute/Harris Interactive Multi-stakeholder Health Care Environment Survey, June 2012
Portals Are Important to Study

Move communication outside of the clinic

- Closer to patients’ everyday lives.
- Particularly important for care coordination and self-management support.

Early evidence that they are linked to better outcomes

- Process measures and intermediate health behaviors.

Primary platform for future integration

- Apps and devices will eventually push data into portals.

First widespread technology to reach diverse patient populations
Assessing Impact of an Acute Care Patient Portal on Patient Engagement and Satisfaction With Care

Ruth Masterson Creber, Ph.D., M.Sc., RN

Study team: Jennifer E. Prey, Ph.D., M.Phil., M.S.; Beatriz Ryan, M.P.H.; Lisa Grossman, M.P.H.; Irma Alarcon, M.P.H.; Fernanda Polubriaginof, M.D.; Min Qian, Ph.D.; Susan Restaino, M.D.; Suzanne Bakken, Ph.D., RN; Steven Feiner, Ph.D.; Jungmi Han; David K. Vawdrey, Ph.D.

Acknowledgements: AHRQ R01-HS21816 (PI: David Vawdrey, Ph.D.) K99NR016275 (PI: Masterson Creber)
Learning Objectives

1. Understand motivation to provide hospitalized patients access to clinical information.

2. Describe methods used for assessing the impact on patient engagement and satisfaction.

3. Describe the acute care portal.

4. Describe lessons learned.
Acute Care Setting
“Making patients active and engaged in their healthcare is certainly a gold standard in the 21st century health policy ... we advocate for innovation in the care models that exploit the undeniable potentialities of new technologies for engaging patients in their own care.” (Graffigna et al., 2014)
Patient Engagement

“Knowledge is power ... A patient goes to the doctor only once in a while, but in between visits, you’re making all kinds of decisions that affect your health every single day.” —Jan Walker, OpenNotes project

Health Affairs

Rx For The ‘Blockbuster Drug’ Of Patient Engagement

Susan Dentzer

Even in an age of hype, calling something “the blockbuster drug of the century” grabs our attention. In this case, the “drug” is actually a concept—patient activation and engagement—that should have formed the heart of health care all along.

(Dentzer, 2013)
“We have a million free fact checkers on standby who are at our disposal to help with quality control of the information in the record, if we can only figure out the technologies and policies to allow those people to participate more fully in this process.”

—Farzad Mostashari (Poetter et al., 2012)
Engaging hospitalized patients in clinical care: Study protocol for a pragmatic randomized controlled trial

Ruth Masterson Creber, Jennifer Prey, Beatriz Ryan, Irma Alercon, Min Qian, Suzanne Bakken, Steven Feiner, George Hripcsak, Fernanda Polubriaginof, Susan Rostaino, Rebecca Schnall, Philip Strong, David Vawdrey

doi: 10.1016/j.cct.2016.01.005

Abstract

Background

Patients who are better informed and more engaged in their health care have higher satisfaction with health care and better health outcomes. While patient engagement has been a focus in the outpatient setting, strategies to engage inpatients in their care have not been well studied. We are undertaking a study to assess how patients' information

Pragmatic randomized controlled trial assessing impact of an acute care patient portal on patient engagement and satisfaction
Study Measures

• Primary outcome measure: **Patient Activation Measure**
  o Thirteen-item survey (PAM-13) (Hibbard, 2005)
  o Validated for inpatient use (Prey, 2016)
  o Designed to assess patients’ knowledge, skill, and confidence in dealing with their health
  o Ordinal scale that assigns patients to one of four levels:
Study Measures

- Patient satisfaction and usefulness
  - Adapted from the 26-item Telemedicine Satisfaction and Usefulness Questionnaire (TSUQ) (Bakken, 2006)
  - 5-point Likert-type questions from “Strongly Disagree” to “Strongly Agree”
Study Design and Hypotheses

