Creating a Shared, Open, and Scalable mHealth Platform for Intervention Innovation

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In collaboration with:

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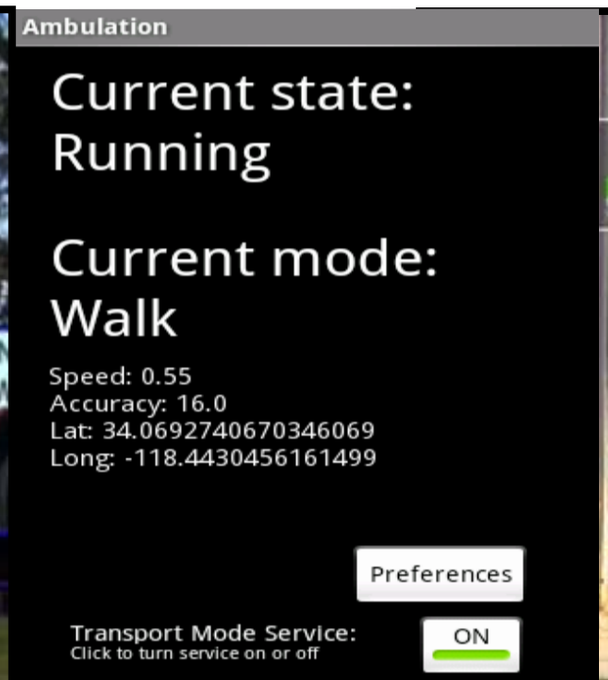
Students/Staff: Peter Capone-Newton, Patrick Crutcher, Betta Dawson, Joey Degges, John Hicks, Hossein Falaki, Brent Flagstaff, Cameron Ketcham, Donnie Kim, Keith Mayoral, Min Mun, Nathan Yau, Sasank Reddy, Ruth West, Vids Samanta, Katie Shilton, Masanao Yajima, Eric Yuen

Enabled by >3 x 10^9 mobile phone users, increasingly with gps, imagers, UI

Motivated by 6 x 10^9 people on planet earth and their concerns…



Why focus on mhealth, smart phones, and open?

mHealth

capacity for impact with access to participants
…all 168 hours of the week…
…all 1440 minutes of the day…

smartphones

real time (always on),
real place (always carried)
real context(always web connected)
real powerful (apps, usability)

