Weill Cornell Medicine

mHealth and Participatory Medicine

JNIVERSITY OF MINNESO

Fernando Martin-Sanchez PhD, FACHI, FACMI ENaPHI Lab Division of Health Informatics Department of Healthcare Policy and Research

> 7.13.2016 hpr.weill.cornell.edu



Big Data Course

for Computational

Medicine



Outline





Weill Cornell Medicine

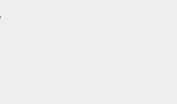
General description of the module



Fernando Martin-Sanchez PhD, FACHI, FACMI

- Assistant Professor (interim) Division of Health Informatics, Dept. of Healthcare Policy and Research
- Environmental and Participatory Health Informatics (ENaPHI) Research Group
- PhD in Informatics, PhD in Medicine, MSc in Knowledge Engineering, BSc Molecular Biology and Biochemistry
- Joined Weill Cornell in December 2015
 - Professor and Chair of Health Informatics, Melbourne Medical School (2011-2015)
 - Director, Health and Biomedical Informatics Research Centre, (HaBIC) the University of Melbourne (2013-2015)
 - Head of Dept. Medical Bioinformatics. National Institute of Health Carlos III of Spain. (1998-2010)
- Research interests: biomedical data integration, participatory health informatics, exposome informatics, precision medicine

→Email: fem2008@med.cornell.edu





mHealth and Participatory Medicine

- Digital health (participatory) technologies
 - smartphone apps,
 - personal sensing devices,
 - direct-to-consumer e-services
 - social media



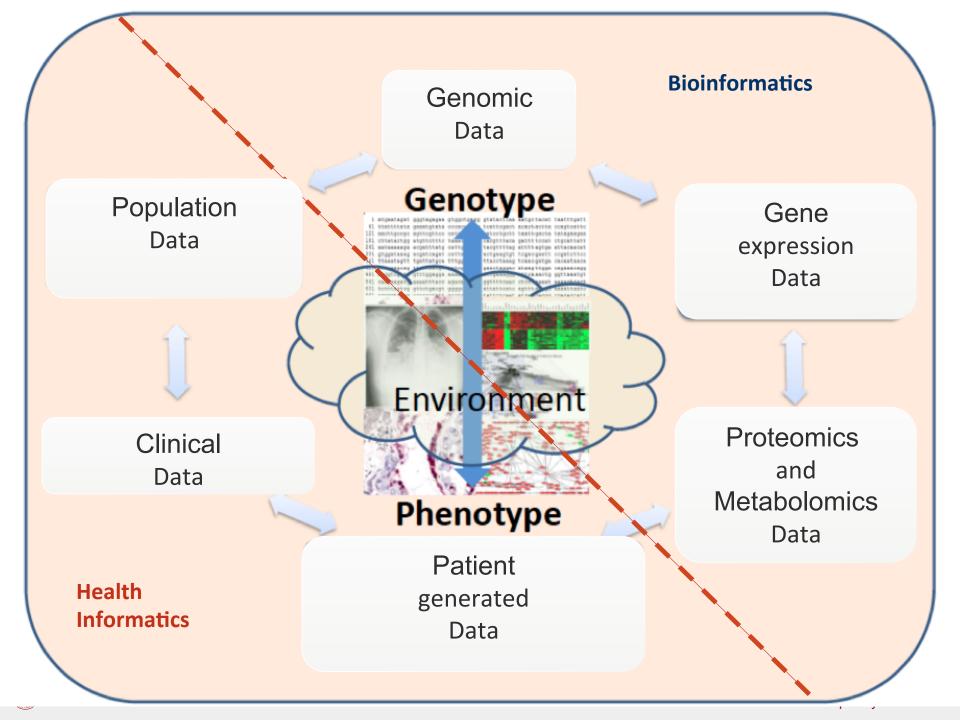
accessible and affordable for individuals

- Health Informatics is moving into new territories, beyond provider-generated clinical data PGHD (**Patient-generated health data**)
 - 1. Monitoring of individual environmental health risk factors. Exposome

2. Participatory Medicine

- This module will examine how participatory health technologies and informatics can contribute to generate richer and more robust data sets for biomedical and clinical research about health conditions, health interventions, and health outcomes.
- These new sources of individual **big and small data** (continuous, comprehensive and personalized) pose great challenges for Health Informatics and will require new approaches to data collection, storage, standardisation, integration, analysis and visualisation.





Person-Generated Health Data



- Gregory Abowd (2011) predicted "within 5 years, the main of clinically relevant data...will be collected outside of clinical settings."
- PGHD—health-related data created, recorded, or gathered by or from individuals to help address a health concern
- Individuals are responsible for recording data and decide how to share it (Personal Health Data)



Key Features	Framingham Heart Study	Precision Medicine Initiative Cohort Program	
Year Started	1948	2016	
Number of Individuals	5,209*	1,000, 000	
Age	30-62	All	
Ancestry	>95% European	Diverse, cross-section of Americans	
Medical data obtained	Every 2 yrs at office visit	Real world, real time, via mobile devices, Web	
Focus	Heart disease	All medical conditions, health	
Data return to participants	No	Yes	
Data available for research community	No	Yes	

* Initial cohort

Dr. Eric Topol

Informatics G R O U P



A different way to recruit research participants



- For a recent breast cancer study, epidemiologist Kathryn H. Schmitz of the University of Pennsylvania sent out 60,000 letters—and netted 351 women. Walking each participant through the paperwork took 30 minutes or more. Such inefficient methods of finding test subjects have been the norm for medical research.
- Apple, working with Stanford University School of Medicine, developed MyHeart Counts, an app for monitoring cardiac health. Within the first 24 hours, 10,000 participants signed up for the study.
- Kelton and Makovsky Health -fifth annual "Pulse of Online Health" found that 66 percent of Americans would use a mobile application to manage health-related issues.
- The patient's voice has largely been missing from most of the design and the focus of clinical studies (Ken Mandl, Harvard).
- Citizen science, participatory health

Contents

Introduction to Participatory Medicine



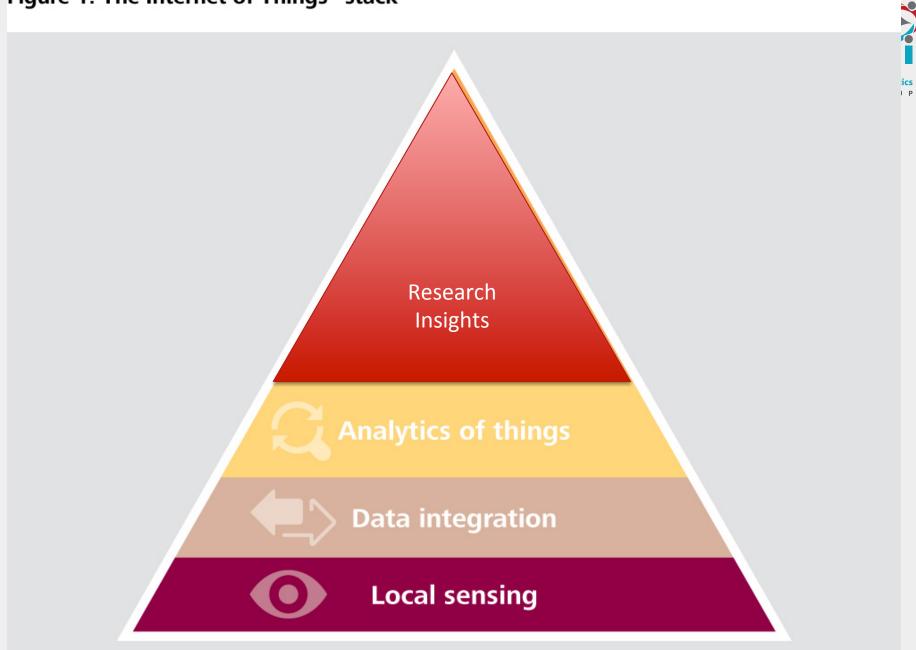
- Participatory technologies and the individual exposome (mobile Health and the Self-Quantification as new sources of Big -and Small- data)
- Participatory Health Informatics
 - From Sensors to information
 - Data collection
 - ✓ Hardware (sensors, portable devices, smartphones)
 - ✓ Software (Apps, Healthkit, Carekit, ResearchKit, ResearchStack)
 - Data storage
 - Data aggregation and integration (Apple Health, Validic, Shimmer, Open mHealth, ohmageomh, Wolfram Connected Devices project, Samsung ARTIK Cloud, Qualcomm Life, Human API, EHR integration aspects)

- From Information to Knowledge

- Data access
- Data analysis
- Data visualization
- From knowledge to Application (relevant initiatives)
 - Health eHeart study, Google Baseline, 100K Wellness Project, Precision Medicine Initiative, Health Data Exploration and Network, mPower study, Open Humans, N-of-1 (single subject) studies, BD2K Centers of Excellence (emobilize, MD2K)



Figure 1. The Internet of Things "stack"



Weill Cornell Medicine

Introduction to Participatory Medicine

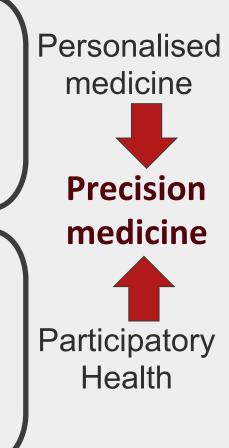


Current challenges in Medicine

- Need of earlier diagnosis
- More personalized therapies
- Clinical trials and the development of new drugs need to be faster and more effective
- Improve disease classification systems
- Risk profiling, disease prediction and prevention
- Control health system costs
- Citizens should take more responsibility for the maintenance of their own health.

→Emphasis on prevention, not cure





Conference PHC



To offer a forum to learn and discuss how health informatics and information technologies can be successfully applied to encourage individuals to play a more active role in their health.

This will enable cooperative models of care that have the potential to contribute to more preventive approaches, better disease management, health promotion and control of health system costs.





Improving YOUR HEALTH using technological advances and information

11 August 2014 Melbourne Convention & Exhibition Centre





- Personalized preventive health maintenance
- Participatory medicine
- Patient-centric care
- Democratization of health information

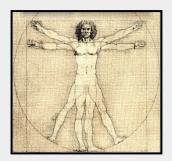
The Convergence of the Digital Revolution and Medicine



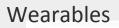
- We are witnessing the impact of the digital revolution in other domains (banking, insurance, leisure, government, ...)
- Although digital technology has greatly affected healthcare at the hospital or research centre level.
- The digital revolution has not yet reached medicine at the patient/citizen level
 - THIS IS STARTING TO HAPPEN NOW !!!







Availability of devices, sensors, apps, **DTC services and Social Networks**







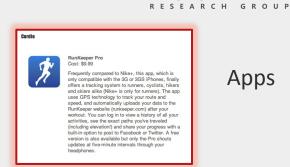
DTC lab tests







S Clustering 80 your microbiome data and how to understand μBiome *





Environmental and Participatory Health Informatics

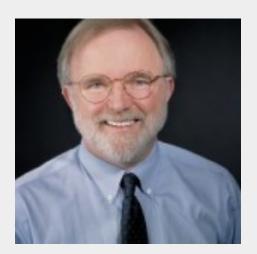




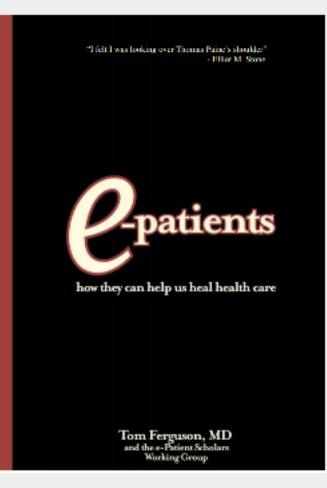
History of Participatory Health



- Tom Ferguson MD (died in 2006)
- Coined the term e-patient
- "e-patient: how they can help us to heal health care"







History of Participatory Health



- September 2009 California Healthcare Foundation Report: *"Participatory Health: Online and Mobile Tools Help Chronically III Manage Their Care"*
- "Partnership between patients and providers and trusted experts, one in which participation is enabled and enhanced by technology and information"
- "Patients are the most under-utilized resource, and they have the most at stake. They want to be involved and they can be involved. Their participation will lead to better medical outcomes at lower costs with dramatically higher patient/customer satisfaction"

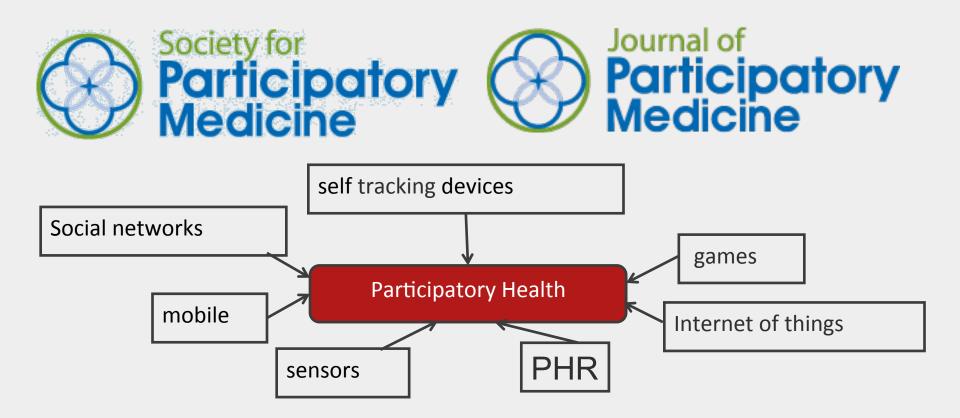
Charles Safran MD



History of Participatory Health



2009. \rightarrow Patients empowered, informed and involved in decision making, prevention and learning



Definition





Society for Participatory Medicine

"Movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which medical care providers encourage and value them as full partners".

Regina Holliday

E-patients

- Gimme my damn data!
- The patient will see you now...
- Let patients help
- Nothing about me without me!
- Dave de Bronkart
- Regina Holliday
- Hugo Campos
- Salvatore laconesi
- Stephen Keating
- Sonia Vallabh & Eric Minikel
- Stephen Damiani
- Matt Might



IQ CUIQ the cure

Un tumore al cervello. Degli Open Data molto personali. Una opportunità. A brain cancer. Some very personal Open Data. An opportunity.



Participatory Health Informatics





Casey Quinlan @MightyCasey

I for one threw privacy overboard like a dead cat by planting this on my chest (PW protected, tho) #hcsmca

🛧 Reply ★ Favorite 📚 Buffer 🚥 More 📲 HootSuite

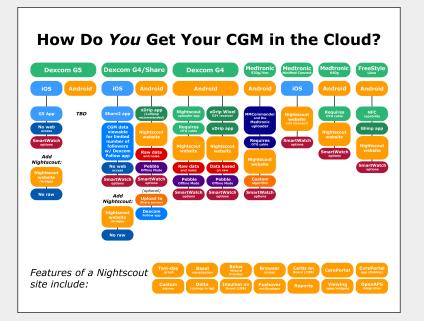






WeAreNotWaiting

Nightscout (CGM in the Cloud) is an open source, DIY project that allows real time access to a CGM data via personal website, smartwatch viewers, or apps and widgets available for smartphones.



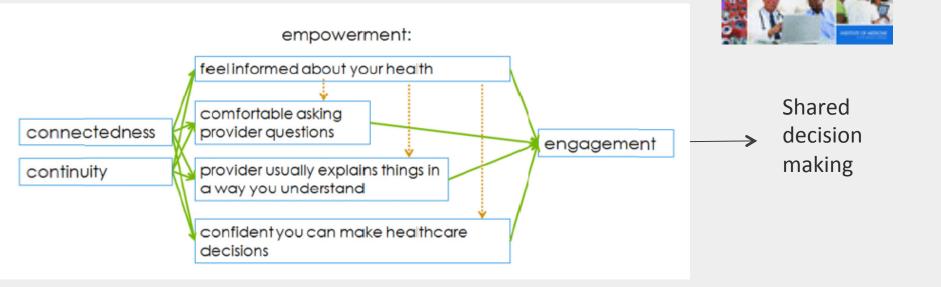


Dana Lewis and her husband Scott Leibrand invented the <u>Do It Yourself Artificial</u> <u>Pancreas System (#DIYPS)</u>

She then took it a step further, founding the #OpenAPS movement to make safe and effective basic Artificial Pancreas System technology more widely available (and sooner).

