

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

Deborah Estrin (UCLA) and Ida Sim (UCSF)

<http://openmhealth.org>

with collaborators from UCLA, UCSF, and openmhealth community



*Patient self-care innovation happens outside traditional clinical workflows
mhealth can transform previously unmeasured behaviors and practices into
personalized, evidence-based, and evidence-producing care*

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

Whose mHealth?

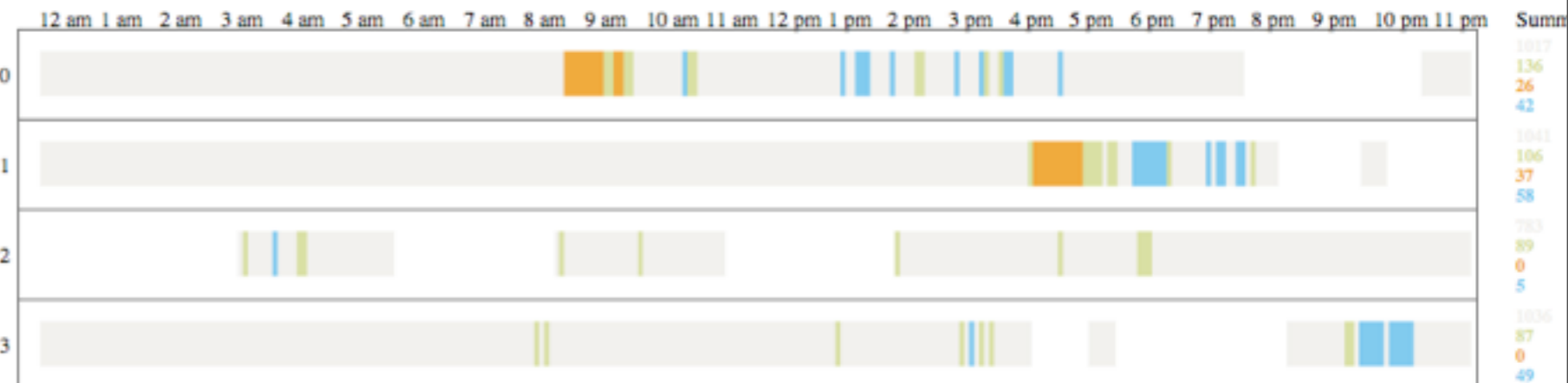
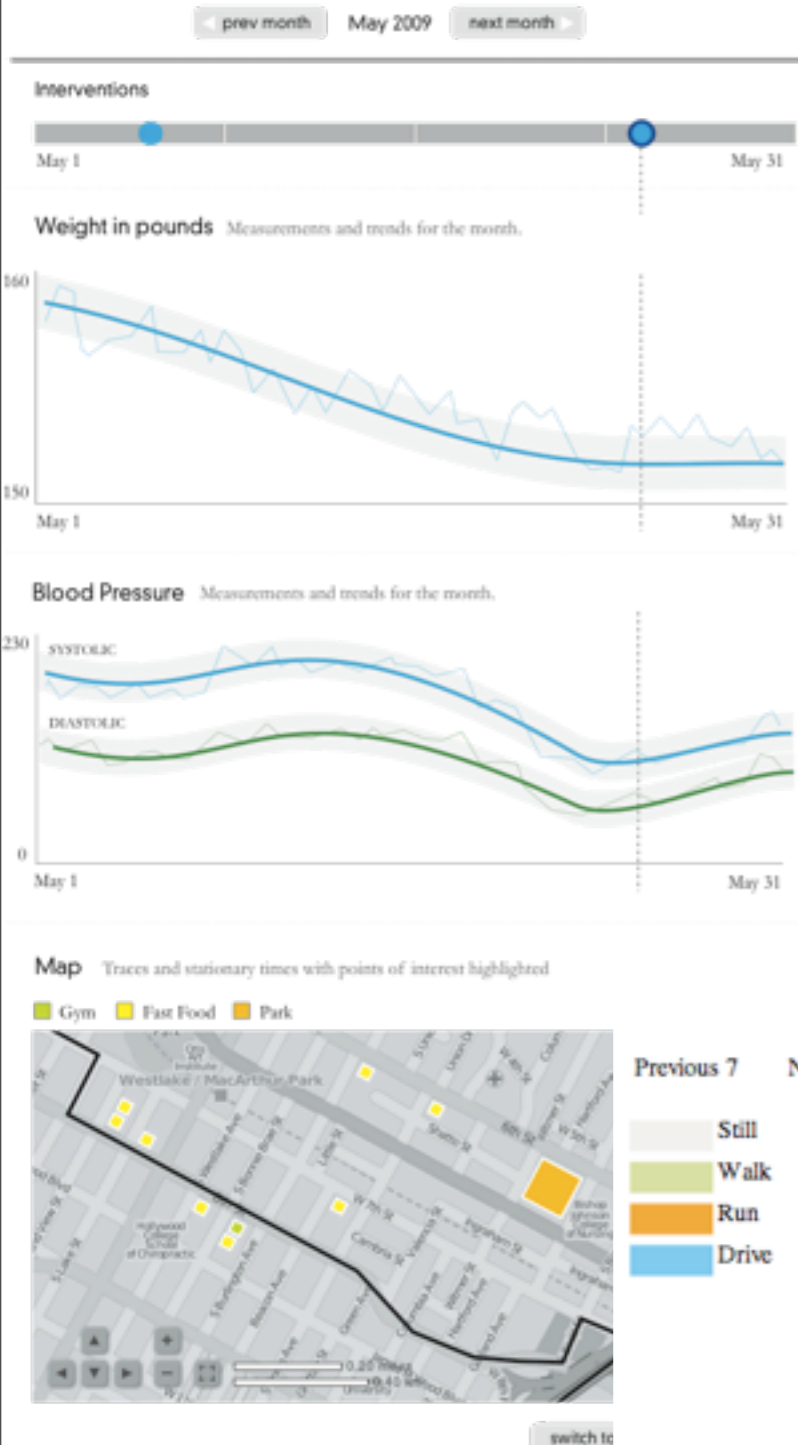
- **A woman who is pre-diabetic** tracks how eating/exercise habits affect weight and fatigue; also explores effective, comfortable blood pressure Rx dosage.
- **A young man who is struggling to find a treatment plan for depression** believes medication dose is ineffective; doctor blames poor sleep habits/non-adherence. 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 will 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)

