Participatory mHealth

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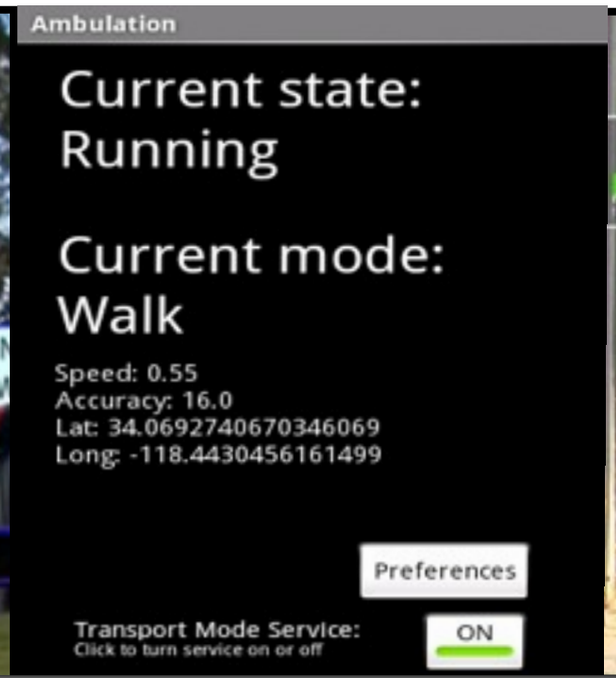
In collaboration with faculty, students, staff at CENS, UCLA, UCSF...

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

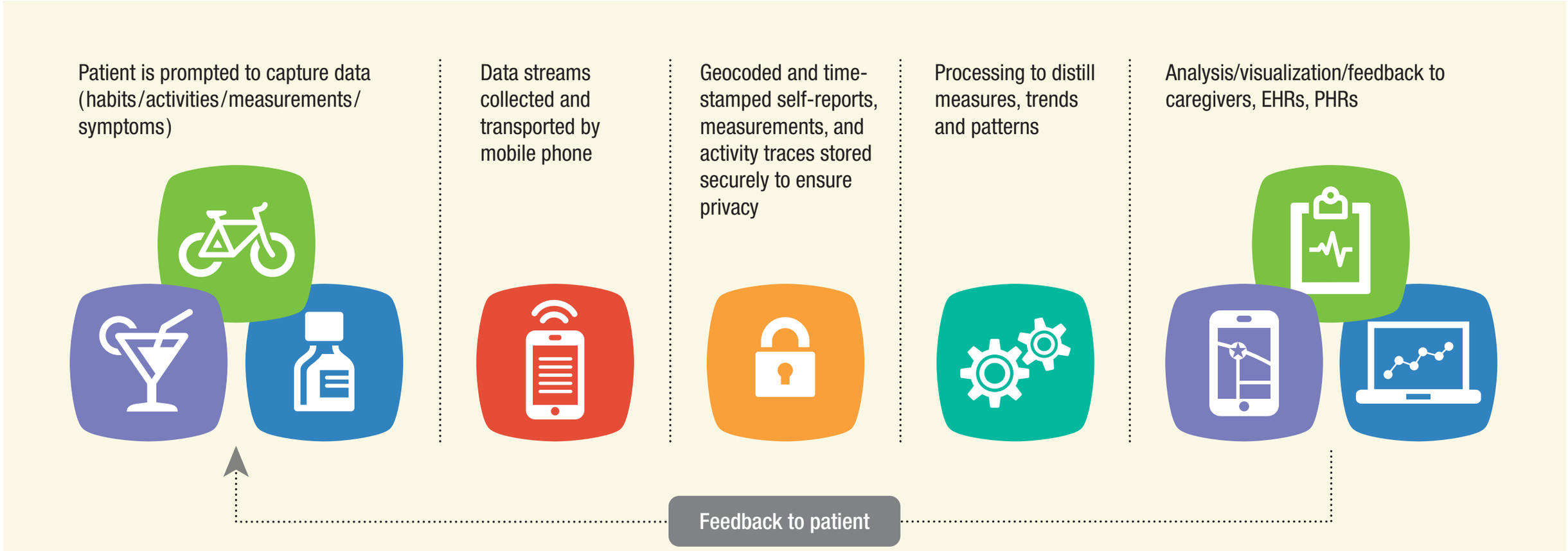
Phones are proximate, pervasive, programmable, personal; offer data/interaction in real time, real place, real context



Participatory mHealth

Use mobile devices to enhance health and wellness by extending health interventions and research beyond the reach of traditional clinical care.

all 168 hours of the week...
all 1440 minutes of the day...
(not all 365 days a year...)



