Personal Health Records: Patient Engagement Technologies

S. Trent Rosenbloom, MD MPH FACMI
Associate Professor and Vice Chair of Biomedical Informatics
Associate Professor of Internal Medicine, Pediatrics & Nursing

Leadership Strategies for Information Technology in Healthcare
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Disclosures

- I have no disclosures to report today
Readings


• Cimino JJ1, Patel VL, Kushniruk AW. The patient clinical information system (PatCIS):. Int J Med Inform. 2002 Dec 18;68(1-3):113-27.

Flu Tool initially deployed February 8, 2011 through April 13, 2011:

- 1017 patients seen at VUMC and affiliated clinics received an ICD-9 diagnosis for influenza (i.e., ICD-9 codes 487.xx or 488.xx)

- Flu Tool accessed a total of 4040 times
“Patient”

- Patient
- Family
- Caregiver
- Consumer
- User
- Person
Patient Engagement

• Guides patients to take an active role in their healthcare, starting with information

• Improves patients’ understanding of health conditions so they take a more active role

• Encourages involvement of families, support systems and caregivers
1. **INFORM ME**

   **ALIGNED:** EMERGING MEANINGFUL USE

   A healthcare provider in this phase demonstrates basic levels of patient engagement with an emphasis on the use of simple tools that make healthcare more convenient and accessible. This also includes providing patients with standard forms, both printable and electronic, and information about advance directives, privacy and specific conditions.

2. **ENGAGE ME**

   **ALIGNED:** MEANINGFUL USE 1

   This phase is indicative of more mature patient engagement strategies and shows increased use of eHealth tools and resources. In this stage patients have access to their electronic health record, are encouraged to use fitness trackers and other eHealth tools, and are able to complete administrative tasks online.

3. **EMPOWER ME**

   **ALIGNED:** MEANINGFUL USE 2

   Providers in this phase demonstrate advanced patient engagement activities through substantive use of health IT. Attributes of this phase include use of secure messaging between patients and providers, integration of basic patient-generated data into EHR systems, online quality, safety and patient experience ratings, and participation in a health information exchange or similar effort to enhance care coordination between provider settings.

4. **PARTNER WITH ME**

   **ALIGNED:** MEANINGFUL USE 3

   This phase reflects providers who use health IT to make the patient a true partner in his or her care. Providers at this stage support patients with condition-specific management tools and access to care summaries. They also integrate significant amounts of ongoing patient generated data, such as preferences, self-care, wellness and home health device data, into their EHR system. Patient records are connected to public health reporting systems and coordination of care happens seamlessly across primary, specialty and acute care providers.

5. **SUPPORT MY E-COMMUNITY**

   **ALIGNED:** MEANINGFUL USE 4+

   This phase is the culmination of a provider's progress in fully leveraging and implementing eHealth tools to connect a patient with their full care team and support his or her care management both in and out of the healthcare setting. Tools and activities here include fully interoperable EHRs, record sharing among providers and non-provider members of the patient's care team, while granting patient access to privacy controls. At this phase, patients and caregivers are also provided with online community support from providers, opportunities for e-visits, and information like cost comparisons and outcomes reporting to help patients make more informed decisions about their care and treatment. Providers at this phase will likely be found participating in an accountable care or patient-centered medical home model.
Meaningful Use Stage 2

Eligible Professional Core Objectives

Computerized Physician Order Entry (CPOE) for Laboratory and Radiology

**D1 - Improve Quality**

- Record Demographics
- Record Vital Signs
- Clinical Decision Support Rule
- Preventative Care

**D1 - Improve Quality, Safety, Efficiency**

**D2 - Engage Patients & Families**

- Patient Ability to Electronically View, Download & Transmit (VDT) Health Information
- Clinical Summaries

**D2 - Engage Patients & Family**

- Patient-Specific Education Resources
- Use Secure Electronic Messaging

@TrentRosenbloom
Figure 1. Range of complexity in various approaches to personal health records (PHRs).
The Pioneers - PCASSO

Patient Centered Access to Secure Systems Online

– Funded 1996, Operational 1998 at UC San Diego
– At the time of the pilot deployment, included demographic, clinical laboratory, radiology and transcribed reports for 178,000 patients
– Patient enrollees typically female (73%), well educated (71% with college degree), had excellent computer skills (49%), had excellent internet knowledge (54%)
– Trivia – shut down 12/31/99 because secure Unix OS environment being used was not Y2K compliant
The patient clinical information system

