Precision Medicine:
Building a Large U.S. Research Cohort

WORKGROUP: Mobile Data Collection and Engagement

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February 11, 2015

Current Landscape


- **World Gone Mobile**
  - Pervasive
  - Rapidly advancing
  - Inter-networked computing and communications environment
  - Extreme power at both the user and cloud level
  - Highly customizable
  - Simple user interfaces and interactions
  - Combined with secure communications enables novel opportunities for engagement and extensive longitudinal data collection.
  - Result is:
    - Entirely New Type of Science
    - Dramatically Lower Measurement Costs and Participant Burden
    - Automated Engagement and Support for Participants

Current Landscape

Cellphone Ownership, 2004-2013

Percentage of American adults who own a cell phone

91% May 2013

65% Nov 2004
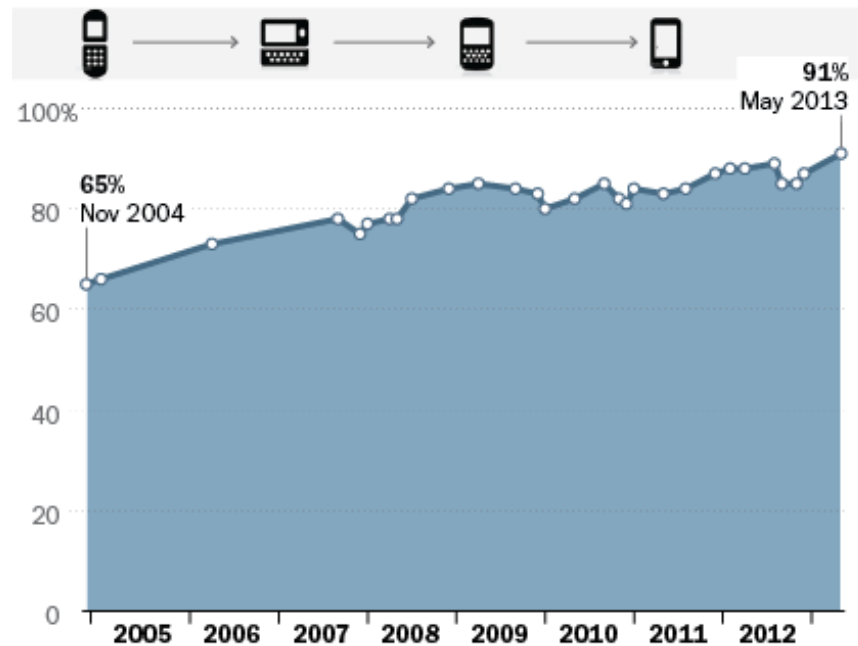
Source: Pew Research Center's Internet & American Life Project, April 17-May 19, 2013 Tracking Survey. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/-2.3 percentage points based on all adults (n=2,252).

PEW RESEARCH CENTER

	2010	2015	2020
World Population, billion	6.8	7.2	7.6
No. connected			
Devices, billion	12.5	25	50
Devices, per person	1.8	3.5	6.6
No. of smartphone subscriptions, billion	0.5	3.0	6.1
No. of wireless hotspots, millions	3.0	47	500
No. of transistors, millions/chip, nm	16/40	19/16	22/8
No. of sensors	20 million	10 billion	1 trillion
No. of individuals sequenced	<10	400000	5 million

From Topol et al, JAMA 2015

Challenges

- **Traditional longitudinal assessment is expensive, burdensome and often based on inaccurate self-report and periodic measures**
  - Vitals and disease specific monitoring (e.g., ECG, blood pressure, spirometry, etc.)
  - Patient reported outcomes (in real-time and context)
  - Medication adherence
  - Cognitive function
  - Physical activity; sleep
  - Geolocation
  - Social Interactions
  - Diet
  - Smoking and secondhand smoke exposure
- **Engaging participants in cohort studies is labor intensive & loss to follow-up is common**
  - People move over time and can fall off the map
  - Infrequent contact can lead to disinterest