In collaboration w/ Ida Sim (MD, PhD), Michael Swiernik (MD), Mark Hansen (PhD), Nithya Ramanathan (PhD)...

Individuals capture/process/act on data from daily living

our actions

Photo: Marshall Astor, WWW

our self report

experience sampling streams

context and activity traces

personal data repository

visualization

aggregate measures, trends, patterns

event detection

processing

self-report/experience sampling, self-measurement, biometrics, activity trace

Why participatory mHealth?

motivation

3 behaviors (diet, exercise, smoking) cause 1/3rd of US deaths

50% Americans have 1 or more chronic diseases

age of onset getting younger

chronic disease prevention/management/research happens in the context of daily life, outside of clinical setting

approach

support individuals, communities, clinicians to continuously improve patient-centered, personalized, health and healthcare through data collection 24x7

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

Whose mHealth?

- **A woman who is pre-diabetic** tracks how eating/exercise habits effect weight and energy levels; also explores effective, comfortable blood pressure Rx dosage.

- **A soldier returning to civilian life with epilepsy** conducts prompted self-reporting on number, duration, severity of each seizure experienced; reveals patterns that were difficult to accurately report during bi-monthly checkups.

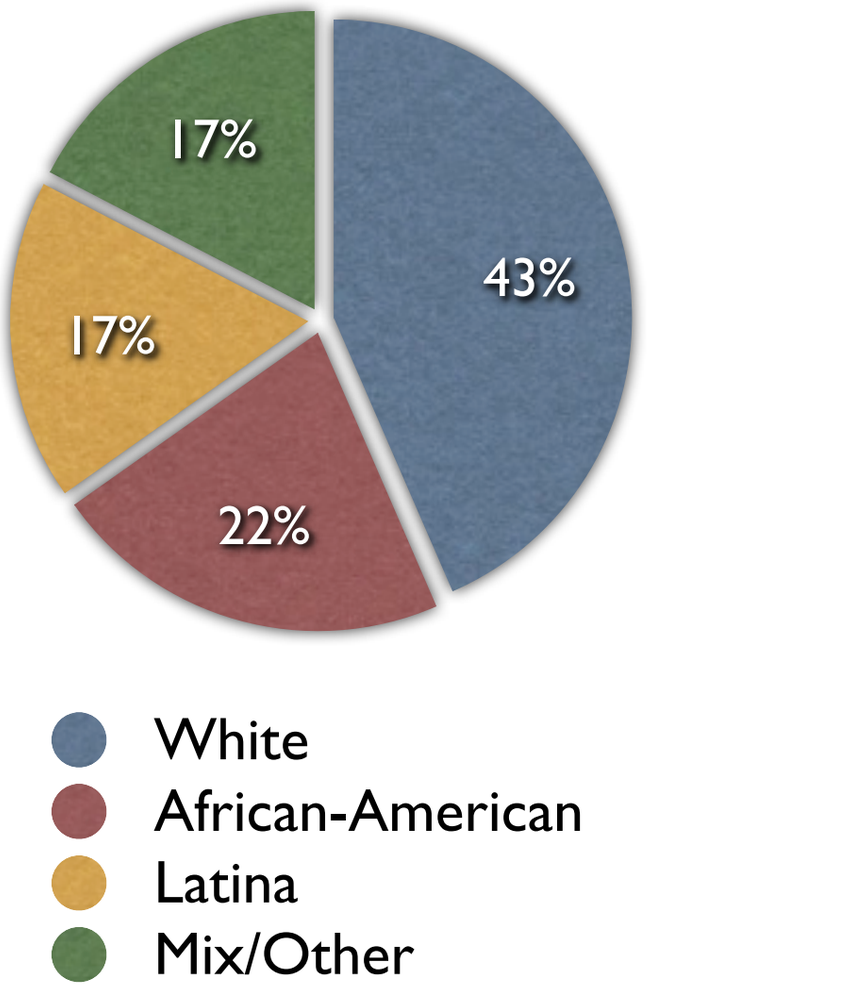
- **A middle-aged woman who does not respond well to medication for psoriasis** monitors diet, stress, environmental factors; initiates data campaign via social networking site for psoriasis sufferers. Each volunteer runs mHealth app for 2-months to create large data set to mine for patterns that precede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

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

Lessons Learned From Targeted Focus Groups for AndWellness

- Key features on the phone to encourage participation:
  - ➡ Customization of prompts and triggers
  - ➡ Images for accountability
  - ➡ Goal setting and monitoring
  - ➡ Stress button
- Privacy not a primary concern
- Survey duration less than 10 questions, 3 times a day

