Alternative & Emerging Technologies in Health Services Research
Joseph Kim, MD, MPH
Miriam Komaromy, MD & Wesley Pak, MBA
Kamal Jethwani, MD, MPH
April 11th, 2012
Agenda

- Welcome
  - Mark Belanger, TA Team, Massachusetts eHealth Collaborative
  - Vera Rosenthal, AHRQ NRC, Health IT Program Manager
- Speaker Presentations
  - Joseph Kim, MD, MPH
  - Miriam Komaromy, MD & Wesley Pak, MBA
  - Kamal Jethwani, MD, MPH
- Questions & Discussion
Goal: To support grantees in the meaningful progress and on-time completion of Health IT Portfolio-funded grant projects

Technical Assistance (TA) is delivered in three ways:
- One-on-one individual TA
- Multi-grantee webinars
- Multi-grantee peer-to-peer teleconferences

Ongoing evaluation to improve TA offerings
Key Resources

- **AHRQ National Resource Center for Health IT**
  - [http://www.healthit.ahrq.gov](http://www.healthit.ahrq.gov)

- **AHRQ Point of Contact**
  - Vera Rosenthal, [vera.rosenthal@ahrq.hhs.gov](mailto:vera.rosenthal@ahrq.hhs.gov)

- **AHRQ NRC TA Team**
  - Kai Carter and Allyson Miller: Booz Allen Hamilton; [carter_nzinga@bah.com](mailto:carter_nzinga@bah.com); [miller_allyson@bah.com](mailto:miller_allyson@bah.com)
  - Mark Belanger and Rachel Kell: Massachusetts eHealth Collaborative, [NRC-TechAssist@AHRQ.hhs.gov](mailto:NRC-TechAssist@AHRQ.hhs.gov)
Housekeeping

- All phone lines are UN-muted
- You may mute your own line at any time by pressing *6 (or via your phone’s mute button); press *7 to un-mute
- Questions may also be submitted at any time via ‘Chat’ feature on webinar console
- Brief online evaluation form for completion by all participants at conclusion of Webinar
- Discussion summary will be distributed to attendees
Grantee Roll Call

- Name, Organization, Project PI
Today’s Presentation
Alternative & Emerging Technologies in Health Services Research
Facilitator: Mark Belanger, AHRQ NRC TA Team, Massachusetts eHealth Collaborative
Today’s Objectives

- Outline current and potential health care applications for specific emerging and alternative technologies of interest to health services researchers
- Discuss obstacles to use of these technologies in health services research
- Provide information on mobile technologies, telemedicine, and social media/networking as they pertain to health care and health services research
- Share experiences and recommendations amongst grantees
## Overview of Technologies

<table>
<thead>
<tr>
<th>Technology</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Past and Present AHRQ Grantee Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient portals</td>
<td>• Improves patient access</td>
<td>• Patients may misinterpret clinical results</td>
<td>• Kevin B Johnson. “My MediHealth: A Paradigm for Children-centered Medication Management”</td>
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<td></td>
<td>• Reduces administrative burden on providers</td>
<td>• Patient-entered data may be inaccurate</td>
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<td></td>
<td>• Improves patient and provider communication</td>
<td>• Providers reluctant to integrate uploading information into their workflow</td>
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<td></td>
<td>• Improves continuity of care between different doctors</td>
<td>• Concerns with payer reimbursement for clinical messaging</td>
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</table>
| Mobile devices | • Improves patient access  
• Use for medication reminders, and to improve treatment compliance   | • Privacy and security concerns  
• Older patients may be unfamiliar with technology- choose audience wisely | • Lorraine Buis, “Text Messaging to Improve Hypertension Medication Adherence in African Americans”  
• Ardis Olson, “Healthy Teens TXT ME; IT to Change Teen Health Risk Behaviors”  
• Kevin Johnson, “My MediHealth: A Paradigm for Children-centered Medication Management”  
• Craig Garfield, “NICU-2-HOME: Using HIT To Support Parents of NICU Graduates Transitioning Home” |