IOM Workshop & Report 2013

Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement - Workshop Proceedings





PARTNERING

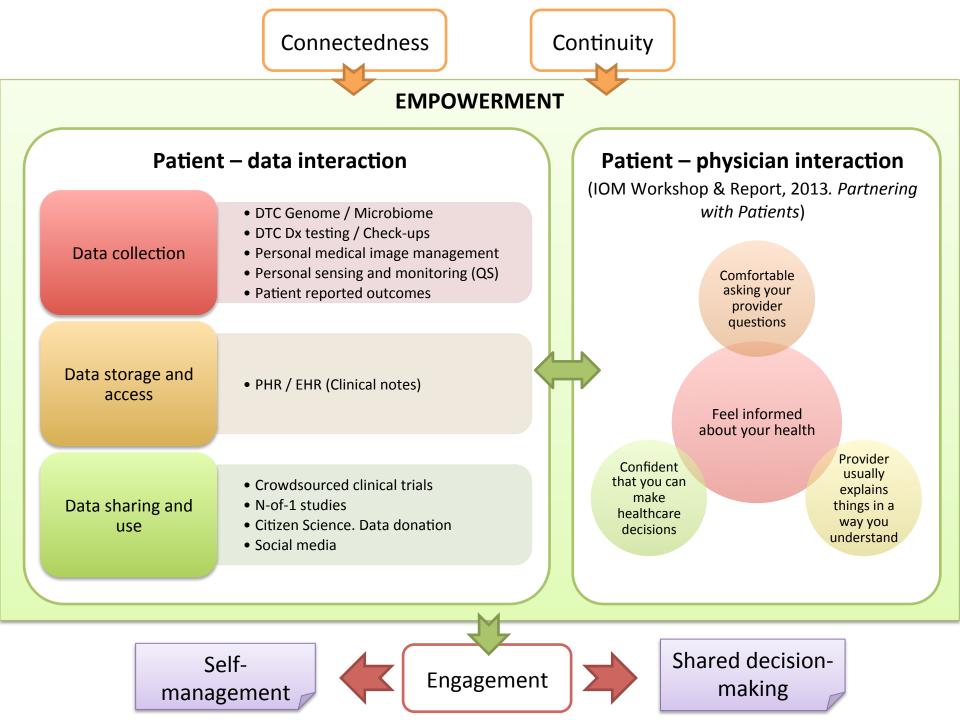


Table 1

Some examples of validated questionnaires capturing (aspects of) patient empowerment



Measure	Conditions- specific or generic?	Construct operationalised	Reference
Patient Enablement Instrument	Generic	Aspects of perceived control over illness	Howie et al. 1998 [19]
Patient Activation Measure	Generic	Activation levels (skills, knowledge, and beliefs needed by patients to self-manage, collaborate with healthcare providers and maintain their health)	Hibbard et al. 2005 [20]
The Empowerment Scale	Conditions- specific: Mental healthcare	Self-efficacy, power-powerlessness, community activism, righteous anger, and optimism-control over the future	Rogers et al. 1997 [21],
Diabetes Empowerment Scale	Conditions- specific: Diabetes	Self-efficacy	Anderson et al. 2000 [22]
Patient Empowerment Scale	Conditions- specific: Cancer	Use of coping resources, an aspect of personal control	Bulsara et al. 2006 [23]
Genetic Counselling Outcome Scale	Conditions- specific: Genetic conditions	Perceived personal control (cognitive, decisional and behavioural control), hope and emotional regulation	McAllister et al. 2011 [24]



Research and events

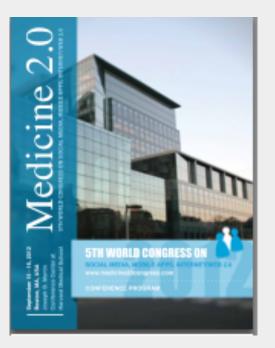


JMIR





self knowledge through numbers



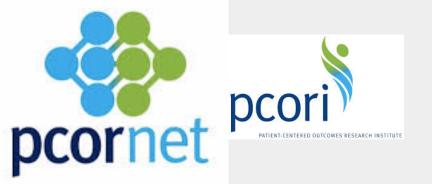
Medicine **x**

THE INTERSECTION OF MEDICINE AND EMERGING TECHNOLOGIES



Interest from Governments





Australian PCEHR myHealth Record



Victorian Health Priorities Framework 2012-2022: Metropolitan Health Plan

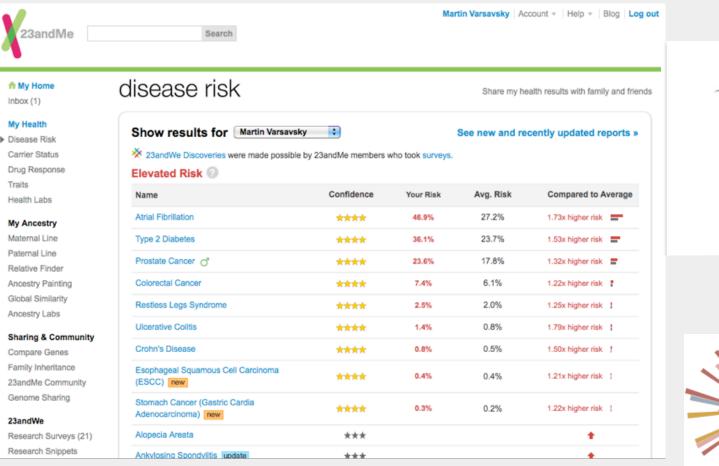
People are managing their own health better.



Available to me Available to my health and care professionals Availa

New NHS Information strategy emphasises patient-centric healthcare records

Personal Genomics & Microbiome





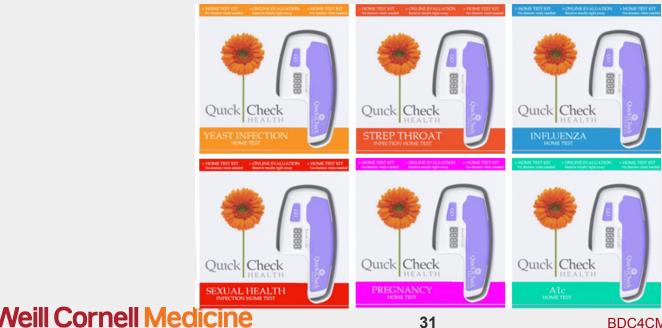
HUMAN MICROBIOME PROJECT



Personal diagnostic testing



- "Test at home, treat online"
- Urinary tract infection, strep throat, flu, cholesterol, Lyme disease, Mono, sexually transmitted diseases, pregnancy, yeast infections and others.
- (Not yet evaluated by regulatory agencies)





Personal medical image management



Access to your personal X-rays, MRIs and other diagnostic images. Get started today with our easy-to-use HealthVault App.





Empowering Patients

Personal Medical Image Archive in the Cloud

- ★ XRFiles is an easy way to share, store and manage your medical image exams. Send them securely and in full fidelity to experts to seek 2nd opinion.
- ★ Your privacy is our priority. No one but you or people you authorized will have access to your exams. Full real-time audit trail and permissions you can review, modify and revoke at any time keep you in full control.

Radiologists, PACS Admins

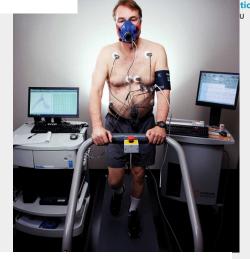
Patient image communications without CDs licensed or hosted solutions

> Call now to schedule a meeting (650) 409-7292 or email to info@XRFiles.com

- Self tracking / self quantifying / self monitoring
- The belief that gathering and analysing data can help them improve their lives!
- Groups 228, Members 67K, Cities 89, Countries 31
- Quantified Self is a collaboration of users and tool makers who share an interest in self knowledge through self-tracking.
- There are three main "branches" to our work.
 - The Quantified Self blog and community site.
 - Show and Tell meetings (Meetup groups) -
 - Quantified Self Conferences (US and Europe

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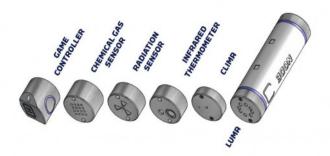


CardioDefender

CardioDefender is the first system to deliver mobile, real-time, beat-by-beat, and quantitative heart monitoring and automated reporting by combining patented analytical smartphone software with a wireless device and electrodes.



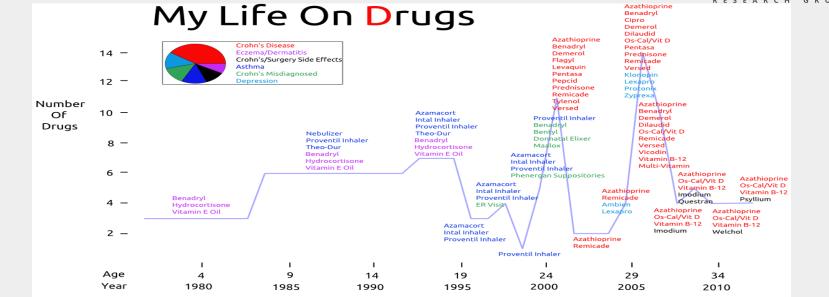




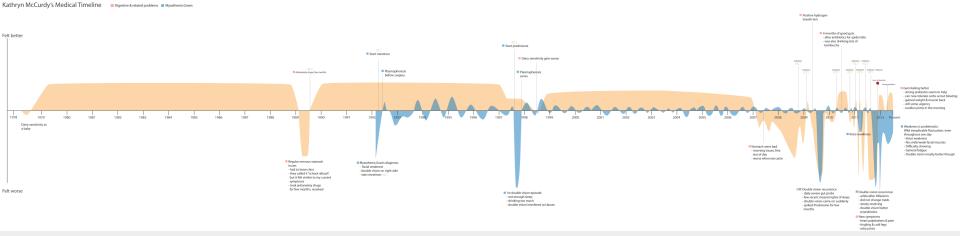


Personal Health Records



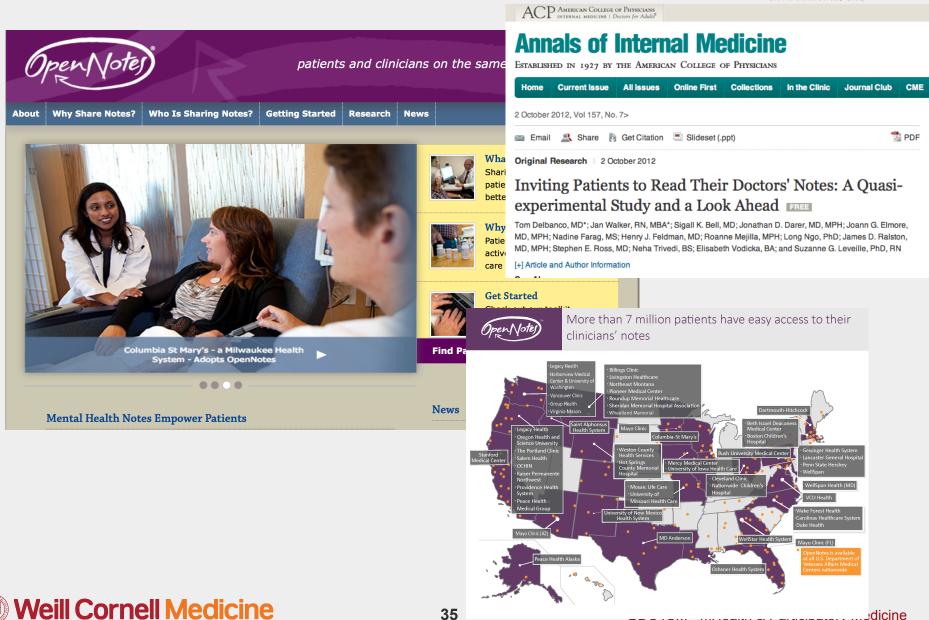


Source: diyehr.com | Kenneth Spriggs



Open Notes – Patients reading Doctor's notes





Open Notes – Patients reading Doctor's notes



- Individuals with access to their health information are
 - better able to monitor chronic conditions,
 - adhere to treatment plans,
 - find and fix errors in their health records,
 - track progress in wellness or disease management programs, and
 - directly contribute their information to research.

Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164.524



Crowdsourced clinical trials



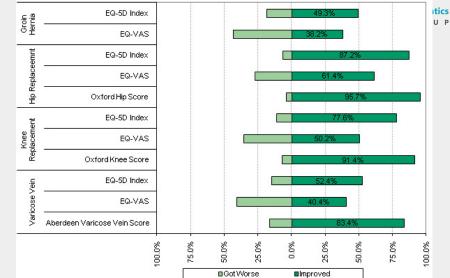
- Clinical Research with the patients, not on the patients
- Examples
 - 23andMe Parkinson's Disease PLoS Genetics, 2 new genetic associations
 - PatientsLikeMe Nature Biotech. Self-reported data from 600 patients on the use of lithium for Amyotrophic Lateral Sclerosis (ALS)
 - Acor, RevolutionHealth, Curetogether, Genomera, Althea Health





Patient reported outcomes

- Health services and outcomes research
- Measuring quality of care from the patient perspective



NHS PROMs



pcornet The National Patient-Centered Clinical Research Network

pcori



Shared decision support





Expert Systems with Applications

Volume 39, Issue 14, 15 October 2012, Pages 11775-11781



Shared decision support system on dental restoration

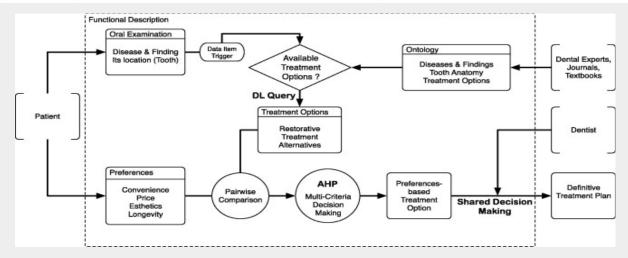
Seon Gyu Park^{a,} 🎽, Sungin Lee^{b,} 🎽, Myeng-Ki Kim^{a,} 🎽, Hong-Gee Kim^{b, c,} 📥 🖓

^a School of Dentistry, Seoul National University, 28 Yongon-Dong, Choong-gu, Seoul 110-749, South Korea

^b Biomedical Knowledge Engineering Laboratory, Seoul National University, 28 Yongon-Dong, Choong-gu, Seoul 110-749, South Korea

^c Dental Research Institute, Seoul National University, 28 Yongon-Dong, Choong-gu, Seoul 110-749, South Korea

http://dx.doi.org/10.1016/j.eswa.2012.04.074, How to Cite or Link Using DOI



The Blue Button and Blue Button +





Blue Button Download My Data

Meaningful use – V/D/T View/ Download/ Tra

Transmit.

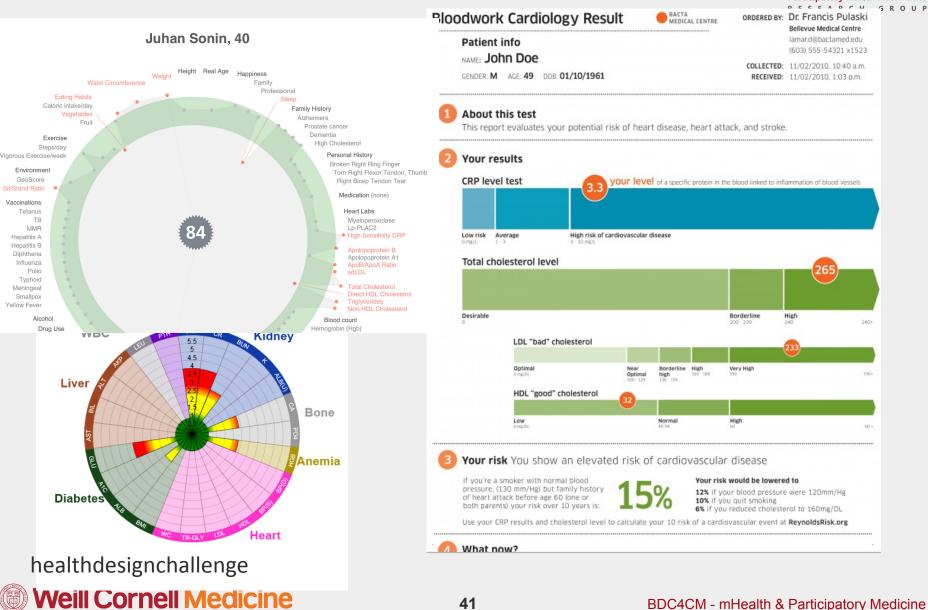
Blue Button+

The Blue Button is a symbol for patients to view online and download their own personal health records.

Blue Button+ extends the Blue Button concept to include a standardized data format and additional functionality



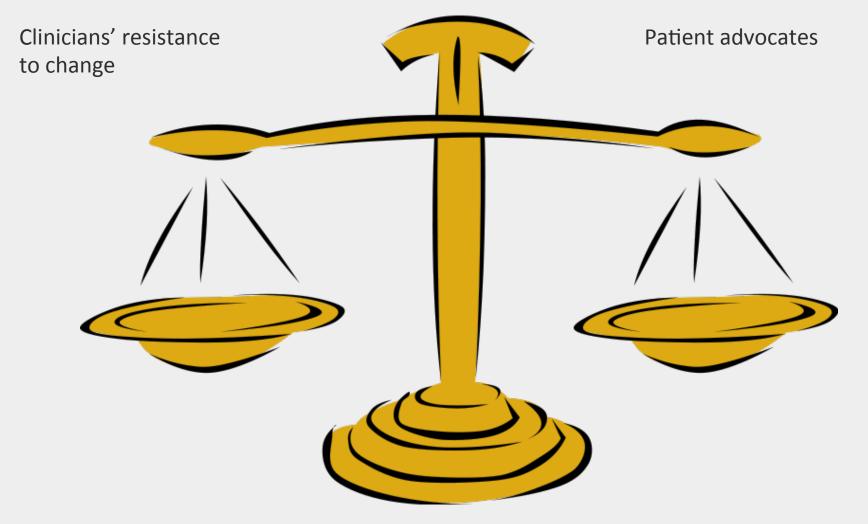
Visualisation tools



Environmental and Participatory Health Informatics











MEDICINE	PARTICIPATORY HEALTH
Provider-centric	Patient or Consumer-centric
Curative	Proactive
Passive role of the patient	Active
Clinical decision making	Shared decision making
Electronic medical record	Patient Health Record

Adherence, compli	ance vs	activation
Literacy	VS	Clarity
Research n=they	VS	n=me and n=we

Patient-generated data

Submissions to Australian PCEHR Review - Nov 2013



AMA

- it must be recognised that as a design feature of the PCEHR, patient control means that the PCEHR cannot be relied on as a trusted source of key clinical information.
- The absence of specific remuneration for medical practitioner contribution to the PCEHR reinforces the need to ensure that using PCEHR functions does not impose any additional workflow requirements on them.