Many common mechanisms apply across mHealth applications



Location and time triggered surveys

- Multiple choice
- Scale
- Free text
- Exercises

Automated capture

GPS ACCELEROMETER

↓ ↓

Actigraphy

Phonetop Buttons

A screenshot of a smartphone displaying the "ANDWELLNESS" app. The app interface is visible, showing the "SURVEYS", "FOOD", and "STRESS" buttons. The phone's status bar at the top shows the time as 4:23 PM. The dock at the bottom contains icons for Dialer, Contacts, Browser, and Google Maps.



Ramanathan, Selsky, et al



Researcher Dashboards



Survey Creation

Your AndWellness Campaign

Campaign Name: MyDemoCampaign
 Campaign Version: 0.1
 Server URL: http://os219.dyndns.org/

Survey

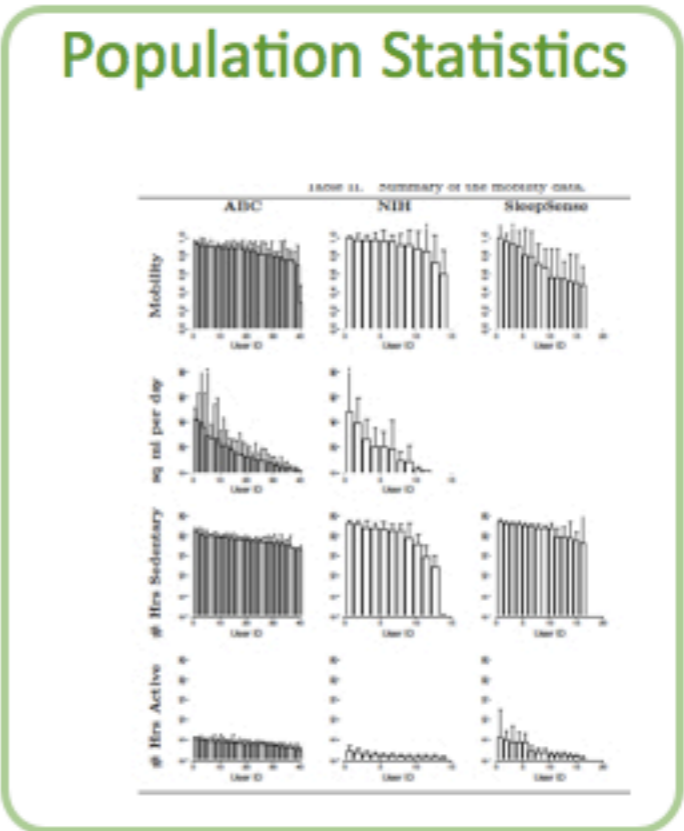
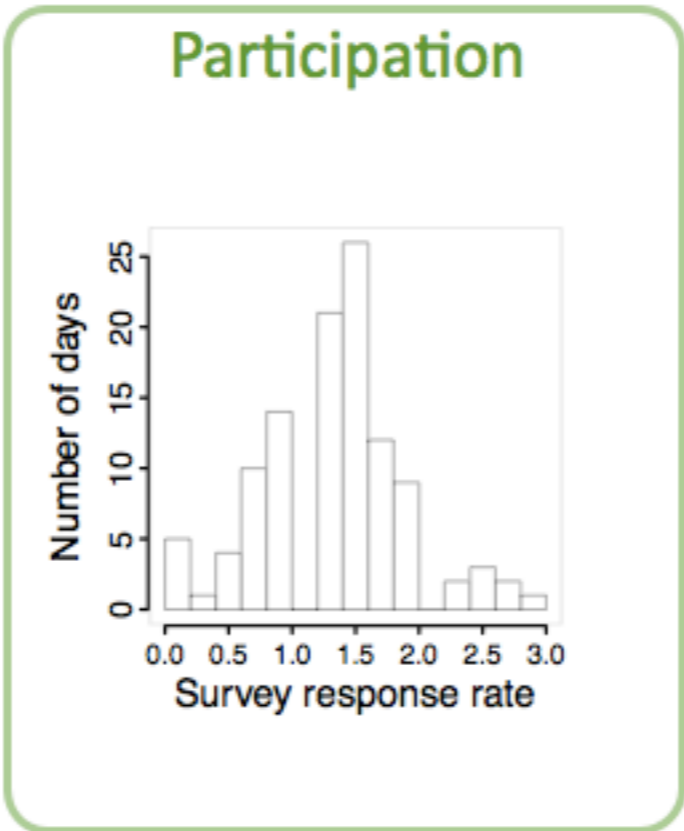
Survey Title: MyDemoSurvey
 Survey may be taken anytime?

Prompt

Prompt ID (auto-generated): prompt1
 Skippable?
 Question:
 Select Prompt Type: (required)

[Add Prompt](#)

[Create this Campaign \(See results below\)](#)



* in progress for release, Dec, 2011

Ramanathan, Selsky, et al

Participatory design: AndWellness functionality shaped by focus groups, interviews