426 subjects from medical and surgical cardiac units

Arm 1
Usual Care

Arm 2
Tablet computer with general health information links

Arm 3
Tablet computer with inpatient PHR portal

Engagement
Satisfaction

Background  Methods  Portal  Lessons Learned
Enrollment Ongoing

Total recruited: 356 participants

<table>
<thead>
<tr>
<th>Arm</th>
<th>Participants</th>
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<tr>
<td>1</td>
<td>123</td>
</tr>
<tr>
<td>2</td>
<td>124</td>
</tr>
<tr>
<td>3</td>
<td>109</td>
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</tbody>
</table>

12% drop-out rate

Demographic Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)/Mean (SD)</th>
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<tbody>
<tr>
<td>Mean Age ± SD</td>
<td>59.39 (16.28)</td>
</tr>
<tr>
<td>Female</td>
<td>140 (39%)</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>90 (25%)</td>
</tr>
<tr>
<td>Language-Spanish</td>
<td>41 (12%)</td>
</tr>
<tr>
<td>White</td>
<td>209 (59%)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>49 (14%)</td>
</tr>
<tr>
<td>Other</td>
<td>77 (22%)</td>
</tr>
<tr>
<td>American Indian</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Asian</td>
<td>7 (2%)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>9 (3%)</td>
</tr>
</tbody>
</table>
Background

Methods

Portal

Lessons Learned
Acute Care Patient Portal

My Care Team

Attending Physician
Nurse
Resident Physician
Physician Assistant
Resident Physician
Nurse Practitioner

My Care Updates

- **Test results**: Estimated Glomerular Filtration Rate (Tap to view results)
- **Glucose (Blood sugar)**: 163 mg/dL
- **Care team assigned**: Dr. [Name] as Resident Physician (Replacing Dr. [Name])
- **Medication given**: fLUoxetine HCl Oral
- **Medication given**: Melatonin Tab
- **Test ordered**: Basic Metabolic Panel
- **Vital signs**: Blood pressure: 195 / 84 mm Hg
  Temperature: 36.9 °C (98.4 °F)
  Heart rate: 69 BPM
Acute Care Patient Portal

Background

Methods

Portal

Lessons Learned
# Acute Care Patient Portal

![Screenshot of myNYP.org portal](image)

## Test Results For Basic Metabolic Panel

<table>
<thead>
<tr>
<th>Test Name</th>
<th>Result</th>
<th>Normal</th>
<th>Unit</th>
<th>Result Date</th>
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<tbody>
<tr>
<td>Calcium Level</td>
<td>8.5</td>
<td>8.8 ~ 10.3</td>
<td>mg/dL</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>Anion Gap</td>
<td>11</td>
<td>5 ~ 17</td>
<td></td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>Glucose Random</td>
<td>104</td>
<td>75 ~ 100</td>
<td>mg/dL</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>Creatinine</td>
<td>0.64</td>
<td>0.50 ~ 0.95</td>
<td>mg/dL</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>BUN</td>
<td>12</td>
<td>7 ~ 26</td>
<td>mg/dL</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>CO2</td>
<td>27</td>
<td>19 ~ 27</td>
<td>mmol/L</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>Chloride</td>
<td>109</td>
<td>98 ~ 107</td>
<td>mmol/L</td>
<td>2017 8:17 AM</td>
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<tr>
<td>Potassium</td>
<td>3.5</td>
<td>3.5 ~ 5.1</td>
<td>mmol/L</td>
<td>2017 8:17 AM</td>
</tr>
<tr>
<td>Sodium</td>
<td>147</td>
<td>137 ~ 145</td>
<td>mmol/L</td>
<td>2017 8:17 AM</td>
</tr>
</tbody>
</table>

© NewYork-Presbyterian Hospital
“I really liked that I had the opportunity to go back [on the portal, after the doctor or nurse left] to see my medication list and my vitals.”
“I liked that medications were linked to a search, so I didn’t have to retype (the name of medication) on Google.”
Acute Care Patient Portal