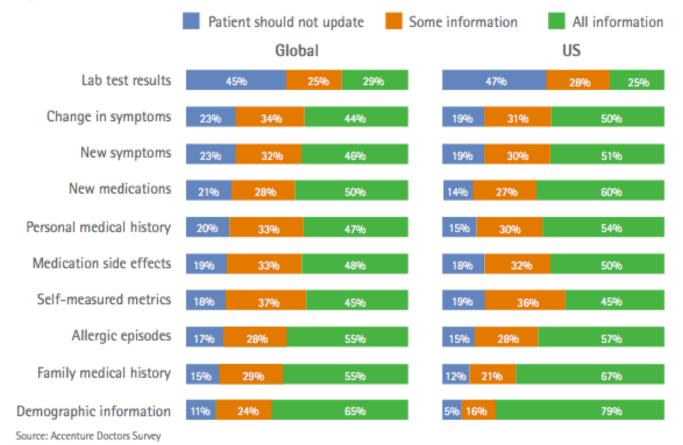
Consumer Health Forum, Consumer e-health Alliance

- The 'personally controlled' aspect of the eHealth record is what makes it such a powerful consumer resource.
- Patients and potential patients – health consumers – must be informed and engaged as the ultimate users of the PCEHR.

US Doctors were the most open toward patients updating the information in their EHRs



Figure 2: Information Patients Should be Able to Update in Electronic Health Record



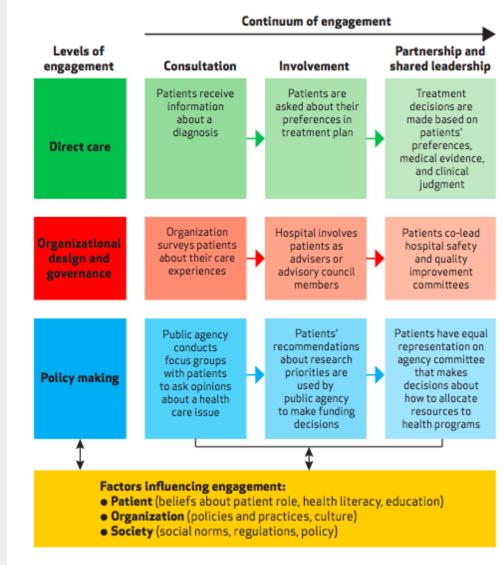
US doctors were the most open toward patients updating the information in their electronic health records, according to Accenture's eight country survey of 3,700 doctors.

Evolution

Shenkin B, Warner D. Giving the patient his medical record: a proposal to improve the system. NEJM, 1973

EXHIBIT 1

A Multidimensional Framework for Patient and Family Engagement in Health and Health Care



SOURCE Kristin L.Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223–31. NOTE Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.



Patients / citizens / scientists /



<u>Stephen Keating</u>
 <u>https://exponential.singularityu.org/medicine/can-selfies-save-us-with-steven-keating/</u>

- Regina Holliday
 <u>https://vimeo.com/24857924</u>
- Matt Might <u>http://healthsciences.utah.edu/innovation/algorithms/2015/five.php</u> <u>http://matt.might.net/articles/my-sons-killer/</u>
- Stephen Damiani
 http://www.missionmassimo.com/
- Sonia Wallabh & Erik Minikel https://www.youtube.com/watch?v=ni4RRMz2mJQ

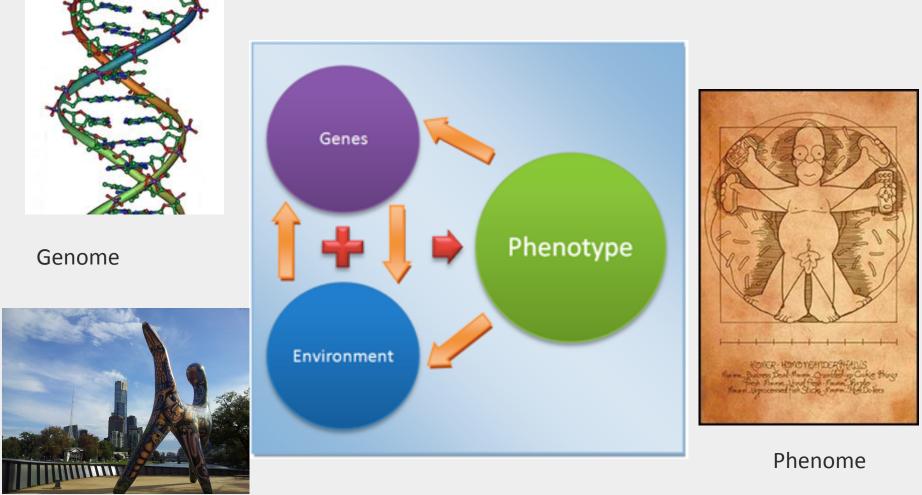
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Participatory technologies and the individual exposome

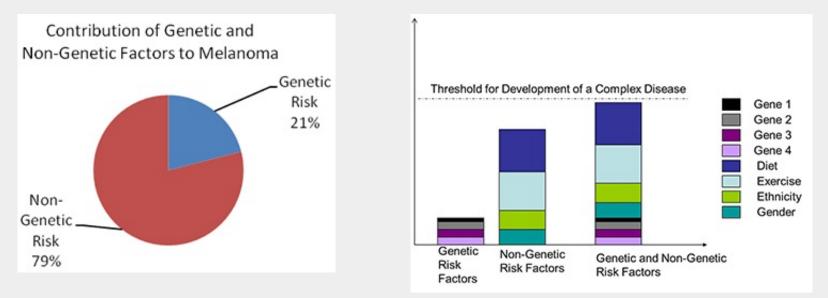




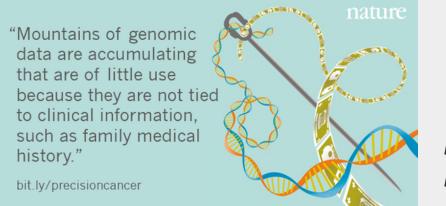




Exposome



Coriell Personalised Medicine Collaborative

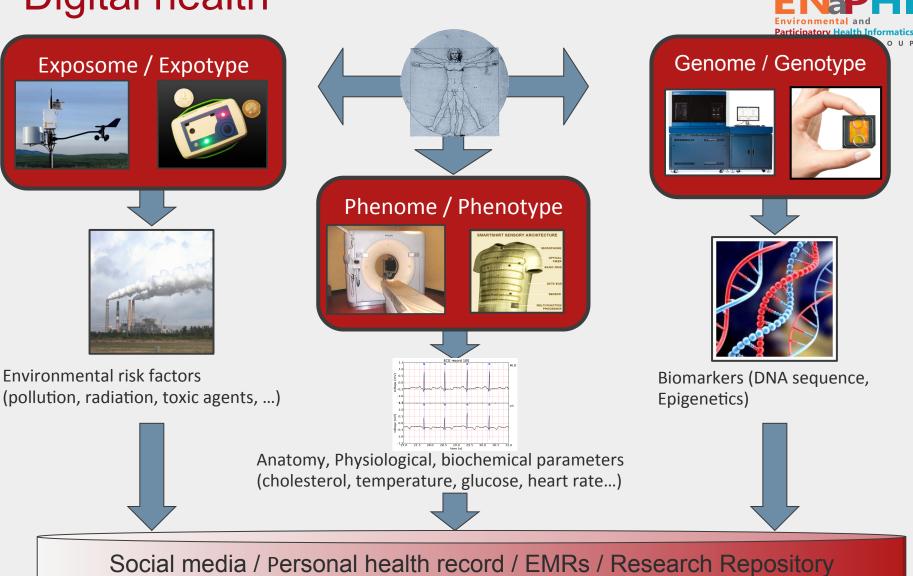


Marc Rubin, Nature 2015

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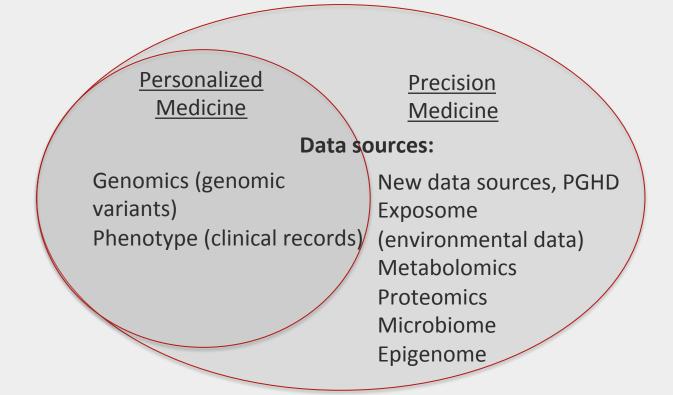
RESEARCH GROUP

Digital health



Personalized vs Precision Medicine



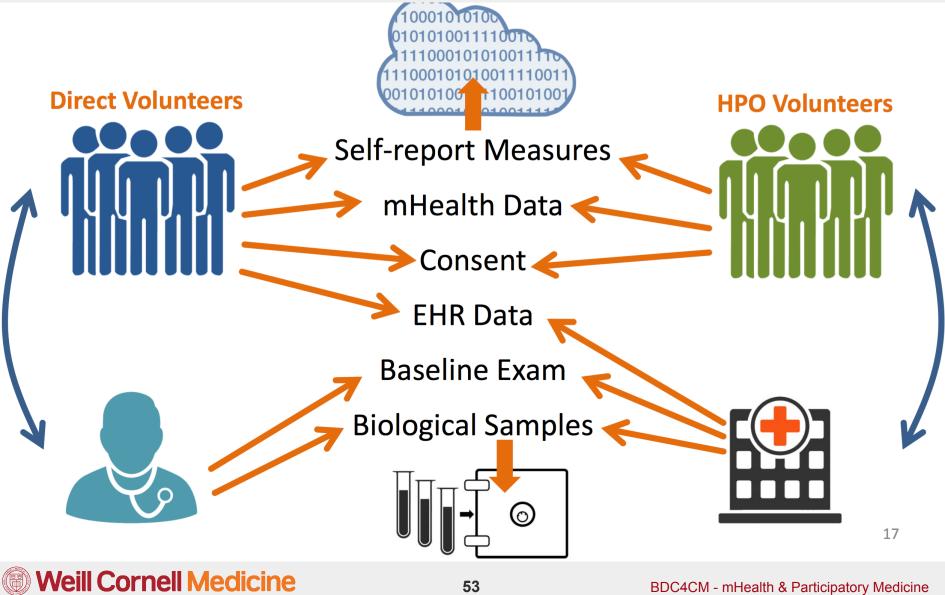


PM combines the knowledge of the patient's characteristics with traditional medical records and environmental information to optimize health.

PM does not only rely on genomic medicine but also integrates any other relevant information such as non-genomic biological data, clinical data, environmental parameters and the patient's lifestyle.

Servant N et al. Front Genet. 2014; 5: 152.

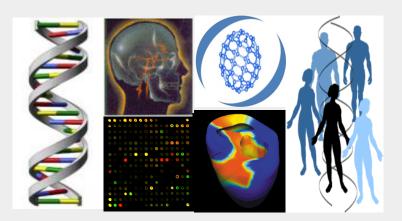




Role of Biomedical Informatics in the PMI



 Emerging approaches to disease prevention, diagnosis, and treatment through detecting, measuring, and analyzing individual variations in molecular, genomic, cellular, clinical, imaging, behavioral, physiological, and environmental data.





Final remarks

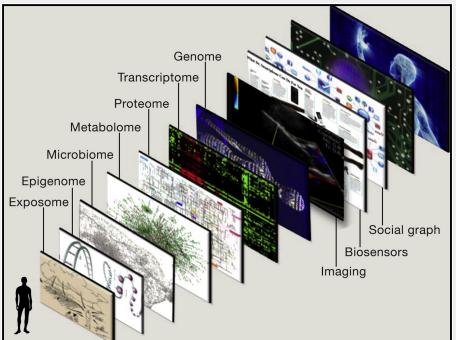


 Precision medicine enables a safer, more efficient, preventive and proactive medicine, but needs to tackle the complexity and diversity of personal health information, beyond the genome sequence.

55

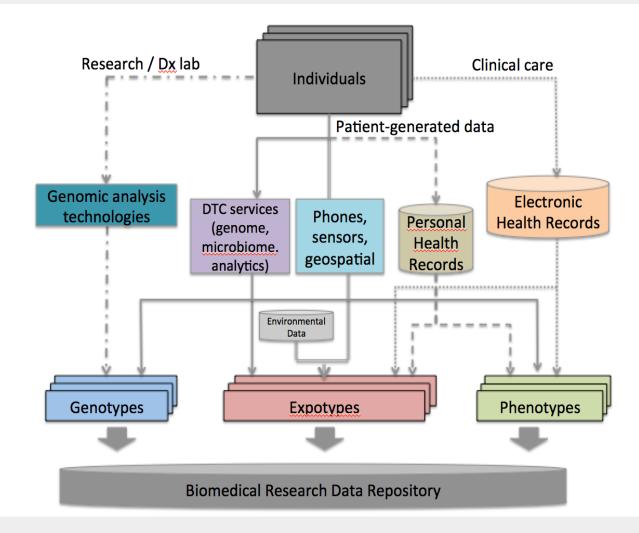






Data flow





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Participatory Health Informatics





From sensors to information





Data collection mApps





Choosing the best app

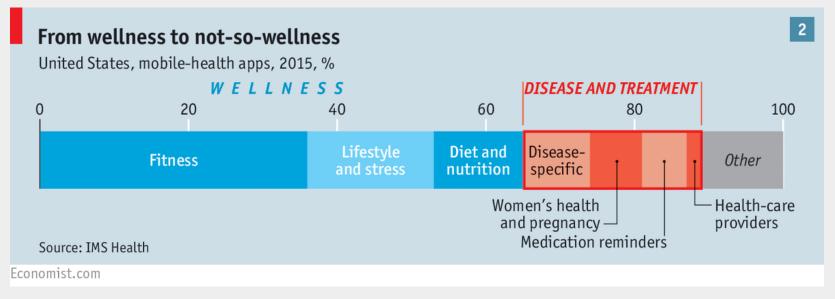


BDC4CM - mHealth & Participatory Medicine

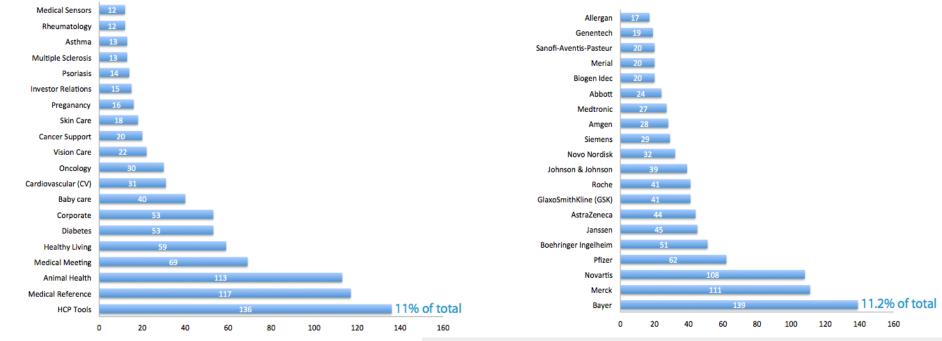
Mobile-health apps



 There are now around 165,000 health-related apps which run on one or other of the two main smartphone operating systems, Apple's iOS and Google's Android. PwC, a consulting firm, forecasts that by 2017 such apps will have been downloaded 1.7 billion times (The Economist)

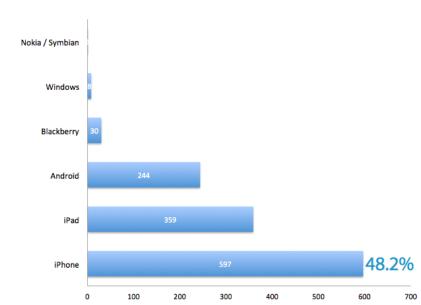


Top 20 Apps by condition (# of apps) Top 20 App Makers (# of apps)



62

Apps by device



The Evolving Landscape of Medical Apps in Healthcare

http://hitconsultant.net/2014/06/23/theevolving-landscape-of-medical-apps-inhealthcare/



VIEWPOINT

Paver + Provider

Massachusetts.

Harvard Medical

School, Boston, Massachusetts

Hospital, Boston,

Partners Information

Systems, Wellesley,

David W. Bates, MD

Brigham and Women's

Harvard Medical School Boston

Massachusetts,

Hospital, Boston,

Systems, Wellesley,

Massachusetts and

Harvard School of Public Health, Boston,

Massachusetts

Massachusetts Partners Information

Massachusetts

Syndicate, Boston,

In Search of a Few Good Apps

mHealth apps are mobile device applications in-Adam C. Powell, PhD tended to improve health outcomes, deliver health care services, or enable health research.¹ The number of apps has increased substantially, and more than 40 000 health, fitness, and medical apps currently are avail-Adam B. Landman, MD able on the market.² Because apps can be used to inexpensively promote wellness and manage chronic diseases, their appeal has increased with health reform and Brigham and Women's the increasing focus on value. The bewildering diversity of apps available has made it difficult for clinicians Massachusetts, and

> most effective. The US Food and Drug Administration (FDA) has paid close attention to mHealth apps, because it has regulatory authority over their safety. The agency recently clarified that mHealth apps acting as medical devices or as accessories to medical devices will require FDA approval, whereas apps that provide users with the ability to log life events, retrieve medical content, or communicate with clinicians or health centers will not be regulated under its jurisdiction.3 For example, an app that tracks glucose levels and suggests insulin dosages would be regulated, whereas an app that tracks a patient's weight and makes general suggestions about exercise would not. In general, apps that provide precise treatment recommendations and diagnostic information will receive more regulatory attention. Although the FDA has focused on safety, it has largely left the review and certification of apps to the marketplace.

and the public to discern which apps are the safest or

The currently available reviews of mHealth apps have largely focused on personal impressions, rather than evidence-based, unbiased assessments of clinical performance and data security. Although evidencebased reviews are not extensively available for mHealth apps, they are available for other categories of health information technology software. For instance, KLAS has successfully made a business out of producing report cards on the quality of health information technology vendors and enterprise software packages, presumably simplifying the lives of hospital leaders.⁴ This model has worked for enterprise software because users of expensive software are seemingly willing to fund unbiased reviews. However, this approach appears unlikely to work for mHealth apps because users of free and inexpensive apps are less financially invested in their decisions than hospitals. Furthermore, certification may be problematic in mHealth because certification companies ordinarily aim to generate revenues by charging the app developers they are evaluating-an inherent conflict of interest. Thus, there is a need for alternative models for app review and certification that are sustainable and free of conflict of interest.