open

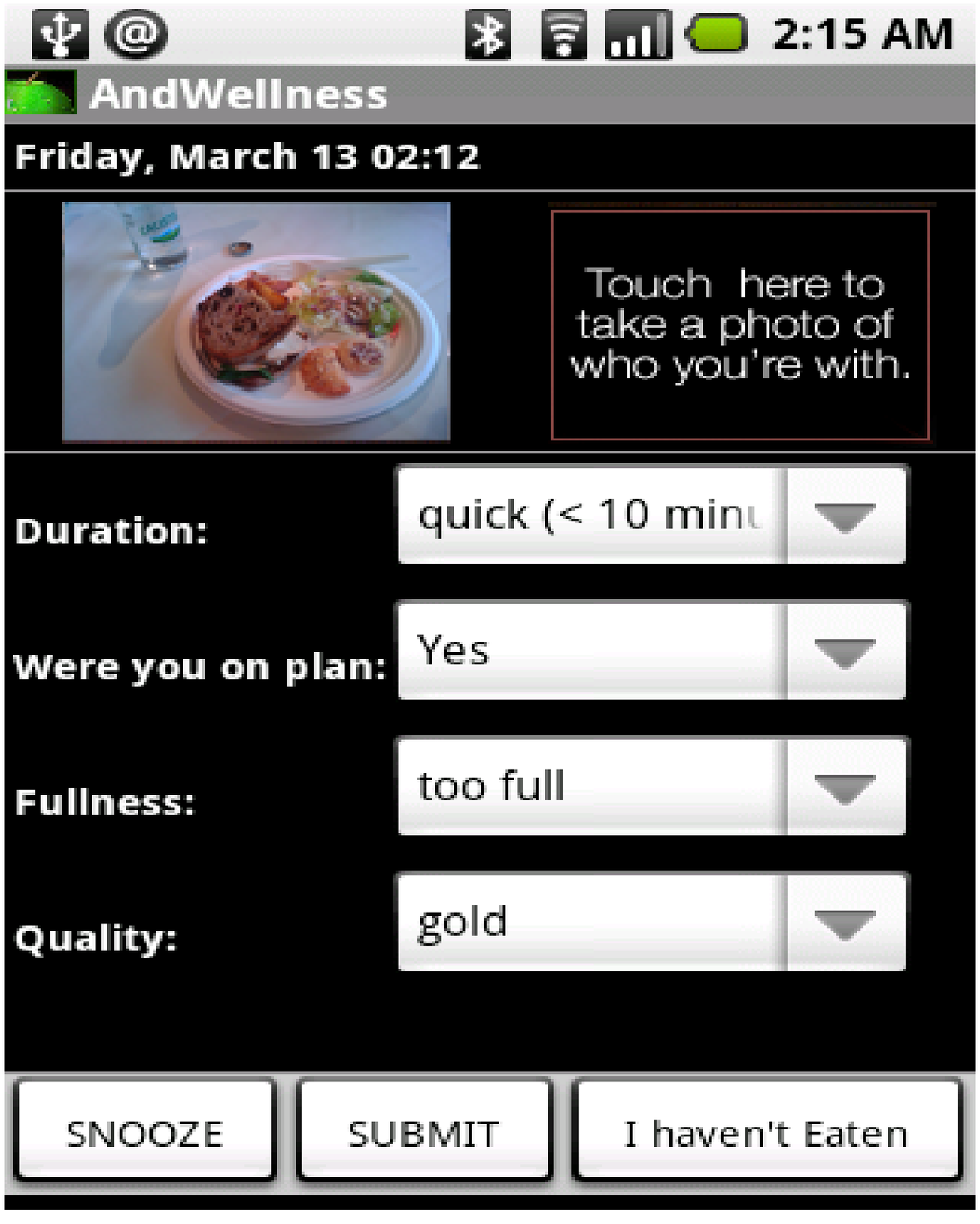
broad applicability
heterogeneous users/uses
evolving methodologies
foster innovation ecosystem

