Innovation and the role of the patient

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Topics

- Translation Science and Social Sciences
- Social Media
- Digital Traces & EMA
- Study 1: Behavioral Interrupts (RWJF Pioneer Project)
- Study 2: Emotions and Health (Google)
- Study 3: Social Influence and Support (NIH, NSF)
Importance of researcher-consumer interaction

Translational research is a two-way street and researchers should seek the input of community members, practitioners, and policymakers for research design.

Barriers to conducting translational research

- Dominance by biomedical research and methods
- Lack of training for social scientists
Key Theme (Wethington, 2012)

- Scientific Findings
- Human health applications
- Trials/interventions
- Diffusion into practice
- Public health impacts
How Did Translational Research Develop?

- Biomedical – cancer research, HIV prevention initiatives in the 1970s through the 1990s

- Social and behavioral sciences – explicit engagement of social science disciplines in cancer research, HIV prevention, research on aging, and mental health services at the National Institutes of Health and the Centers for Disease Control and Prevention, 1980s – 2000s
The Biomedical Model Has Expanded to Include Social and Behavioral Science

- An Institute of Medicine panel in 2003 added “medical decision-making” as a target for translational research
- 2007 Journal of American Medical Association article argued for inclusion of public health improvement as the ultimate outcome
- Genetic research and public health panels called for infusion of basic social and behavioral research on diffusion of knowledge, implementation in complex systems, and dissemination of new information to the public
What is Social Media?

- A type of online media created by people
- A shift in how people discover, read, and share news, information and content
- Expedites conversation and allows readers, listeners and viewers to participate in the creation and development of the content
- Does not require expensive equipment or a government-granted license
Different Types of Social Media

- Collaborative projects (e.g., Wikipedia)
- Blogs and microblogs (e.g., Twitter),
- Content communities (e.g., YouTube)
- Social networking sites (e.g., Facebook)
- Virtual game worlds (e.g., World of Warcraft)
- Virtual social worlds (e.g., Second Life)

(Kaplan and Haenlein)
Social Networks and Social Influence

- We are social beings
  - We transmit data via our networks (opinions, viruses, etc.)
  - We tend to cluster with similar others

- Networks can be accessed and studied
  - Email, SMS, Facebook, Twitter, Contacts lists
  - Location, nearby people, who is talking to who

- Can we influence health behaviors?
  - Take advantage of the network properties
Social influence

- Obesity
- Alcohol and substance abuse
- Contraceptive use
- Depression

Social support

- Weight loss (Wing & Jeffery, 1999)
- Immune system functioning (Kiecolt-Glaser et al., 1987)
- Depression (Nolen-Hoeksema et al., 2002)
Obesity proliferates through social networks

One obese friend increases your chance for obesity by 57% (Christakis & Fowler 2007)
Mobile Phones and Health

- Mobile technology is UBIQUITOUS and PERVERSIVE and can tie together most important aspects of healthcare:

  - Biofeedback
  - Behavior Change
  - Data Collection
  - Information Dissemination
  - Geo-Location
  - Social Networks

Mobile Devices
Behavioral Interrupts

- Need to interrupt mindless choices:
  - Environmental Interruptions
    - Menu reorganization
    - Smaller food packaging
  - Personal Interruptions
    - Text messages
    - Reminders
  - Social Interruptions
    - Awareness of being monitored
    - Positive peer pressure
Mindless Eating

- We’re inherently bad at knowing when we’re full
- Eat thousands of calories we don’t need without even realizing we’re eating that much
- Following simple tips can trick the mind into thinking we’re full and eliminate these calories without feeling like we’re dieting

(Wansink, 2006)
Mindless Eating Challenge, Phase 1

1. Players adopt a pet, then receive healthy eating tips from the pet that they must complete.
Mindless Eating Challenge, Phase 1

2. Players use their mobile phone’s camera to document their completion of the tip, and submit it to the system for review by peers or administrators.
Mindless Eating Challenge, Phase 1

3. The pet responds to the results with a display of positive, neutral, or negative emotion.
Completed two three-week studies with ~70 participants each from central NY middle and high schools. Apple iPhones were loaded with the game and provided to each subject.
Study One: Solitary Play

We examined the overall effectiveness of the game and the role of feedback.

- **Play Mindless Eating Challenge**
  - Receive positive and negative feedback
  - Receive only positive feedback

- **Control Groups**
  - Take pictures of food consumed
  - Take pictures of items of importance
Preliminary Findings

The trend across multiple variables appears to be:

- **Play Mindless Eating Challenge**
  - **Receive positive and negative feedback**
  - **Receive only positive feedback**

- **Control Groups**
  - Take pictures of food consumed
  - Take pictures of items of importance
Players can see the current state of their friends’ pets, and clicking a friends’ pet shows recently uploaded photos.
Study Two: Social Play

We examined the impact of adding a social component to the game.

Play game *individually*

Play game *socially*
Gender Effect

- Boys who were able to view others’ pets did better than those who did not
- Girls who did not view others’ pets did better than those who did
- No change in control
Gender Effect—Why?