However, given the sheer number of mHealth apps, it is unlikely that all will ever be meaningfully reviewed by a single organization. As a start, an organization could feasibly review the quality of the most widely used and clinically useful mHealth apps, Furthermore, guidelines could be established to help developers build highquality apps and to serve as a basis for app review. The guidelines might include a broad range of categories, such as safety, accuracy, and security. By telegraphing these guidelines, as well as standardized approaches to achieving them, the organization will be able to influence mHealth app developers early in their planning process, enabling them to build their apps with these principles and a review process in mind.

App review organizations would likely need to include in their reviews a certification process to ensure that apps do not pose potential harm to their users or have significant security and privacy vulnerabilities. Certification entities in other industries are successfully protecting people from harm. For instance, the Health On the Net Foundation, a nonprofit, nongovernmental organization, plays an active role in evaluating the quality of online medical content and provides websites a certification that assures both consumers and clinicians of the accuracy of the medical content.⁵ Similarly, Underwriters Laboratories is a well-respected for-profit entity that provides meaningful but optional information that consumers can use to evaluate the safety of electronic devices. In mHealth, the startup Happtique began certifying the operability, privacy, security, and content of apps but ultimately suspended its operations after a developer discovered that 2 certified apps handled data insecurely.⁶ The attention that Happtique received suggests that many people consider the security of mHealth apps to be important and want them to be evaluated rigorously. From these cases, it appears that both nonprofit and for-profit certification are viable means of improving the quality of low-cost and free consumer products and services and that there is demand for mHealth apps to be certified. The Office of the National Coordinator for Health Information Technology (ONC) could help support the development of mHealth app guidelines and eventually commission app certification entities, as it is now doing for electronic health records (EHRs).

Another important role for app review organizations is illuminating the effectiveness of mHealth apps. Although more rigorous evaluations are needed across all mHealth, many apps share components (eg, reminders, logging, pedometer). Evidence for these common features might be cited in app reviews. For example, because countless apps use smartphone-based accelerometers as makeshift pedometers, it would be help ful to highlight that evidence suggests that pedometerbased walking interventions are associated with an average weight loss of 0.05 kg per week.7 Greater focus on outcomes may shift the focus of app develop-



Opinion

Environmental and Participatory Health Informatics RESEARCH GROUP

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> JAMA May 14, 2014 Volume 311, Number 18 1851



Evaluation - IMS Institute





6-10 11-15 16-20 21-25 26-30 31-35 36-40 31-45 46-50 51-55 56-60 61-65 65-70 71-75 76-80 81-85 86-90 91-95 96-100 Functionality score

Source: IMS Health analysis of widely available consumer targeted healthcare apps

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6

Evaluation – RankedHealth.com RANKED =ρ

Curated Health Apps & Devices

With a Focus on Clinical Relevance, Safety, and Efficacy

Reviews by Clinicians, Researchers, & Patients.

Led by Experts From Top Ranked Teaching Hospitals & Universities.



CARDIOVASCULAR

Hello Heart Premium

Acceptable: 70

An outstanding mobile app for people interested in monitoring and tracking their blood pressure. However, it lacks high-quality evidence to backup their claims of helping people manage/ optimize blood pressure control.



REPRODUCTIVE HEALTH/ PREGNANCY

Ovia Fertility

Acceptable: 70

A well designed app intended for women of childbearing age for fertility planning



Acceptable

Clinical Effectiveness

Functionality

Usability

MIT

Hacking

Medicine

Institute

Version: 1.9.6 Developer: Hello Doctor, Ltd Review Date: 2016-03-02 Cost: \$59.99; OR requires premium code from employer

> 1. Mental Health 1. Fitness

2. Heart Disease 2. Medication Adherence

3 Diabetes 3. Symptom Tracking

4. Obesity 4. Reproductive Health

5. Sleep Disorders

5. Emergency/ Acute Care

Evaluation - MARS



 Mobile App Rating Scale: A New Tool for Assessing the Quality of Health Mobile Apps

Criterion category	Frequency, N=349	(%)
App classification, confidentiality, security, registration, community, affiliation	12	(3.4)
Aesthetics, graphics, layout, visual appeal	52	(14.8)
Engagement, entertainment, customization, interactivity, fit to target group, etc	66	(18.9)
Functionality, performance, navigation, gestural design, ease of use	90	(25.8)
Information, quality, quantity, visual information, credibility, goals, description	113	(32.4)
Subjective quality, worth recommending, stimulates repeat use, overall satisfaction rating	16	(4.6)

Evaluation - FDA



- The US Food and Drug Administration (FDA) has paid close attention to mHealth apps, because it has regulatory authority over their safety.
- The agency recently clarified that mHealth apps acting as medical devices or as accessories to medical devices will require FDA approval, whereas apps that provide users with the ability to log life events, retrieve medical content, or communicate with clinicians or health centers will not be regulated under its jurisdiction.

US Department of Health and Human Services, Food and Drug Administration. *Mobile Medical Applications: Guidance for Industry and Food and Drug Administration Staff.* <u>http://www.fda.gov/downloads/MedicalDevices/</u> <u>DeviceRegulationandGuidance/GuidanceDocuments/UCM263366.pdf.</u> <u>September 25, 2013. Accessed January 3, 2014.</u>



mHealth Evidence



- Resource for cataloging, categorizing and grading mHealth evidence
 - Peer-reviewed and grey literature on mHealth activities in developed and developing countries
 - Curated
 - Classified using a harmonized taxonomy
 - Scored based on objective criteria
 - Easily filtered and searchable
 - Facilitate the identification of evidence-based, high-impact mHealth practices
- Launched by Johns Hopkins University via the federally funded Knowledge for Health project (5 years, \$40 million)
- Partners
 - Center for Communication Programs (JHU·CCP)
 - WHO mHealth Technical & Evidence Review Group (mTERG)/JHU Global mHealth Initiative (GmI)





My Health apps



It has been launched by patient research firm PatientView in partnership with GSK, Janssen, Novo Nordisk and telecoms companies O2/Telefonica Europe and Vodafone Foundation.

307 apps, which have been selected by 456 patient groups, disability groups or















Browse by Category













Muscles



Health





Older System and people



Sexual Skin



Staying Healthy



Stomach.

Bowel and

Continence

Travelling





Senses,

Mobility

and Learning

Other



Conditions

Brain

Breathing

and Lungs

Neill Cornell Medicine

Health app directory





European Directory of Health Apps 2012-2013

A review by patient groups and empowered consumers PatientView's European Directory of Health Apps 2012-2013 contains mobile apps across 62 health specialities and features apps in 32 different European languages.

WHO mHealth Technical Evidence ENPIRE Review Group

- Guidelines for reporting of health interventions using mobile phones: mobile health (mHealth) evidence reporting and assessment (mERA) checklist
- BMJ 2016; 352 doi: http://dx.doi.org/10.1136/ bmj.i1174 (Published 17 March 2016) Cite this as: BMJ 2016;352:i1174



WHO mHealth Technical Evidence ENPIREMENTAL AND Review Group



Veill Cornel

mHealth evidence reporting and assessment (mERA) guidelines, including mHealth essential criteria

Criteria	Iten no	n Notes
Infrastructure (population level)	1	Clearly presents the availability of infrastructure to support technology operations in the study location. This refers to physical infrastructure such as electricity, access to power, connectivity etc. in the local context. Reporting X% network coverage rate in the country is insufficient if the study is not being conducted at the country level
Technology platform	2	Describes and provides justification for the technology architecture. This includes a description of software and hardware and details of any modifications made to publicly available software
Interoperability/Healtl information systems (HIS) context	h 3	Describes how mHealth intervention can integrate into existing health information systems. Refers to whether the potential of technical and structural integration into existing HIS or programme has been described irrespective of whether such integration has been achieved by the existing system
Intervention delivery	4	The delivery of the mHealth intervention is clearly described. This should include frequency of mobile communication, mode of delivery of intervention (that is, SMS, face to face, interactive voice response), timing and duration over which delivery occurred
Intervention content	5	Details of the content of the intervention are described. Source and any modifications of the intervention content is described
Usability/content testing	6	Describe formative research and/or content and/or usability testing with target group(s) clearly identified, as appropriate
User feedback	7	Describes user feedback about the intervention or user satisfaction with the intervention. User feedback could include user opinions about content or user interface, their perceptions about usability, access, connectivity, etc
Access of individual participants	8	Mentions barriers or facilitators to the adoption of the intervention among study participants. Relates to individual- level structural, economic and social barriers or facilitators to access such as affordability, and other factors that may limit a user's ability to adopt the intervention
Cost assessment	9	Presents basic costs assessment of the mHealth intervention from varying perspectives. This criterion broadly refers to the reporting of some cost considerations for the mHealth intervention in lieu of a full economic analysis. If a formal economic evaluation has been undertaken, it should be mentioned with appropriate references. Separate reporting criterion are available to guide economic reporting
Adoption inputs/ programme entry	10	Describes how people are informed about the programme including training, if relevant. Includes description of promotional activities and/or training required to implement the mHealth solution among the user population of interest
Limitations for delivery at scale	11	Clearly presents mHealth solution limitations for delivery at scale
Contextual adaptability	12	Describes the adaptation, or not, of the solution to a different language, different population or context. Any tailoring or modification of the intervention that resulted from pilot testing/usability assessment is described
Replicability	13	Detailed intervention to support replicability. Clearly presents the source code/screenshots/ flowcharts of the algorithms or examples of messages to support replicability of the mHealth solution in another setting
Data security	14	Describes the data security procedures/ confidentiality protocols
Compliance with national guidelines or regulatory statutes	15	Mechanism used to assure that content or other guidance/information provided by the intervention is in alignment with existing national/regulatory guidelines and is described
Fidelity of the intervention	16	Was the intervention delivered as planned? Describe the strategies employed to assess the fidelity of the intervention. This may include assessment of participant engagement, use of backend data to track message delivery and other technological challenges in the delivery of the intervention

h & Participatory Medicine

Creating and prescribing personalized apps



AppScript[®] The leading discovery and distribution platform for mobile health technologies.

Today, an increasing number of patients are asking healthcare professionals about mobile health. With over 100,000 mobile health apps and devices in the marketplace, recommending the best solution can be overwhelming. AppScript™ is a simple and effective mobile health tool that lets you recommend apps, connected devices and content to improve patient engagement, satisfaction and outcomes.

mHealth delivered.







	Apple	Google	Cornell Tech	Samsung
DB smartphone	HealthKit	Google Fit		S Health
Apps for researchers	ResearchKit	Study Kit (Baseline)	Research Stack	
Apps for consumers	CareKit		Q OHMAGE-omh	





- ResearchKit (Apple) and ResearchStack (Android) are open source frameworks for researchers to inform and consent patients, and to collect personal health data from participants in trials.
- ResearchKit/ResearchStack have out-of-the box functionality for patient consent, surveys for
 Patient Reported Outcomes and collecting health data from sensors in the phone or devices connected to the phone.



IN LOVING MEMORY OF

1999-2064

672 Twitter Followers 1,673 Clubcard Points 60,590,000 Calories Consumed 92% Positive eBay Feedback 184 Tinder Matches 76,928 km Jogged

REST IN PEACE

Data collection SQSs (wearables, mobile sensors, Quantified Self)

BDC4CM - mHealth & Participatory Medicine

Collecting individual genome data



Human Genome Project

DNA Sequencer – designed to sequence the entire human genome in a day for \$1,000

DTC genomics – 23andMe, \$100

Microbiome





Benchtop Ion Proton™

Measuring the phenome (physiology, ...)









Measuring the Exposome (environmental risk)

- Compilation of exposures experienced over an individual's lifetime (*Christopher Wild, 2005*)
- Industrial chemicals, combustion emissions, radiation, response to stress, physical activity levels – heat/cold, noise, food, microbiome
- Evaluating Personal Exposures
 - Phones: Light meters, GPS, Accelerometer
 - Senspod Monitor (Ozone, carbon monoxide, CO2, NO, Noise and UV)
 - Petroleum derived hydrocarbons (Benzene, Toluene)

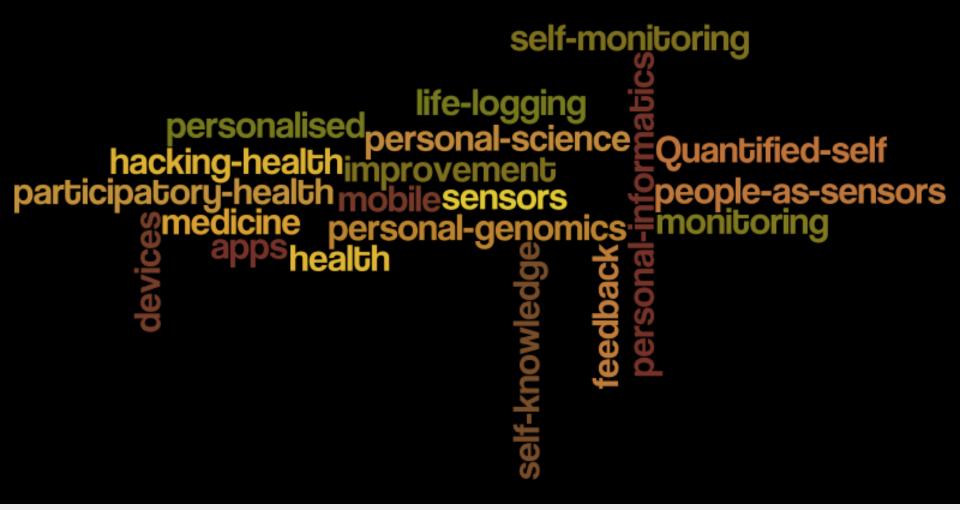






Quantified Self: The concept





Quantified Self: The community





II D

CALIFORNIA HEALTHCARE FOUNDATION

JANUARY 28, 2013

Tracking for Health

69% of U.S. adults track a health indicator like weight, diet, exercise routine, or symptom. Of those, half track "in their heads," one-third keep notes on paper, and one in five use technology to keep tabs on their health status.

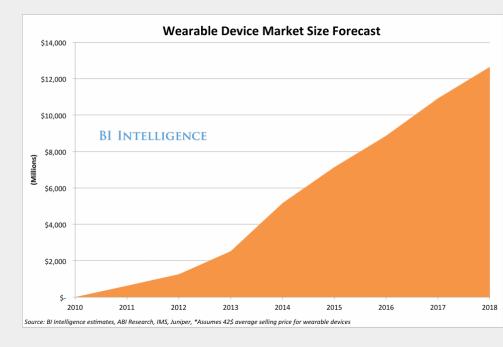






By 2018, 81.7 million users will own a wearable fitness device, according to eMarketer.











The Quantified Self community

- Quantified Self is a collaboration of users and tool makers who share an interest in self knowledge through self-tracking.
- We exchange information about our personal projects, the tools we use, tips we've gleaned, lessons we've learned. We blog, meet face to face, and collaborate online. There are three main "branches" to our work.
 - The Quantified Self blog and community site.
 - Show and Tell meetings (Meetup groups) Melbourne
 - Quantified Self Conferences (US and Europe)
- Groups 228, Members 67,719, Cities 122, Countries 38





You can't imp

- You can't improve what you can't measure P. Drucker...
- Using mobile and wearable digital devices to collect data on one's body function and everyday activities
- Self tracking through technology to improve health and medical conditions
- To reveal patterns and correlations that can help you improve your life







The IBES SELF-OMICS Project



- Addressing the information and communication needs of the 'quantified individual' for enabling participatory and personalised medicine
- Funded by IBES (Institute for a Broadband Enabled Society)
 2012-2013
- Resources:

http://www.broadband.unimelb.edu.au/health/monitoring/selfomics.html http://www.scoop.it/t/selfomics http://pinterest.com/hbir/self-omics-self-monitoring-quantified-self-omics/

QS Lab



How to find the best SQS...

- Wellocracy.com
- Wareable.com
- vandrico.com/wearables/



Vandrico | Deloitte.