Example: health behavior change through self monitoring

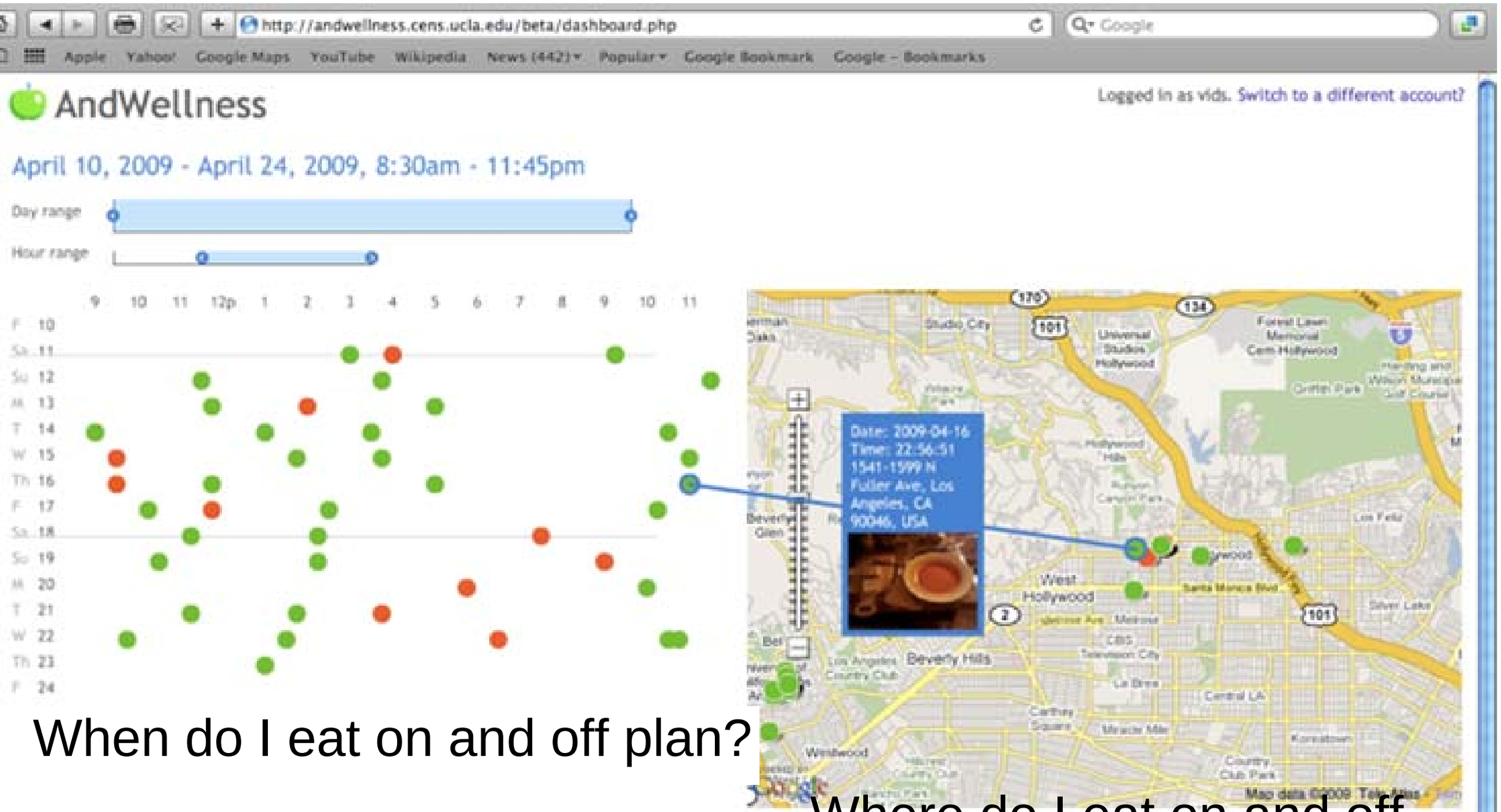
real time
prompting

real place
observations

real context
from mapping,GIS,
social networking



Web services provide historical, environmental context



When do I eat on and off plan?

Where do I eat on and off plan?

http://andwellness.cens.ucla.edu/beta/demo.php

Health & Wellness: observations in daily living/EMAs

Hybrid of time-location trace with media capture and self-report.

