TECHNOLOGY AND DIGITAL HEALTH: IMPLICATIONS FOR IMPROVING RACIAL AND ETHNIC EQUITY

Andrea Grimes Parker, Ph.D.

Assistant Professor College of Computer & Information Science Bouvé College of Health Sciences Northeastern University

May 9, 2014

 $www.ccs.neu.edu/{\sim}andrea$

| a.parker@neu.edu

(a) andreagparker

OVERVIEW

What do we mean by digital innovation?

A people-centered approach

Case Studies: Community-based health promotion

Summary: Take-aways

DIGITAL INNOVATION: WHAT DO WE MEAN?

- Tools for the provider
 - EHR/EMRs
 - Health Information Exchange
 - Meaningful Use
 - Decision support systems
- Tools for provider + patient
 - PHRs
- Tools for the lay person

3

DIGITAL INNOVATION: WHAT DO WE MEAN? • mHealth - Promotion through mobile devices - Portability, ease of access, context, sensors

DIGITAL INNOVATION: WHAT DO WE MEAN?

- Ubiquitous computing
 - Public displays / kiosks
 - Smart clothing
 - Smart homes & spaces





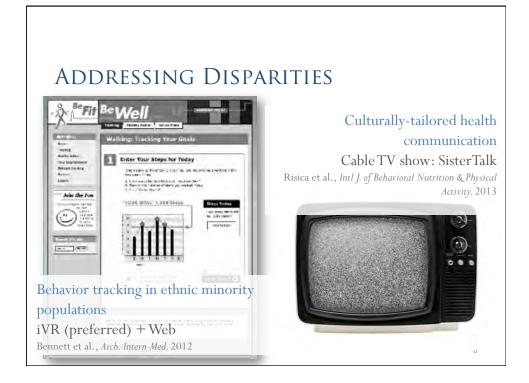
DIGITAL INNOVATION: WHAT DO WE



- Online communities + social computing
 - Connect over distance
 - Leverage existing social networks

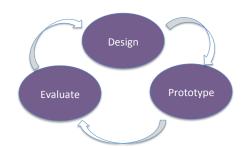
Personal/Consumer Health Informatics

- How can technology empower end users to be
 - More involved in self-care?
 - Advocates for the health of others?
- Dearth of research focused on disparities



USER-CENTERED DESIGN

- Outcomes: behavior + attitude change
 - What else?
- A people-centered approach
 - Useful
 - Usable
 - Used
 - How & why?
- Formative evaluations
 - Context, needs & values
- User studies
 - Adoption, design opportunities



9

USER-CENTERED DESIGN

- Why do this?
 - Increase buy-in
 - Preemptively address novelty effect
 - Contextual fit
 - Catch unintended consequences
 - Develop theory, frameworks & guidelines
 - Design
 - Behavioral, social, psychological

LO

Social Determinants of Health

Substance Abuse Chronic Disease Management Rural Issues
Reproductive Health
Trauma Sexuality Social Justice Employment Health Policy
Social Welfare System
Disability Ethnicity
Community Health Access to Healthcare Gender
Cancer Health Services Wellbeing Mental Health Disparities
Discrimination Poverty Violence Environmental Issues
Child Development Health Promotion
Child Development Health Promotion
Feducation
Physical Environment
Immigration
Maternal Health Aging Health Economics
Critation Justice Involvement Adolescent Health
Obesity
http://www.pdx.edu/social-determinants-health/

Functionality Adoption

11

CASE STUDY: EATWELL

FORMATIVE RESEARCH

- 15 participants
- Focus groups
 - existing nutrition-related practices and attitudes to gain a deeper appreciation for the socio-cultural context
- Participatory design sessions
 - with what aspects of nutrition are individuals most interested in receiving support?

14

FORMATIVE RESEARCH

- Design Implications
 - Acknowledge & support learning from community experience
 - Account for cultural uniqueness without alienating

"I even get frustrated on television when I see something, where they say Blacks [have problems].

Why is it always got to be Blacks? What make them think Black dominate just the low, the lowest of all?"





COLLECTIVISM

- Many relevant cultural values in African American health
 - One is collectivism [Triandis et al. 1995]
 - Value contributing to the community's wellbeing
 - Contrasts individualism: values personal goals, independence
- Premise of many health interventions for African Americans [Kreuter et al. 2006; Karanja 2002]
- Lay health advisors
 - community members who are trained and encouraged to take responsibility for the community's health
 - Health advice [Russell et al. 2010]

16

How can interactive systems facilitate collectivistic health promotion?

Lay health advocacy through technology: **residents as health promoters**.

EATWELL

- Use existing cell phone
 - Record & share audio "memories"
- Sharing experiences for the benefit of others
 - Neighborhood residents
 - Anonymous
- 5 categories
 - Cooking at home, restaurants, fast food, markets, other



Grimes, A. et al. (2008). EatWell: Sharing nutrition-related memories in a low-income community. In Proceedings of the 2008 ACM Conference on computer supported cooperative work (CSCW'08).