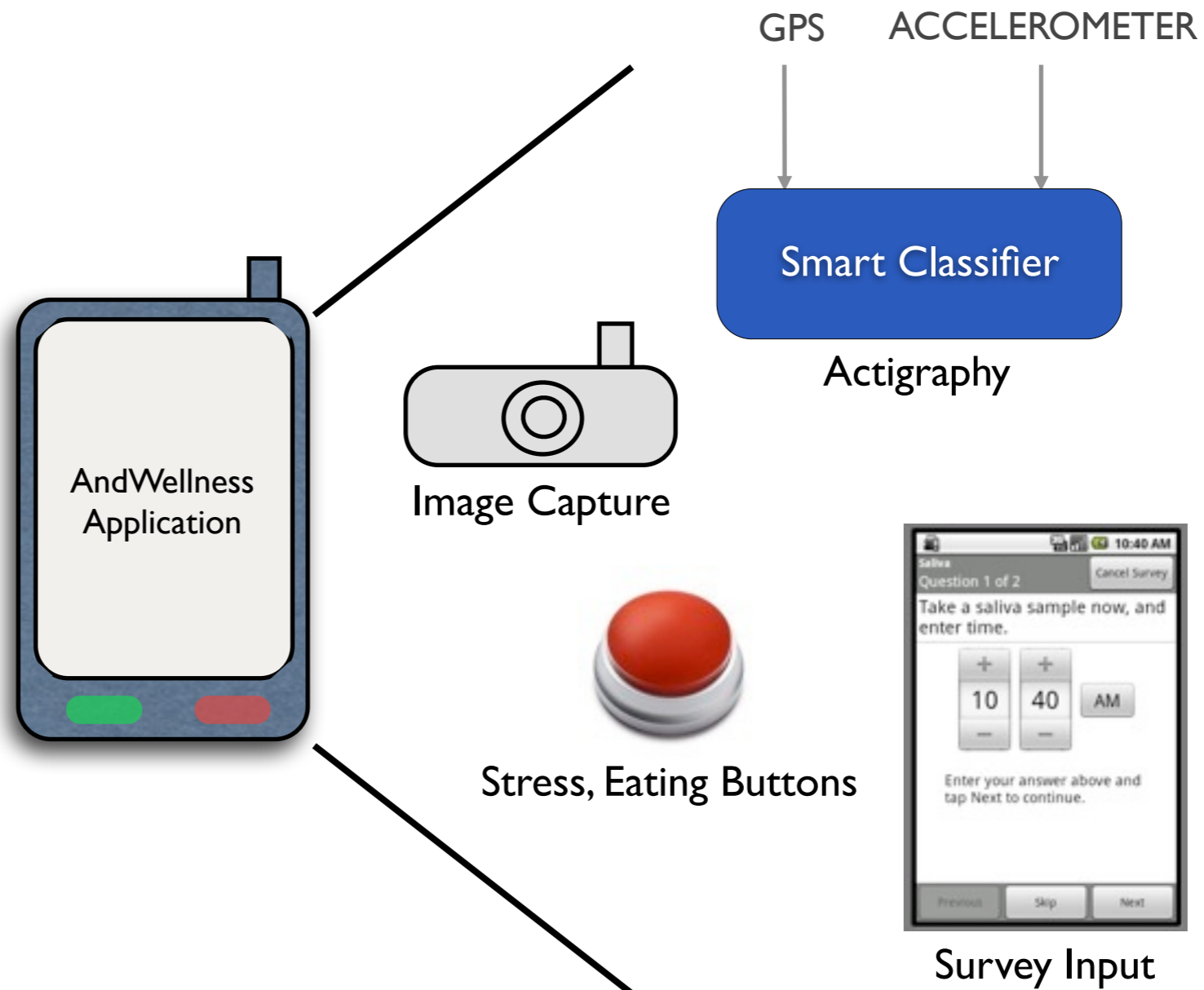
Trigger Authoring

trigger logic as function of
location, time, activity,
prompt responses

Server

Survey Authoring

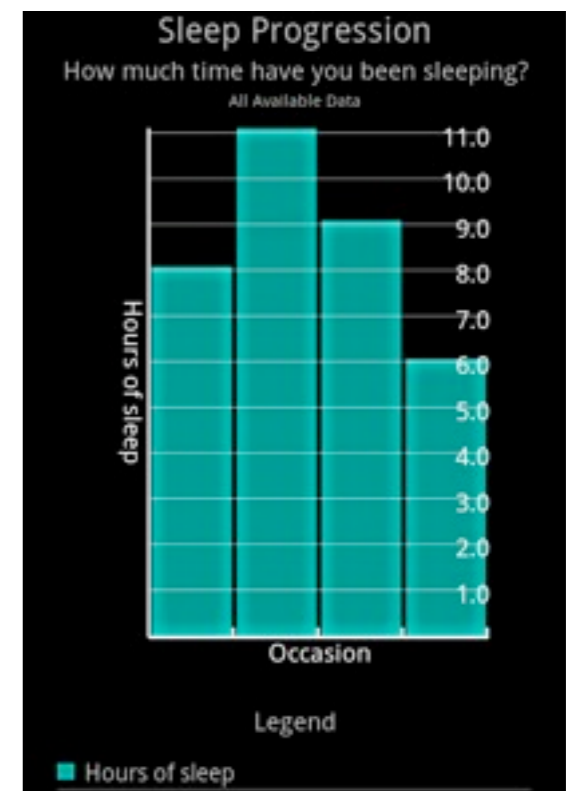
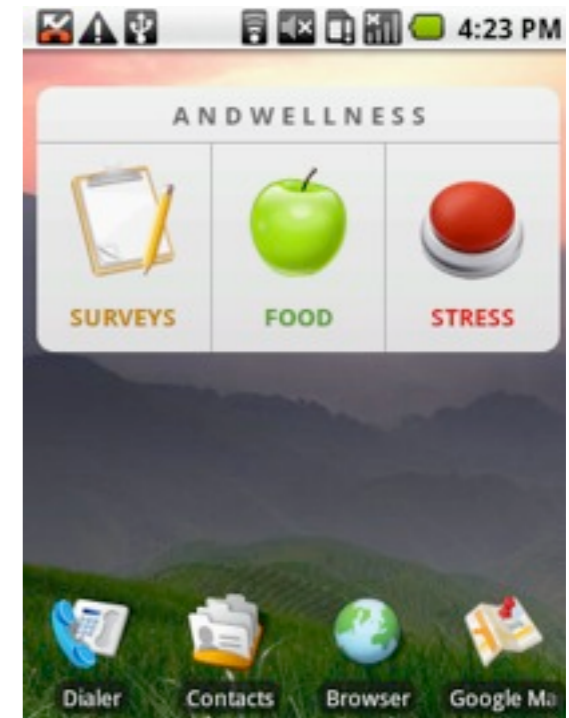
```
<survey>  
  <title>Alcohol</title>  
  <prompt>  
    <text>How many drinks did  
    you have today?</text>  
  </prompt>  
</survey>
```