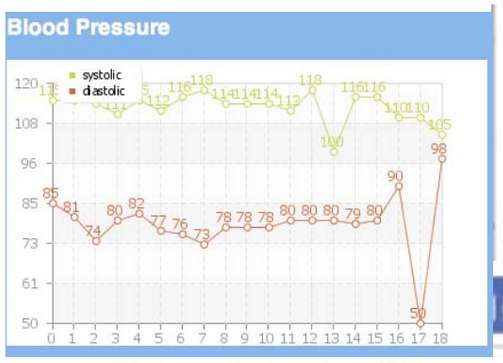
Our Actions

Our Self Report

Geocoded and time-stamped EMAs

Mobility traces

Private Data Storage



Visualization

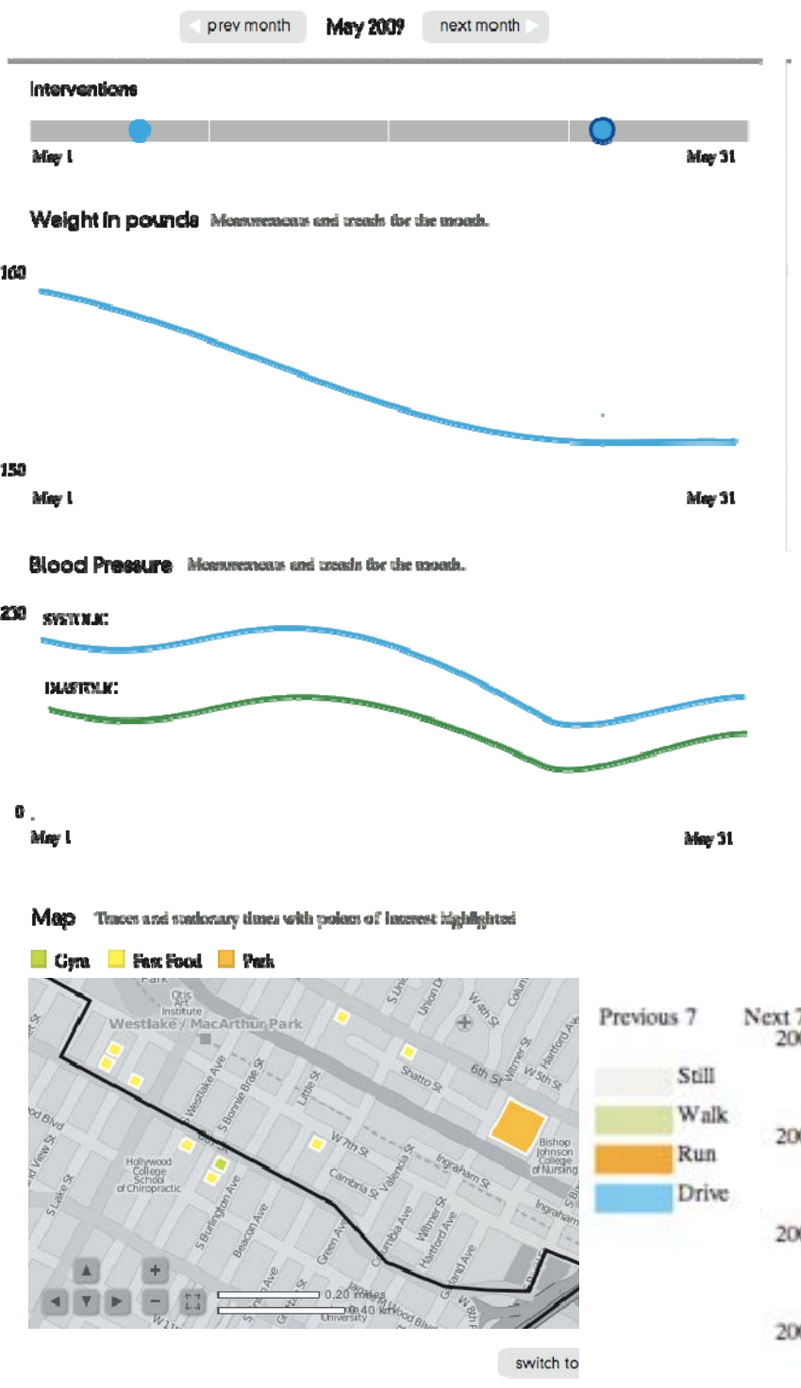
aggregate measures, trends, patterns

event detection

Processing

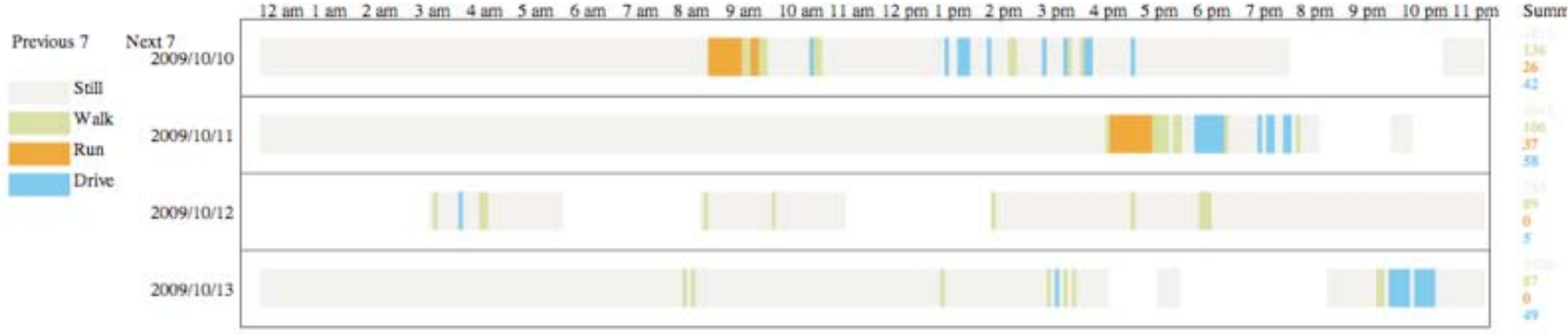
Photo – Marshall Astor

Integrated personal data stream creates a *Living Record*



Automatically prompted, geocoded, uploaded:

