Participatory mobile health (mHealth): innovative approaches to data collection, analysis, and use

Deborah Estrin and collaborators
UCLA Computer Science Dept, and openmhealth.org
destrin@cs.ucla.edu

Enabled by >5 x 10^9 mobile phone users, increasingly with: GPS, imagers, touch screens, Internet, app stores

Motivated by 6 x 10^9 people on planet earth, their health needs, and economic realities

ubifit UW/Intel
moodphone (TM) Intel
welldoc (TM) The Eatery (TM) Tonic-app (TM) openmhealth.org
why focus on participatory mHealth and chronic disease?

3 dimensions of mhealth ‘space’

- **end-user** of “the mobile tool” (patient, clinician, intermediary (nurse/coach/…))
- **purpose** (self-care, clinical care, research/evidence/evaluation)
- **functionality** (messaging, adherence tools, prompted self report, passive data collection, self-care tools/just in time treatment/exercises, …)

**Participatory mHealth**

- end-user of mobile tool is **patient participant** (in the US we call them consumers), across broad range of relevant purposes and functionalities
- aligned with increasing activity in consumer health, Health 2.0, patients like me, quantified self, social media…

**Chronic Disease**

- burden and opportunity for observation, care in the hand of the patient (or their family).
- lifestyle behaviors cause large portion of US deaths; increasing co-morbidity/complexity; age of onset getting younger; over next 20 years, Non Communicable Diseases will cost worldwide > $30 trillion; mental health > $16.1 trillion (WEF 2011)
- Target demographic: ~ ages 15-55…no interfering impairments…owns smartphone (w/ data plan, gps, downloadable apps…43% and growing in US); no apparent digital divide other than age…
Participatory mHealth

transform previously unmeasured behaviors and practices into personalized, evidence-based, and evidence-producing care

symptoms, side-effects, outcome measures, actions, activities, exposures..
capture/record activity, mobility, self-reports, “digital exhaust”

visualize, summarize, highlight; inform, advise, persuade
store, analyze, classify, fuse, mashup, filter, aggregate data

Photo: Marshall Astor, WWW
Example use cases

• A pre-diabetic woman with hypertension tracks diet, physical activity, weight, fatigue, blood pressure, dizziness, to inform Rx dosage.

• A young man with ADHD tracks medication dose/adherence, sleep, cognitive-control (PVT, go/nogo), physical activity, daily patterns (e.g. arrival time at work/school), to inform Rx dosage and timing and catch lapses early.

• A 30-something woman w/IBD monitors diet, stress, physical activity, bowel movement, meds, alcohol consumption, sleep; shares with peer patient community to explore flare-up triggers.

• A veteran with PTSD, depression, and sleep disorders uses mobile app to augment CBT treatment: app provides just in time tools for relaxation and prolonged exposure; and easy recording of symptoms, sleep patterns, meds, substance use.

• 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.
Many features found to apply across mHealth applications

- Location and time triggered surveys
  - Multiple choice
  - Scale
  - Free text
  - Image capture
  - Personalization

- Phone-based activities
  - Games
  - Assessments
  - Exercises
  - Interventions

- Phonetop Buttons

- Passive Monitoring
  - GPS, Wifi
  - Accelerometer
  - Actigraphy, Mobility

- End-User Dashboards

Ramanathan, Selsky, et al
Essential data driven feedback loops

Participant self-care
*How is this new medication working for me?*

Clinical care
*How is the patient responding to new care plan?*

Research evidence
*What works best in different contexts?*
How do we inform those processes now (a caricature)

- **Patient**
  - informal, ephemeral records of how they feel and behave day to day/hr to hour (unless they are a quantified selfer...)
  - casual and flawed hypothesis formation on what works for them
  - prescribed behaviors challenging to achieve and sustain

- **Clinician**
  - under-samples the process they are trying to manage (only through necessarily infrequent clinical encounters)
  - has few tools to offer patients outside of clinical encounters
  - has little information about individual’s phenotype

- **Evidence:**
  - derives mostly from population level RCTs
  - does not even attempt to address finer grain, patient behaviors and differences that are otherwise not practical to manage outside of clinical settings
Not just a mobile app: data analysis, sensemaking, as critical as data capture