## Overview of Technologies (cont)

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<tr>
<td><strong>Online patient education</strong></td>
<td>• Improves patient access&lt;br&gt;• Patients receive health information from reliable online resources&lt;br&gt;• Reduces providers’ need to educate during appointment&lt;br&gt;• Cost effective</td>
<td>• Patients may receive inaccurate information from external, non monitored web sources</td>
<td>• Kathleen McGtigue, “Online Counseling to Enable Lifestyle-focused Obesity Treatment in Primary Care”&lt;br&gt;• Katia Delrahim-Howlett,” Web Based Intervention for Alcohol Use in Women”</td>
</tr>
<tr>
<td><strong>Social networking sites</strong></td>
<td>• Patients may feel more comfortable interacting with peers than with providers&lt;br&gt;• Way to recruit for less common conditions</td>
<td>• Privacy and security concerns&lt;br&gt;• Unless site is specific to program, difficult to monitor information (less control over what is said)</td>
<td>• Jason Glanz, “An Evaluation of an Interactive Social Media Website for Parents who are Concerned About Immunizing Their Children”</td>
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Overview of Technologies (cont)

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<tr>
<td>Cloud Technology</td>
<td>• Device / location independent • Reliable and scalable • Can reduce cost,</td>
<td>• Security concerns (many providers opt for private cloud models) • Concerns</td>
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<tr>
<td></td>
<td>space, time and power • Option for small organizations that lack IT</td>
<td>with cloud vendor having data access • Reliability concerns in rural areas</td>
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<td>infrastructure, IT support, or capital • Many institutions have relocated</td>
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<td>radiology to cloud in order to reduce storage costs and facilitate image</td>
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<td>transfer</td>
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<tr>
<td>Telemedicine</td>
<td>• Improves patient access due to transportation or provider shortage issues</td>
<td>• Concerns with payer reimbursement</td>
<td>• Sanjeev Arora, “Project ECHO Hepatitis C Ambulatory Care Quality Improvement in New Mexico through HIT”</td>
</tr>
<tr>
<td>*Interactive voice response (IVR), automatic telephone system medicine (ATSM) *Remote monitoring *Virtual providers</td>
<td>• Monitoring chronic conditions • Improves compliance • Reduces cost • Provider education</td>
<td>• How to upload data to medical record • Patient satisfaction may be compromised</td>
<td>• Jennifer Haas, “Health IT Enhanced Family Health History Documentation and Management in Primary Care”</td>
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<td></td>
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<td>• Margaret Handley, “Implementation Outcomes of a Health IT Program for Vulnerable Diabetes Populations”</td>
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<td>• Kevin McConnochie, “Facilitators and Barriers to Adoption of a Successful Urban Telemedicine Model”</td>
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<td>• Flory Nkoy “Improving Post-Hospital Transitions and Ambulatory Care for Children with Asthma”</td>
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<td>• William Kearns, “Evaluation and Integration of an Automatic Fall Prediction System”</td>
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<td>• Brian, Jack, “Virtual Patient Advocate to Reduce Ambulatory Adverse Drug Events”</td>
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<td></td>
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<td></td>
<td>• William Adams, “Conversational IT for Better, Safer Pediatric Primary Care”</td>
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Today’s Presenters

• **Dr. Joseph Kim**, President of Medical Communications Media, Inc.
  - *The Evolving World of Mobile Health and Healthcare*

• **Dr. Miriam Komaromy**, Medical Director for the Integrated Addiction and Psychiatry TeleECHO Clinic, University of New Mexico School of Medicine and **Wesley Pak**, MBA Systems and Programming Manager Project ECHO, Department of Medicine, University of New Mexico Health Sciences Center
  - *Use of Telehealth Technology for Research: The ECHO Model*

• **Dr. Kamal Jethwani**, Lead Research Scientist Center for Connected Health, Partners Healthcare
  - *Social Media: Opportunities and Applications for Health Services Research*
Joseph Kim, MD, MPH