	Absalt EasyWakeup	Azumio Sleep Time	Basis Peak	Beddit
	Contraction of the second seco		9722	
Price	\$4.99	\$0.00	\$199.99	\$149.00
Device or App	App	App	Device	Device
Tracks sleep duration	*	*	*	*
Tracks sleep	×	×	*	*
Tracks deep sleep/little	*	*	*	*
Tracks light sleep/more	*	*	*	*
Tracks awake	×	×	*	*
Has sleep score	×	*	*	*
Where to put it	On bed	On bed	Wrist	On bed

Buying guides











Samsung Welt





And other 437 devices from 304 companies



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Comparison of five self-monitoring devices that measure physical activity

	FITBIT FLEX (Activity + Sleep Wristband)	FITBIT ZIP (Activity tracker)	FITBIT ONE Activity + Sleep tracker)	JAWBONE UP (Activity + Sleep Wristband)	NIKE FUELBAND (Activity Wristband)
STEPS	Yes	Yes	Yes	Yes	Yes
CALORIES BURNED	Yes	Yes	Yes	Yes	Yes
DISTANCE TRAVELLED	Yes	Yes	Yes	Yes	Yes
ACTIVE MINUTES	Yes	No	No	Yes	Fuel activity
SPEED	No	No	No	Yes	No
FLOORS CLIMBED	No	No	Yes (it has an altimeter)	No	No
SLEEP TIME	Yes	No	Yes	Yes	No
NUMBER OF TIMES AWOKEN	Yes	No	Yes	Yes	No
TIME SPENT IN DEEP VS. LIGHT SLEEP	No	No	No	Yes	No
QUALITY OF SLEEP	Yes	No	Yes	Yes	No
TO WAKE SILENTLY	Silent alarm	silent alarm No Silent alarm		Silent alarm. It vibrates the band up to 30 minutes ahead of your designated waking up time if it senses you are sleeping lightly around that time	No
POWER NAP	No	No	No	Yes. UP will wake you up at the optimal time (around 26.5 minutes) after you fall asleep	No
CLOCK	No	Yes	Yes	No	Yes
DISPLAY	5 LEDs that represent step progress for the day	There's an LCD (liquid crystal display) that shows the data when you touch it: steps, distance, calories burned, smiley and clock. The screen is not backlit	There's an OLED (organic light- emitting diode) display. Push button control: Each push cycles through one of six modes: steps, distance, calories burned, Floors climbed, Flower (grows and shrinks based on your recent activity)and Clock. The screen is backlit	Dual LEDs: it has a button to put the band into various modes. No data readouts on band itself	20 LEDs Push the single button on the ban and you can see: steeps, calories, time and fuel
MOOD	No	No	No	Yes	Yes



HOW TO SYNC THE DEVICE WITH A COMPUTER OR PHONE	Wirelessly with a dongle plugged into your computer PC and select smartphones. Bluetooth 4.0. (within about 20 feet of the wireless sync dongle)	Wirelessly with a dongle plugged into your computer PC and select smartphones. Bluetooth 4.0. (within about 20 feet of the wireless sync dongle)	Wirelessly with a dongle plugged into your computer PC and select smartphones. Bluetooth 4.0. (within about 20 feet of the wireless sync dongle)	Just plug it in (you can do so by either plugging it directly into your USB port, or using the USB cable and dock provided with your FuelBand)	Bluetooth with a smartphone app (iOS-exclusive). Syncs are a little less tempting than with the Jawbone UP or <u>Fitbit</u> Flex
PC & MAC REQUIREMENTS	Windows XP/Vista/7/8, Mac OS X 10.5 and up, USB port and Internet connection	Windows XP/Vista/7/8, Mac OS X 10.5 and up, USB port and Internet connection	Windows XP/Vista/7/8, Mac OS X 10.5 and up, USB port and Internet connection	It doesn't work with personal computers	Windows XP/Vista/7/8, Mac OS X 10.5 and up, USB port and Internet connection
COMPATIBLE MOBILE PHONES			iPhone 4S, 5,iPad 3, Retina, iPad mini, iPod touch, 5th generation, Samsung Galaxy S4,Samsung Galaxy S III, Samsung Galaxy Note II, Samsung Galaxy Note 10.1	iPhone and iPod: iQS 5.1 or greater and Android 4.0 (Ice Cream sandwich) or later	Only with i <u>QS</u> 5.0+
CHARGING THE DEVICE	Extra dongle that interface with USB (a proprietary docking port)	Extra dongle that interface with USB (a proprietary docking port)	Extra dongle that interface with USB (a proprietary docking port)	Extra dongle that interface with USB (a 3.5 mm-to- USB converter)	It plugs directly into a USB port, because it's a loose fit and lacks the external USB structure

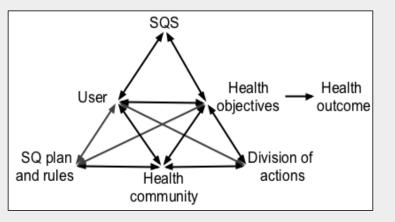


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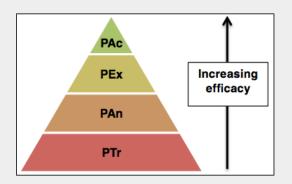


BDC4CM - mHealth & Participatory Medicine

White Paper



Activity Theory + Patient Activation





Institute for a Broadband-Enabled Society

Self-Quantification

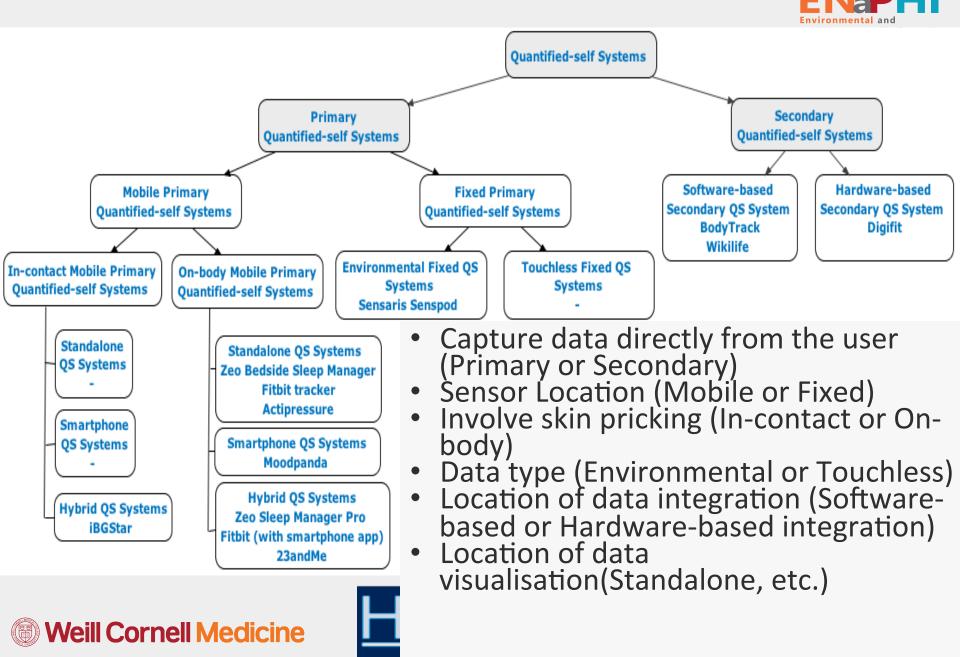
The Informatics of Personal Data Management for Health and Fitness



www.broadband.unimelb.edu.au

(htt Weill Copredicting elb.edu.au

Classification of self-quantification systems



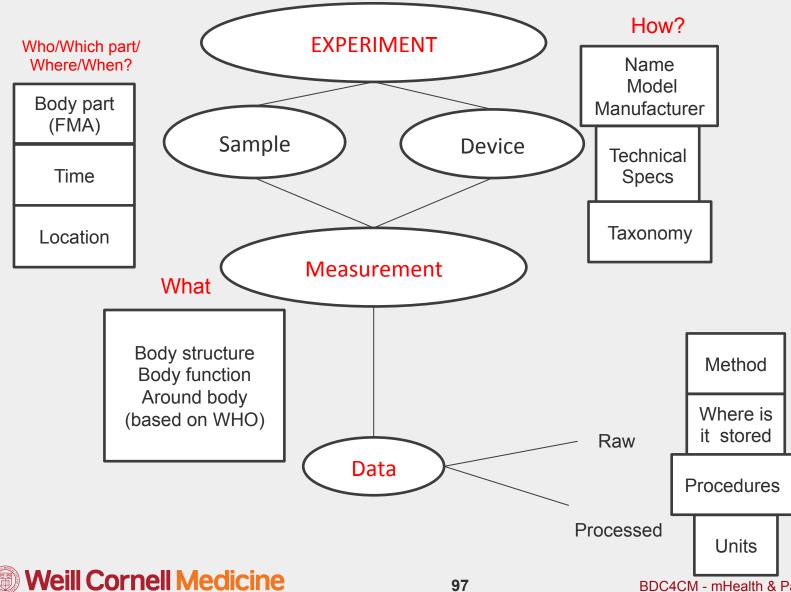
Classification of Data and Activities

Environmental and Participatory Health Informatics RESEARCH GROUP

	Pody structures and	Pody actions (activities	Around hody
#	Body structures and	Body actions/activities	Around body
	functions		The second se
1	Mental functions	Learning and applying	Relationships and attitudes
		knowledge	
2	Sensory functions	Communication	Products or substances for personal
			consumption
3	Sensation of pain	Mobility	Products and technology for use
4	Voice and speech	Self-care	Natural environment and human-made
-	functions		changes to environment
5	Cardiovascular system	Domestic life	
6	Haematological system	Interpersonal	
0		interactions	
7	Immunological system	Education	
8	Respiratory system	Work and employment	
9	Digestive system	Economic life	
10	Metabolic system	Recreation and leisure	
11	Endocrine system	Religion and spirituality	
12	Genitourinary functions		
13	Reproductive functions		
14	Body structures		
15	Skeletal system		
16	Muscular system		
17	Nervous system		
18	Skin		
19	Hair		
20	Nails		
21	Genome (DNA, RNA and		
21	genes)		
22	Microbes		

Minimum Information about a Self Monitoring Experiment (MISME)



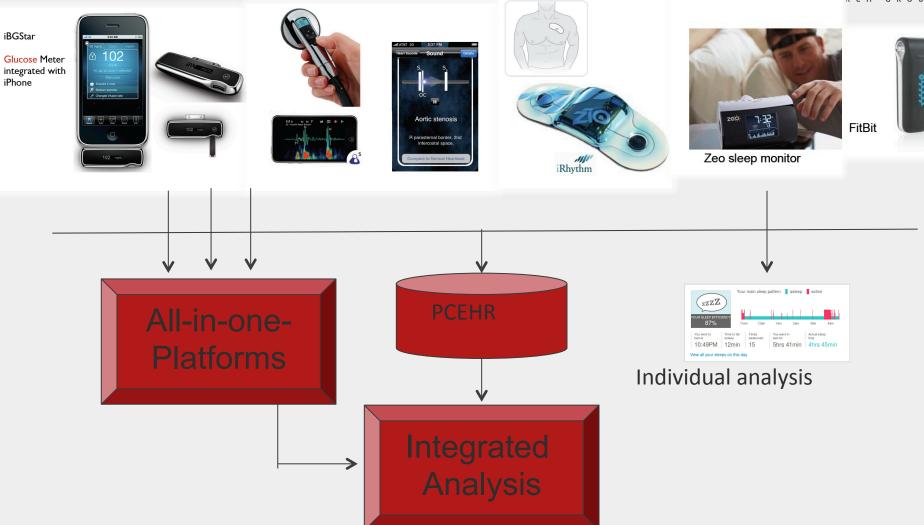


97

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Data integration methods





Terminology

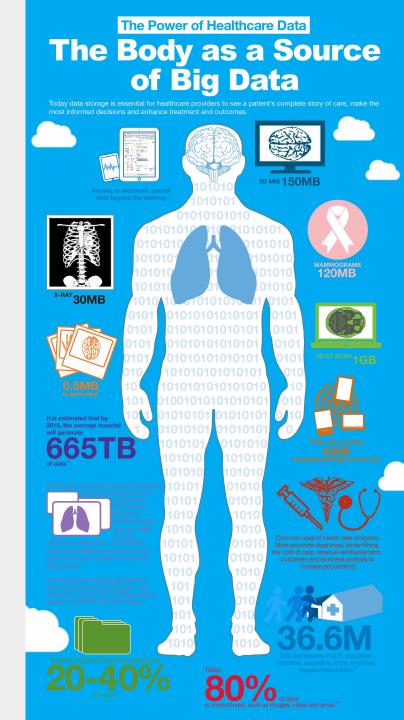


- Self-quantification, converting manually or automatically the collected data into numbers or categories.
- Self-monitoring, on the other hand, is more like watching a specific health factor to ensure keeping it at a satisfactory level and this requires regular medical interventions such as monitoring blood glucose.
- Self-tracking or life-logging can be described as continuous recording of one or more health factors for future use.
- For example, keeping diaries is a form of self-tracking while turning these unstructured data into numbers and categories is self-quantification.
- Self-tracking and self-quantification together could be described as self-monitoring.

Self-Omics

- QS as an interface to the Human Body
- How much information?
- Requirements for exchange, storage and processing of data
- People-as-sensors
- Making the personal public
- The transparent body
- From population surveillance to individual surveillance

Infography: Institute for Health Technology Transformation



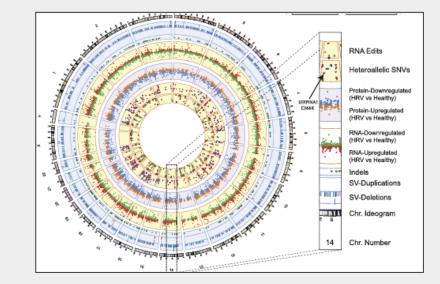
How much information



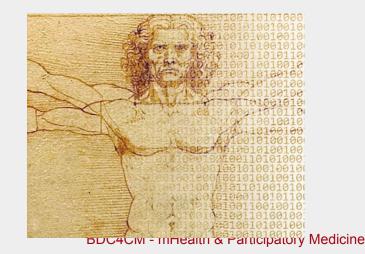
CR (computer radiography) 30 MB DR (direct radiography) 54 MB Computer Tomography (CT) - 32 MB Multi-Slice CT - 630 MB Magnetic Resonance 21 MB Angio 15 MB

The project "Experimental Man" reports that one man has been collecting information about his exposure to toxins and has generated +100GB of data (only toxins)

Individual genome data:: from 20MB to 30 TB
3 Billion data points were collected along 20 time points during 14 months.
150 million data points per analysis.
Microbioma (gut) 35GB



(Chen et al, Cell 148, 1293-1307 March 16 2012)











http://www.bbc.com/earth/story/the-making-of-me-and-you#/results/top

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Data storage



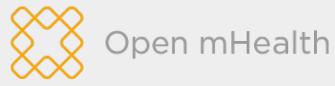
Open mHealth



- Free, open-source code that makes it easy for developers to standardize, store, integrate, share, process and visualize mobile health data
 - Simple extensible and clinically valid schemas
 - RESTful API

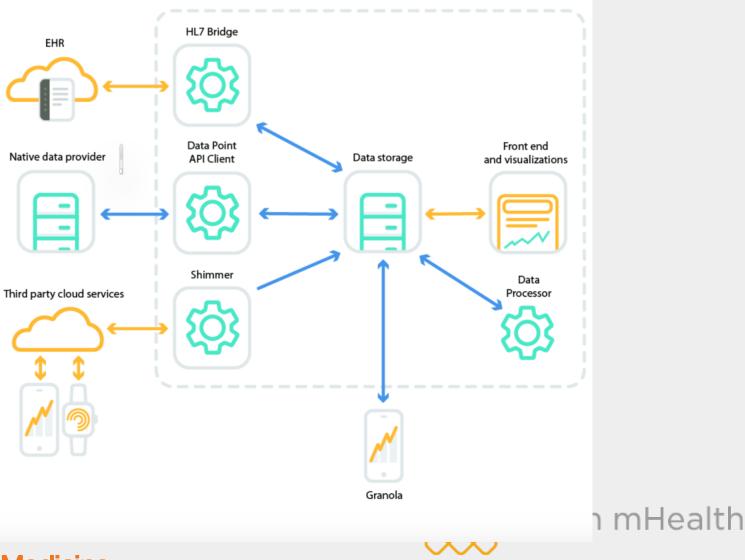
- Conforms to schemas
- Authorizes access using Oauth 2.0
- Open-source adapters linked to the APIs of large providers (e.g., RunKeeper, Fitbit, Google, Apple)
- Library of visualization examples





Open mHealth





Weill Cornell Medicine

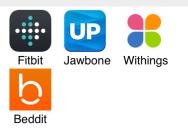
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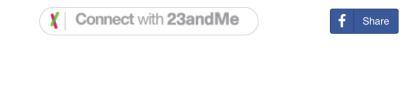
Infinome – open science





Connect a tracker:





#TRUTH

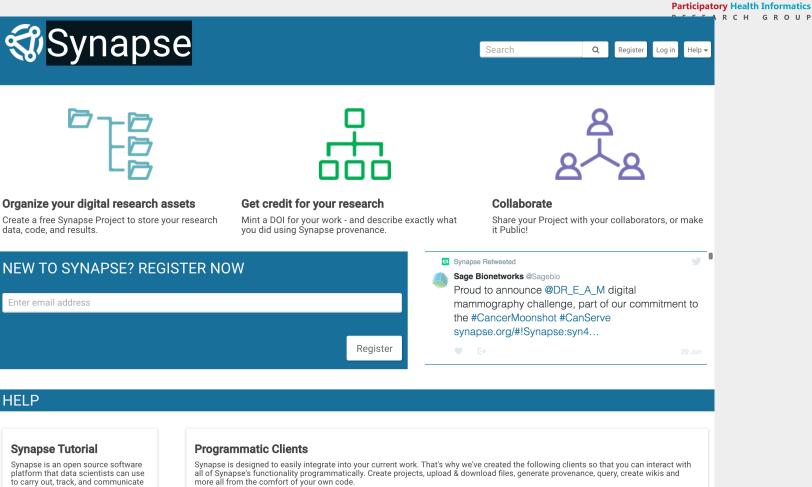
The obesity problem is killing most of us.