Background
Methods
Portal
Lessons Learned
Acute Care Patient Portal

### Clinical Notes

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Authored Date</th>
<th>Provider Name</th>
<th>Provider Role</th>
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<tbody>
<tr>
<td>Neurology Free Text Note</td>
<td>2017 12:25 PM</td>
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<td>Physician</td>
</tr>
<tr>
<td>Neurology Free Text Note</td>
<td>2017 7:43 AM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Neurology Free Text Note</td>
<td>2017 4:39 PM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Physical Therapy-PT,Treatment Note</td>
<td>2017 1:17 PM</td>
<td></td>
<td>PT/OT</td>
</tr>
<tr>
<td>Neurology Free Text Note</td>
<td>2017 5:21 PM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Neuro Transfer Summary Note</td>
<td>2017 1:22 PM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Occupational Therapy-OT,Re-evaluation</td>
<td>2017 1:16 PM</td>
<td></td>
<td>PT/OT</td>
</tr>
<tr>
<td>Medicine Consult Follow-up Free Text Note</td>
<td>2017 9:47 AM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>NeuroSurgery Resident Progress Note</td>
<td>2017 6:30 AM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>NeuroSurgery Resident Progress Note</td>
<td>2017 8:22 PM</td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Anesthesia PACU Discharge Documentation</td>
<td>2017 4:44 PM</td>
<td></td>
<td>Physician</td>
</tr>
</tbody>
</table>
Themes on Access to Notes

Useful for patients

– Informational supplement to verbal communication
– Objective indicator of health and progress in the hospital
– Gave patients ownership over data
– Wanted access to outpatient notes as well

"It’s very, very useful, because from the note we know exactly what’s going on. And when we talked to the doctor, we were able to ask questions, and we know what the doctor is saying."
Themes on Access to Notes

Improved comprehension
  – “Truth tellers”
  – Clarity about condition’s severity
  – “Getting on the same page”
  – Answered questions

"I really thought I was going to be able to go home without any drugs... But then you look at the notes. And they say the total opposite... Every patient that walks through that door wants the raw deal of what's going on with their health situation."
Themes on Access to Notes

Emotional response

– Decreased anxiety
– Increased trust and appreciation for clinicians

Health behavior change

"I started drinking the Ensure. Honestly, I never really gave it a shot before... But once I saw everything, I felt like, the nutritionist is giving me this food for a reason, so I should try too, and do what I can to make my numbers as good as they can be."
Lessons Learned

- Patient provider communication
- Patient education
- Care plan
- Clinical data
Lessons Learned

- Actionable steps to improve patient safety
- Caregiver access
- Amenities
Lessons Learned

Engagement/Culture

- Stakeholder buy-in for design/development.
- Hospital culture of innovation facilitates adoption.
- Health care providers need to adopt and use the portal with patients.
- Portals are never a replacement for in-person communication; rather, an opportunity to optimize it.
Contact Information

Ruth Masterson Creber
rm3284@cumc.columbia.edu
Expanding Access to Patient Portals and Making Them More Useful

Jessica S. Ancker, M.P.H., Ph.D.
Weill Cornell Medical College
in collaboration with the Institute for Family Health
Neil Calman, M.D., Sarah Nosal, M.D., Diane Hauser, M.P.A.
In theory, portals produce a virtuous cycle.
Problem 1
The patients in the greatest need have to have access.