Correlations in time and space

Actigraphy over space

Actigraphy over time

Ramanathan, Selsky, et al
Use case example--PTSD Coach™

PTSD Coach -- a tool designed for self-care
- Self-assessment tool
- Portable skills to address symptoms between sessions
- Direct connection to crisis support
- Guide users toward treatment

(Julia Hoffman, Joe Rusek, et al, VA NCPTSD)
Sensemaking for clinical use of PTSD usage data
(openmhealth’s first driving pilot)

Capture data from application usage
tool participation, symptom severity,
support types, coping and substance use,
medication use; sedentary, leaving/
returning home/work, self-reports

Data stream processing (DPUs)
feature extraction, historical trends, fusion,
mashups…

Data views for clinician (DVUs)
zoomable, selectable timelines: categorical,
continuous data; scatterplots, smooth lines,
histograms, maps
open source software infrastructure for mHealth prototypes and pilots: Ohmage
(code available http://ohmage.org)

Campaign/collection management, Data management, Visualization

Server

Data storage, Security & access control, Data aggregation/analysis

Data Capture, Reminders, Feedback

Ramanathan, Selsky, Tangmunarunkit, et al
Ohmage evolved to address needs of health collaborations

- Functionality for health innovators:
  - Survey authoring
  - Researcher dashboards: System, study monitoring

- Usability for end-user/participant
  - Experience sampling, light-weight data capture, automated actigraphy and location
  - Smart reminders, including location and activity
  - Battery-preserving sensor services
  - End-user dashboards: Visualization, analysis dashboards

- Developer community engagement:
  - Open-source releases
  - Admin dashboards: Rich user analytics
Clinical pilots drive our process

• Patricia Ganz, MD, UCLA Oncology
  • Mood and energy among breast cancer survivors (Completed Aug, 2011)

• Mary Jane Rotheram-Borrus, PhD & Dallas Swendeman, PhD Psychiatry UCLA
  • Cardiovascular disease risk factors in young moms (To be completed February 2012)
  • Risk behaviors for people living with HIV (To be completed December 2011)

• Namratha Kandula MD, Medicine Northwestern
  • Diet, mood, exercise in South Asian immigrant populations (To be completed October 2011)

• Fred Sabb PhD, Psychiatry UCLA
  • ADHD in Young Adults, validity and efficacy of self monitoring through self-report, go-nogo games, and activity traces (Pre-pilot completed august 2011; Phase I pilot to be completed December 2011)

• Joe Rusek, Julia Hoffman et al, NCPTSD VA
  • With openmhealth.org, Leveraging data from a modified version of the VA PTSD Coach application (see appstore) to create data for clinicians to use in treatment (Phase I pilot to be completed May 2012)
Notable feature requests from participatory design process with end-users (participants)

- **Images**: Moms LOVED this feature for food, immigrant women did not.

- **Reminders**: Control of timing important to all—need reminder authoring and personalization.

- **Buttons**: Most moms willing to answer at least briefly ‘in the moment’, while immigrant women almost all wanted to answer only at the end of the day.

- **Feedback**: Very few interested in seeing simple quantifications of their responses. Helpful tips and motivational messaging most popular.

- **Server vs Phone**: Very few willing/interested to access server. Most wanted interaction solely on phone.

Based on >100 (somewhat) diverse participants: young moms, young men living with HIV, immigrant women, breast cancer survivors, and recruited UCLA student testers

Ramanathan, Swendeman, et al
Smart Reminders

Location-based

Time range
Trigger only during the following interval

Start Time
5:35 pm

End Time
5:35 pm

Trigger always
Trigger at End Time even if it is not reached

Minimum re-entry
120 minutes

Done

Time-based

Trigger Time
11:27 am

Repeat
Everyday

Time range
Enforce a range for the trigger

Start Time
11:27 am

End Time
11:27 am

Randomize
Use random trigger times within the range

Done

Tangmunarunkit, et al
User engagement needs tailored infographics, informational incentives, feedback, game mechanics

ubifit participants who...

had the garden  did NOT have the garden

Informational incentives:
analytics about actions, encourage participation initially--See Consolvo, Choudhury, Mynatt

Clearly needed:
social media tie-ins, goal setting and monitoring tools, adaptive over time for sustainability, configurable

ubifit
(S. Consolvo et al, UW/Intel)

ubifit participants who…

Mobile Ambient Wellbeing Display
(T. Choudhury, Cornell)
As expected user engagement improves when people use their own phones

Ramanathan, Hossein, et al

Ramanathan, Hossein, et al
System analytics are themselves important data streams

Remaining battery on phone

User interaction with phone

Memory usage on phone

Filter by location, time, user

Ramanathan, Falaki, et al
Participant
- Interacts with phone beyond surveys
- Retrospective: “No trouble with battery”

Participant
- Minimal interaction, but better with surveys.
- Retrospective: “Surveys are easy”

Participant
- Power user
- Retrospective: “Excess battery drain increased burden.”