- physiological (BP, glucose…)
- patient reporting (medication, symptoms, stress factors)
- location traces
- contextual, environmental, social factors

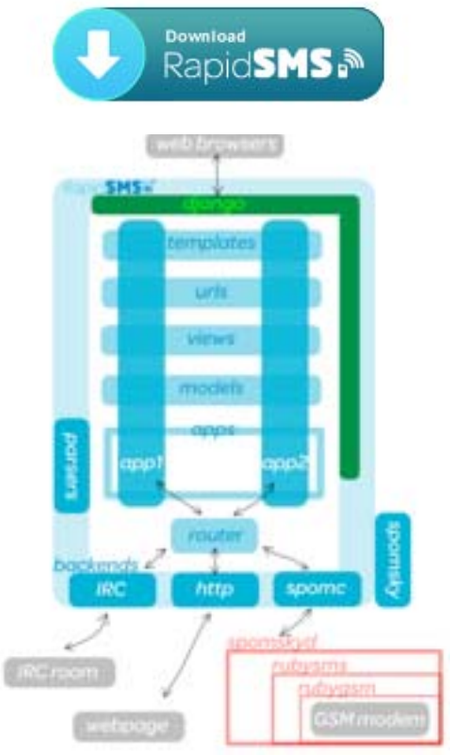


And it doesn't require a smartphone to generate telling traces…

http://your.flowingdata.com

Smart proxy: can support data from simple featurephones

- gateway for contributions from featurephones (i.e., no special app, no data plan, with or without gps)
  - prompted, encoded sms responses
  - uploaded messages parsed and stored as if from smartphones
  - location can be optionally coded with reference to map
- leverage extensive global health community experience
  - promising precedents: episurveyor, mobileactive, ushahidi, UN, other users of RapidSMS, FrontlineSMS…