Problem 2
The patients in the greatest need have to understand what they see.
If only affluent, well-educated patients can access portals and understand them, then these technologies could potentially worsen health disparities.
Setting

The Institute for Family Health

- Federally qualified health center receiving Federal/State funds to provide primary care regardless of insurance status
- 18 sites in NYC + small towns north of NYC
- Epic since 2003
- *MyChart* patient portal since 2007
- *MiRecordMiSalud* since 2011

Patient population
- Relatively low income
- Large proportion of Spanish speakers
- Relatively young
- Skews female
Two Projects

Project 1
To reduce disparities in access

Project 2
To add value to the portal with information resources
## Project 1: Disparities in Portal Access

### IFH patients in 2010

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Active patients</td>
<td>74,368</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>40 (16)</td>
</tr>
<tr>
<td>% white</td>
<td>44%</td>
</tr>
<tr>
<td>% privately insured</td>
<td>39%</td>
</tr>
<tr>
<td>% uninsured</td>
<td>23%</td>
</tr>
<tr>
<td>% with a chronic condition</td>
<td>35%</td>
</tr>
<tr>
<td>% who received portal access code</td>
<td>16%</td>
</tr>
<tr>
<td>% who activated portal</td>
<td>10%</td>
</tr>
</tbody>
</table>
### Project 1: Disparities in Portal Access

#### Predictors of receiving portal access code

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>1.06</td>
</tr>
<tr>
<td>For each additional 10 years of age</td>
<td>0.97</td>
</tr>
<tr>
<td>White (v. black)</td>
<td>1.60</td>
</tr>
<tr>
<td>Preferred language English (v. Spanish)</td>
<td>2.80</td>
</tr>
<tr>
<td>Privately insured (v. uninsured)</td>
<td>4.10</td>
</tr>
<tr>
<td>For each additional chronic condition</td>
<td>1.15</td>
</tr>
</tbody>
</table>

#### Predictors of activating the access code (among the subset of people who received a code)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>1.07</td>
</tr>
<tr>
<td>For each additional 10 years of age</td>
<td>1.05</td>
</tr>
<tr>
<td>White (v. black)</td>
<td>1.69</td>
</tr>
<tr>
<td>Preferred language English (v. Spanish)</td>
<td>1.60</td>
</tr>
<tr>
<td>Privately insured (v. uninsured)</td>
<td>1.71</td>
</tr>
<tr>
<td>For each additional chronic condition</td>
<td>1.01</td>
</tr>
</tbody>
</table>

Disparities began with who was offered an access code.

Ancker, Barron, et al., *JGIM* 2011
Disparities Project: What Happened Next

Opt-in policy
You may have a portal account if you ask for one.

Opt-out policy
You have a portal account unless you decline it.

- Automatic code generation
- Medical assistant involvement
- Clinician check-in
- Method for recording declines
Disparities Project: What Happened Next

Ancker et al., in press, *Health Policy & Technology*
Disparities Project: What Happened Next

2011 saw access disparities on basis of:

- Race
- Hispanic ethnicity
- Insurance status

In 2014:

- Race differences disappeared.
- Difference between English-speaking Hispanics and non-Hispanics disappeared.
- Access rates still lower for Spanish-preferring Hispanics and uninsured.

Ancker et al., in press, *Health Policy & Technology*
Local Trends Were Different From National Trends

- These findings cannot entirely be explained by national increases in Internet use.
  - 2011: National Internet use among blacks lagged white rate by 18 percentage points.
  - 2014: National Internet use among blacks lagged white rate by 18 percentage points.

• We found the disparities in access originated in who was being offered access.

• Replacing an opt-in policy with an opt-out policy effectively increased enrollment while reducing disparities.

• There are still limits to what the health care system can do to address external systemic causes of disparities.
Project 2: Adding Value to the Portal Through Information Resources
Project 2: Information Resources

The technology: MedlinePlus Connect (MPC)

In EHR: 034.0 Streptococcal sore throat

In portal view: Strep throat

www.nlm.nih.gov/medlineplus
Results: The Encyclopedia Was Popular

Of the 30,000+ patients with portal accounts:

- 12,877 (42% of portal users) used MPC.
- This represents 10% of all IFH patients.
Ancker et al., *AMIA Annual Proceedings* 2016