23 Total Focus Group Participants



Hicks, Monibi, Ramanathan, Selsky, et al

Participant Data Flow Based On AndWellness Focus Groups

Trigger Authoring

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

Server

AndWellness Application

GPS ACCELEROMETER

Smart Classifier

Actigraphy

Image Capture

Stress, Eating Buttons

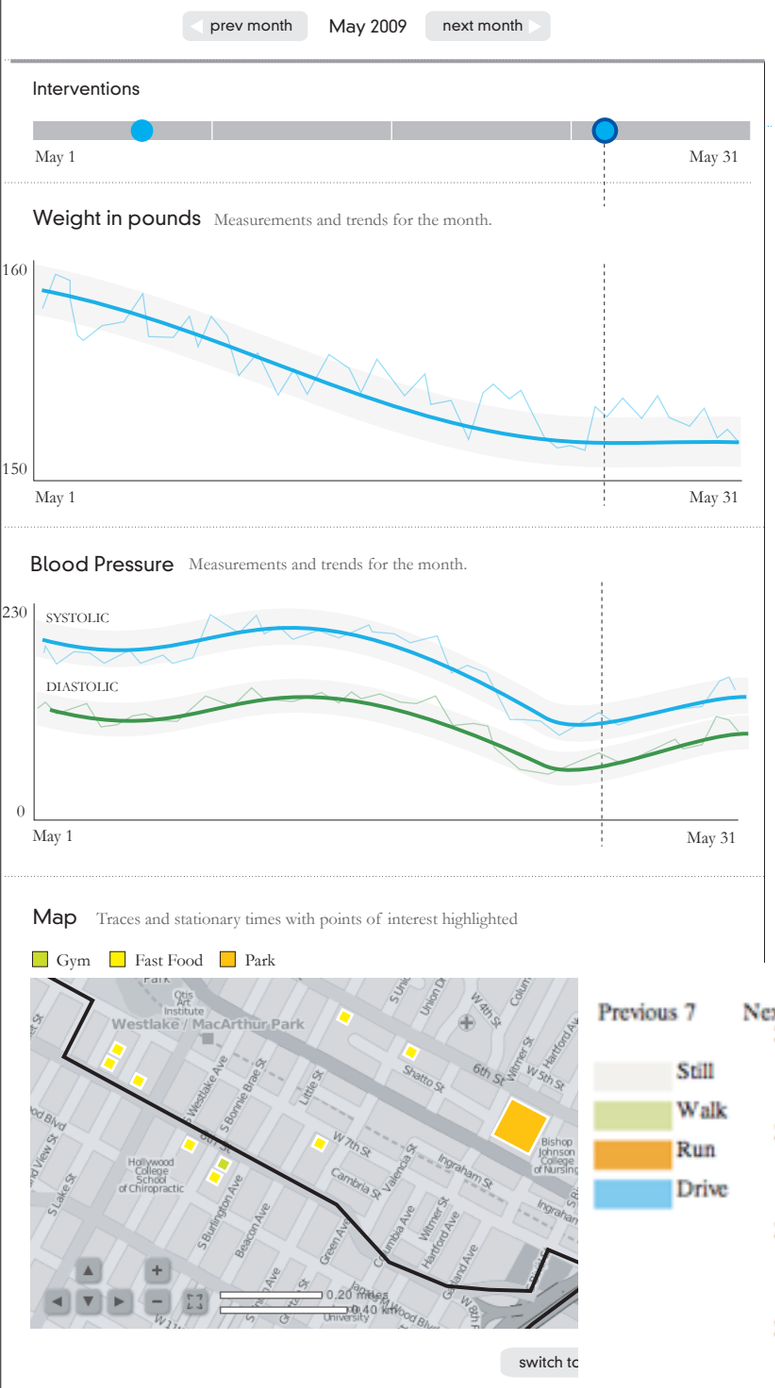
Survey Input

Survey Authoring

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

Hicks, Monibi, Ramanathan, Selsky, et al

Resulting integrated personal data streams create *Living Records*



Automatically prompted, geocoded, uploaded, analyzed:

- biometrics (BP, glucose...)
- patient reporting (medication, symptoms, stress factors)
- location traces
- contextual, environmental, social factors
- inferred patterns such as sleep