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

Notable feature requests

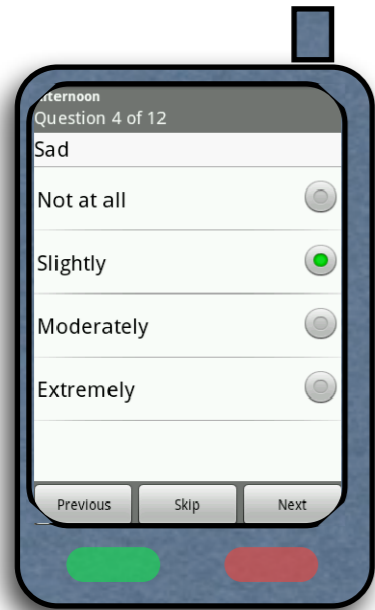
- **Images:** Moms LOVED this feature for food, SA women did not.
- **Triggers:** Control of timing important to all--need trigger authoring and personalization
- **Buttons:** Most moms willing to answer at least briefly 'in the moment', while SA women almost all wanted to answer only at the end of the day.
- **Feedback:** Very few interested in seeing simple quantifications of their responses. Helpful tips and motivational messaging most popular. SA explicitly preferred *against themselves* vs competitive feedback with group.
- **Server vs Phone:** Very few willing/interested to access server. Most wanted interaction solely on phone.



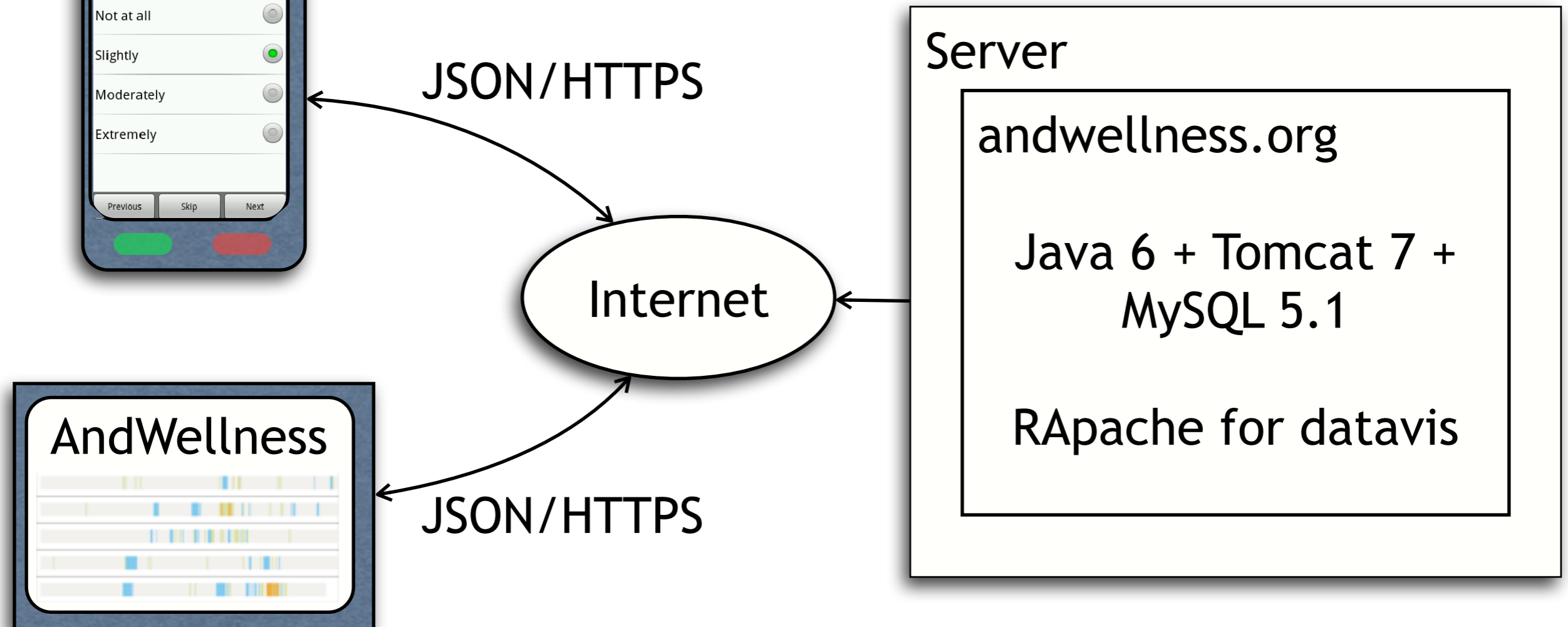
Ramanathan, Swendeman, et al

AndWellness system implementation

Smartphone



Server-side defined by HTTP APIs: GET and POST using JSON, standard HTTP data packaging