Socioeconomic Disparities in MPC Access Were **Not** as Expected

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Level</th>
<th>Adjusted Odds Ratio</th>
<th>CI</th>
<th>P</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>(per 1-year increase)</td>
<td>1.004</td>
<td>1.002</td>
<td>1.007</td>
</tr>
<tr>
<td>Sex</td>
<td>Women</td>
<td>1.167</td>
<td>1.109</td>
<td>1.227</td>
</tr>
<tr>
<td></td>
<td>Men</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
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<td>Race</td>
<td>Black</td>
<td>1.100</td>
<td>1.027</td>
<td>1.180</td>
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<td></td>
<td>All other</td>
<td>1.143</td>
<td>1.056</td>
<td>1.237</td>
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<td>1.106</td>
<td>1.010</td>
<td>1.211</td>
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<tr>
<td></td>
<td>White</td>
<td>Reference</td>
<td></td>
<td></td>
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<tr>
<td>Ethnicity with preferred language</td>
<td>Latino, does not prefer Spanish</td>
<td>1.077</td>
<td>1.001</td>
<td>1.159</td>
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<td></td>
<td>Latino, prefers Spanish</td>
<td>0.607</td>
<td>0.525</td>
<td>0.702</td>
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<td></td>
<td>Unknown ethnicity</td>
<td>0.993</td>
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<tr>
<td></td>
<td>Not Latino</td>
<td>Reference</td>
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<td>Medicaid</td>
<td>0.897</td>
<td>0.847</td>
<td>0.951</td>
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<td></td>
<td>Medicare</td>
<td>0.865</td>
<td>0.782</td>
<td>0.957</td>
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<td>Other Public or dual</td>
<td>0.960</td>
<td>0.859</td>
<td>1.073</td>
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<td></td>
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<tr>
<td></td>
<td>Private</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encounters</td>
<td>&gt;3</td>
<td>2.164</td>
<td>2.049</td>
<td>2.287</td>
</tr>
<tr>
<td>Provider workload</td>
<td>&lt; 794 patients a year</td>
<td>1.093</td>
<td>1.022</td>
<td>1.169</td>
</tr>
<tr>
<td></td>
<td>794 – 1715</td>
<td>1.173</td>
<td>1.094</td>
<td>1.257</td>
</tr>
<tr>
<td></td>
<td>1716 – 2714</td>
<td>1.034</td>
<td>0.965</td>
<td>1.109</td>
</tr>
<tr>
<td></td>
<td>2715 or more</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Region</td>
<td>Hudson Valley</td>
<td>1.019</td>
<td>0.844</td>
<td>1.235</td>
</tr>
<tr>
<td></td>
<td>Bronx</td>
<td>1.379</td>
<td>1.161</td>
<td>1.639</td>
</tr>
<tr>
<td></td>
<td>Manhattan</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Black patients more likely than whites
- English-speaking Latino patients more likely than non Latinos
- Bronx residents more likely than others
Many Terms Explored

![Graph showing term popularity against number of patients with diagnosis.]

- **Multiple myeloma (5 of 9 with this diagnosis clicked it)**
- **Aneurysm (17 of 58)**
- **Endometriosis (43 of 176)**
- **Female infertility (52 of 200)**
- **Sickle cell (57 of 230)**
- **Other congenital anomaly (76 of 400)**
Project 2: Lessons Learned

• A plain-language encyclopedia hyperlinked directly to unfamiliar terms is used frequently by patients accessing their medical records via a portal.

• The encyclopedia was appropriately used most by those with greatest information needs (more medical conditions and visits).

• The encyclopedia was disproportionately used by members of minority groups with known high prevalence of low health literacy.

• It appears that MedlinePlus Connect is providing particular value to patients who have less familiarity with medical vocabulary.
Overall Take-Home Points:
Expanding Portal Access and Usefulness

System-level interventions can address what have traditionally been considered individual-level barriers.

