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

Deborah Estrin and many collaborators
UCLA, openmhealth.org, iSTC, ...
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Enabled by $>5 \times 10^9$ mobile phone users, increasingly with: GPS, imagers, touch screens, Internet, app stores

Motivated by $6 \times 10^9$ people on planet earth, their health needs, and economic realities
preface
my path from wireless sensor networks to mHealth

mHealth for chronic disease as the ‘killer’ app
rationale, examples, common software components

challenges (and research opportunities)
processing, modeling, presenting, protecting personal data streams;
open architecture and community

prolog and closing remarks
an end-to-end argument for systems-research design: why work in
the context of authentic applications and open architectures
Lessons from the field of embedded sensing 2002-2010

Early themes: many simple measurements
small platforms
autonomous operation
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Early themes: many simple measurements
small platforms
autonomous operation

Midterm themes: multi-modal measurements
varied platforms
human-assisted operation

Saturday, July 7, 12
Lessons from the field of embedded sensing 2002-2010

Early themes: many simple measurements, small platforms, autonomous operation

Midterm themes: multimodal measurements, varied platforms, human-assisted operation

Eventual themes: model-based measurement, mobile platforms, assistive systems, infovis
Participatory Sensing (starting ~2006)

individuals and communities using personal mobile devices and web services to systematically explore and document their lives
(builds on methodologies of experience sampling [Csik85] and photovoice [Wang95])

Real time
(always on)

Real place
(always carried)

Real context
(historical, environmental, spatial, social)

Real applications
(environment, education, community, health)

w/ Mark Hansen (Statistics/DMA), Jeff Burke (REMAP/TFT)
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Chose applications that scaled **down**... as well as **up**: *i.e.*, utility at small *n* so real use can guide iterative cycles of innovation

w/ Mark Hansen (Statistics/DMA), Jeff Burke (REMAP/TFT)
Early foray into health: DietSense (2007)
continuous, automated, image capture for dietary recall

• “Mobile phone imager” as sensor in our first health related, IRB governed, pilot

• Participants used their image logs to improve recall accuracy of diet survey (L. Arab’s DietDay™)

• Technical challenge: computer vision object categorization, identification, classification

w/ Lenore Arab (Health Sciences), Mark Hansen (Statistics/DMA), Jeff Burke (REMAP/TFT)
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• What we/I really learned
  – automated image capture less practical than manual (bystanders caught in field of view)
  – automated location traces are rich in information when bound to individual

w/ Lenore Arab (Health Sciences), Mark Hansen (Statistics/DMA), Jeff Burke (REMAP/TFT)
Telling traces: PEIR (2007-08)
model-based estimation using continuous location-activity-time series

Personal time-location trace used to automatically estimate daily personal carbon impact and air particulate exposure

http://peir.cens.ucla.edu

Wired NEXTFEST, Chicago 2008

Technical challenge: processing pipeline and model validation

w/ Mark Hansen (Statistics/DMA), Jeff Burke (REMAP/TFT); Funded by Nokia
Participatory mHealth as the “killer” app
Participatory mHealth as the “killer” app

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 as the “killer” app

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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

Photo: Marshall Astor, WWW
Participatory mHealth

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

...symptoms, side-effects, outcome measures, actions, activities, exposures..

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symptoms, side-effects, outcome measures, actions, activities, exposures...
capture/record activity, mobility, self-reports, tool-use, “digital exhaust”
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, tool-use, “digital exhaust”
- store, analyze, classify, fuse, mashup, filter, aggregate data
Participatory mHealth

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

Photo: Marshall Astor, WWW
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 pre-diabetic woman with hypertension tracks diet, physical activity, weight, fatigue, blood pressure, dizziness, to inform Rx dosage.
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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 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
mHealth derived data serves 3 essential workflows

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

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

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

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

**Research evidence**
*What works best in different contexts?*

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

*mHealth evidence-base: which mHealth techniques are effective, and for whom*
rephrasing ‘does it work?’