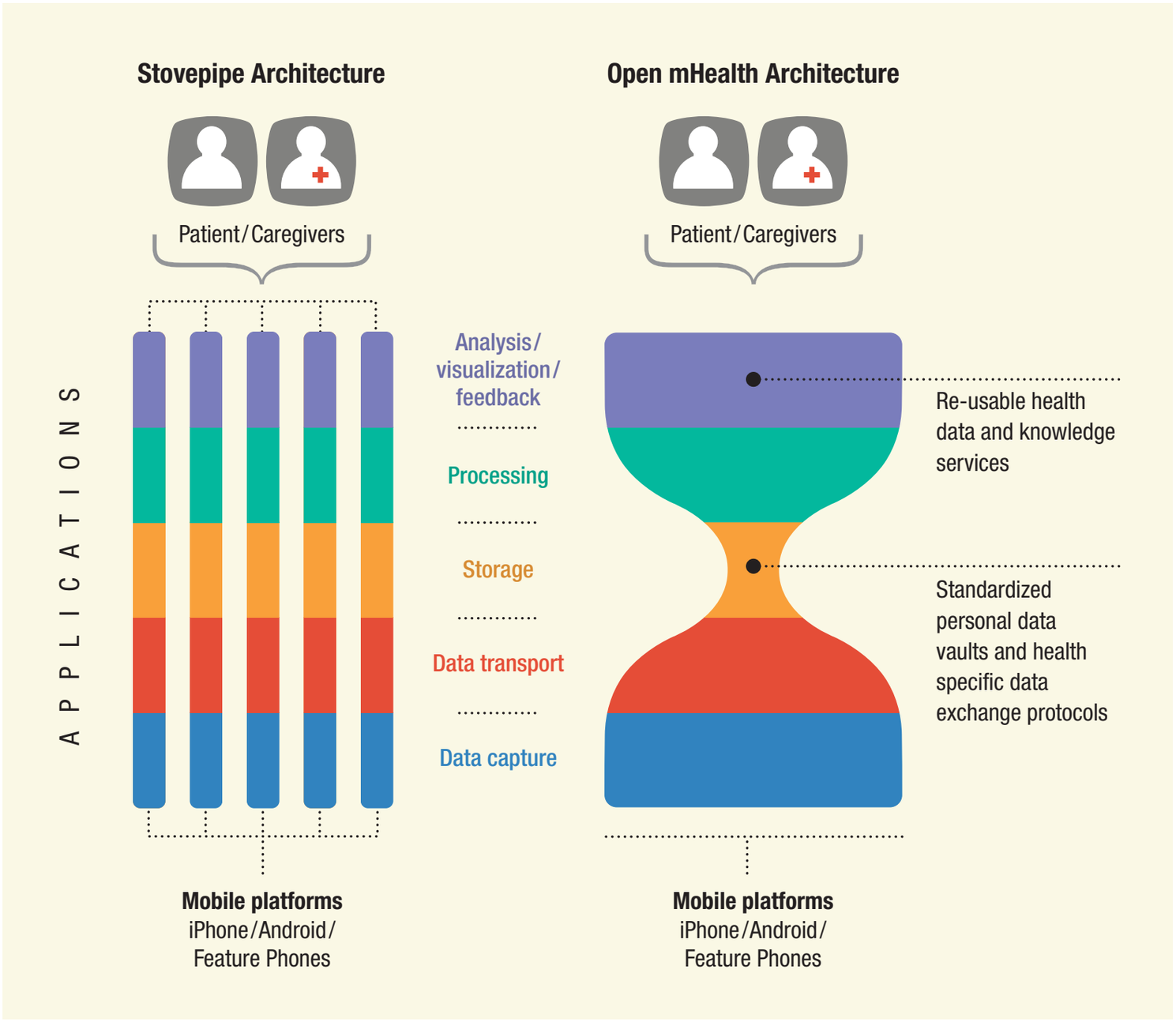
Processed/filtered personal data streams would become part of emerging PHR/EHRs (complementary not duplicative)

Study	Sample Size	Diet	Stress / Mood	Exercise	Mobility	Alcohol	Drug	Sleep	Sex
Validation study with accelerometer	9				X				
Reducing heart disease in moms	60	X	X	X	X				
MSM at risk for HIV	30		X			X	X		X
Breast cancer survivors	100		X	X	X	X		X	
Sedenterism in immigrant women	30		X	X	X				

Hicks, Monibi, Ramanathan, Selsky, et al

Open mHealth initiative: http://openmhealth.org

open, shared, scalable architecture for innovation in healthcare, wellness, research



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

Open architectures enable privacy to be architected as well:
Personal Data Vault (PDV):

allow participants to retain control over their raw data

Mobile App

- Data Capture / Upload (Prompted, Automated)