Ancker, “System Approaches to Health Literacy,” in Patel et al., Cognitive Health Informatics, 2017
Acknowledgments

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• MedlinePlus Connect was developed by the National Library of Medicine, the Institute for Family Health, and Epic Systems Inc.
Jessica Ancker

jsa7002@med.cornell.edu
Evaluating the Usability of Portals: Focus on Safety Net Health Care Settings

Courtney R. Lyles, Ph.D.
Courtney.Lyles@ucsf.edu
Assistant Professor
Division of General Internal Medicine at Zuckerberg San Francisco General Hospital
UCSF Center for Vulnerable Populations
Portal Uptake in an Early Adopter Site: Kaiser Permanente Northern California

EXHIBIT 1

Use Of Online Applications At kp.org, 2008-13

- Viewing lab results
- Secure e-mail with providers
- Rx refills
- Booking appointments

Registered
As of September 2013 approximately 73 percent of KPNC patients had registered on the kp.org website.
Significant Racial/Ethnic Differences in Portal Uptake and Use Among Early Adopters

Portal Use at Kaiser Northern California in 2006

- 2 to 4 times lower odds of use.
- Differences persisted in adjusted models controlling for age, SES, health status and utilization, Internet use in everyday life, and provider factors.

Portal Use at Group Health, 2009

- Lyles et al. Medical Care 2012
- Sarkar JAMIA 2011; Goel JGIM 2011; Roblin JAMIA 2009
Moving Portal Implementation to San Francisco’s Safety Net

San Francisco Health Network launched portal in Jan 2015.

Racial/ethnic makeup:

- 32% Latino
- 24% Asian
- 22% White
- 17% African American/Black

Portal available only in English to date.

- 45% of San Francisco households speak primary language other than English.
  - 19% Cantonese or Mandarin, 12% Spanish
Formative Work: In-Depth and Observational Patient Interviews

Patient in-depth interviews (n=16)
Thinkaloud semi-structured observations (n=25)

- Inclusion criteria:
  - English speakers
  - Diagnosed with diabetes or other chronic condition

1. In-depth interviews were open ended about perceptions of portal use.

2. Thinkaloud interviews were videoed observations of patients interacting with newly launched portal interface.

Funded by AHRQ K99/R00 HS022408
In-Depth Interview Findings

Strong interest in portal overall:

• 88% of participants reported a willingness to use a portal Web site to manage their health care.

• Highest interest in accessing lab results, appointments, and visit summaries (81%).
“[If] I had a consultation with my pharmacist and they’re telling me of the side effects to watch out with some medications I’m taking ... [and] I have one of those side effects, I might discuss it with a doctor on email. That would be really helpful.”
Patient Barrier to Creating a Secure Password

“You got to have so many words and letters. You know, characters, so how do you distinguish that? I mean you say characters, are they letters?”
“Probably [log on] to see a blood test result. I wouldn’t really—unless somebody explained it, I wouldn’t know what I was looking at, really.”
“Is there any other options like other languages that you can kind of change the message to? ... If I teach my dad how to go online and he can look up for himself, can he click a certain button that’s not that hard for him to change it, let’s say to Vietnamese?”
Thinkaloud Interviews: Study Protocol

• Participants asked to speak aloud as they interacted with the portal Web site.

• Video-recorded computer screen and participant while completing 5 tasks:
  1. Logging on
  2. Viewing visit summary
  3. Reviewing medication factsheet
  4. Viewing lab results
  5. Looking at health information in online dictionary

• Interviewer gave assistance if participant was stuck after 2 attempts, or gave up on the task.
Thinkaloud Analysis

• Recorded time to complete, number of attempts, assistance needed

• Barrier types:
  1. Novice computer
  2. Routine computer
  3. Reading/writing
  4. Health/medical content

• Overall and stratified on a validated, single item measuring self-reported health literacy:
  o “Confidence in filling out medical forms on your own”
## Participant Sample: Thinkalouds

