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

Deborah Estrin and many collaborators
UCLA, openmhealth.org, iSTC, ...
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
Participatory mHealth
Participatory mHealth

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, …)
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Participatory mHealth

• end-user of mobile tool is **patient participant**, 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…

• broad but not universal demographics--15-55 w/smarphone
Participatory mHealth

*transform previously unmeasured behaviors and practices into personalized, evidence-based, and evidence-producing care*
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symptoms, side-effects, outcome measures, actions, activities, exposures..
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capture/record activity, mobility, self-reports, tool-use, “digital exhaust”
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store, analyze, classify, fuse, mashup, filter, aggregate data
Participatory mHealth
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symptoms, side-effects, outcome measures, actions, activities, exposures...
capture/record activity, mobility, self-reports, tool-use, “digital exhaust”

visualize, summarize, highlight; inform, advise, persuade
store, analyze, classify, fuse, mashup, filter, aggregate data
Chronic Disease as the ‘killer’ app (~2009-present)

Extend health interventions and research beyond the reach of traditional clinical care: 168 hours/week, 1440 minutes/day, but not all 365 days/year

- 3 behaviors (diet, lack of exercise, smoking) cause 1/3rd of US deaths
- 50% Americans have 1 or more chronic diseases, age of onset getting younger
- Non-communicable disease burden worldwide over next 20 yrs > $30 trillion; mental health additionally > $16.1 trillion (WEF 2011)

w/ Ida Sim (MD, PhD), Nithya Ramanathan (PhD), many others
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Why leverage mobile?

- chronic disease prevention, treatment, management happen in the context of daily life, outside of clinical setting
- we have lacked adequate evidence base for individual chronic disease management in the course of everyday life
- we no longer lack feasible tools and infrastructure to generate such evidence, and to realize truly personalized health management

w/ Ida Sim (MD, PhD), Nithya Ramanathan (PhD), many others
Example use cases
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- 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.
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• 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
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- 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.
mHealth derived data serves 3 essential workflows

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?

patient apps: personal-evidence and clinically-informed tools to engage and support healthy behaviors

‘relevant-time’ clinical dashboards: summarizing and correlating symptoms, side effects, meds, and health behaviors

mhealth-enabled n-of-1 studies: systematic, individualized studies of treatment alternatives

mHealth evidence-base: which mHealth techniques are effective, and for whom

w/ Ida Sim, Open mHealth
rephrasing ‘does it work?’

(Complexes of)
Exposures
sertraline

strength of association?
individual

Outcome
depression

population
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‘does it work on average?’ (RCT)

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Depression (PHQ-9)

50

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N-of-1 study design: ‘does it work for Mr. Jones?’

Effexor

Zoloft

PHQ-9

Effexor

Zoloft

PHQ-9

individual


Sim, Kravitz

Tuesday, June 19, 12
Many features apply across mHealth applications

- Self Report (EMAs)
  - Multiple choice
  - Scale
  - Free text
  - Image capture
  - Personalization

- Phonetop Buttons

- Passive Monitoring
  - GPS, Wifi, Accel
  - sms, calls, calendar, social media
  - actigraphy, mobility, comm

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

Ramanathan, Selsky, et al
Not just a mobile app: data analysis, sensemaking, as critical and more challenging.

Correlations in time and space

Actigraphy over space

Actigraphy over time

Ramanathan, Selsky, et al
Low-level state classification: create time series of states after data cleaning
- sedentary/ambulatory
- at home/work
- interacting with app, people...
- ‘standard’ ML techniques

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sms, calls, calendar, social media
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w/ Ramanathan, Longstaff, Alquaddoomi, et al
Transform continuous passive traces into bio/outcome markers

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Mid-level semantic features:
calculate domain-specific features
  • daily minutes ambulatory, sedentary durations, walking speed
  • sleep times, social interactions
  • time spent before leaving house, “diameter of day”...

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**Higher level individual markers:**
fuse features, metrics into ‘marker’ assessing persons state, variations
- fatigue, pain, depression, insomnia, cognitive function...
- in-person variance, patterns, correlations

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• ranging from simple functions to machine learning classifiers
from phones to fitbits...
from chronic pain to depression...
from mobility to text...

w/ Ramanathan, Longstaff, Alquaddoomi, et al
Minutes ambulatory per day

Hours spent at home per day

Walking periods > 6 minutes per day

Time left home (AM)
Traces can drive tailored infographics, informational incentives, feedback, game mechanics

Informational incentives:
analytics about actions, encourage participation initially [Consolvo, Choudhury, Mynatt]

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

ubifit participants who...