7 IN 10 AMERICANS WEIGH TOO MUCH



Synapse (SAGE)



Don't see your language of choice here? Check out our full REST API documentation

R client

💎 Python client

🖆 Java client

Command line

liand

Weill Cornell Medicine

their research in real time

research data, share with your

This tutorial steps you through how to create your first Project, store your

Environmental and



Data aggregation and integration



All-in-one platforms for digital health

- WebMD Healthy Target
- Philips Salesforce
- Samsung S.A.M.I ARTIK cloud
- Apple HealthKit
- Google Google Fit
- Microsoft HealthVault
- Qualcomm Life 2net
- Validic
- Open Humans
- Human API







Human API



DHILIDS

Philips and salesforce.com announce a global strategic alliance.







salesforce

ALIDIC

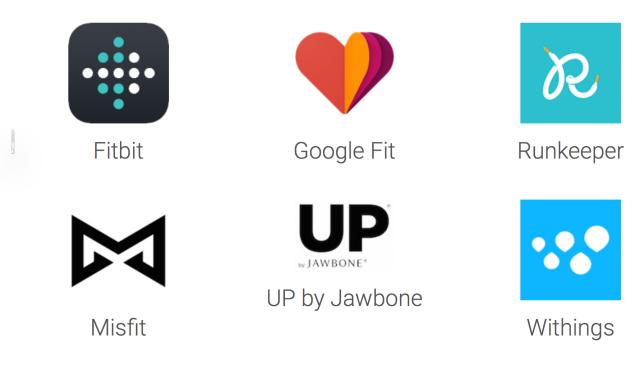
Google Fit

Shimmer (Cornell Tech)



Integrations

Shimmer supports some of the best-in-breed apps and devices. To see the next set of tools we'll be supporting, check it out on Github.



iHealth

Samsung ARTIK Cloud





https://artik.cloud/works-with

Wolfram Connected devices





http://devices.wolfram.com



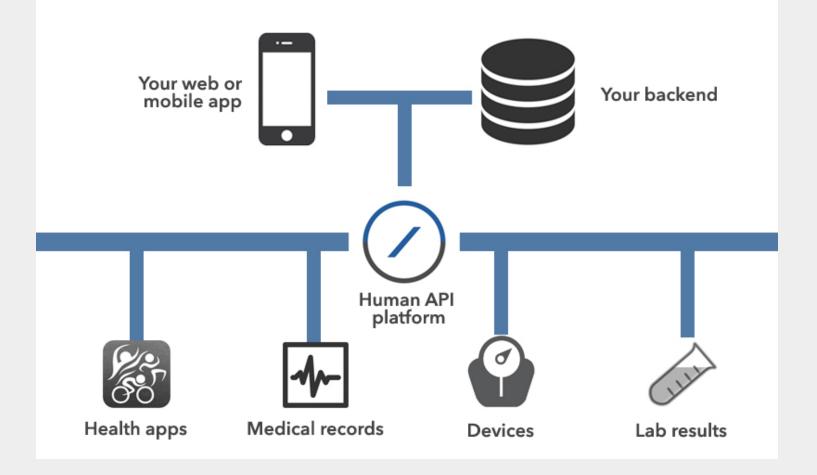






Human API





Integration into PHR



- eClinicalWorks Announces Integration Between Wearable Devices and healow Platform
- Fitbit, iHealth, Jawbone and Withings



eClinicalWorks "Improving Healthcare Together"

https://www.eclinicalworks.com/pr-eclinicalworks-announces-integration-between-wearable-devices-and-healow-platform/



Apple to add support for HL7 Continuity of Care Documents to iOS 10



- iOS 10 will be available this fall.
- "Bloomfield (Duke): "It will enable any app to create and share a CCD with HealthKit, and another app can read that by using HealthKit."
- So a doctor can create a CCD, let her patients have that, and patients, in turn, can share that document with other caregivers and clinicians.
- Apple has not made an official announcement yet.

EHR integration with HealthKit



- 2014 Ochsner Health System in Louisiana
- 2015 Deaconess Health System in Indiana integrates Fitbit into EHR portal
- 2015 Duke is using HealthKit to get patient-generated data into the EHR.
- 2015 Cerner with Validic
- 2015 EPIC MyChart at Cornell Medicine has full HealthKit functionality



SMART on FHIR®



- Medical apps that integrate into diverse EHR systems at the point of care.
- Open standards for healthcare data, authorization, and UI integration.
- Harvard Medical School and Boston Children's Hospital
- SMART Reference Platform, custom set of data models and a corresponding RESTful API.
- In 2014, FHIR[®] arrived: Fast Health Interoperability Resources.
- FHIR is open healthcare data standard from HL7.
- Like SMART, FHIR provides for RESTful access to clean, granular data.
- FHIR specifically represents granular clinical concepts as a set of resources that may be addressed individually or in aggregate.
- SMART on FHIR
- SMART on FHIR, will provide a complete open standards-based technology stack.
- With SMART on FHIR, developers can integrate a vast array of clinical data with ease.



The Consent, Contact and Community framework for Patient Reported Outcomes

A set of <u>FHIR[®]</u> compliant research software tools for <u>ResearchKit</u> and <u>ResearchStack</u>







What is C3-PRO?

For Developers

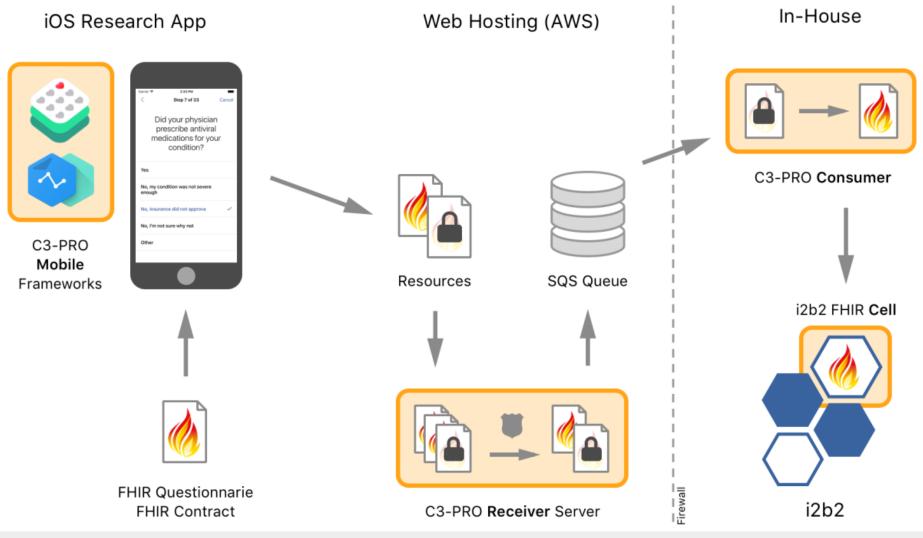
Modules!

http://c3-pro.org

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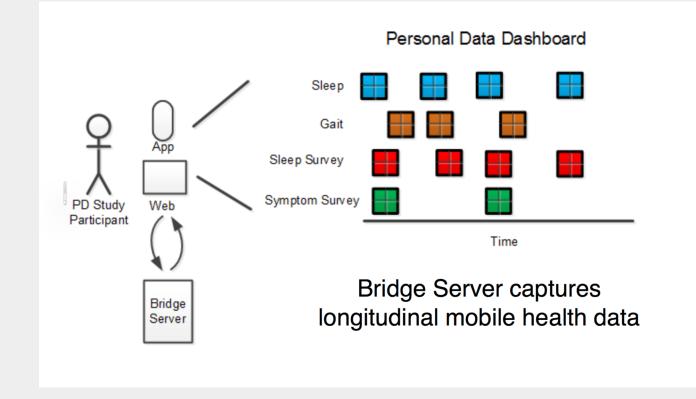
BDC4CM - mHealth & Participatory Medicine





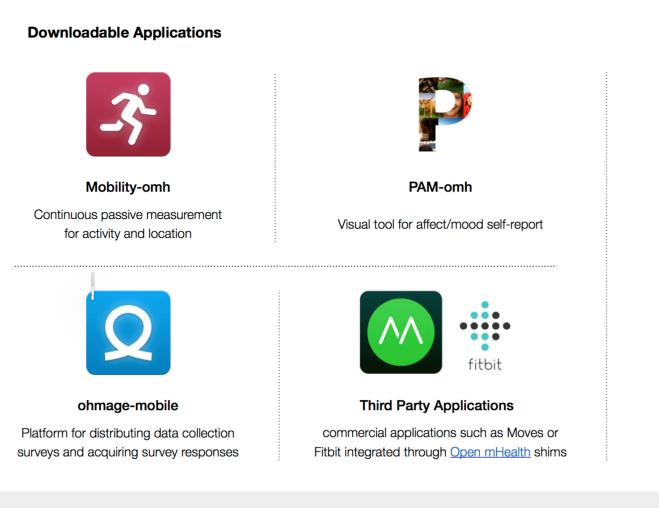
SAGE Bionetworks Bridge + Synapse





OHMAGE-omh (Cornell Tech)





Admin Dashboard

retrieve data from authorized participants of their studies

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User Management

Data Visualization



Data Retrieval



From information to knowledge



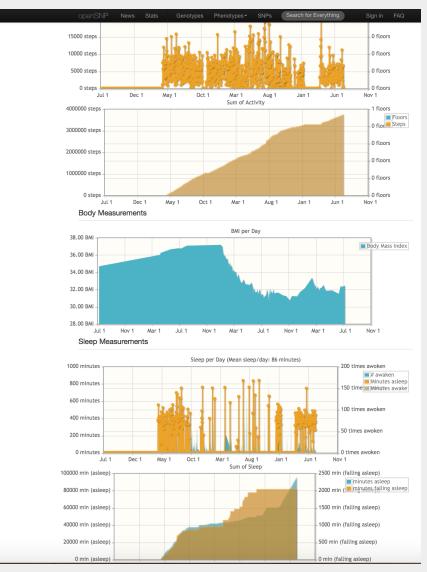


Data access



OpenSNP





https://opensnp.org/fitbit/

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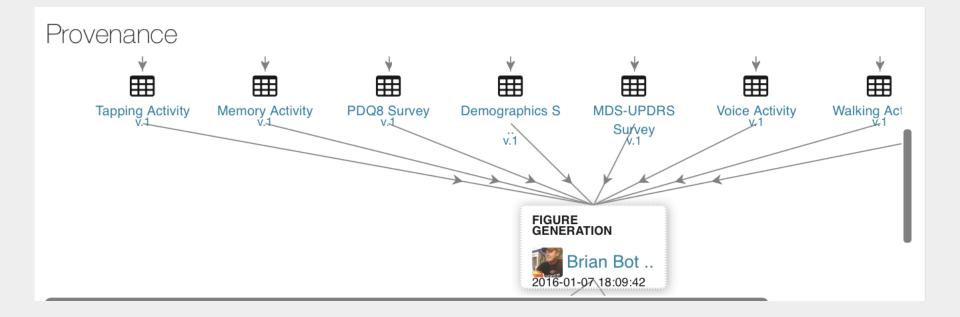
mPower



- First six months of data from the app. mPower, a Parkinson's-focused app, one of the first five Apple ResearchKit studies
- Of the 12,000 mPower study participants, about 9,500 participants chose to share their data with all researchers.
- mPower stands for "mobile Parkinson's observatory for worldwide, evidence-based research".
- The mPower app aims to help users track their symptoms using activities including a memory game, finger tapping, speaking, and walking. The app will also collect data from wearable devices

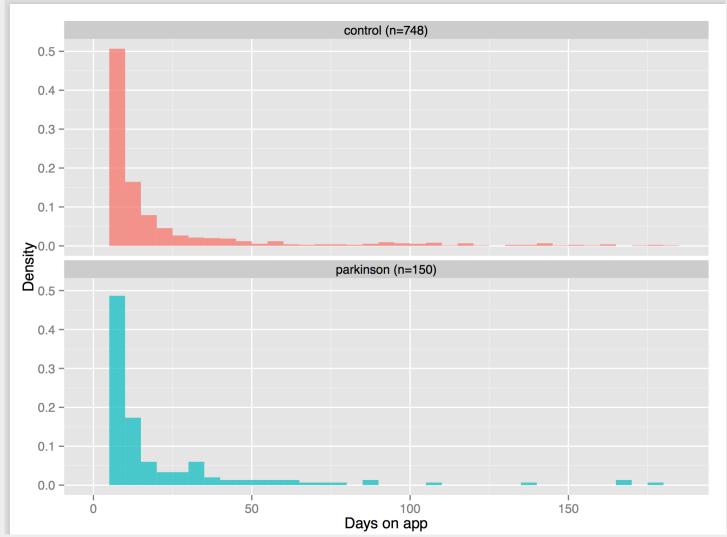






mPower





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Data analysis



Challenges



- Comparative usage—how your consumption of a resource (for example, calories) compares with others in similar situations
- Understanding patterns and reasons for variation—developing statistical models that explain variation
- Predictive asset maintenance—using sensor data to detect potential problems in machinery (or your body) before they actually occur
- Optimization—using sensor data and analysis to optimize a process, as when a lumber mill optimizes the automated cutting of a log, or a poultry processor automates the preparation of a chicken, or when is the healthiest time to go to sleep or when in your sleep cycle to wake up
- Prescription—employing sensor and other types of data to tell the user what to do, as when an activity tracker nudges you to get off the couch or sit up straight
- Situational awareness—piecing together seemingly disconnected events and relating them to a larger repository of data to put together an explanation, as when a series of readings from activity trackers, glucose monitors, connected scales, and other devices tells you that you are in danger of contracting diabetes

http://dupress.com/articles/internet-of-things-wearable-technology/

Analyzing and interpreting smartphone data



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SUBMIT ARTICLE



NOT PEER-REVIEWED

"*PeerJ Preprints*" is a venue for early communication or feedback before peer review. Data may be preliminary. Learn more about preprints or browse peer-reviewed articles instead.

A framework for smartphone-enabled, patient-generated health data analysis

Shreya S Gollamudi¹, Eric J Topol^{1,2,3}, Nathan E Wineinger^{™1}

March 30, 2016

Analyzing and interpreting smartphone data

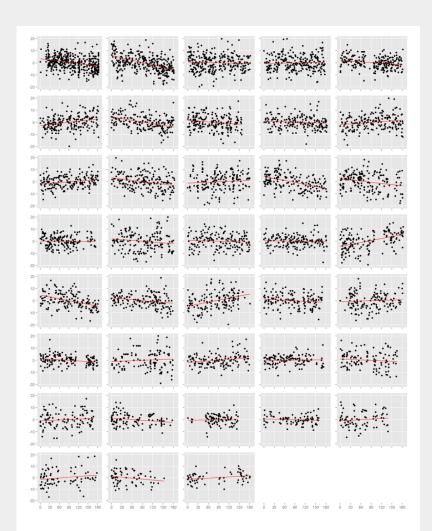


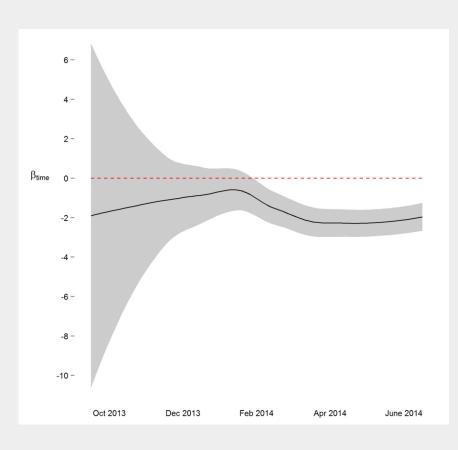
- 38 individuals, 6290 blood pressure readings over a 11-month trial
- Withings BP monitor, iphone app, HealthyCircles account and app. Qualcomm Life Health HealthyCircles server.
- Hypothesis testing framework for unstructured time series data.
- Mixed model approach using autoregressive models
 - Multiple n-of-1 (analysis of individual data)
 - Combination of all individuals data
- 2mmHg decrease in both systolic and diastolic
- Sequential analysis approach allowed them to observ results three months prior to the official study end.

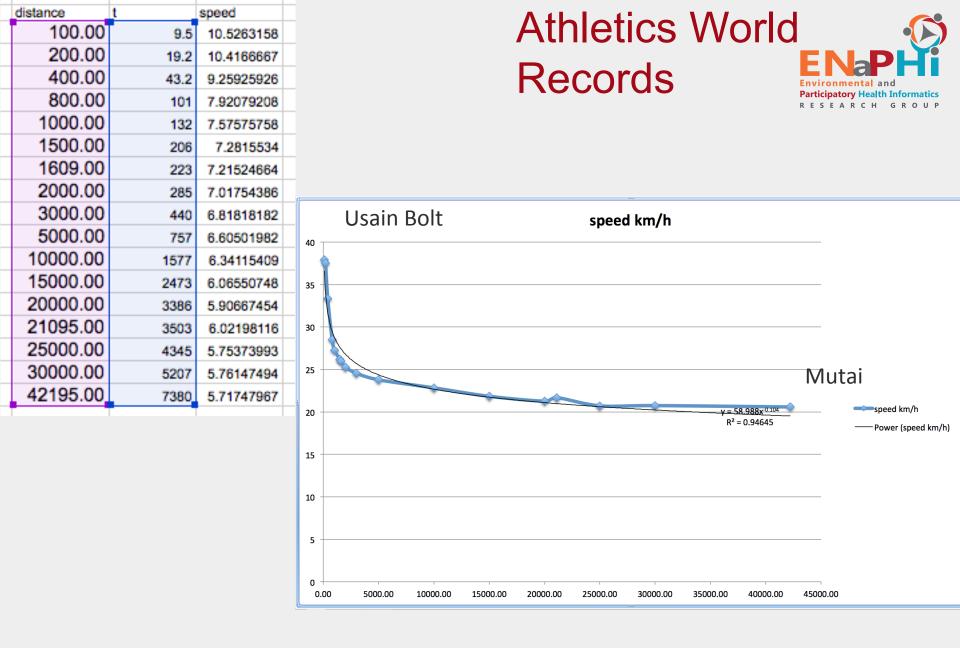


Analyzing and interpreting smartphone data



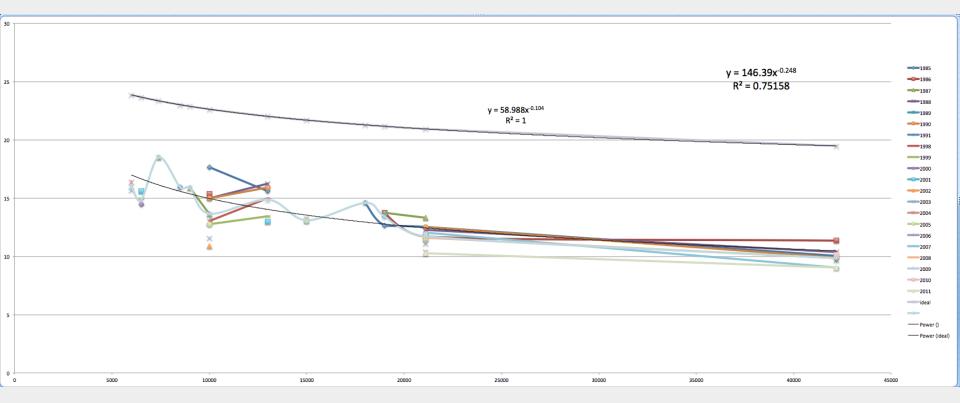






PREDICTIVE MODEL





IF distance=6km and time=25.30 (speed=14km/h) THEN 42.195km \rightarrow 4h 10m





- More than 80 races <u>completed</u>, including 12 Marathons and 21 Half-Marathons
- <u>No injuries</u>
- No competitive goal or performance improvement
- <u>Decision making tool</u> (whether to run or not to prevent damage and ensure having a good time – less than 5 hours)





THE CONVERSATION US PILOT



Fernando Martin-Sanchez

Director, Health and Biomedical Informatics Centre (HaBIC), University of Melbourne

Profile

Articles Activity



September 4, 2013

How can big data go the distance for runners (and the rest of us)?