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Limited HL N=15</th>
<th>Adequate HL N=10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>56</td>
<td>61</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>33%</td>
<td>30%</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>45%</td>
<td>60%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>27%</td>
<td>0%</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Interest in Internet to Manage Health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>45%</td>
<td>80%</td>
</tr>
<tr>
<td>Some</td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td>None</td>
<td>18%</td>
<td>0%</td>
</tr>
<tr>
<td>Frequency of Internet Use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>27%</td>
<td>70%</td>
</tr>
<tr>
<td>Weekly</td>
<td>33%</td>
<td>20%</td>
</tr>
<tr>
<td>Every 2-3 Weeks</td>
<td>13%</td>
<td>10%</td>
</tr>
<tr>
<td>Never</td>
<td>20%</td>
<td>0%</td>
</tr>
</tbody>
</table>
# Overall Barriers Across Thinkaloud Tasks

<table>
<thead>
<tr>
<th></th>
<th>Limited Health Literacy</th>
<th>Adequate Health Literacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean # tasks completed without assistance</td>
<td>1.3</td>
<td>4.2</td>
</tr>
<tr>
<td>% with Novice Computer Barrier</td>
<td>69%</td>
<td>10%</td>
</tr>
</tbody>
</table>
% of Participants Needing Assistance to Complete Tasks, by Health Literacy

Limited Health Literacy

Adequate Health Literacy

- Logging In
- Visit Summary
- Reviewing Rx Factsheet
- Lab Results
- Looking up Health Info
Patients in safety net settings are very interested in using portals.

- Once patients are signed in and oriented to the Web site, many can use most of the functionality.

The most vulnerable patients need extra one-on-one assistance or coaching to be able to effectively use portal Web sites.

- Limited health literacy seemed to be an accurate predictor of those needing the most assistance.
Conclusions and Next Steps
Current Testing of Online Video Training for Patients to Use MYSFHEALTH Portal
### Preliminary Findings: Online Video Training for Patients to Use MYSFHEALTH Portal

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total N=93</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean</td>
<td>54</td>
</tr>
<tr>
<td>Male, %</td>
<td>48%</td>
</tr>
<tr>
<td>Non-White, %</td>
<td>62%</td>
</tr>
<tr>
<td>Limited Health Literacy, %</td>
<td>51%</td>
</tr>
<tr>
<td>2+ Chronic Conditions</td>
<td>65%</td>
</tr>
<tr>
<td>Morisky Medication Adherence, mean (0-4, higher score notes lower adherence)</td>
<td>1.5</td>
</tr>
<tr>
<td>Self-Efficacy for Managing Chronic Disease, mean (0-10, higher score notes higher self-efficacy)</td>
<td>6.5</td>
</tr>
<tr>
<td>Moderate to High Interest in Internet to Manage Health, %</td>
<td>90%</td>
</tr>
<tr>
<td>Daily Use of Internet, %</td>
<td>76%</td>
</tr>
<tr>
<td>Self-Reported Lack of Skills to Use Portal Web site</td>
<td>32%</td>
</tr>
<tr>
<td>Accessed Online Training at Least Once</td>
<td>70%</td>
</tr>
</tbody>
</table>
Next Steps

• In the near term, we are partnering with community groups and libraries on overall digital literacy promotion.
  o Current Internet use ≠ sophisticated technology proficiency.
  o Broadband, Wi-Fi, and device ownership remain issues.

• In the longer term, we need to partner with patients to co-design interfaces for maximum accessibility and relevance.
  o Address literacy as well as language barriers.
  o Ultimate accessibility depends on both usability and the implementation strategy for engaging patients.
Contact Information

Courtney Lyles
Courtney.Lyles@ucsf.edu
• At any time during the presentation, type your question into the “Q&A” section of your WebEx Q&A panel.
• Please address your questions to “All Panelists” in the drop-down menu.
• Select “Send” to submit your question to the moderator.
• Questions will be read aloud by the moderator.
If you would like to receive continuing education credit for this activity, please visit

http://hitwebinar cds.pеспеgce.com/eindex.php