18

EATWELL: METHOD

- 3 week, in-depth field study of use
 - Is this a compelling system for people to use?
 - Do people listen & share, and if so, why?
 - 12 participants
 - Interviews, log analyses & content analysis of memories

Grimes et al. (2010). Characteristics of Shared Health Reflections in a Local Community. In Proceedings of the 2010 ACM Conference on computer supported cooperative work (CSCW'10).

EATWELL RESULTS

- Intimate
 - Loved ones
 - Small & large victories, daily life

"Everybody has stories. And [EatWell] reminded me of just the days of old where everybody has a story to tell."

"We [share experiences] all the time anyway with our friends, so this was just one more friend."



22



"Hi um, I basically heard the gentleman talking about the fast food Burger King veggie burger. So I just went by there 'cause I hadn't had anything to eat before I went to work. And I actually enjoyed the veggie burger. And it was very cheap.

And actually, I went back to the fast food place later on and got another veggie burger (but that's another story). But it's actually real good, and it's an experience. I let my girlfriend try it and she loved it too.

So I recommend the veggie burger from Burger King. I got it from 2 different Burger Kings so that means it's at every Burger King. But, I just wanted to share my experience. Thank you."

EATWELL RESULTS

- In the midst of local challenges, usergenerated content shared by culturally & geographically-similar contributors yields key benefits.
 - Identification
 - **–** Норе
 - Excitement: interdependence

"It definitely was a plus to hear that so many African Americans are moving into eating well. I mean it just gave me hope."



24

EATWELL RESULTS

- The mobile phone helped support the conveyance of emotion.
 - Ability to *listen to* experiences
 - Storytellers infused clips with personality & excitement
 - Audio is a valuable, under-designed for medium

"You getting to experience they joy, you get to hear the joy in they voice. You can't get the joy in a text." - P1

"You definitely found out a lot about the person's personality. It gave you a personal touch **when they, you know, talk**, and they leave a message. Rather than an email? Oh yeah absolutely." – P12

Grimes, A. et al. (2008). EatWell: Sharing nutrition-related memories in a low-income community. In Proceedings of the 2008 ACM Conference on computer supported cooperative work (CSCW'08).

eatwell

"I have a great memory for a lentil loaf. I actually got it off the Food Network. That Italian cook, the one they say is so sexy, did a lentil loaf. So it's like meatloaf only it's made with lentils! And it is absolutely fabulous!

It took me a long time to make it the first time. Actually, as I was making it I said, 'I am never doing this again 'cause it's just too much trouble.' In reality it's not that much trouble but you just gotta remember to soak the lentils like a day ahead of time.

It is so good that my daughter who is 4 and a half wanted to take it for lunch the next day and asked if we had any extra to take to her teacher. Now you know it must be really tasty. Good and good for you! I also gave the recipe to a friend of mine who is vegetarian. She said she has made that lentil loaf 5 times since I gave it to her! So, give it a try."

ONGOING WORK

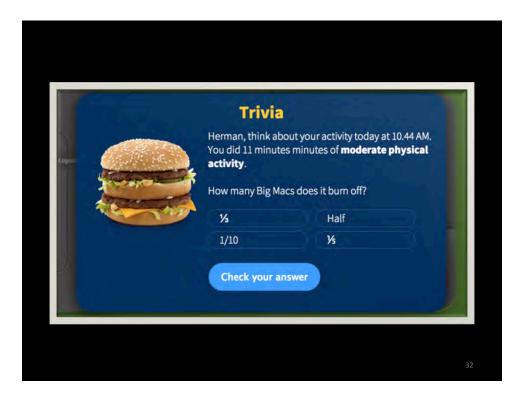


ONGOING WORK

- Year-long design iteration
 - Formative research
 - Focus Groups, Interviews, Phone Surveys & Observations
 - Prototype design & Deployment
 - Redesign
- Design Requirements
 - Connect outside PA to Family Gym PA
 - Child-driven parental activity
 - Intra-family reflection + learning + motivation
 - PA intensity, energy balance









GOING FORWARD

- Important areas of inquiry in health disparities research that incorporates tech
 - What are important culturally-specific values & practices that will shape how we design systems, and how these systems are appropriated?
 - How can technology help people overcome the existing barriers to wellness? (eg, EatWell)
 - How can technology help people disrupt & dismantle these barriers to wellness?



SUMMARY

What do we mean by digital innovation?

Many platforms (mobile + beyond)

User-centered design

Much opportunity:

social determinants neighborhood local & cultural contextualization self-care & health advocacy

Effectiveness

Health outcomes "useful", "usable", "used"

TECHNOLOGY AND DIGITAL HEALTH: IMPLICATIONS FOR IMPROVING RACIAL AND ETHNIC EQUITY

Andrea Grimes Parker, Ph.D.

Assistant Professor College of Computer & Information Science Bouvé College of Health Sciences Northeastern University

May 9, 2014

www.ccs.neu.edu/~andrea

a.parker@neu.edu

(a) andreagparker