The Evolving World of Mobile Health and Healthcare
Evolving World of Mobile Health

- For physicians/health care professionals:
  - Telemedicine: diagnosis and treatment
  - Clinical decision support
  - Communicating with other clinicians
  - Social media interactions
  - Medical information updates, and education

- For patients/consumers:
  - Health education
  - Disease self-management
  - Behavior modification
FDA Regulation

- Draft Guidance for Industry and Food and Drug Administration Staff - Mobile Medical Applications
  - Document issued on July 21, 2011
  - Center for Devices and Radiological Health (CDRH)
  - Center for Biologics Evaluation and Research (CBER)
- Awaiting final draft

http://www.fda.gov/MedicalDevices/DeviceRegulationandGuidance/GuidanceDocuments/ucm263280.htm

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Dermatology

- Handyscope
  - iPhone attachment
  - Polarized light
  - 20x magnification
  - Skin cancer screening
  - Encrypted data

Not approved in the USA

http://www.handyscope.net/
Detecting E. coli

Researchers at UCLA

- Developed a cell phone–based fluorescent imaging and sensing platform that can detect the presence of the bacterium *Escherichia coli* in food and water.
- The cost-effective cell-phone attachment acts as a fluorescent microscope, quantifying the emitted light from each capillary after the specific capture of E. coli particles within a sample.

Conducting Eye Exams

Researchers at the MIT Media Lab:

- CATRA is a phone camera attachment designed to detect cataracts. It “scans the lens of the eye and creates a map showing position, size, shape and density of cataracts.”
- NETRA is phone camera attachment designed for refractive tests

Cardiology: Heart Rate to EKG

Instant Heart Rate app by Azumio Inc. (consumer app)

iPhone ECG by AliveCor (not approved)

AirStrip Technologies Medtronic Physio-Control
CancerTrials App by MedTrust Online

- Features include:
  - Quickly locate Clinical Trials that are recruiting patients within 150 miles of your location
  - View search results of Clinical Trials on a map relative to your location (or manually enter a US Zip Code)
  - Simple text search to locate Clinical Trials within your area

- Developed in collaboration with GlaxoSmithKline

Medical Education Going Mobile

- Epocrates Mobile CME powered by RealCME
- QuantiaMD
- References: Medscape, UpToDate, Skyscape, Unbound Medicine, etc.
- Journals
- ReachMD (Satellite radio)
Online Medical Communities

• Sermo
• QuantiaMD
• Doximity

HIPPA Data Security
Sermo by Sermo, Inc.

- iConsult – instantly share clinical images and ask questions to capture feedback and advice from colleagues across the United States.
- Discussions - Share insights and expertise on clinical cases, practice management, healthcare policy, and more.

QuantiaMD

- Compete in the Monthly Medical Challenge – real cases and expert knowledge challenges
- Expert Practice Series segments – 8-10 minute clinical presentations
- Interact with colleagues
- Earn Q-Points

Doximity By Doximity

- Secure messaging among physicians (HIPAA-compliant)
- Refer patients
- Follow-up on consultations
- Send and receive faxes

Texting Underserved Communities

- Temple’s School of Medicine received a $100,000 grant from Verizon Foundation
- Telemedicine Light, a program designed to educate members of the surrounding neighborhoods on cardiovascular health by crafting and sending targeted, customized e-mail messages
- Patients will receive a weekly message from Temple containing facts and tips on cardiovascular disease and how to prevent it.
- Overcoming barriers to disseminating health information effectively in a medically underserved community

http://www.temple.edu/medicine/verizon_foundation.htm
Texting & Medication Adherence

- Ongoing studies:
  - Geriatric patients
  - Smoking cessation
  - Schizophrenia
  - HIV
  - Diabetes

Free Mobile Phones

• FREE Phone + 250 FREE Voice Minutes
• Assurance Wireless is a Lifeline Assistance program brought to you by Virgin Mobile and supported by the federal Universal Service Fund.
• For qualifying government programs or are income eligible: Medicaid, Food Stamps/SNAP, Social Security Income (SSI),

http://www.assurancewireless.com/Public/Welcome.aspx
Pill Reminder Pro (Push Notification) By Winkpass Creations, Inc.