had the garden          did NOT have the garden

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

Mobile Ambient Wellbeing Display
(T. Choudhury, Cornell)
Example mobile feedback for NIH-funded new-moms study
Broad potential use of activity based outcome markers
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By patient
• to inform behavior change apps/social media
• in quantified self/PEA exercises around “what causes this change”, is this helping, self-administered medication dosage
• to drive just in time tool apps like PTSD coach
• as context stream for adaptive UI
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By the clinician
- to inform treatment progress
- detect relapse/recovery, etc;
- clinical research evidence (trials, outcomes, …)
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Across a range of use cases
- depression, adhd, insomnia, trauma
- chronic pain, IBD, asthma, migraines
- integrative medicine effectiveness
- behavior change for physical activity, substance use
Role in personalized medicine?
discovery (phenotype data) and delivery (data for patient and clinician)
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Technology side is ready to start

• Hardware is available and already in peoples hands and budgets.
• Software has been prototyped, and its not *rocket science*.
• Algorithms can iteratively (and rapidly) improve with use
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  - extract relevant features from noisy bursty time series full of biases
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  - fuse different features into health markers
- how to use the data
  - look for each individuals relevant patterns/correlations/etc)
  - collect evidence on effectiveness (clinical-outcomes and behavior)
mHealth leverages 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 data repository that decouples capture and sharing
allow participants to retain control over their raw data

Third party services

Internet

raw data

filtered data

A cloud service PDV

A personal server PDV

Mun, Burke, et al
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Challenges
• User burden
• Supporting good sharing decisions
• Encouraging ongoing engagement
• Legal and business models (Kang)
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Related efforts
- Pentland, MIT
- Caceras, AT&T
- Song, UCBerkeley
- Sire, Cornell

Mun, Burke, et al
Open architecture and community promote rate, range, rigor of innovation and productization

non-profit with seed funding from RWJF (project of Tides center, incubator)

http://openmhealth.org

Estrin, Sim, et al

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- Open, modular architecture allows innovators to focus on market offerings while increasing the validity, robustness and efficiency of shared components and methods

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Estrin, Sim, et al

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- Development of techniques like activity-based biomarkers requires co-innovation by health and technology experts

- Open, modular architecture allows innovators to focus on 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 well, now and over time

Estrin, Sim, et al

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
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
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• 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)
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• Not commercial/pharma processes
  • Can use and share modules of techniques without disclosing process

architecture, reference implementations, community
First pilot:
Sensemaking for clinical use of PTSD Explorer data

Capture data from application usage
tool participation, symptom severity, support
types, coping and substance use, medication
use, self-reports (EMA), physical activity,
communication, offboard sensors, text...

Data stream processing (DPUs)
data cleaning, feature extraction, historical
trends, correlation, text analysis, ...

Data views for clinician (DVUs)
zoomable, selectable timelines: categorical,
continuous data; scatterplots, smooth lines,
histograms, maps

Open mHealth pilot w/ Julia Hoffman, Joe Rusek, et al, VA NCPTSD

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Second pilot: Chronic pain medication management

Data views for clinician (DVUs)
- zoomable, selectable timelines: categorical, continuous data; scatterplots, smooth lines, histograms, of self report and activity

Data stream processing (DPUs)
- data cleaning, feature extraction, historical trends, correlation, ...

Capture data from application usage
- symptom severity, participation, medication use, self-reports (EMA), physical activity, location traces...

Open mHealth pilot w/ R. Kravitz, et al UC Davis
Open mHealth technical activities

GETTING FURTHER TOGETHER FASTER

Connecting innovators, ideas, and techniques to create new tools and share the collective work of the m-health community. By contributing and reusing tools, together we can make mHealth data more meaningful for individual and clinical care.

Diabetes 3.0
mPain

Closed APPLICATION

Open mHealth ARCHITECTURE APPLICATION
Open mHealth technical activities

Modular infovis for sensemaking

- Reusable data processing and visualization units with well defined APIs, simple data format standards: json over http with lite common metadata (github)

- Developer tools to catalyze decentralized, innovative, co-development community (templates, test suites, data sets)
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Personal Evidence Architecture components

• Scripting and analysis of individual-focused validation studies (e.g., N-of-1)
• Libraries of shared, validated measures (e.g., PHQ-9, PROMIS)
• Metadata to support data aggregation about variables (e.g., datatype, code system, and value), and context (e.g., OS and version, activity state, demographics)
Innovative infrastructure will fuel a learning health system

- Health Data Exchanges
- Personal evidence architecture
- Sense Making and Action
  - Infovis
- mHealth applications
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(TM))
• Progress in mobile health requires intensive, iterative, health-tech co-innovation
• It takes a healthy research ecosystem to bring information technology innovations to meaningful societal use
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only peripherally relevant favorite reads

Thinking, fast and slow, Kahneman

The filter bubble, Pariser

The Success of Open Source, Weber
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Collaborators

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