Web Browser Clients

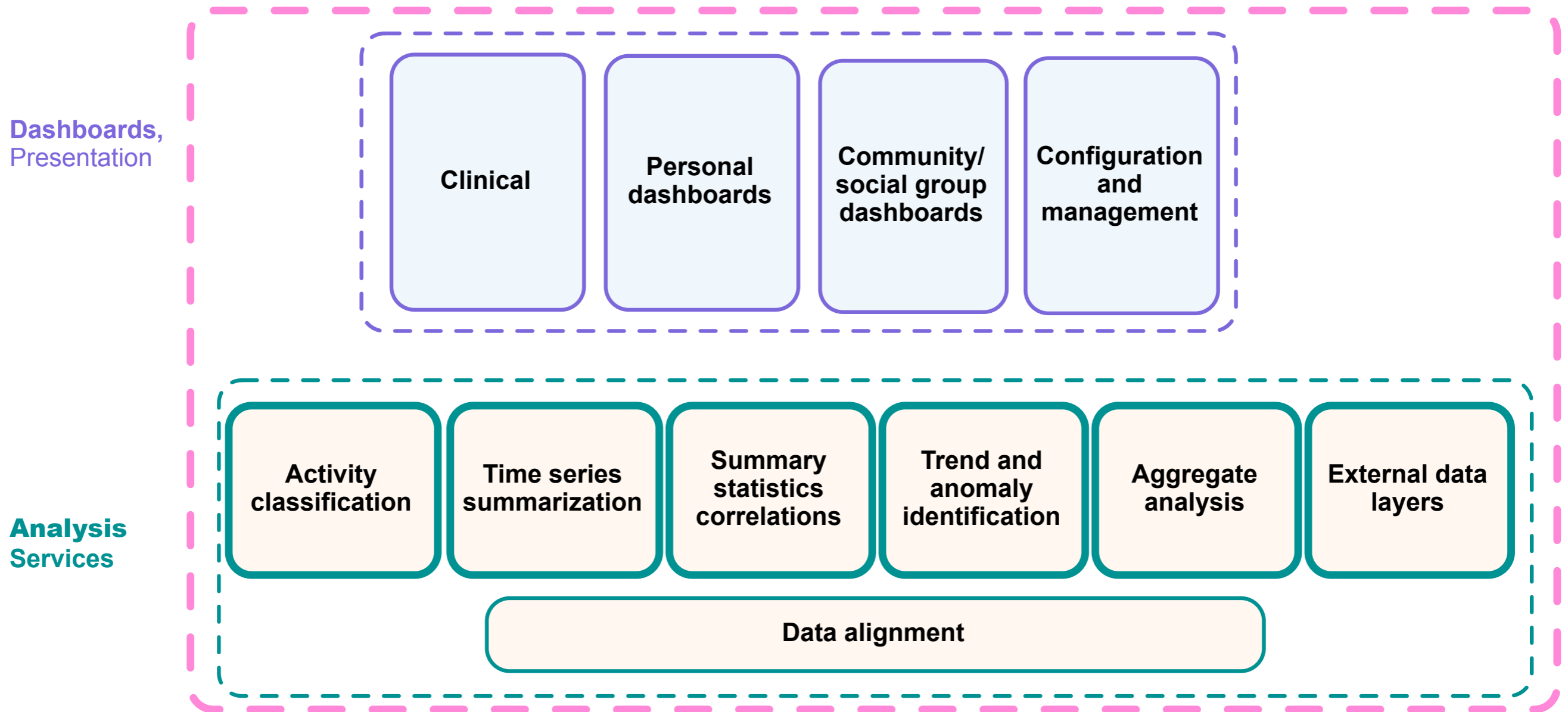
What lies behind exposed API calls could be written in any programming language.

Key *research* challenges

- Health sciences community:
 - Establish validity and reliability of mHealth instruments
 - Derive efficacy evidence base from rich usage, system analytics
 - Behavior change: defining, implementing, and adapting interventions that support sustained and beneficial change across populations
- Technical community:
 - **Infovis: analysis, presentation, visualization, for self, clinician, researcher**
 - Resource management, efficiency (enable full-day phone operation with background activity and data capture)
 - User modeling for activity classification, context, triggers
 - User engagement/experience: motivate sustainable user participation with game mechanics, adaptive interfaces
 - **Selective sharing, usable privacy tools**
 - **Open systems**

InfoVis

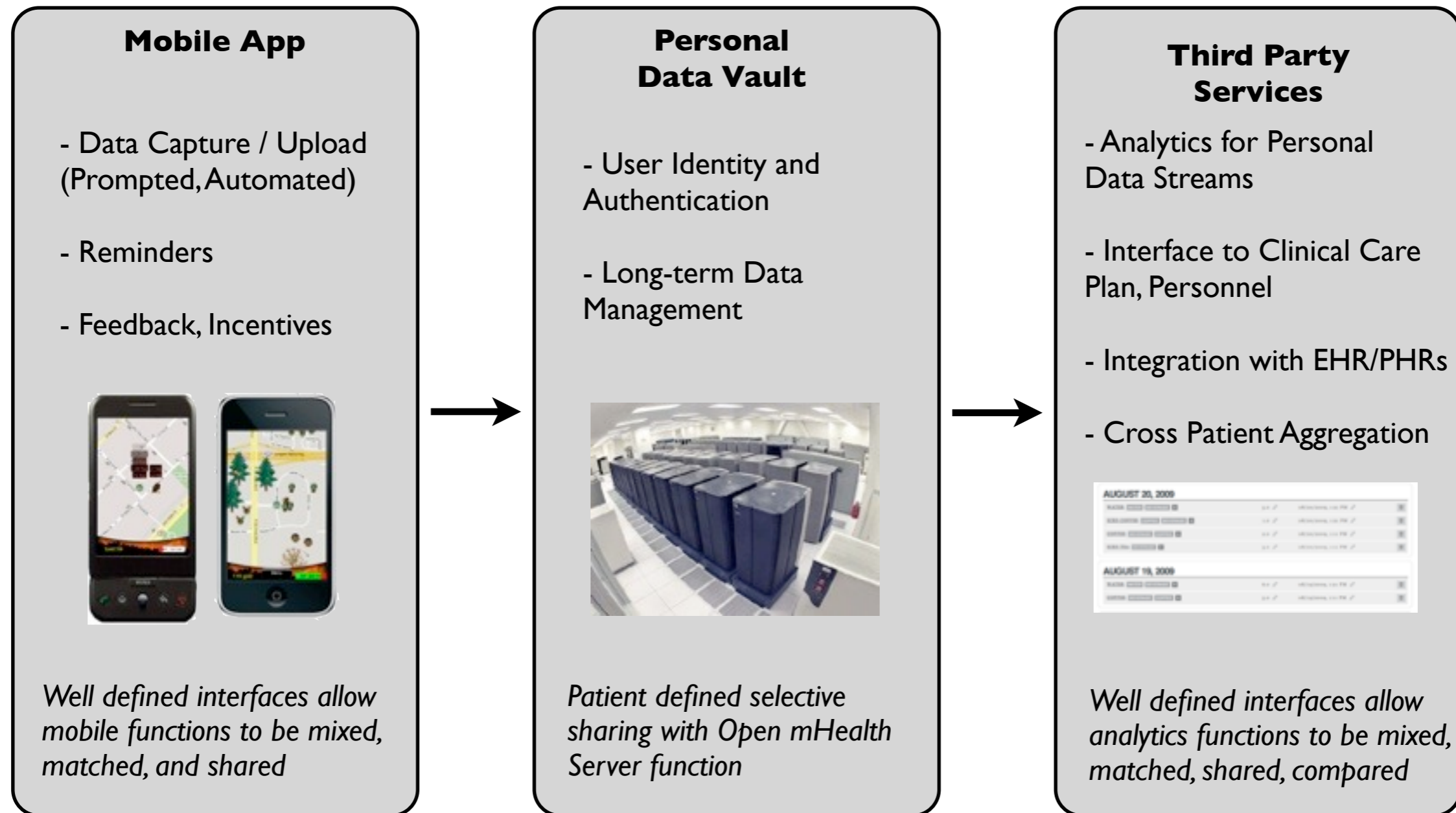
extract and present relevant trends, patterns, anomalies, correlations across diverse data streams and to diverse audiences