Features:

- Reminds you with PUSH alerts when to take your pills
- Great for medication, birth control pills and supplements
- Tracks pill names, dosage and frequency
- Keeps track of your pills

Walgreens Mobile App By Walgreens

- Express refills by scanning the bar code
- SMS when you prescription is ready for pickup
- Text FLU to 21525 and find the nearest Walgreens with flu shots


Walgreens Mobile App By Walgreens
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Dangers of Mobile Health Apps

- Not regulated (yet)
- Confusion regarding “medical” vs. “health” apps
- Anyone can develop and release a mobile app that gets classified as “medical” or “health”
- Medical information may be outdated, erroneous, or misleading
- Patient privacy & data security concerns

Dangers of Mobile Health Apps

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- Patient privacy & data security concerns
Swine Flu “Apps”

Diabetic Dosage: an Insulin Calculator By Kalianne Neumann

“It uses the correction number recommended by your physician, your current blood glucose level, and the amount of carbohydrate units you are anticipating to consume in order to assist you in calculating your fast-acting insulin dosage.”

MelApp By Health Discovery Corporation

- “MelApp for iPhone is an image-based risk assessment mobile app that assists in the early detection of melanoma.”

Data Security & Patient Privacy

- Questions and concerns:
  - Encryption requirements for video conferencing (telemedicine)
  - Encryption requirements for texting/SMS
  - Privacy of information stored on a mobile device
  - Privacy of online communities

- No clear guidance around HIPAA and mobile technology
“iPhone keeps record of everywhere you go”

“Privacy fears raised as researchers reveal file on iPhone that stores location coordinates and timestamps of owner's movements” April 2011

http://www.guardian.co.uk/technology/2011/apr/20/iphone-tracking-prompta-privacy-fears
“FaceTime calls are HIPPA compliant”
Apple gear is HIPAA compliant when using WPA2 Enterprise security. It’s arguable that WPA and WPA/Personal connections are also compliant, but it’s debatable.

Sept 2011

Miriam Komaromy, MD & Wesley Pak, MBA

Use of Telehealth Technology for Research: The ECHO Model
Most telemedicine involves one medical provider and one patient

The ECHO model connects specialists located in a hub (e.g. academic medical center) with a network of individual healthcare providers

Model lends itself to supporting community-based research
What is the ECHO model?

- A consultative healthcare model designed to support primary care providers (PCPs)
- Mission: develop capacity to safely and effectively treat common, complex diseases in rural and underserved areas
- Method: multiple, geographically dispersed PCPs connect weekly via video & telephone with disease specialists located in a central hosting location, such as an academic medical center
TeleECHO
Video Conferencing Infrastructure
Project ECHO University of New Mexico Video Infrastructure
iHealth Disease Management Tool
### iHealth Disease Management Tool

#### Main Question/For Presentation
- Management of hypertension, diabetes, obesity, etc.
- What should be done for management of hypertension?

#### Hypertension
- Elevated systolic, systolic: 140 mmHg, diastolic: 90 mmHg

#### Medications
- Vyvanse 30 mg, Sertraline 50 mg, Citalopram 15 mg, Placebo

#### Allergies
- None

#### Symptoms
- Weight Change

#### Birth Details
- Unknown

#### Smoking
- Yes

#### Alcohol
- Yes

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**List Note:**
- Current patient 33, increasing weight, hypertension

**Clinical Notes:**
- Recent lab tests:
  - **Hemoglobin A1c:** 6.5%
  - **Creatinine:** 1.2 mg/dL
  - **Urea Nitrogen:** 22 mg/dL
  - **Sodium:** 135 mEq/L
  - **Potassium:** 4.5 mEq/L