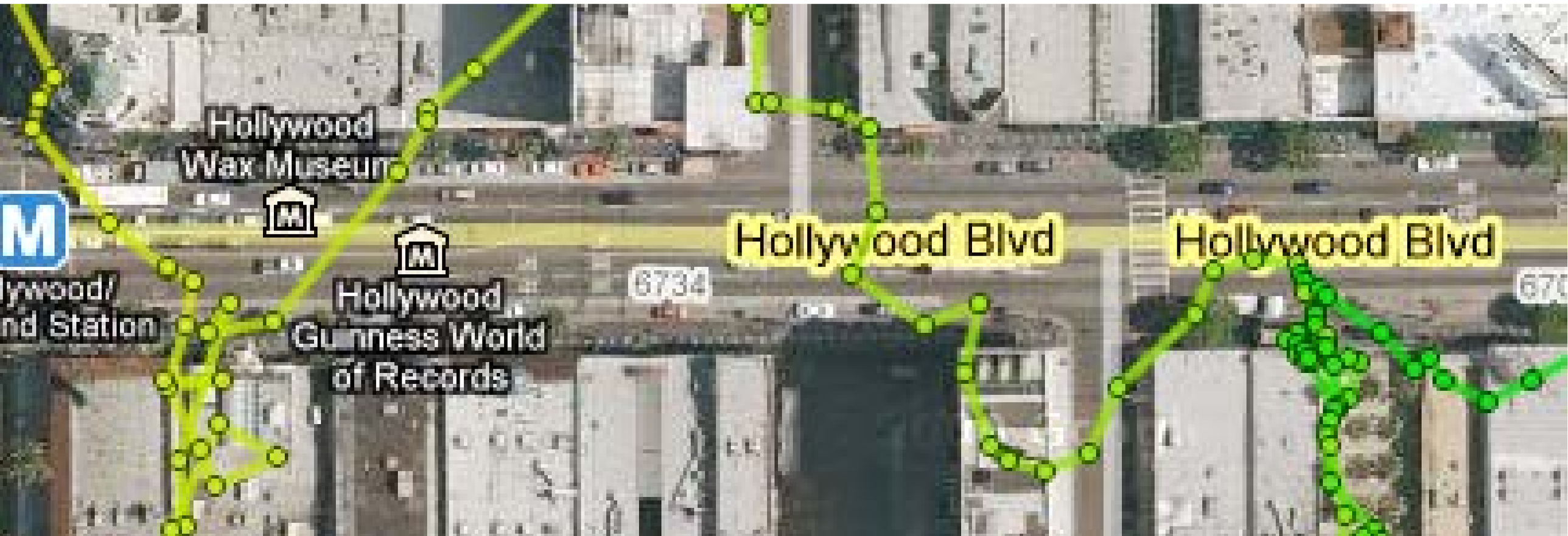


Opportunity to promote new privacy infrastructure and best practices

Individual captures and shares her own data

- different from data held by regulated mobile carriers, credit card companies.

- lure of *free* apps, *free* services: "*Everything is free to you, except for the data we collect about you"*



- *Personal Data Vault (PDV)*
- allowing participants to retain control over their raw data

vault + filters = granular, assisted control over what you send to who, what that data says about you, whether you reveal who you are or share anonymously, …

Data Capture

Personal Data Vault (PDV)

Data Filters

Partitioned applications

User Interface

data legally-accessible only to Individual

Third Party Applications

filtered data shared with specific service providers, public health databases

non-technical challenges:

protection of vault data from subpoena, discovery?

professionalization of data vault services

Example: CHIPTS Pilot Summer 2010 (Ramanathan, Swendeman)

- **Goal:** feasibility, acceptability, reliability, validity, preliminary behavioral impacts of mobile phone EMAs for substance use, sexual behavior, emotional distress

  Population: HIV+ and HIV- clients at AIDS Project Los Angeles (APLA)

- **Methods:**

- Focus groups to assess feasibility, acceptability, UI, privacy concerns, honesty of self-reports

- 6 week self-monitoring assessment, n=60 randomly assigned across 3 conditions

1. Mobile EMA framed as a "Diary Study" to document contexts of risk
2. Mobile EMA framed as a "Behavior Change Support Tool"
3. No phone use, control

General mobile to web architecture supports scalable, affordable, quickly-deployable use-cases

General flow	Meaningful use-cases		
APPLICATIONS web, researchers/ health providers/community	Chronic disease monitoring/mngmt	Health behavior change/adherence	Health worker/Caregiver support
PROCESSING mobile device and web Services	Activity, mobility trends	Health behavior diaries	Environmental assessments, Client dashboards: followups, triggers
DATA CAPTURE mobile device and individual	Location traces	Geo-coded, prompted entries	Geo-coded entries, image, annotation

Basic technology/systems are (almost) ready to use …but their use still poses technical challenges

- Feature extraction for range of applications, multiple timescales
- Smart/personalized triggering/prompting
- HCI, usability: data visualization, multiple timescales
- Power consumption
- Privacy

Key components of an Open Platform product and process

- **Open source and standards**
  - Open Source--available for others to inspect, modify, enhance.
  - Clear and well defined interfaces and modularity.
  - Openness promotes competitive marketplace of ideas--innovation.
- **"Rough consensus and running code" (DDC)**
  - Implement systems for iterative quality improvement, adaptation, reuse.
  - Rapid cycles of field deployment influence system design, methodologies.
  - Formal standardization of software and methods *follows* experience.
- **Development in the context of real applications and use**
  - Collaborative/participatory design process with continual feedback from users: providers, researchers, participants.
  - Not an abstract/general purpose software architecture effort: diverse targeted pilots inform generalization, adaptation, expansion.