- Operational - 1998 at New York Presbyterian Hospital
- Provided access to health information, including their own medical records (permitting them to contribute selected aspects to the record), educational materials and automated decision support
- Expanded to include Info Buttons in 1999
- Mostly used as Proof of Concept, small user base
The Pioneers - SPPARO

System Providing Patients Access to Records Online

- Operational - 2002 at the UofC Hospital in Denver
- Provided access to clinical notes and test results and also provides a method of sending and receiving electronic messages to and from the clinic staff
- 2002 RCT found patients enthusiastic, physicians more cautious. By the end, all were supportive
- Patient Portal use associated with improved adherence among patients with CHF

Earnest MA - Use of a patient-accessible electronic medical record in a practice for congestive heart failure
The Pioneers - PG

Patient Gateway

- Operational in 2003 at Partners Healthcare System
- Was initially standalone, was integrated with the EMR
- Included modules for secure communication, health information, prescription renewal and appointment requests, decision support.
- Ultimately expanded to include clinical data, diabetes care planning, patient-driven medication modules
- Still in use today - https://patientgateway.partners.org

Wald JS - A Patient-Controlled Journal for an Electronic Medical Record - Issues and Challenges
Typical Patient Portal Functionality

• Access health record data
  – lab results, reports, notes
• Secure messaging
• Targeted educational materials
• Bill pay
• Appointment management
• Medication refills
MHAV Access Tiers

- Tier I Access (limited access)
  - send secure messages
  - request appointments

- Tier II Access (full access)
  - view portions of the clinical record
  - view educational materials, lab interpretations
  - view past and upcoming appointments

- Proxy Access (surrogate / delegate)

<table>
<thead>
<tr>
<th>Access Level</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Access</td>
<td>247,684</td>
</tr>
<tr>
<td>Limited Access</td>
<td>115,801</td>
</tr>
<tr>
<td>Surrogate</td>
<td>22,395</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>385,353</strong></td>
</tr>
</tbody>
</table>
Proxy Accounts

- Adults
- Adolescents
- Children
- Special Cases
  - Non-competent Adults
  - Emancipated Minors
# Unique Outpatients Seen

<table>
<thead>
<tr>
<th></th>
<th>Single Year</th>
<th>3 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
<td>137,091</td>
<td>149,336</td>
</tr>
<tr>
<td>18 &amp; Over</td>
<td>391,789</td>
<td>413,130</td>
</tr>
<tr>
<td>Total</td>
<td>528,880</td>
<td>562,466</td>
</tr>
</tbody>
</table>
## MHAV Statistics

<table>
<thead>
<tr>
<th>Time period</th>
<th>New User Registrations</th>
<th>Total User Logins</th>
<th>Distinct User Logins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month</td>
<td>4,577</td>
<td>324,099</td>
<td>62,689</td>
</tr>
<tr>
<td>3 Months</td>
<td>13,304</td>
<td>950,785</td>
<td>103,597</td>
</tr>
<tr>
<td>6 Months</td>
<td>25,546</td>
<td>1,868,100</td>
<td>135,147</td>
</tr>
<tr>
<td>12 Months</td>
<td>48,959</td>
<td>3,778,835</td>
<td>172,240</td>
</tr>
</tbody>
</table>
MHAV Statistics

Accounts by patient age
Medicines I am currently taking

Maxalt-MLT 10 mg disintegrating tablet take 1 tablet (10 mg) and place on top of the tongue where it will dissolve, then swallow by oral route once, may repeat at 2 hour intervals; do not exceed 30 mg in 24 hours
Flovent HFA 220 mcg/actuation aerosol inhaler 1-2 puffs from the inhaler twice a day
albuterol sulfate HFA 90 mcg/actuation aerosol inhaler 2 puffs from the inhaler every 4 hours as needed for cough, wheezing, or shortness of breath
ibuprofen 2 tabs by mouth as needed
Patanase 0.6 % nasal spray 2 spray in each nostril twice a day
azelastine 137 mcg nasal spray aerosol 2 sprays in each nostril twice a day as needed
prednisone 10 mg tablet 3 tablets by mouth daily for 2 days then 2 tablets by mouth daily for 2 days then 1 tablet by mouth daily for 2 days
fluticasone 50 mcg/actuation nasal spray,suspension (Also Known As Fionase) 2 spray in each nostril daily