- **Hypothesis 1**
  - Boys interpret others’ pets/foods as a form of competition

- **Hypothesis 2**
  - Too much peer pressure for girls who could see others’ pets/food
Ecological Momentary Assessment

- Class of methods to collect data that are
  - Contextually relevant
  - Frequent and timely
- Data collected synonymously with target behaviors/ events
- Increases the resolution of data
  - Fluctuations? Time sensitivity?
- Reduces recall bias and reporting error
EMA

- Need to interrupt autonomous, mindless choices:
  - Environmental Interruptions
  - Menu reorganization
  - Smaller food packaging
- Personal Interruptions
  - Text messages, reminders
- Social Interruptions
  - Awareness of being monitored
  - Positive peer pressure
Common Uses of EMA in Health

- Situations where context or frequency matter
  - Drug, alcohol, and smoking habits
  - Blood pressure
  - Stress
  - Pain
  - Emotion
  - Symptoms
Data Collection with Mobile Phones

- Sensor technology: stress
Data Collection with Mobile Phones
Self tracking data

- Sleep Quality (Body Media, Sleep Time app readings, and subjective assessment)
- Caloric expenditure and intake
- Steps taken and miles biked
- Happiness measurements, taken in the morning, afternoon, and evening
- Stress and mood measurements physical and mental energy subjective measures, taken in the morning, afternoon, and evening
- Entropy measure, measured in the morning, afternoon, and evening
- Weight, body fat and flexibility
The Biomaps

- Galvanic Skin Response (GSR) + GPS
- Participants wander around the campus
- Individual maps
- Participants examine, interpret the signals, engage in a discussion on what the data means
PAM: Photographic Affect Meter

- A new measure of \textit{state} affect that correlates with accepted measures
- Easily embeds in existing apps or as a stand alone app
- Works on:
  - Android
  - iOS (iPhone, iPod Touch, iPad
  - Blackberry
  - Many simple J2ME-compatible phones
  - Web-based applications
Photographic Affect Meter (PAM)
Photographic Affect Meter (PAM)
Photographic Affect Meter (PAM)

- State vs. Trait affect
- PANAS
  - Most widely used in health
  - “How strongly have you felt…”
    - Enthusiastic, proud, excited, attentive, etc.
    - Guilty, upset, irritable, scared, etc.
- Too lengthy for EMA
- State? Trait?
- Need a new brief reliable measure
PAM Development

- **Approach**
  - Images as the medium
    - Legibility/ shared meaning (Lang, 1995)
    - Interpretive Flexibility (Boehner, DePaula, Dourish, & Sengers, 2007)
  - How do we incorporate
    - User-derived meaning
    - Interpretive Flexibility
  - But be quantitatively valid?
Photographic Affect Meter (PAM)

- 7,714 Flickr photos, emotion word tags
- Testers (N=70) choose 1/72 randomly selected images for mood (2-5x daily)
- Top 100 photos placed in a grid based on emotion words and piloted in same way (N=70) but subjects subsequently completed PANAS
- 48 best-match images with PANAS kept and re-arranged for the final grid
Measurement of Affect

- Emotion is complicated:
  - 2-dimensions (at least!)
    - Arousal
    - Valence

- Traditionally assessed at baseline and closeout
  - Recall bias
  - State vs. Trait?

Russell, 1980; George, 1996
Photographic Affect Meter (PAM)

- e-Moms of Rochester
  - Mobile & web-based intervention for weight in pregnant & post-partum
- Elderly patient activity monitoring
  - Elderly leukemia patients with phones and actigraph arm-bands
- VERA
- Commercial downloads
VERA

• Social photo-journaling of health-related decisions as both intervention and recording tool:
  • Behavioral interruption
  • Social influence
  • Increased awareness
  • Reflection
VERA

- How it works

 Photograph a behavior
VERA

- How it works

Self-rate behavior
VERA

• How it works

Emotion assessment
VERA

• How it works

Social interaction & reflection
1,200 posts
Average 2/day

“sweet tooth always tempts me”

“wish I could swim more often”

“want to do better for dinner”
VERA Preliminary Findings

- Initial studies found VERA to improve:
  - Health-related decisions
  - Self efficacy toward healthy behavior
  - Open ended social awareness
  - Normative behavior

- Users of social version of VERA > user of individual for same measures
Social Support, Influence and Health

- Social Networking Websites: the problem & solution?
Social Support, Influence and Health

- Diffusion of behavior
Social Support, Influence and Health

- Diffusion of behavior
Social Support, Influence and Health

- Diffusion of behavior
Social Support, Influence and Health

• Diffusion of behavior

Relationships Between Ties
Social Support, Influence and Health

- Diffusion of behavior
Social support

group102 messages

group101 messages
Findings

- Subjects are more comfortable sharing their emotions with peers in VERA than in person.
- Subjects are more likely to share emotions in person with their peers after they have used VERA.
- Subjects using VERA feel more socially connected.

VERA: Emotion and Health

- Subjects used PAM with each VERA post
  - Positive Affect correlates with healthiness
  - Healthy choices = more positive PAM scores

- PANAS at post-test did not correlate with healthiness
  - *State* not *trait* affect drives day-to-day health decisions!
### VERA: Emotion and Health

<table>
<thead>
<tr>
<th>Positive Emotion Decisions</th>
<th>Negative Emotion Decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Feeling good</strong></td>
<td><strong>Feeling bad</strong></td>
</tr>
<tr>
<td><img src="image1" alt="V8" /></td>
<td><img src="image2" alt="Breyers Ice Cream" /></td>
</tr>
<tr>
<td><img src="image3" alt="Indulgence" /></td>
<td><img src="image4" alt="Missing the good things" /></td>
</tr>
</tbody>
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*Cornell University Interaction Design Lab*
Behavior Change

How do behaviors form and what can we do to shape them?

- Attitude
- Perceived Norm
- Self-Efficacy

Intention

Behavior

Theory of Reasoned Action (Fishbein)
Behavior Change

Theory of Reasoned Action (Fishbein)
Publications


Cornell Mobile Health

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