Ramanathan, et al
Ohmage software architecture: intentionally not novel

Browser-based clients: Firefox, Chrome, Safari

Mobile phone clients: Android 1.x, 2.x

Server: CentOS + SELinux

Java 6 + Tomcat 7 + mySQL 5.1

Rapache 1.1.4

JSON/HTTPS

API Endpoints

Java 1.6 + GWT + JavaScript + CSS + HTML

Mozilla + JSON/HTTPS

Mobile phone clients: Android 1.x, 2.x

Browser-based clients: Firefox, Chrome, Safari
Android cross-platform app: in development with developers of mobile web framework (MWF)

- **Self-reported surveys**
- **Feedback**
- **Reminders**
- **Automated capture**

Data presentation:
- Form
- Plots
- Maps

Access to native device:
- Camera
- GPS
- Accelerometer

Access to native applications:
- Mobility classifier
- Background process

HTML5, MWF

PhoneGap (or tools that support plugins to native devices and apps)

Tangmunarunkit, et al
Ongoing work

open mHealth ‘community’ current activities (please join in!)

- modular sense-making architecture and repository: Infovis
- methods for transforming activity traces to personalized bio-markers
- personal evidence architecture, n-of-1 methods (Sim, Kravitz)

areas in need of experimental research attention

- user experience, persuasive technologies, engagement
- mobile device: energy management, probe architecture (Aharony/Pentland)
- selective sharing supported by usable privacy tools (Caceras, Lam, Mun, Song)
- ...

http://openmhealth.org
Essential features of innovation infrastructure for mHealth: 
**Modularity, Sharing, Analytics, Iteration**

- **Modular** components w/well defined interfaces
  - enable decentralized, parallel, asynchronous innovation
  - broad participation, rapid iteration.

- **Shared** architectures benefit from economies of scale, shared learning
  - all the boats float higher
  - state of knowledge, tools improve exponentially

- **Iteratively** design, deploy, evaluate, and adapt mHealth innovations
  - mHealth data collection and interventions are new--a lot to learn about what works for whom
  - takes health science domain experts, technologists, designers, statisticians

- **Analytics** drive iterative adaptation, improvement in *relevant* time
  - leverage digital nature to continually collect data on usage and behavior
  - like Internet search engines, underlying Internet transport protocols
InfoVis

extract and present relevant trends, patterns, anomalies, correlations across diverse data streams and to diverse audiences

scaffolding for creating processing pipelines with R and Java modules: Jeroen Ooms (opencpu.org), Josh Selsky (openmhealth.org)
Data Processing Units  
(R, Java)

- DPU: aggregation
- DPU: smoothing
- DPU: time offset between x, y
- DPU: descriptive statistics
- DPU: covariance \((x,y)\)
- DPU: feature extraction

Internet  
JSON over HTTP

Third party mHealth apps, data

Web browser based clients

Mobile phone clients

Hosted or cloud-based data store

Data Visualization Units  
(HTML5, Javascript)

code easily embedded in other applications

- IGU: ambient display
- IGU: clustering
- IGU: calendar view
- IGU: participation rates
- DVU: simple timeline
- DVU: advanced timeline
- DVU: clustering
- DVU: map
Open architecture and community promote rate, range, rigor of innovation and productization

- Requires co-innovation by health and technology experts
- Allow innovators and entrepreneurs to focus on their unique market offerings while increasing the validity, robustness and efficiency of shared components and methods
- No one (group/research or commercial entity) can do it all, now and over time

http://openmhealth.org

Estrin, Sim, et al
what do we mean by open?