Fernando Martin-Sanchez, University of Melbourne

The number of Australians running or jogging has almost doubled since 2005-06 and - with the rise of smartphones - running and fitness app development has

also exploded. So how many of these runners have...

EMORY | news center

CONTACT US NEWS

Cor

Jen (me 404jenn

Emory study focuses on heart	
health of AJC Peachtree Road	
Race runners	

Woodruff Health Sciences Center | June 26, 2015



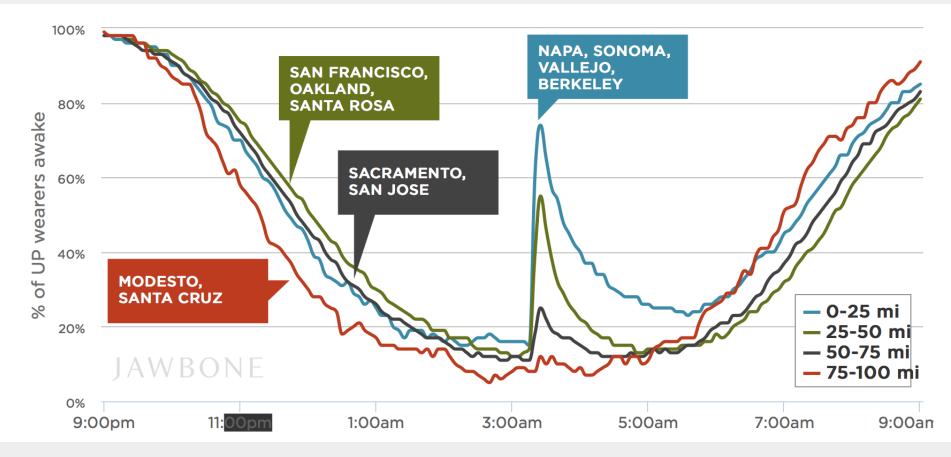


Data visualization



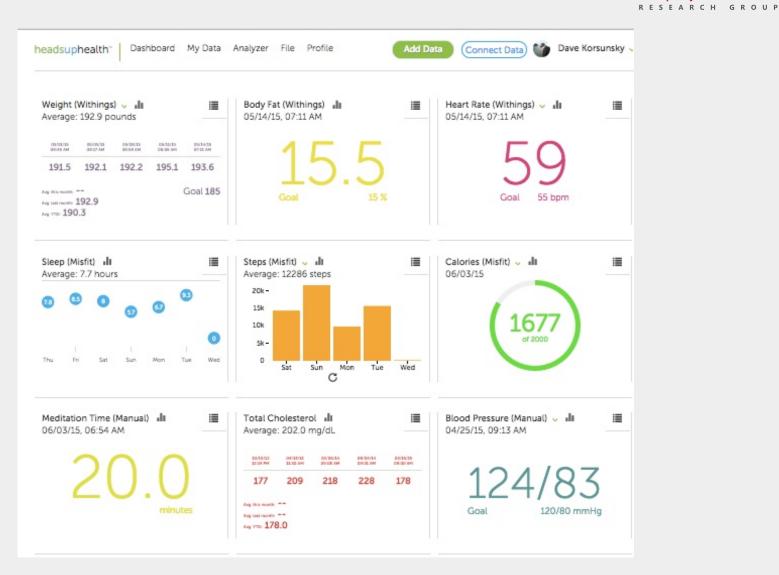
Jawbone and Bay Area Earthquake Sept 2014





https://jawbone.com/blog/napa-earthquake-effect-on-sleep/

Mashing data – HeadsUp Health

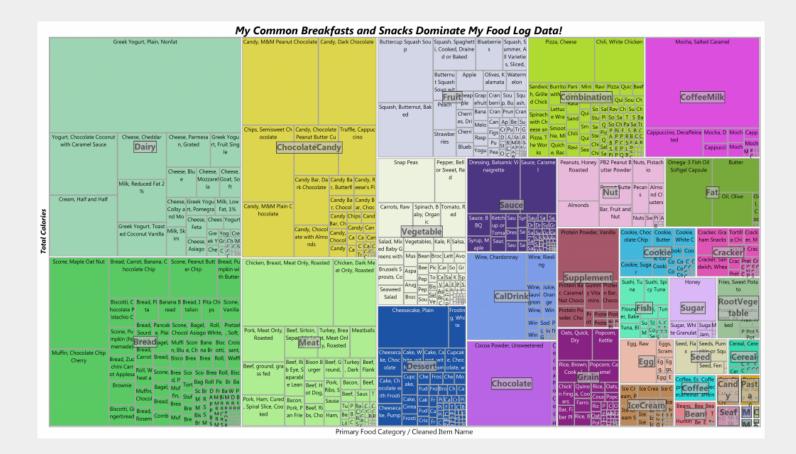




Environmental and Participatory Health Informatics

Food log data – Shanonn Conners EN

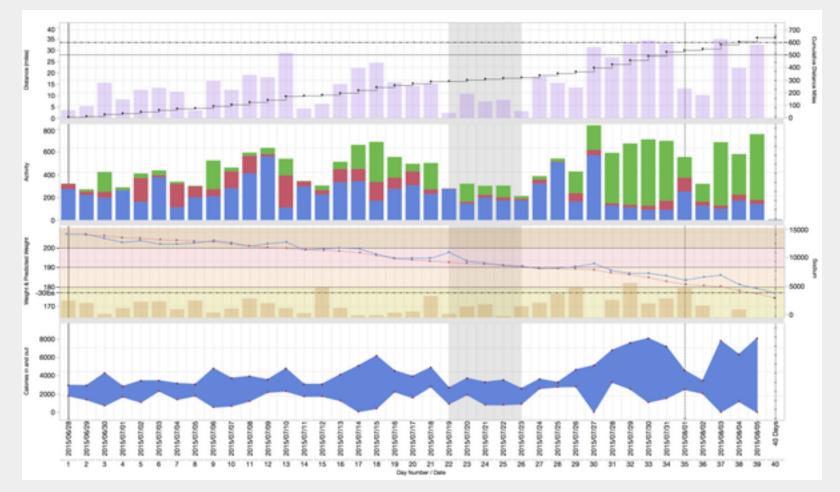
Environmental and Participatory Health Informatics RESEARCH GROUP



SAS - JMP

Quantified Weight Loss – Julian Parris





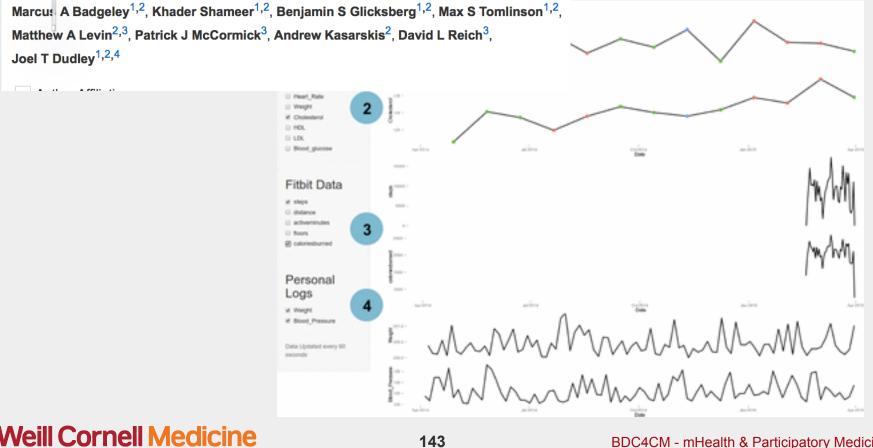
EHDVIZ



BMJ Open 2016;6:e010579 doi:10.1136/bmjopen-2015-010579

Health informatics

EHDViz: clinical dashboard development using open-source technologies





From knowledge to application (relevant initiatives)

Health eHeart study, Google Baseline, 100K Wellness Project, Precision Medicine Initiative, Health Data Exploration and Network, mPower study, Open Humans, N-of-1 (single subject) studies, BD2K Centers of Excellence (emobilize, MD2K)

Clinical Benefits

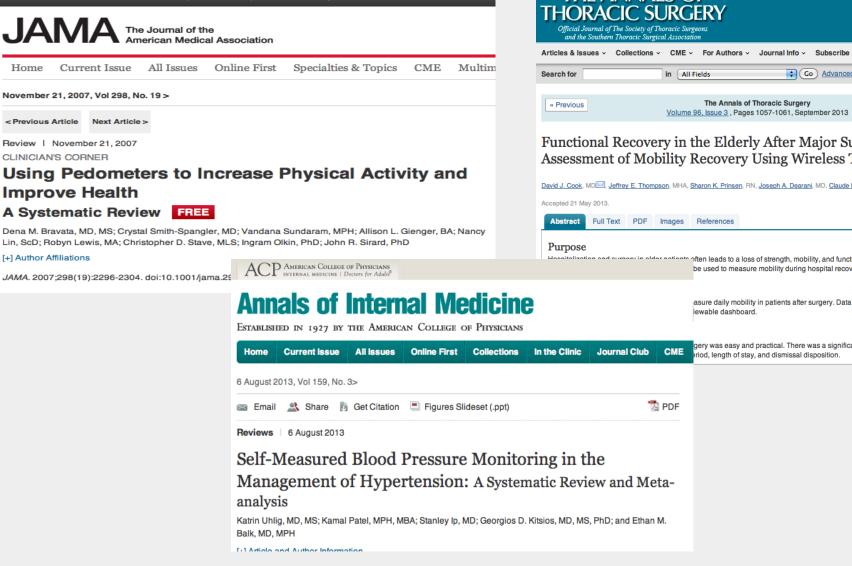
The JAMA Network Journals > Specialties & Topics Store Physician Jobs

Home

< Previous Article

[+] Author Affiliations





About Mobile

ENTRAIN app



Science Advances MAAAS

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RESEARCH ARTICLE | SLEEP RESEARCH



A global quantification of "normal" sleep schedules using smartphone data



8+

11

Olivia J. Walch¹, Amy Cochran¹ and Daniel B. Forger^{1,2,*}

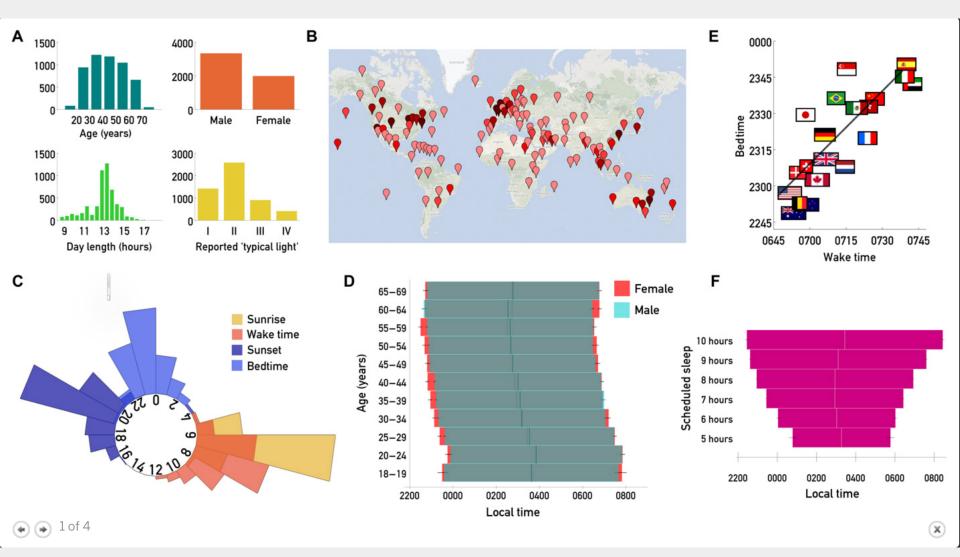
- + Author Affiliations
- ←^{*}Corresponding author. Email: forger@umich.edu

Science Advances 06 May 2016: Vol. 2, no. 5, e1501705 DOI: 10.1126/sciadv.1501705



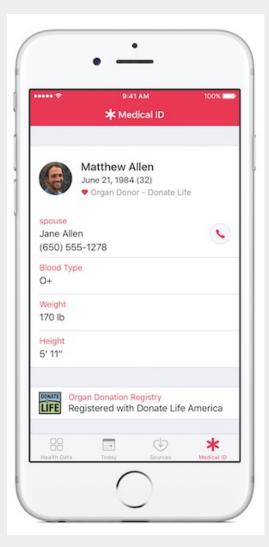
ENTRAIN app





With iOS 10, iPhone users can become organ donors via Health app

When iOS 10 is released, the Apple Health app will include a new feature, allowing iPhone users across the United States to become organ, eye, and/or tissue donors with just a few taps.



Participatory Health Informatics



Health eHeart





Home Study

v Community

Join the study to end heart disease.

Be a part of an ambitious study to end heart disease. It only takes a few minutes to make a big difference. Anyone can join — whether you have heart disease or not.









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ets Opinion

Arts Life

Real Estate



Hunt for Pokémon Has Led to Painful Discoveries

World



Economy

Social Media Wrestles With Policing Violent Live Video



KEYWORDS Startups Try to Spread Outside of Silicon Valley



TECH

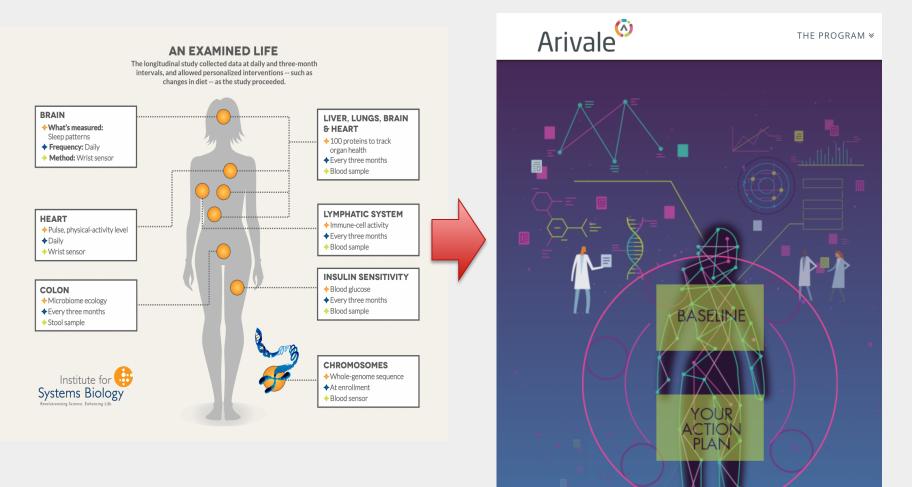
Google's New Moonshot Project: the Human Body

Baseline Study to Try to Create Picture From the Project's Findings



100K Wellness Project





Human Longevity, Inc. Launches the Health Nucleus, a Comprehensive and Personalized Health Platform for Individuals

(SAN DIEGO, CA) OCTOBER 13, 2015 – Human Longevity, Inc. (HLI), the genomics-based, technology-driven company working to revolutionize the practice of medicine, announced today the launch of the company's first Health Nucleus™, a genomic powered clinical research project that has the potential to transform healthcare. The inaugural Health Nucleus is located in San Diego, CA, at HLI's headquarters facility. More Health Nucleus facilities are slated to open in 2016 in other US and International cities.

The Health Nucleus platform uses whole genome sequence analysis, advanced clinical imaging and innovative machine learning – combined with a comprehensive curation of personal health history – to deliver the most complete picture of individual health.

The Health Nucleus provides a novel approach devoted to exploring, quantifying and beginning to understand as much as possible about individual health and disease risk. Supported by the world's largest genome sequencing center and the leading experts in translating genomics data into clinically relevant information, this platform embodies HLI's philosophies and ideas on how individuals can better understand their health. It is the first center to combine genomics with a complete array of other clinical and biological measures, including:

- Whole human genome sequencing, spanning all 6 billion base pairs of DNA (most DNA tests examine less than 2% of the full genetic code);
- Microbiome sequencing which quantifies the collective genomes of the microorganisms that live inside and on the human body (it is estimated that there are 10 times more microbial cells than human cells in our bodies);
- Metabolome characterization which enables us to measure the unique chemical fingerprints that cellular processes leave behind;
- A comprehensive body MRI scan to screen for any abnormalities and provide a baseline for the future;
- Customized laboratory tests and screenings.

Precision Medicine Initiative



- Precision medicine is an approach to disease treatment and states and prevention that seeks to maximize effectiveness by taking into account individual variability in genes, environment, and lifestyle. Precision medicine seeks to redefine our understanding of disease onset and progression, treatment response, and health outcomes through the more precise measurement of molecular, environmental, and behavioral factors that contribute to health and disease. This understanding will lead to more accurate diagnoses, more rational disease prevention strategies, better treatment selection, and the development of novel therapies.
- Coincident with advancing the science of medicine is a changing culture of medical practice and medical research that engages individuals as active partners – not just as patients or research subjects. We believe the combination of a highly engaged population and rich biological, health, behavioral, and environmental data will usher in a new and more effective era of American healthcare.