Needs: pre-processing, feature extraction, integration with machine learning libraries and statistical analysis tools, incorporation of external datasets, geo-spatial analyses, informative and configurable presentation

Personal Data Vault (PDV):

allow participants to retain control over their raw data by decoupling capture and sharing



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, ...

M. Mun, et al, CONEXT 2010

Importance of an open platform: avoid silos, promote innovation and transparency

Bootstrap rapid cycle of learning, sharing, deployment

- ~80 % (guesstimate) system components reusable

Facilitate research in methodology, treatment

- Systems gather usage data automatically for evaluation, iterative improvement
- Encourage modularity and reuse/sharing in methodologies, practice

Development in the context of real applications and use

- Collaborative/participatory design process and continual feedback from use
- Diverse targeted pilots inform generalization, adaptation, expansion.

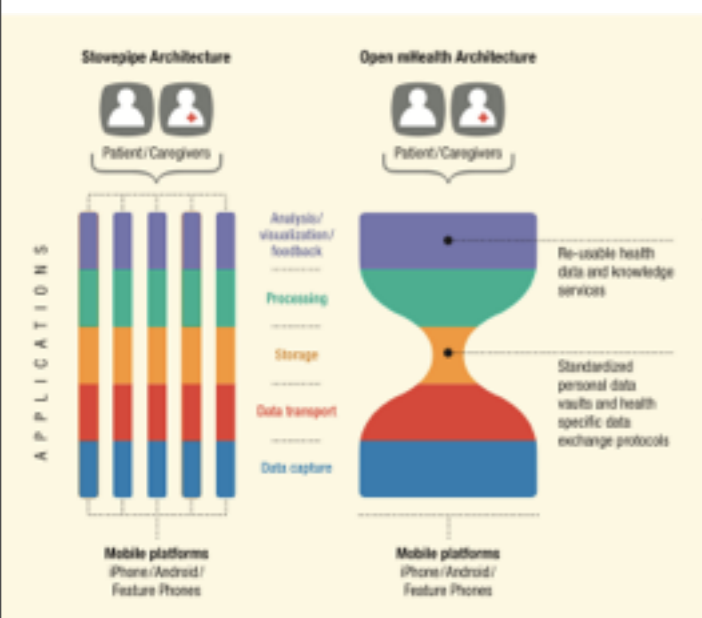
Explore balancing of privacy protection and data sharing

- Variety of privacy/sharing policies
- Transparency of research and data processes for participants

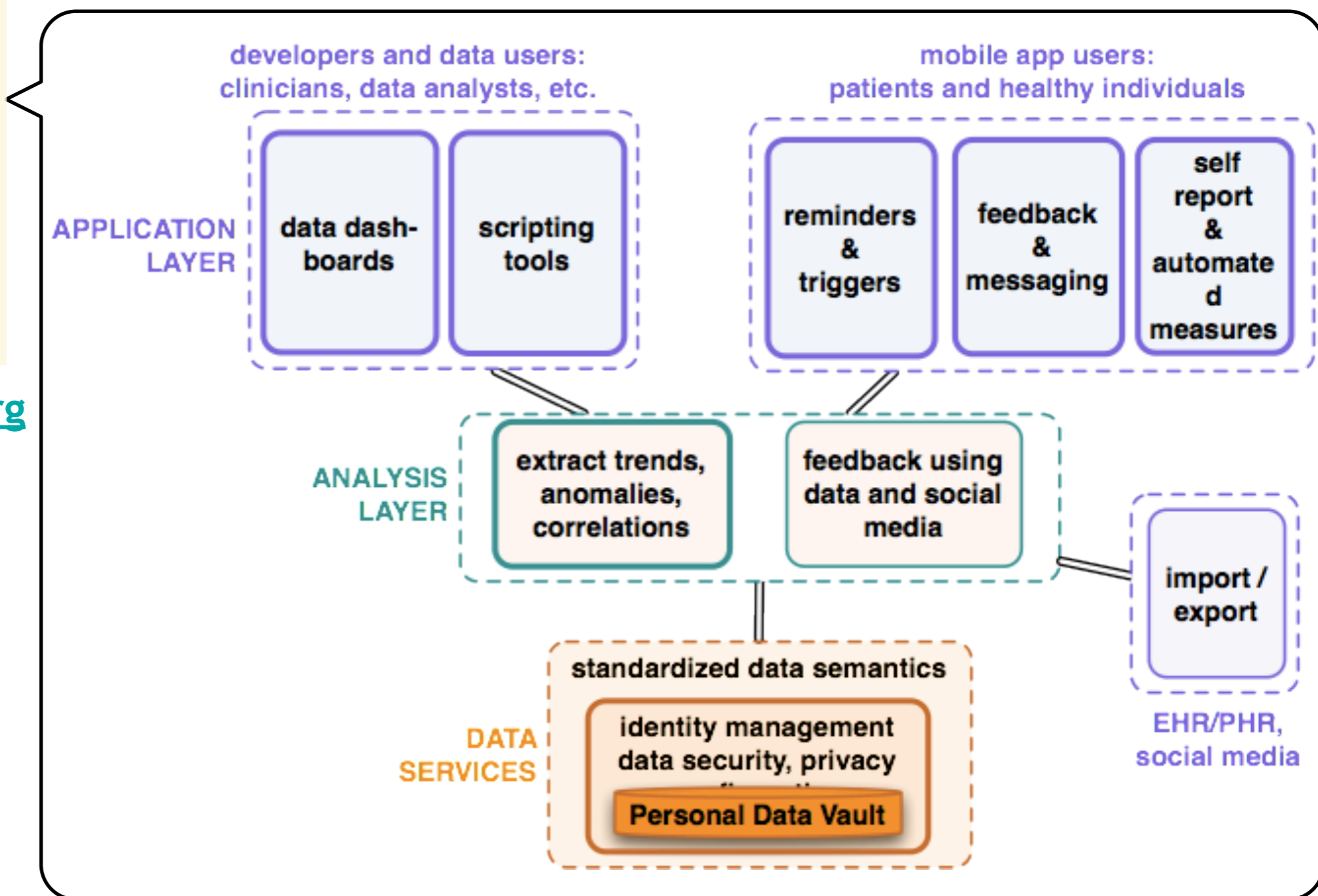
An open modular system is critical to foster rapid and meaningful exploration and innovation