• Not the data… that’s another story.
  • Data can be private to patient, to clinical practice, to clinical trial
  • Of course there are benefits to opening, sharing some de-identified, aggregated data. But that is not particular to mHealth
  • It is an important, challenging problem with huge potential discovery benefits….but far from my expertise

• Not commercial technology products
  • Can use open source components within closed/proprietary products and services (e.g., how most web servers work now (Apache))
  • Incentives to do so is to take advantage of component products and services and advances by others
  • Economic basis of open source (See Weber)

• Not commercial/pharma processes
  • Can use and share modules of techniques without disclosing process architecture, reference implementations, community
Transforming continuous passive traces into bio/health markers (from phones to fitbits...from depression to diabetes)

Offer rich information about daily patterns
- physical activity, mobility/location patterns
- communication patterns
- phone app usage analytics
- detected light levels
- acoustic data sampling (crowds, voice tone, ...)

Convert to personally, clinically useful information w/modular layered processing (modules require a mix of simple functions and machine learning)
- **Low-level state classification**: time series of states (eg sitting/ambulatory or walking/driving; interacting with app/not; alone/with others; communicating/not; sleeping/not...).
- **Mid-level semantic feature extraction**: domain-specific features (distribution of ambulatory/sedentary durations, distribution of speedXduration of walks, % time sedentary in a day, communication event distribution over day, sleep times, work arrival/departure times, “diameter of your day”, ).
- **Higher level markers**: fuse features, metrics (along w/ self report etc) into bio/health ‘marker’ for a persons state (e.g., fatigue, pain, depression, insomnia, cognitive function...)
- **In-person variance/patterns** in markers over time and correlated w/other factors
Potential uses of bio/health markers

Potential use/output of information extraction chain

• By patient
  • to inform behavior change apps/social media
  • in quantified self/PEA exercises around “what causes this change”, is this helping
  • to drive just in time tool apps like PTSD coach

• By the clinician
  • to inform treatment progress
  • detect relapse/recovery, etc;
  • clinical research evidence (trials, outcomes, …)

Candidate pilot use cases
• depression, adhd, insomnia, trauma
• asthma, IBD, MS, back pain management, migraines
• integrative medicine effectiveness, behavior change for physical activity, substance use
‘does it work on average?’

100 people

PTSD Coach
50 people

Usual care
50 people

PTSD symptoms

PTSD symptoms

population

Sim, Kravitz et al

Monday, January 30, 12
'does it work for me?'

N-of-1 study design

Sim, Kravitz et al
Personal evidence architecture

Patient/care provider/researcher asks a question

They choose a study design template and complete the template for their question

An mHealth application is used to collect data and provide feedback

Infovis is used to analyze data based on the question and study design selected
priority components

• N-OF-1 scripting and analysis
  - chronic pain management pilot (I. Sim, UCSF; R KRAVITZ, UC DAVIS)

• Libraries of shared, validated measures
  - E.G., PROMIS measures

• Metadata to support data aggregation
  - ...About variables (e.g., datatype, code system and value)
  - ...About context (e.g., OS and version, activity state, weather, demographics)
Innovative infrastructure will fuel a learning health system

Learning system

Personal evidence architecture

Sense Making and Action

Infovis

Health Data Exchanges

mHealth applications

Innovative infrastructure will fuel a learning health system
mHealth will leverage powerful traces of our daily lives ...but are these raw traces sometimes too telling?

Quantify habits, routines, associations
Easy to share and mine; but difficult to anonymize
Data handling by mobile carriers, credit card companies, is regulated
But...individual is free to capture and share her own data for free apps and services: “Everything is free to you, except for the data we collect about you”

Calls for new privacy practices...
Personal Data Vaults (PDVs): individually-controlled, secure data repository allow participants to retain control over their raw data by

Challenges:
• Reducing user burden.
• Supporting good sharing decisions.
• Encouraging ongoing engagement
• Business model
• Legal model (data guardianship? Kang)
“Approximately 25 years ago, government and industry invested in expanded access at a crucial time in the Internet’s development. The resulting networks and ubiquity of access provided fertile ground for technologies, ideas, institutions, markets, and cultures to innovate. The payoff from this investment created a commercially viable and largely self-governing ecosystem for innovation.

The same can be done for global health. Government, commercial, and nongovernmental entities involved in health IT and innovation should cooperate to define and instantiate architecture, governance, and business models and to steer initial mHealth investments into open architecture.”


Winter reading recommendations:

The filter bubble, Pariser

Everything is Obvious*, *once you know the answer, Watts

The Success of Open Source, Weber

Open mHealth initiative: http://openmhealth.org
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Collaborators

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