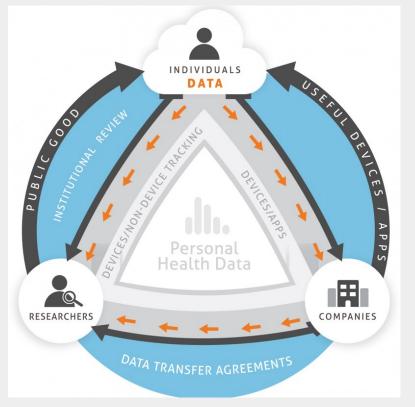
	Ten Years Ago	Now – 2014 (most recent data)
Cost of sequencing a human genome	\$22,000,000	\$1,000 - \$5,000
Amount of Time to Sequence a Human Genome	2 years	<1 day
Number of smart phones in the United States	1 million (<2%)	160 million (58%)
EHR Adoption (% hospitals)	20-30%	>90%
Computing Power	n	n x 16 Deep Learning
Weill Cornell Medicine	154	BDC4CM - mHealth & Participatory Medicine

NIH awards \$120M to Scripps, others, to enroll 350K participants in Precision Medicine Initiative via mobile apps



- Scripps Research Institute, Vibrent Health, PatientsLikeMe, Sage Bionetworks, and Walgreens will help build apps and enroll participants
- The National Institutes of Health announced a number of partners today who will receive a total of \$55 million in grant money for 2016 to build the foundational structures of the White House's Precision Medicine Initiative (PMI). The PMI Cohort Program includes five companies that make up the <u>Participant Technologies Center</u>, which will be responsible for creating mobile apps to enroll, consent, <u>collect data from and communicate with PMI Cohort Program participants</u>.
- In addition to Scripps and Vibrent, NIH has designated several sub-awardees which will share the \$20 million award and work together on the Participant Technologies Center: Cambridge, Massachusetts-based online patient community platform PatientsLikeMe, Seattle-based Sage Bionetworks, which is best known for its work on Apple's ResearchKit, and Walgreens. According to its own statement, Walgreens will allow its customers to enroll in the program at its stores, at Walgreens Healthcare Clinics, online through Walgreens.com and through the Walgreens mobile app.
- Sage Bionetworks, meanwhile, "will be responsible for the patient consent and data governance related to the PMI Cohort Program's software products, as well as the community outreach and participant engagement efforts of the Participant Technologies Center", Sage said in a statement. They'll also develop new ways of monitoring health factors using smartphones and wearable devices.

Health Data Exploration and Network





PERSONAL HEALTH DATA FOR THE PUBLIC GOOD



A California Institute for Telecommunications and Information Technology project with support from the Robert Wood Johnson Foundation

Weill Cornell Medicine

BDC4CM - mHealth & Participatory Medicine

Open Humans



- Project of PersonalGenomes.org funded by Knight Foundation and the Robert Wood Johnson Foundation
- Objectives
 - o Break down data silos in human health and research
 - o Public data sharing
 - Connect individuals willing to share data about themselves





N-of-1 studies

Weill Cornell Medicine

<u>https://</u> <u>www.theguardian.c</u> <u>om/science/2016/</u> <u>jul/03/citizen-</u> <u>science-how-</u> <u>internet-changing-</u> <u>amateur-research?</u> <u>CMP=share_btn_fb</u>



METHODS of Information in Medicine

N-OF-1

METHODS OF INFORMATION IN MEDICINE FOCUS THEME: SINGLE SUBJECT RESEARCH DESIGN AND DATA PROCESSING

Scientific progress in medicine and public health during the last century has been dominated by studies performed with groups of people. Today, thanks in part to advances in computing and information technology, many people collect data to help investigate a health problem, make progress towards a goal, or simply because we are curious. Such investigations need not be conducted on groups. Often, they involve just a single person who is both the subject and the investigator. They are "N-of-1" trials, where data are generated by the individual, normally making use of self-quantification systems, including mobile apps and portable monitoring devices. This focus theme of "Methods of Information in Medicine" on single subject research encourages submission of original articles describing data processing and research methods using a "N-of-1" design where the questions and analysis are guided by the interests and participation of the subject. We encourage submissions that focus on challenges and questions involving data collection, processing, integration, analysis and visualization in the context of single subject research.

AREAS OF FOCUS MAY INCLUDE, BUT ARE NOT LIMITED TO:

Personal health and well-being * Chronic disease management * Mental health * Autonomous selfexperimentation in the context of health and well-being * Health education and autodidactic learning * Privacy, ethics and regulation issues



EXAMPLE METHODS AND TECHNOLOGIES THAT ARE RELEVANT INCLUDE. BUT ARE NOT LIMITED TO:

IT infrastructures for Single-Subject-Research trials * Aggregating data from multiple sensors * Ontologies and knowledge representation * Integrating N-of-1 data with other clinical information systems (health records, decision support) * Data analysis and visualization * Data quality, metadata and annotation aspects

WE ENCOURAGE SUBMISSIONS IN THE FORM OF:

- · Original contributions of individual or a series of N-of-1 trials.
- Original contributions with Single Subject Research Design, Single Case Experimental Design or Patient
 Led Research Design
- · Original contributions on methodological aspects of informatics and statistics applied to N-of-1 trials.
- · Reviews in the field of Single Subject Research Design and data processing of patient generated data
- Perspective and opinion papers

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SUBMISSION DEADLINE

to a rigorous peer review

Submissions must follow

the submission guidelines of

Methods of Information in Medicine, available at: http://methods.schattauer. de/en/authors/manuscript-

submission.html

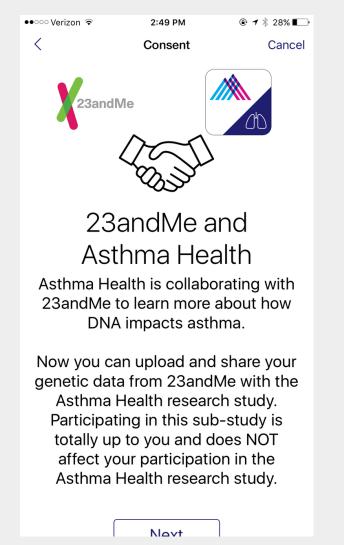
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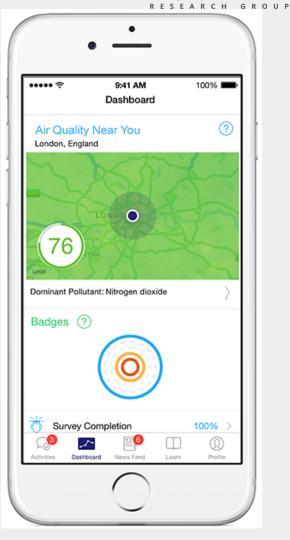
NOVEMBER 1, 2016 High quality, original manuscripts will be subject

Research studies: Asthma Health

Icahn School of Medicine at Mount Sinai

23andMe integrates with Apple's ResearchKit app





Environmental

Participatory Health Informatics

Research studies: GlucoSuccess



Massachusetts General Hospital (MGH) in Boston.

To keep track of health behaviors important for people with type 2 diabetes, such as physical activity, diet, and taking your medicines

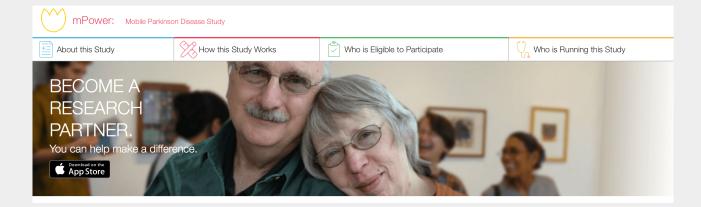


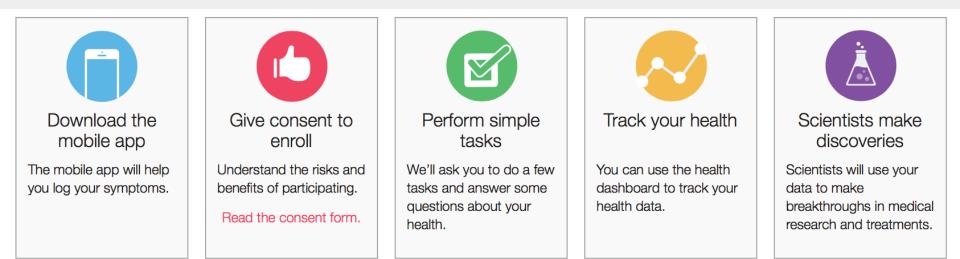


Research studies: mPower



SAGE BioNetworks





Research studies: MyHeart Counts Englishing Health Informatics



Make *your* heart count!

What keeps your heart its healthiest? Help us find out. New version of MyHeart Counts App now available for download at the App Store

Weill Cornell Medicine

RESEARCH GROUP

Research study: Share the Journey



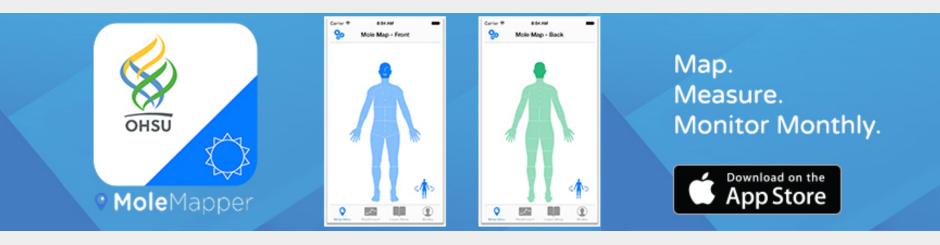
- Mind, Body and Wellness after breast cancer is a clinical study that aims to understand the symptoms after breast cancer treatment, why these symptoms vary over time, and what can be done to improve them.
- SAGE Bionetworks
- Dana Farber Cancer Institue



Research study: MoleMapper



OHSU Dermatology



Using your iPhone camera, Mole Mapper tracks moles and how they change and grow over time. Rapid change or growth may indicate malignancy. Mole Mapper also reminds you to re-check your moles regularly. By sharing mole images over time, researchers can develop new ways of evaluating moles and may (at some point in the future) be able to tell whether you need to see a doctor or have a mole removed based upon a cell phone picture.

More research studies:



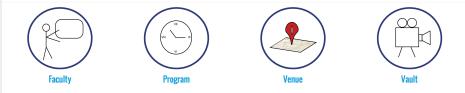
- <u>http://mobihealthnews.com/47611/apple-researchkit-is-a-pipeline-for-future-diagnostic-medical-apps/</u>
- Duke Autism and Beyond Recording children reactions to videos
- Johns Hopkins EpiWatch Seizure detector
- USC Biogram 2– Biometrics and personal/social
- uBiome Microbiome and weight management
- U Nebraska Med Center Hand in Hand HIVneurocognitive disorders
- Boston Children's C Tracker. Chronic Hep C PROs
- Yale Cardiomyopathy Index –
- UCSF PRIDE LGBTQ sexuality and health
- Over 100,000 participants



Training



Immersive blended learning with mHealth thought leaders





Health Data Exploration project

HDE SUMMER INSTITUTE 2016

July 10-16, 2016, Calit2, UCSD, San Diego, CA



The Future



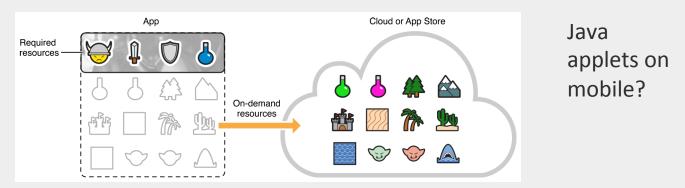
Future without apps



- Problem with apps: Delivery and Discoverability
- Solutions:
 - App linking (apps automatically linked to content)
 - App indexing (apps through search queries)

"I don't want to maintain a walled garden of apps. I want to consume and create content."

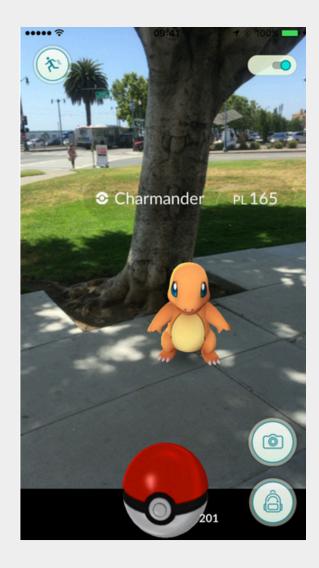
- App streaming from Google: you tap a link to the content and Google will stream the right parts of the app to you on-demand.
- On-demand resources from Apple (ODR): technology released with iOS 9 that downloads a small core application only on installation, and then downloads extra parts and content as needed



https://medium.com/fwd-thoughts/the-future-is-without-apps-ddf43ec52aab#.127sqwf61

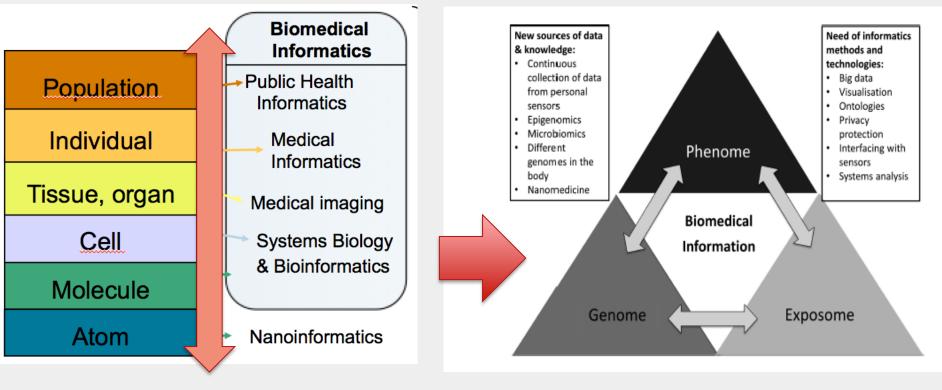
Pokemon Go





Biomedical Informatics



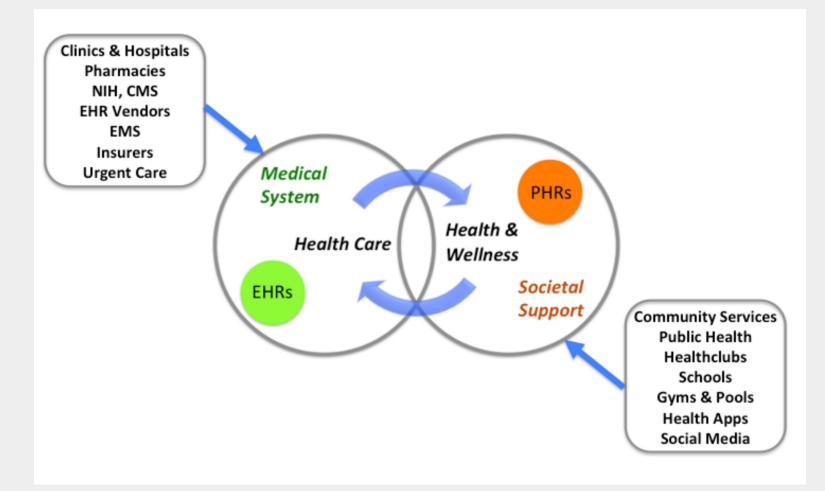


Environment

Martin-Sanchez et al, JAMIA 2015

Integrating patient data with clinical data for a learning healthcare system





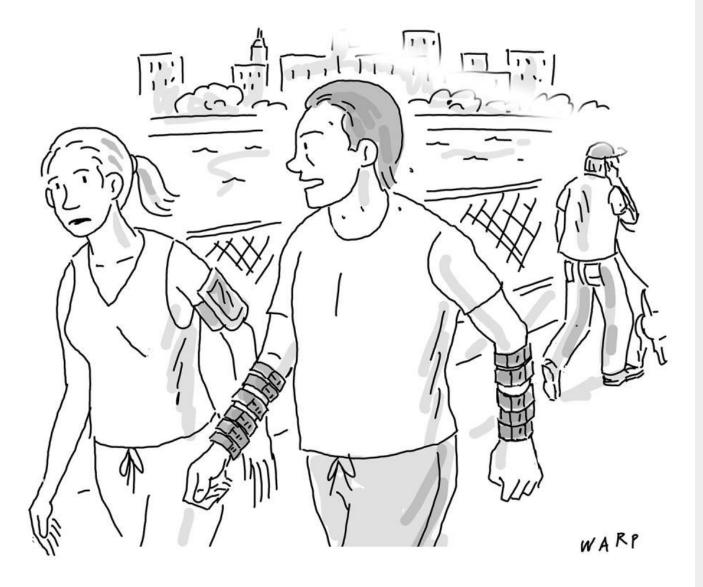
JASON, MITRE Corp. November 2014. Data for individual health. Agency for Healthcare Research and Quality. http://healthit.ahrq.gov/sites/default/files/docs/publication/2014-jason-data-for-individual-health.pdf

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BDC4CM - mHealth & Participatory Medicine



New jobs?



"People pay me to put steps on their Fitbits."







- Understand the concept and importance of Participatory Health and PGHD
- Identify opportunities for biomedical and clinical research using participatory technologies
- Discern the quality of mobile apps
- Find the most appropriate wearable sensor for your project
- Understand how information flows from sensors to information systems
- Identify methods for aggregating and integrating data from multiple sensors
- Understand methods to analyze and visualize participatory health data
- Learn from the most relevant initiatives in this area
- Appreciate challenges for biomedical informatics research and education derived from the use of digital health technologies and participatory health