Support systematic learning through shared methods and tools

It takes more than just a mobile app



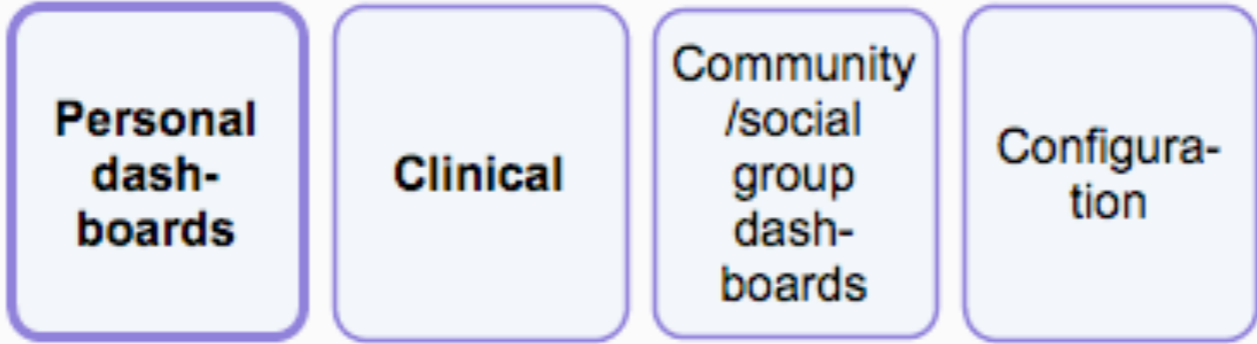
<http://openmhealth.org>



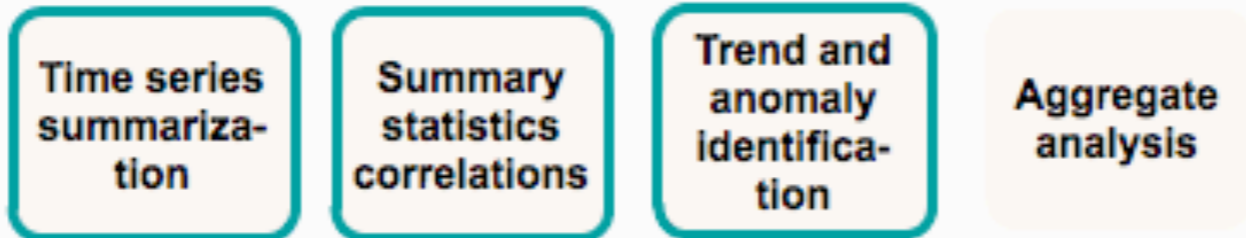
Crowdsourcing what matters

- (Complexes of) Exposures
 - does chocolate trigger (my) asthma?
 - testing common regimens (ACEI, statin, b-blocker), complementary medicines
- (Complexes of) Outcomes
 - what outcomes do patients care about?
 - share validated instruments (e.g., PROMIS)
 - develop and test instruments as a community
- (Complexes of) Novel techniques
 - mobility traces as a biomarker/metric/indicator of disease symptoms: depression, fatigue, pain, ...?
 - social media and gameification as tool for sustained health behavior change