Mobile Possibilities

GPS

EEG

Pulmonary Function

SpO$_2$

Posture

ECG

Gait

Blood Pressure

Balance

Step Height

Step Size

- Population Statistics
- Epidemiology
- Evidence
- Inference
- Data-mining

Illustration From Wactlar et al., 2011

Challenge [1]: Proposed Solution

- **By providing a smart phone and sensor devices**:
  - Longitudinal passive assessment:
    - Physiological parameters
    - Physical activity; Sleep
    - Geolocation
    - Social interactions
    - Stress
    - Smoking
  - Longitudinal active assessment of:
    - Medication adherence
    - Patient reported outcomes
   - Audio and video sampling of target questions
      via mobile media
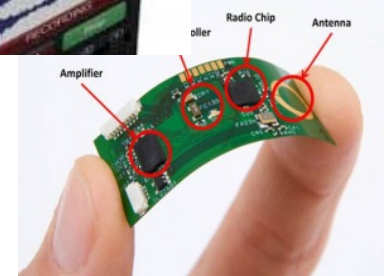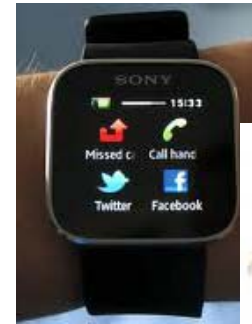
Challenge [2]: Proposed Solution

- **Using disease-specific devices in sub-groups**:
  - Longitudinal Assessment:
    - **Glucose** (glucometer, but could be CGM and pump data for those who have them)
    - **Heart function** (e.g., ECG, pacemaker data for those that have them)
    - **Blood pressure** via Pressure Cuff
    - **Lung Function** via Spirometry
    - **Weight; Temperature**
  - Incorporate emerging sensor technologies as they become available

  e.g., tattoo or subcutaneous and
  gum-based nested nanosensors to monitor
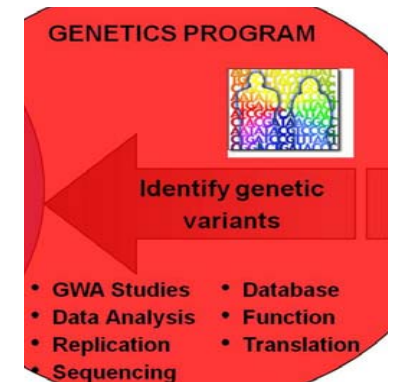 biological activity
  (Jeong et al., Adv Healthc Mater 2014,
  3(5):642-8).
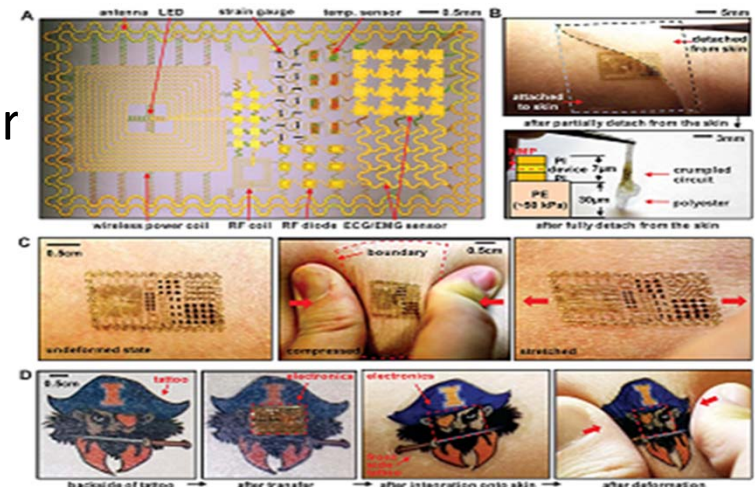
Challenge [3]: Proposed Solution

Mobile Data Systems Use :

- Establish dedicated effort within Precision Medicine initiative
- Leverage the current research in this area (HCI, UX, UI, user-centered design)
- Share best practices

- **Cohort Research Staff Attuned to Digital Needs**
- Research support staff work from the same protocols, policies and procedures manuals and technical assistance guidelines.
  - Goal is combination of Apple Genius Bar & optimal tech support
- Develop user-friendly protocols (e.g., Kindle for older adults).