**Previous Prescriptions:**
- **Omeprazol 40 mg/dl
  - 2 tablets daily**

**Sign Off Person:**
- [Signature]

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**Current Labs:**
- **Hemoglobin A1c:** 6.5%
- **Blood Pressure:** 140/90 mmHg
- **Creatinine:** 1.2 mg/dL
- **Urea Nitrogen:** 22 mg/dL
- **Sodium:** 135 mEq/L
- **Potassium:** 4.5 mEq/L

**Previous Labs:**
- **Hemoglobin A1c:** 6.3%
- **Blood Pressure:** 130/80 mmHg
- **Creatinine:** 1.1 mg/dL
- **Urea Nitrogen:** 21 mg/dL
- **Sodium:** 136 mEq/L
- **Potassium:** 4.4 mEq/L
iHealth Disease Management Tool
iHeath Disease Management Tool
### iHealth Disease Management Tool

#### Patient Information
- **Date of Birth:** 01/01/1987
- **Age:** 35
- **Gender:** Male
- **Start Date:** 01/01/2019
- **RX Genotypes:** 1a
- **Correct Viro:** 00

#### Medications
- **Viral Load:** 7.2
- **HBV:** 4,275
- **HIV:** 39,478
- **HIV RNA:** 18,345
- **CD4:** 325
- **CD4:** 325

#### Laboratory Results

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
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<tbody>
<tr>
<td>Weight</td>
<td>150 lbs</td>
</tr>
<tr>
<td>Height</td>
<td>6 ft 2 in</td>
</tr>
<tr>
<td>BMI</td>
<td>25.5</td>
</tr>
<tr>
<td>BP</td>
<td>120/80</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>200</td>
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#### Diagnosis
- **Diagnosis:** Hepatitis C

#### Treatment
- **Antiviral Therapy:** Interferon

#### Follow-up
- **Next Appointment:** 03/01/2019

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iECHO
Online TeleECHO Management Tool
iECHO Clinic Records
**Project ECHO: Methods**

- Use technology to leverage scarce healthcare resources: tele/video conferencing with Primary Care Providers (PCPs) in underserved areas
- Case-based learning: PCPs present cases on weekly statewide teleconference and receive feedback from specialists at UNM and other PCPs
- Disease management model improves outcomes by sharing best practices
- “Learning loops” help PCPs develop confidence and expertise of their own, become resources in their own communities
- Force Multiplier
Research Opportunities Through Echo

- Study outcomes of care: Hepatitis C Trial
- Study impact of ECHO on access to care: Addiction Program
- Use ECHO to disseminate innovations and study impact: SBIRT with DWI offenders
Hepatitis C Trial Objectives

- To train primary care Clinicians in rural areas and prisons to deliver hepatitis C treatment to rural populations
- To show that outcomes of such care are as safe and effective as that given in a University Clinic
- To show that Project ECHO improves access to hepatitis C care for minorities

Arora et al, NEJM, 2011
Study Design

- Prospective cohort study
  - Randomization by patient, Clinician, or site not feasible
- Advantages
  - Uniform eligibility criteria
  - Standardized treatment
  - Prospective measurement of end-points
- Limitation: groups unbalanced with respect to patient covariates
Principal Endpoint

Sustained viral response (SVR): no detectable virus 6 months after completion of treatment
### Treatment Outcomes

SAE = significant adverse event  
SVR = sustained viral response

<table>
<thead>
<tr>
<th>Outcome</th>
<th>ECHO</th>
<th>UNMH</th>
<th>P-value</th>
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<tbody>
<tr>
<td>Minority</td>
<td>68%</td>
<td>49%</td>
<td>P&lt;0.01</td>
</tr>
<tr>
<td>SVR (Cure) Genotype 1/4</td>
<td>50%</td>
<td>46%</td>
<td>NS</td>
</tr>
<tr>
<td>SVR (Cure) Genotype 2/3</td>
<td>70%</td>
<td>71%</td>
<td>NS</td>
</tr>
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</table>
Conclusions from Hep C Trial