Current allergies
No Known Allergies

Health problems
Gene Information / Personalized Medicine

Each person responds differently to medicines. Your genes play a role in how you respond to medicines. Many factors, including your genes, are used to choose the right medicine and dose for you. Based on your history, your provider has ordered a test to learn more about which drugs are right for you. Having this information can help predict and prevent bad drug side effects.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Does your genetic test result affect your response to medicines?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clopidogrel/Plavix®</td>
<td>Yes</td>
</tr>
<tr>
<td>Tacrolimus/Prograf®</td>
<td>Yes</td>
</tr>
<tr>
<td>Thiopurine Therapy</td>
<td>No</td>
</tr>
<tr>
<td>Warrarin/Coumadin®</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Female patients ages 40 and older can schedule their own screening mammograms.
Reminders

Lastly, after scheduling the patient may add this appointment to their personal calendar or print a .pdf summary.
Each data point represents mean office visits from the preceding 30 days. The tinted area indicates a 30-day period on either side of the index date. Data from this 60-day period were excluded from the rate calculations reported in Table 2 and the generalized estimating equations analysis reported in Table 3.
Why implement open notes at your institution? +

How will open notes work for your institution? +

What do open notes look like at other sites? +

Introducing the OpenNotes Toolkit:
Tell us what you think!

What is OpenNotes?
Sharing clinicians' notes with patients—a simple idea for better health More >

Why it Works
Patients become more actively involved in their care More >

Get Started
Check out our toolkit More >

Find Participating Sites >

Mental Health Notes Empower Patients

INSIDE CHIME: MAKING THE CASE FOR OPENNOTES — ONE ORGANIZATION'S
More than 7 million patients have easy access to their clinicians’ notes.
Table 4  Relationships between self-reported frequency of patient portal feature use and glycemic control among patient portal users (N=54)

<table>
<thead>
<tr>
<th>Feature number</th>
<th>How often do you use MHAV to...</th>
<th>Percentage reporting frequent use† (%)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>A1c value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Review laboratory results?</td>
<td>76</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>2</td>
<td>View your medical record?</td>
<td>61</td>
<td>0.69**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>3</td>
<td>Send a message to your doctor? (SM)</td>
<td>63</td>
<td>0.60**</td>
<td>0.63**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.26#</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Request an appointment? (SM)</td>
<td>36</td>
<td>NS</td>
<td>0.36**</td>
<td>0.36**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-0.29*</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Access billing information?</td>
<td>19</td>
<td>NS</td>
<td>0.31*</td>
<td>NS</td>
<td>0.31*</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Access telephone directory?</td>
<td>19</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td></td>
<td></td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Find a doctor?</td>
<td>11</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td></td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Pay medical bills?</td>
<td>11</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>0.37**</td>
<td>0.31*</td>
<td>1.00</td>
<td>NS</td>
</tr>
<tr>
<td>9</td>
<td>Access clinic maps/directions?</td>
<td>6</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>0.36**</td>
<td>0.52*</td>
<td>0.59*</td>
<td>0.37**</td>
</tr>
<tr>
<td>10</td>
<td>Access insurance information?</td>
<td>2</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>0.37**</td>
<td>0.56**</td>
<td>NS</td>
<td>0.44**</td>
</tr>
</tbody>
</table>

*p<0.08; **p<0.05; ***p<0.01.

†Self-reported use of MHAV features; ≥4 indicate frequent use (on a scale from 1=’never’ to 6=’very often’).

A1c, hemoglobin A1c; MHAV, MyHealthAtVanderbilt; NS, not significant; SM, secure messaging.
From 2008-2010, there were a total of 18,519 pediatric patient-initiated messages, 587,745 pediatric visits, 399,032 adult patient-initiated messages and 1,834,327 adult outpatient visits. Secure messages were more likely to be initiated by pediatric patients who were older and White and by adult patients who were younger, female, and White (all p.<.001).

Table 2. Adjusted logistic regression models examining the relationship between demographics and access to care (SM compared vs. outpatient visit).