GENETICS PROGRAM

Identify genetic variants

- GWA Studies   • Database
- Data Analysis   • Function
- Replication   • Translation
- Sequencing

Challenge [4]: Proposed Solution

- **Through the use of digital device data correlated with other cohort data, the initiative can:**
  - Generate more precise and longitudinally characterized behavioral phenotypes and endophenotypes
  - Assess gene-environment interactions on treatment and health
  - Better characterize treatment, adherence to treatment
  - Improved assessment of immediate and long range outcomes
  - Provide a platform for rapid testing of interventions to improve health
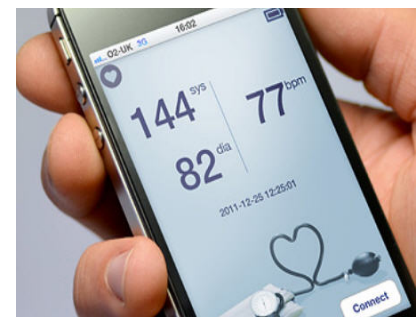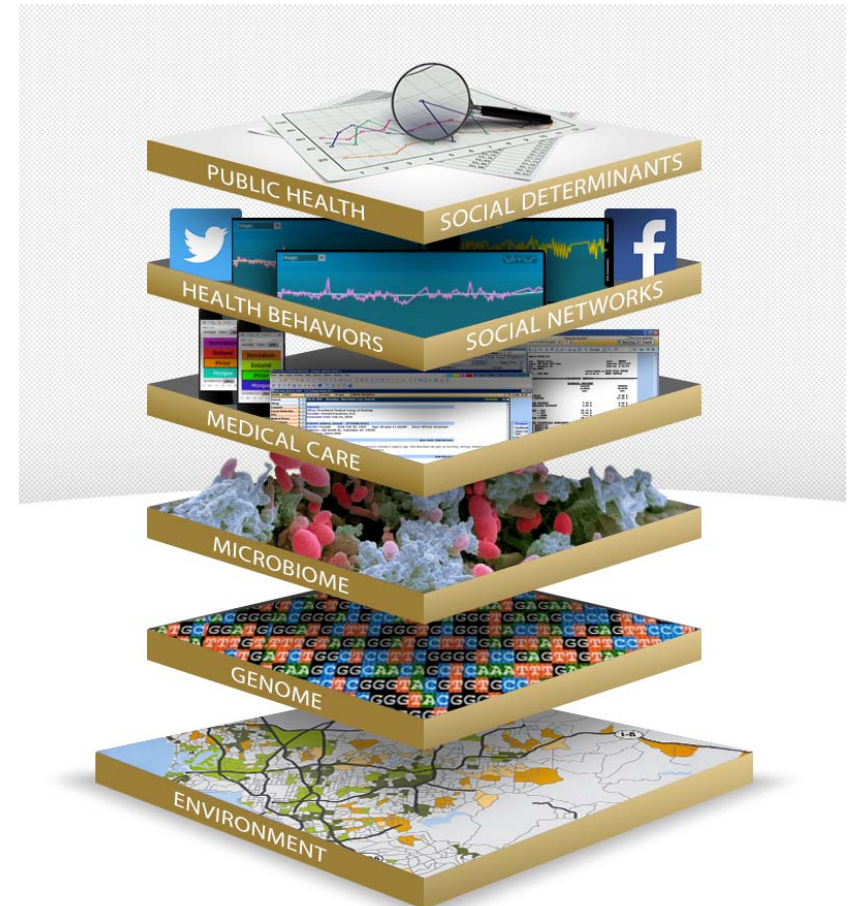
Challenge [5]: Additional Challenges

- Standards for sensor data
- Privacy, security and verification
- Support individual motivation with social, financial and personalized incentives for consistent participation
- Sociocultural acceptance to inform research
- Data quality in the wild
- Ease of use for people with varied technology backgrounds, socioeconomic and educational factors, and medical conditions.
- Sufficient connectivity and bandwidth must be available
- Measuring exposures to environmental factors is nascent
- Technical interface of sensors with varied digital platforms
- Rapid proliferation of new technologies
- Ownership of the data

Audacious Ideas

- **Recruit volunteers to open up <u>all</u> of their data** – genome, microbiome, medical/EMR, behavioral, social, precise geospatial (via addresses & GPS data) – so that multiple influences between and among these can be understood

- **Develop new culture of motivated participatory research:** Promote competitions between communities across the US to become "Framingham 2.0".

Major influences on health