Discussion topics and open platforms

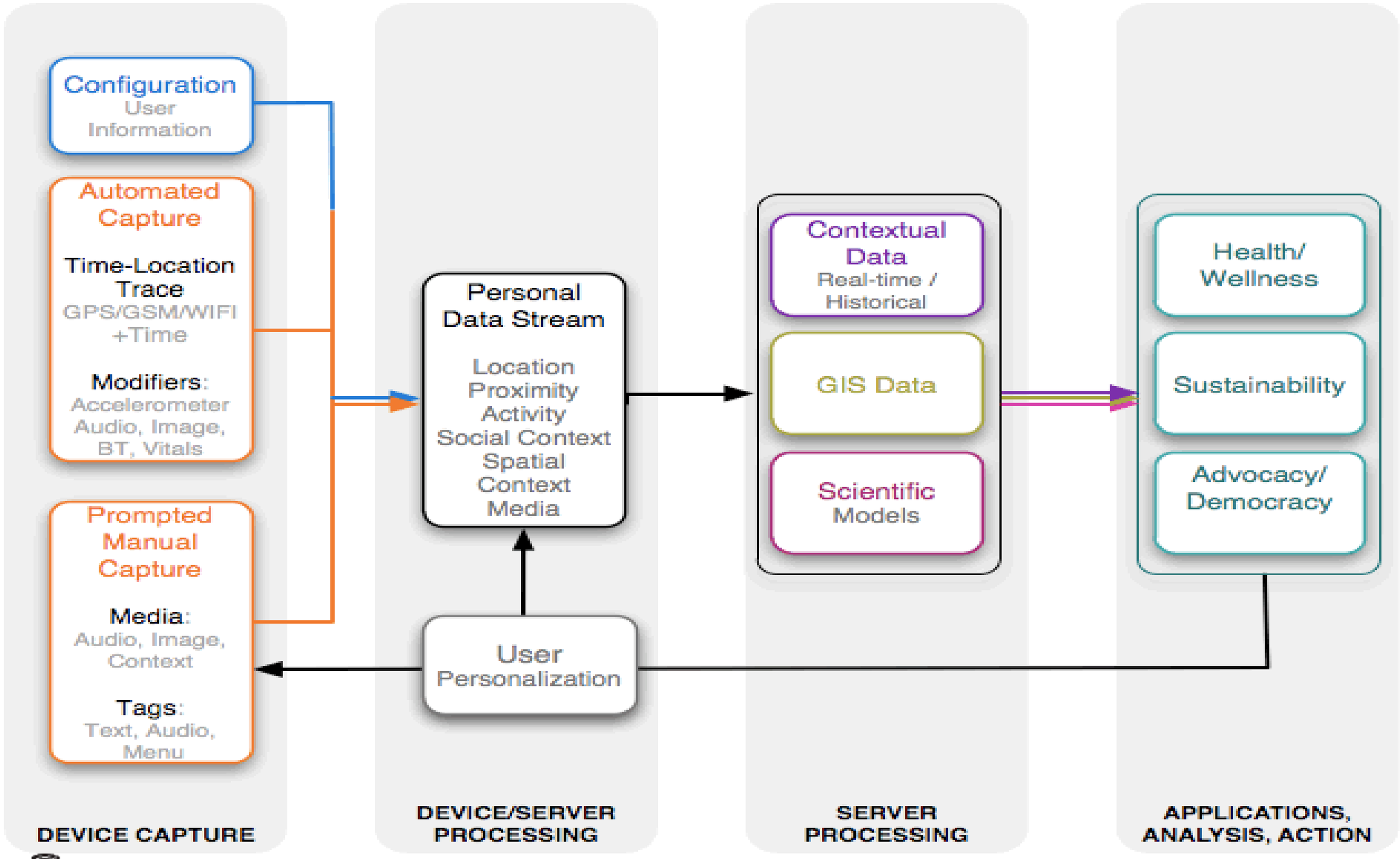
- **Bootstrap rapid cycle of learning, sharing, deployment**
- Deployment costs low if platform development, maintenance, and enhancement is shared (amortized) across many projects
- Basic capabilities can be specialized to particular populations, addictions, treatment protocols while 80-90% of system shared.

- **Shared platform will facilitate research in methodology, treatment**
- Systems can be built to gather usage data automatically, facilitating key components of evaluations
- Facilitate comparative effectiveness studies
- Facilitate natural experiments and RCTs in natural environments
- Explore details of adherence protocols and incentive mechanisms and share learning across field
- Encourage modularity and sharing in methodologies themselves

- **Explore balancing of privacy protection and data sharing**
- Systems can support variety of privacy/sharing policies
- Support greater transparency of research and data processes for participants

Our role?: foster innovation and public good

Explore and develop architecture, services, APIs, best practices, through iterative and open prototypes and pilots



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 platforms are a key building block.

Acknowledgments: Collaborators and Sponsors

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