- Rural primary care Clinicians deliver hepatitis C care under the aegis of Project ECHO that is as safe and effective as that given in a University clinic
- Project ECHO improves access to hepatitis C care for New Mexico minorities
Echo Addiction Treatment Program

- Weekly telehealth clinic since 2006
- Addresses all addictions, but #1 focus is expanding buprenorphine treatment for opioid addiction
- Used ECHO to recruit providers to become trained in use of buprenorphine, and to support their practice and track impact
Statewide Participation
### Ranking of # of Buprenorphine-Certified Providers Per Capita

CSAT database of certified MDs 2005, 2009

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<td>VT</td>
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<td>31</td>
<td>1</td>
<td>160</td>
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<tr>
<td>ME</td>
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<td>CT</td>
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<td>8</td>
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<tr>
<td>PA</td>
<td>8</td>
<td>185</td>
<td>9</td>
<td>1200</td>
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<tr>
<td>AK</td>
<td>6</td>
<td>17</td>
<td>10</td>
<td>62</td>
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</tbody>
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**Ranking of # of Burprenorphine-Certified Providers Per Capita**
CSAT database of certified MDs 2005, 2009
Increase in Bup-certified PCPs in Poor, Rural, and Heavily Hispanic Areas
Survey of ECHO Bup Prescribes

What has been the impact of prescribing buprenorphine on your clinical practice?
Response choices from 0=strongly negative impact, 4=no impact, 5=somewhat positive, 7=strongly positive impact
N=51, survey response rate 70%, 2010

Survey of ECHO Bup Prescribes
What has been the impact of prescribing buprenorphine on your clinical practice?
Response choices from 0=strongly negative impact, 4=no impact, 5=somewhat positive, 7=strongly positive impact
N=51, survey response rate 70%, 2010
Use of ECHO to Disseminate Innovations

- Recent study in urban health systems showed that a single SBIRT intervention for heavy drinkers decreased DWIs for 5 years; effect stronger in Latinos
- Designing an ECHO study to implement in rural, predominantly Latino, community-based settings in rural NM

Davis et al, Population Health Mgmt, 2012
How is ECHO useful for research?

- Network of rural PCPs with positive relationship with an academic medical center program
- Recruitment of rural, low income, minority patients
- High quality data collection through iHealth and iECHO
- Conduit for rapid dissemination of innovations, EBPs
- Opportunity to study uptake, provider knowledge, attitudes, and beliefs, outcomes, impact on healthcare and health of the community
Kamal Jethwani, MD, MPH
Social Media: Opportunities and Applications for Health Services Research
What is Social Media?

- Forms of electronic communication through which users create online communities to share information, ideas, personal messages, and other content
  - Blogs
  - Location-based Social Networks
  - Virtual Worlds
  - Bulletin Boards
What is Social Media?

• What is social media currently used for?
  – INTERACTIVITY
• How is it used and by whom (for healthcare)?
  – Doctor to Doctor (Sermo)
  – Doctor to Patient (Facebook + Twitter)
  – Patient to Patient (PLM + CureTogether)
• All used for health information/guidance/support
Opportunities

• Recruitment
• Engagement
• Observation of social interactions
• Direct interaction with patients
• Crowd-sourced data for research
• Dissemination of research
Patient Recruitment

- Opportunities for Recruitment
  - Especially suited for:
    - Certain hard to reach populations (teenagers, rare diseases)
    - Large sample size recruitments
    - Multi-site recruitments
    - Studies needing very frequent contact with subjects
Patient Recruitment

- Distinguish between simply advertising on SM platforms, and actually using SM

- Opportunities for recruitment
  - Targeted Promotion to prospective subjects
  - Open Forum
  - Listening/Monitoring for leads
  - Using the ‘network’ effect
Patient Recruitment

- Some tips on using Social media effectively:
  - Most social media users are tech-savvy. Focus on design and content of your campaign.
  - Do not sell the campaign, sell the service/trial
  - Pay attention to the following privacy issues:
    - Can potentially interested participants be identified by other users/other agencies if they express interest?
    - Are you collecting any PHI with or without the knowledge of the participant? How is this stored?
    - Are you following the user-terms and privacy guidelines of the platform you’re using?
    - Once enrolled, can study participants identify each other on the SM platform?
What’s in it for Patients?