<table>
<thead>
<tr>
<th></th>
<th>Pediatric Patients</th>
<th>Adult Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AOR 95%CI</td>
<td>P value</td>
</tr>
<tr>
<td>Sex [Females]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>1.02 0.98-1.05</td>
<td>ns</td>
</tr>
<tr>
<td>Race [Whites]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asians</td>
<td>0.37 0.32-0.42</td>
<td>***</td>
</tr>
<tr>
<td>AAs/Blacks</td>
<td>0.21 0.20-0.22</td>
<td>***</td>
</tr>
<tr>
<td>Others</td>
<td>5.05 4.50-5.65</td>
<td>***</td>
</tr>
<tr>
<td>Time/Year [2008]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>2.19 2.09-2.29</td>
<td>***</td>
</tr>
<tr>
<td>2010</td>
<td>3.11 2.98-3.25</td>
<td>***</td>
</tr>
</tbody>
</table>

Note. SM = secure messaging, AA = African American. Referents: outpatient visits, Females, Whites, 2008.*P<.05, **P<.01, ***P<.001.

Disparities in Adoption

- Age
- Gender
- Race and Ethnicity
- Socioeconomic Status
- Health Literacy
- Computer Literacy
- Health and Disease
Disparities in Adoption

Devices
See which type of device is being utilized the most. The category "Desktop" includes other devices such as gaming consoles and smart TV.

- Bar chart
- Trend graph

<table>
<thead>
<tr>
<th>Device</th>
<th>Visits</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desktop</td>
<td>1,466,179</td>
<td>32.8 %</td>
</tr>
<tr>
<td>Mobile</td>
<td>1,066,012</td>
<td>24.0 %</td>
</tr>
<tr>
<td>Tablet</td>
<td>241,832</td>
<td>5.5 %</td>
</tr>
</tbody>
</table>
Not Just Patient Portals

- Consumer Apps
- Mobile Devices
- Small Data (Alan Bonde, Debra Estrin)
- Quantified Self
- Wearable Devices
- Pervasive Monitoring
Not Just Patient Portals

Defining the Quantified Self

With a flurry of new health devices on the market and data coming in from those new portals, we are entering an era of what we are calling the quantified self. And so in this post I want to talk about the quantified self.

So, after spending time figuring out the Power of Big Data, I was interested in seeing how markets are reacting with these new portals, what we are calling the quantified self.

In fact, while this is the definition with our portal, it is given the response the data is actionable for everybody.

A New Definition for the Quantified Self

At TED@Cannes, Gary Wolf gave a talk about the quantified self and how apps and always-on gadgets tell us about everything in daily life.

Sure You Can Track Your Health Data, But Can Your Doctor Use It?

JANUARY 19, 2015
3:32 AM ET

AMY STANDEAN

Listen to the Story

Health News from NPR

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treatments & tests
health inc.
policy-ish
public health

your health

Free
$15:
$100-
$150:
$150-
$200:

SGO:

3 min
g 10 sec

Transcript

from KQED
Not Just Patient Portals
Prescriptions & Health

Shop Products

Photo

Weekly Ad & Coupons

Refill by Scan

Balance Rewards

Store Locator

Refill Prescriptions

Refill from Account

Refill by Scan

Refill for Family

Transfer Rx

Rx Status & History

Pill Reminder

Contact Lenses

Health Services & Info

New Feature
Balance Rewards for healthy choices™

New Feature
Rolling Run totals

- Last 7 days: 44.2 mi, 10:00:55, 13.36 / mi
- Last 30 days: 176.5 mi, 34:05:45, 11.36 / mi

Weekly Run stats

- 4/24/2017 – 4/30/2017: 0.0 mi, 0:00
- 4/10/2017 – 4/16/2017: 53.6 mi, 8:58:11
- 3/27/2017 – 4/2/2017: 16.6 mi, 4:54:45

Monthly Run stats

- April: 159.8 mi, 30:04:38
- March: 193.2 mi, 33:14:36
- February: 205.5 mi, 33:14:39
- December: 103.5 mi, 16:23:42
- November: 30.8 mi, 5:02:57

Quest for the Crest

- Count Down
- 25 days 20:56:50

Barkley Fall Classic

- Count Down
- 144 days 20:56:50

Monkey

http://www.runningahead.com
Mobile Health App (?)