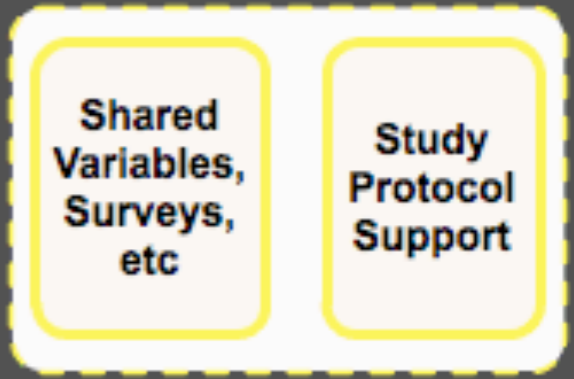
DATA PRESENTATION



ANALYSIS Services



Pre-processing of raw data streams, Data alignment

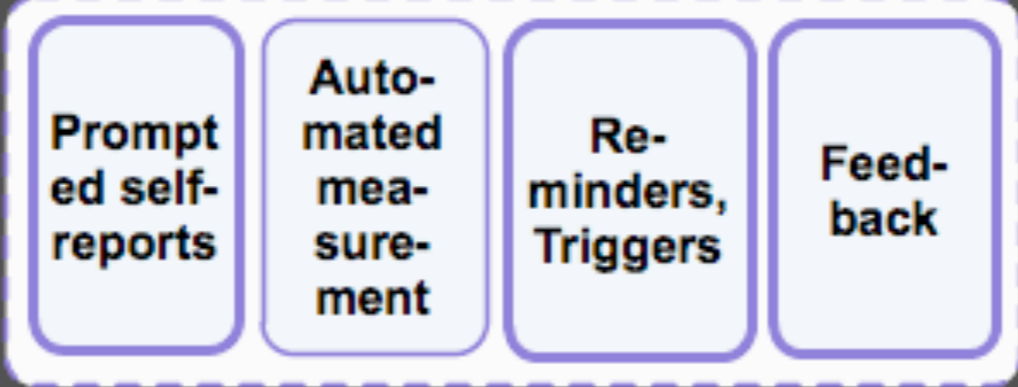


SYSTEMATIC LEARNING

DATA STORE



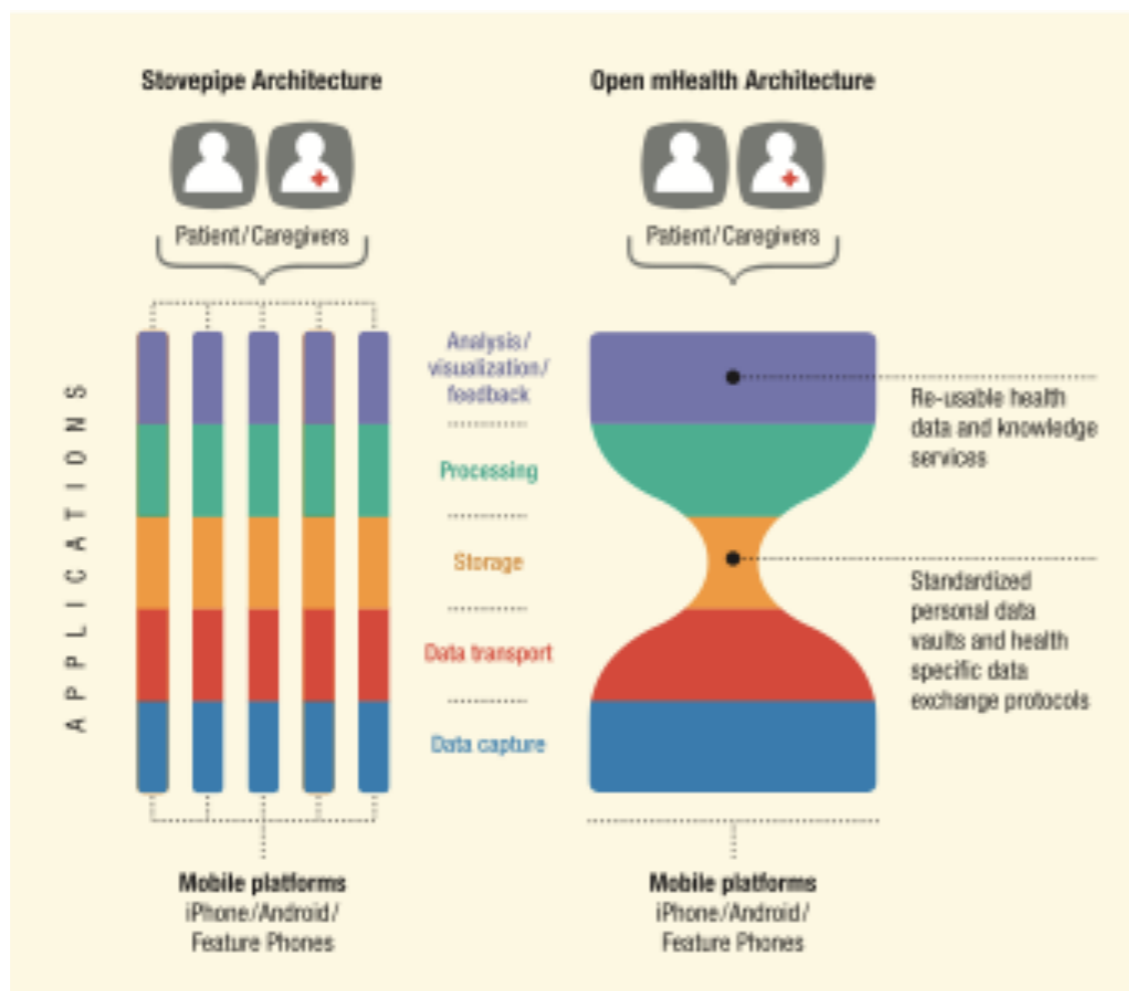
Mobile DATA COLLECTION



External applications interface (EHR/PHR, social media)

Closing remarks

- mHealth ecosystem can become a learning community enabled by an open architecture, to more effectively innovate, share, and deploy best technology and best practices for improving individual and population health
- Requires open, iterative, co-development of innovative methodologies and technologies



<http://openmhealth.org>

Acknowledgments: Collaborators and Sponsors

Collaborators

Technology faculty, PIs:

Deborah Estrin, Mark Hansen, **Nithya Ramanathan**

Application/domain expert faculty/Pis (Health science):

Robert Bilder, Jacqueline Casillas, Scott Comulada, Patricia Ganz, Mary Jane Rotheram-Borus, **Ida Sim** (UCSF), Fred Sabb, Dallas Swendeman, Michael Swiernik

Students, staff:

Staff: Betta Dawson, John Jenkins, Mo Monibi, **Joshua Selsky**

Graduate students: Faisal Alquaddoomi, Hossein Falaki, Brent Flagstaff, John Hicks, Jinha Khang, Donnie Kim, Min Mun, Katie Shilton

Sponsors and Partners/Collaborators

UCLA centers: CENS, Global center for families and children, Health Sciences, JCCC

Federal funding: NSF STC and NETS-FIND Program, NIH

Corporate funding: Google, Intel, MSR, Nokia, T-Mobile

Foundations/NGOs: The California Endowment, RWJF, CHCF, CRA