- Ability to provide more information
- Self-directed learning
- Better relevancy
- Save time/effort
- Maintain anonymity wherever possible
Monitoring Success

- Google analytics / other free or paid tracking tools
- Split testing – find out exactly ‘what’ works
- Pre-enrollment segmentation – target the population you want.
- Post-enrollment segmentation – find out who is responding better, and tailor the campaign accordingly

Remember to include this in the consent form!
Recruitment Successes

- Mayo Clinic – SCAD* Study
  - Research focusing on a rare disease
  - Concentrated and organized patient population
  - Patient-initiated research and ownership
  - Favorable demographics for patient recruitment
  - Widespread positive brand awareness
  - Lack of geographic constraints

*SCAD: Spontaneous coronary artery dissection
Recruitment Challenges

- People on social media sites vary from general population.
- Reliability of data collected (self reported)
- General digital eco-system can impact your campaign
- Changing rules or formats of SM platforms can greatly impact your campaign
- Increased clutter in the SM space makes it hard to stand out
- Privacy/security concerns
Recruitment Challenges

- Pfizer – REMOTE 2.0
  - World’s first “virtual” clinical trial
  - Aimed to recruit 600 patients for overactive bladder research
  - Failed to see what patients needed
    - Apprehension around divulging medical information online [privacy concerns]
    - Elderly population [not internet users]
    - Complicated enrollment [for the patient]
- Know your target audience
Overcoming Recruitment Roadblocks

- Overcoming challenges:
  - Study design and population should dictate the use of SM
  - Use ‘social interaction’ creatively
  - Do not rely extensively on specialized design features of a specific SM platform – keep it simple
  - Focus on using appropriate design – your users are likely to appreciate it!
  - More is more – when giving out information about your study – make information readily available
  - Think hard about privacy and patient safety
Research Design

• 80% adults online (or 59% of all adults) seek health information online.
• Seeking health information is the 3rd most common activity online today!
• What do people talk about on SM?
  – Treatment of disease conditions
  – Knowledge about diseases / adverse events
  – Social Implications of disease conditions
Research Design

• 66% adults use at least one SM platform regularly
• SM allows researchers to study:
  – Health seeking behaviors
  – What do people ask? Where do they look?
  – How do people help each other?
  – If SM can be used to improve care delivery?
  – If SM can be used to engage new populations?
  – Do social factors impact health?
Wicks et al. (2012). Perceived benefits of sharing health data between people with epilepsy on an online platform. Epilepsy & Behavior, 23(1), 16–23.


CureTogether

- Patient-driven Research
- Anonymous to encourage those dealing with the stigma of conditions/diseases
- Focus on under-funded/under-researched conditions
- LIVE research
Social Media in Study Design

- Opportunities in clinical research
  - The data is already public; we have implied consent
  - Surfing personal data for screening is much more efficient than sending preliminary questionnaires.
  - The data provides a more holistic view of participants and their behaviors.
  - The data is free of certain biases
Research Design

- Barriers
  - Users may not think their data will be reviewed this way
  - Data gathered from such efforts may be false or misleading
  - Publishing results with such data may make it easier to identify participants, causing harm
  - May violate web sites’ terms of service
Research Dissemination

- Redefining “Bench to Market.” Shifting focus from evidenced based outcomes in pharma to population validated outcomes [instantaneous]
- Instantaneous dissemination of research findings via Twitter, Facebook, etc. invites instantaneous feedback
- Meaningful dissemination
  - Target populations for specific results (i.e. teens w/ asthma)
  - Collaborate with Sponsor on dissemination (Sponsors have full-time marketing departments)
Privacy Case Study