Results 560 (47.4%) of the survey participants reported playing Pokémon GO and walked on average 4256 steps (SD 2697) each day in the four weeks before installation of the game. The difference in difference analysis showed that the daily average steps for Pokémon GO players during the first week of installation increased by 955 additional steps (95% confidence interval 697 to 1213), and then this increase gradually attenuated over the subsequent five weeks. By the sixth week after installation, the number of daily steps had gone back to pre-installation levels. No significant effect modification of Pokémon GO was found by sex, age, race group, bodyweight status, urbanity, or walkability of the area of residence.
HR reading consistently high last few days

Submitted 6 days ago by YoungPTone

My wife's fitbit is showing her heartbeat being consistently high over the last few days. 2 days ago, a somewhat normal day, she logged 10 hours in the fat burning zone, which I would think to be impossible based on her activity level. Also her calories burned do seem accurate. I would imagine if she was in the fat burning zone she would burn a ton of calories, so it's not lining up.

I'm not sure if something is wrong with the sensor. Is there a way to reset or recalibrate the device? I'd like to try that before I contact customer service about a possible replacement.

Thatwasunpleasantcharge 5379 points 1 year ago

Has she experienced anything really stressful in the last few days or is it a possibility she is pregnant?

YoungPTone - Charge HR [S] 4361 points 1 year ago

In the plot twist of twists, upon completion of a home pregnancy test, she is indeed, pregnant as we speak!
Advancing Patient Centered Care, Collaboration, Communication and Coordination

– December 18-19, 2013, Washington, DC

“The future state of health, wellness, and care will increasingly include the active participation of patients, families, and caregivers through data use, re-use, stewardship and governance in the delivery and management of patient-centered care”

Meeting funded in part by AHRQ R13 HS 1R13HS021825-01

Background Video - http://vimeo.com/81160654
Address the informatics-related challenges posed by engaged patients and caregivers

- Supporting the sharing and managing of health data
- Recommending updates to current policies
- Defining a research agenda
AMIA 2013 Health Policy Meeting on Patient Engagement Technologies

• Patient Centered Care:
  “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”


• Patient engagement is critical to the success of patient-centered care
AMIA 2013 Health Policy Meeting

Sally Okun, Vice President for Advocacy, Policy and Patient Safety at Patients Like Me - https://www.patientslikeme.com

- A social network where patients can share real-world health experiences to help themselves, other similar patients and organizations that care for patients with their conditions

TED Talk “Does anyone in healthcare want to be understood?” - https://www.youtube.com/watch?v=W1RGRpqzRIA
Patient-centered care: not just a nice thing to do

- Self-care environment is a point of care
- Patient-generated health data provide essential context
- Important patient experiences occur outside clinical gaze
- Enabling data collection with the right tools is empowering
- Meaningful data sharing supports meaningful communication
- Mutual understanding of the illness experience by patient, caregivers and providers encourages shared decision-making
AMIA 2013 Health Policy Meeting

Danny Sands, Speaker, consultant, thought leader, PCP at the intersection of healthcare, IT, and business. Co-Founder of the Society for Participatory Medicine

https://drdannysands.wordpress.com

@DrDannySands
We need to get to a world in which patients, caregivers and providers are co-creating knowledge

- Our electronic medical records are not made to incorporate patient-generated data, trust also limits it.
- We don't just need patient-facing tools, we also need better collaboration tools for patients and caregivers.
- We don't think much around patient, family workflows. “The invisible work of being a patient” -Wanda Pratt
- Patients at home, providing themselves “the care between the care”, generating health information
Key Findings –

1. Direct access to personal health data increases patient engagement and improves provider understanding, leading to a better patient experience.

2. Policies should be enacted to support patients having full access to data in their electronic health records as soon as the data are entered.

2. EHR systems are necessary but not sufficient to engage patients and foster improvements in the quality of care.
AMIA 2013 Health Policy Meeting

Key Findings –

4. Health information needs to flow across the healthcare continuum, from health at home to clinical and medical data

4. New types of clinical information tools, such as personal health records and participatory care records may accelerate patient engagement
Questions?

Happy to hear from you

trent.rosenbloom@vanderbilt.edu