- Reminders

- Feedback, Incentives

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

Personal Data Vault

- User Identity and Authentication

- Long-term Data Management

Patient defined selective sharing with Open mHealth Server function

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 analytics functions to be mixed, matched, shared, compared

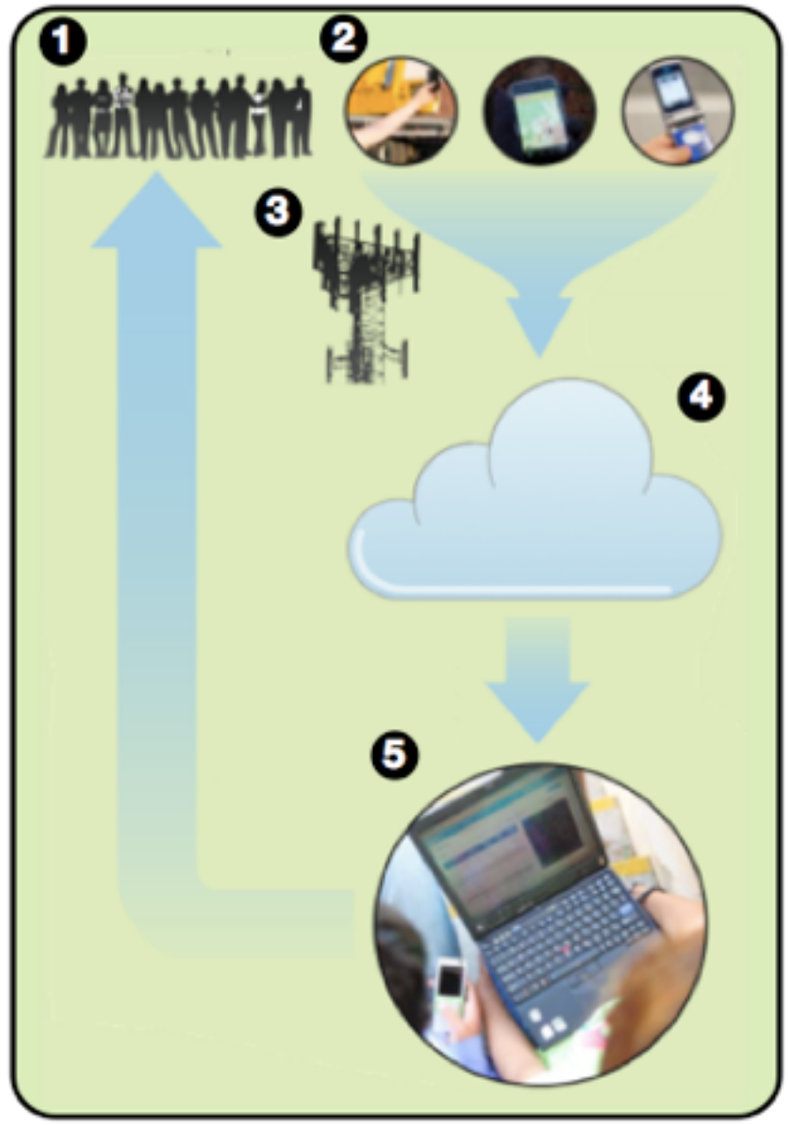
vault + filters = granular, assisted control over what/when you send to whom, what data says about you, whether you reveal who you are or share anonymously, ...

Shared architecture with Participatory Sensing *writ large*

PS is an approach to data collection and interpretation in which individuals, acting alone or in groups, use their personal mobile devices and web services to systematically explore interesting aspects of their worlds, ranging from health to the environment and culture.

Participatory Sensing Campaigns

- spatially and temporally constrained, systematic data collection.
- human-in-the loop sensing to gather data.
- manual and automatic classification, audit, analysis.
- precedent: Community-Based Participatory Research (CBPR), Photovoice, Experience Sampling, Flickr, Citizen Science
- Projects: Building a health boyle heights, Stress/Chill



MOBILIZE: Math Science Partnership with LAUSD and Center-X

(Estrin, Hansen, Margolis, Priselac, Ullah: began 10/1/10)

Bring computational thinking into the classroom and into everyday life with:

Participatory Sensing Software
Flexible, open, tools for authoring, implementing, analyzing data campaigns using mobile phones and web services

High School Curriculum
Data are everywhere: teach students spatial analysis, temporal analysis, text interpretation, through their own data

Multidisciplinary teacher teams
Focus data campaigns on Science and Math topics, including local ecosystems

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.