(Complexes of)
Exposures
sertraline

strength of association?
individual

Outcome
depression

population
### (Complexes of)

<table>
<thead>
<tr>
<th>Exposures</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>sertraline</td>
<td>depression</td>
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**strength of association?**

- individual
- population

---

### ‘does it work on average?’ (RCT)

<table>
<thead>
<tr>
<th>Depression (PHQ-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>sertraline 50</td>
</tr>
<tr>
<td>venlafaxine 50</td>
</tr>
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- population
- 100
rephrasing ‘does it work?’

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‘does it work on average?’ (RCT)

sertraline

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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

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Many features apply across mHealth applications

Data collection

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

End-User Dashboards

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

Passive Monitoring
GPS, Wifi, Accel
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w/ Ramanathan, Longstaff, Alquaddoomi, et al
Transform continuous passive traces into behavioral biomarkers

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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”...

Passive Monitoring

GPS, Wifi, Accel
text

sms, calls,
calendar,
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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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Estimate personally- and clinically-useful information:
• modular layered processing
• ranging from simple functions to machine learning classifiers

w/ Ramanathan, Longstaff, Alquaddoomi, et al
Estimate personally- and clinically-useful information:

- modular layered processing
- 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
Telling Traces

mobility, actigraphy data from one atypical day

UI: E. Wang
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)

ubifit
(T. Choudhury, Cornell)

Mobile Ambient Wellbeing Display
(T. Choudhury, Cornell)
Example mobile feedback for NIH-funded new-moms study

Food Quality
- Low
- Med
- High

Food Quantity
- Small
- Healthy
- Large

Did Exercise
- No
- Yes

Stress Amount
- None
- Low
- Med
- High

Time For Self
- 0
- <.5
- < 1
- > 1
- > 2

CHARTS
*Last 30 responses shown

Food Quality

Hours Active

**Ramanathan, Ketcham, et al**
Broad potential use of activity based behavioral biomarkers
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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
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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 people's hands and budgets.
- Software has been prototyped, and its not *rocket science*.
- Algorithms can iteratively (and rapidly) improve with use
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- 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

raw data

Mun, Burke, et al
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Challenges
• User burden, UX design
• Supporting good sharing decisions
• Information flow control assurances
• Encouraging ongoing engagement
• Legal and business models (Kang)
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Related efforts
• Pentland, MIT
• Caceres, AT&T
• Song, UC Berkeley
• Sire, Cornell
• personal.com

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)

Estrin, Sim, et al

http://openmhealth.org
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- Development of techniques like activity-based biomarkers requires co-innovation by health and technology experts

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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

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http://openmhealth.org
Essential features of innovation infrastructure for mHealth:

*Modularity, Sharing, Analytics, Iteration*
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- **Analytics** can drive iterative adaptation, improvement in *relevant* time by leveraging digital nature to continually collect data on usage and behavior, as with Internet search engines, underlying Internet transport protocols
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

Data Visualization Units (HTML5, Javascript)
- code easily embedded in other applications

- DVU: ambient display
- DVU: clustering
- DVU: calendar view
- DVU: rates
- DVU: simple timeline
- DVU: advanced timeline
- DVU: steamgraph
- DVU: map

Third party mHealth apps, data

Web browser based clients

Mobile phone clients

Hosted of cloud-based data store
what do we mean by open?

• Not the data... thats 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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  • 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
Second pilot:  
Chronic pain medication management

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

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

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

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 mHealth community. By contributing and reusing tools, together we can make mHealth data more meaningful for individual and clinical care.
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)
Open mHealth technical activities

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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-techco-innovation
• It takes a healthy research ecosystem to bring information technology innovations to meaningful societal use
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• The power of the Internet, the reach of the phone (Voxiva(TM))
• Progress in mobile health requires intensive, iterative, health-techco-innovation
• It takes a healthy research ecosystem to bring information technology innovations to meaningful societal use

only peripherally relevant favorite reads

Thinking, fast and slow, Kahneman

The filter bubble, Pariser

The Success of Open Source, Weber
Acknowledgments: Collaborators and Sponsors

Collaborators

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