Participatory mHealth: an opportunity for innovation in healthcare, wellness, research

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Patient self-care innovation happens outside the traditional enterprise and clinical workflows

but it can still contribute to, and be, evidence-based
Why mobile/mHealth?

• 3 lifestyle behaviors (poor diet, lack of exercise, smoking) cause 1/3rd of US deaths; 50% Americans have 1 or more chronic diseases; age of onset getting younger.

• mHealth apps allow care support/data collection 24x7--chronic disease prevention/management/research as part of daily life

• affordability/adoptability could support groundswell of medical discovery, evidence-based practice about treatment/prevention

**vision: support individuals, communities, clinicians to continuously improve patient-centered, personalized, health and healthcare**

**mobile devices offer proximity, pervasiveness, programmability, personalization**

**complementary to Internet interventions**
Mobile devices can extend interventions and research beyond the reach of traditional clinical care

168 hours a week...1440 minutes a day... (but not necessarily 365 days a year)

**our actions**

**our self report**

**personal data repository**

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**visualization**

**aggregate measures, trends, patterns**

**event detection**

**experience sampling streams**

**context and activity traces**

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Photo: Marshall Astor, WWW

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Whose mHealth?

· A woman who is pre-diabetic tracks how eating/exercise habits affect weight and fatigue; also explores effective, comfortable blood pressure Rx dosage.

· A young man who is struggling to find a treatment plan for depression believes medication dose is ineffective; doctor blames poor sleep habits/non-adherence. Patient self-monitoring includes medication reminder/verifications, sleep survey, activity traces, to guide adjustments in care plan, discussion of root causes.

· A middle-aged woman who does not respond well to medication for psoriasis monitors diet, stress, environmental factors; initiates data campaign via social networking site for psoriasis sufferers. Each volunteer runs mHealth app for 2-months to create large data set to mine for patterns that precede flare-ups.

· A group of high schoolers with asthma map their inhaler use and make a case for shifting track practice to an alternate location farther from the freeway.
Integrated personal data streams create *Living Records*

Automatically prompted, geocoded, uploaded, analyzed:

- physiological (weight, BP, glucose...)
- patient reporting (medication, symptoms, stress factors)
- activity (location traces, exercise, sleep)
- contextual, environmental, social factors

Technical challenge to extract relevant features, trends, patterns, anomalies

Processed/filtered personal data streams would become part of emerging PHR/EHRs (complementary not duplicative)
Why focus on open architecture?

broad applicability (diseases, demographics), heterogeneous/‘dual’ use (treatment, engagement, evidence), evolving methodologies, need for innovation ecosystem

Stovepipe Architecture

Mobile platforms
iPhone/Android/Feature Phones

Patient/Caregivers

Analysis/visualization/feedback
Processing
Storage
Data transport
Data capture

Open mHealth Architecture

Mobile platforms
iPhone/Android/Feature Phones

Patient/Caregivers

Re-usable health data and knowledge services
Standardized personal data vaults and health specific data exchange protocols

Its not just a mobile app:

- **authoring prompts, triggers**
- **Individual feedback, tailoring**
- **analysis and visualization**
- **Personal data vaults**
An open modular system is critical to foster rapid and meaningful exploration and innovation.
Open architectures enable privacy to be architected as well: Personal Data Vault: allow participants to retain control over their raw data

Mobile App
- Data Capture / Upload (Prompted, Automated)
- Reminders
- Feedback, Incentives

Personal Data Vault
- User Identity and Authentication
- Long-term Data Management

Third Party Services
- Analytics for Personal Data Streams
- Interface to Clinical Care Plan, Personnel
- Integration with EHR/PHRs
- Cross Patient Aggregation

Well defined interfaces allow mobile functions to be mixed, matched, and shared

Patient defined selective sharing with Open mHealth Server function

Well defined interfaces allow analytics functions to be mixed, matched, shared, compared

vault + filters = granular, assisted control over what/when you send to whom, what data says about you, whether you reveal who you are or share anonymously, …
Closing remarks

“If you can’t go to the field with the sensor you want…go with the sensor you have!”
“The power of the Internet, the reach of the phone (Voxiva)”

Humans are in this loop--so HCI, privacy, visualization, bias, are part of research agenda, and end to end systems that users can exercise are part of the process

It takes a healthy research ecosystem to bring information technology innovations to meaningful societal use--Open architectures and platforms are a key building block.
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Collaborators

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