• The “Tastes, Ties and Time” Study
  • Study to evaluate how people’s friendships and tastes evolve over time
  • Researchers downloaded 1700 ‘anonymous’ Facebook profiles.
  • The cohort was released publicly, and soon cracked to reveal that the cohort was Harvard’s 2009 UG class.
  • Conclusions about specific people’s ‘ties and tastes’ were now public, without their consent!
Privacy Case Study (cont)

- Where did they go wrong?
  - Using ‘in network’ RA’s – to use their privileged access to download profile data
  - Did not Remove or encode ALL “identifying” information
  - Release of ‘raw de-identified’ data to the public
  - Relative inexperienced IRB
Addressing Privacy Concerns

- IRB: Understanding federal regulations (ensure compliance for medical research)
  - Protect all identifying information
  - Do subjects know their data can be analyzed? If not, tell them!
  - Can anyone who has access to de-identified data trace it back to subjects?
  - Are all your sub-contractors (developers etc) HIPAA compliant?
Privacy (cont)

• IT:
  - Where is the data being stored?
  - For how long?
  - Can it be de-identified completely?
  - Can it be destroyed completely?
  - Who owns it?
  - How public is it?

• Legal:
  - Understand terms of use and/or service,
  - Understand patient rights
Conclusion
Understanding the power of social media and fitting it in with regulatory environment of clinical research
Think like a marketer.
Discussion

- We welcome your comments and questions
- Reminder: press *6 to mute; press *7 to un-mute
- Questions may also be submitted via ‘Chat’ feature on webinar console at any time
Final Comments

- Discussion Summary
  - Will be distributed to all Webinar participants and posted on the AHRQ TA website

- Evaluation Form
  - Online evaluation form will appear on your screen at conclusion of Webinar; we value your feedback.
  - Thank you for joining us today!
Panelist Bio

Joseph Kim, MD, MPH

Dr. Kim is the President of MCM Education. Established in 1995, MCM develops certified continuing medical education (CME) activities in joint-sponsorship with accredited organizations. He is also the founder of several mobile health websites like MedicalSmartphones.com and MobileHealthComputing.com and currently serves on the Medical Advisory Board of Doximity.

Dr. Kim holds a bachelor of science in engineering from the Massachusetts Institute of Technology, a doctor of medicine from the University of Arkansas College of Medicine, and a master of public health from the University of Massachusetts Amherst School of Public Health.

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Panelist Bio

Miriam Komaromy, MD

Dr. Komaromy is a practicing physician, board certified in both internal medicine and addiction medicine. She launched the addiction treatment arm of Project ECHO in 2006 and has been serving as Medical Director, Integrated Addictions and Psychiatry Program Project ECHO, University of New Mexico Health Sciences Center since it’s creation. In addition, Dr. Komaromy is the Medical Director for Turquoise Lodge Hospital, an addiction treatment hospital funded by the New Mexico Department of Health. Her main research interest is in studying the use of telehealth technology, in the form of the ECHO model, to expand access to health care for traditionally underserved communities.

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Wesley Pak, MBA

Wesley Pak is a Systems and Programming Manager at Project ECHO at the University of New Mexico. He received a Bachelor of Science degree from the University of Maryland, a Master of Business Administration from the University of Phoenix, and is currently completing his PhD at the University of New Mexico. His areas of research are telehealth adoption, knowledge management and dissemination.

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Panelist Bio

Kamal Jethwani, MD MPH; Lead Research Scientist, Center for Connected Health; Instructor in Dermatology, Harvard Medical School

Dr. Jethwani currently leads the research and program evaluation initiatives at the Center for Connected Health. His research is focused on technology-based models of health delivery and use behavior change as a tool for preventive and supportive care in a tertiary health care setting. His work at the Center for Connected Health has spanned from designing and implementing clinical trials to leading efforts in predictive modeling using behavioral parameters.

Kamal's research has evolved over time to include exploration of newer health delivery models, like employer based health programs and electronic social network based programs. He is also exploring newer tools to deliver feedback to patients, like simple text message based platforms, applications for smart phones, etc. The ability to personalize care and understand behavioral motivations that dictate health choices remains central to all his work at the Center.

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