



PGHD: ARE NURSES READY FOR THE DATA TSUNAMI?

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CPHIMS

ANIA 2015 Annual Conference
Philadelphia, PA

AGENDA

Intro

- ❑ Define and describe PGHD
- ❑ Challenges of PGHD and PGHD Exchange
- ❑ Triple AIM and PGHD
- ❑ PGHD Use Cases – Improved Outcomes?
- ❑ Concerns: Clinicians and Patient/Care Team
- ❑ Practical Guidance
- ❑ Where are we now?
- ❑ What's Next?

OBJECTIVES

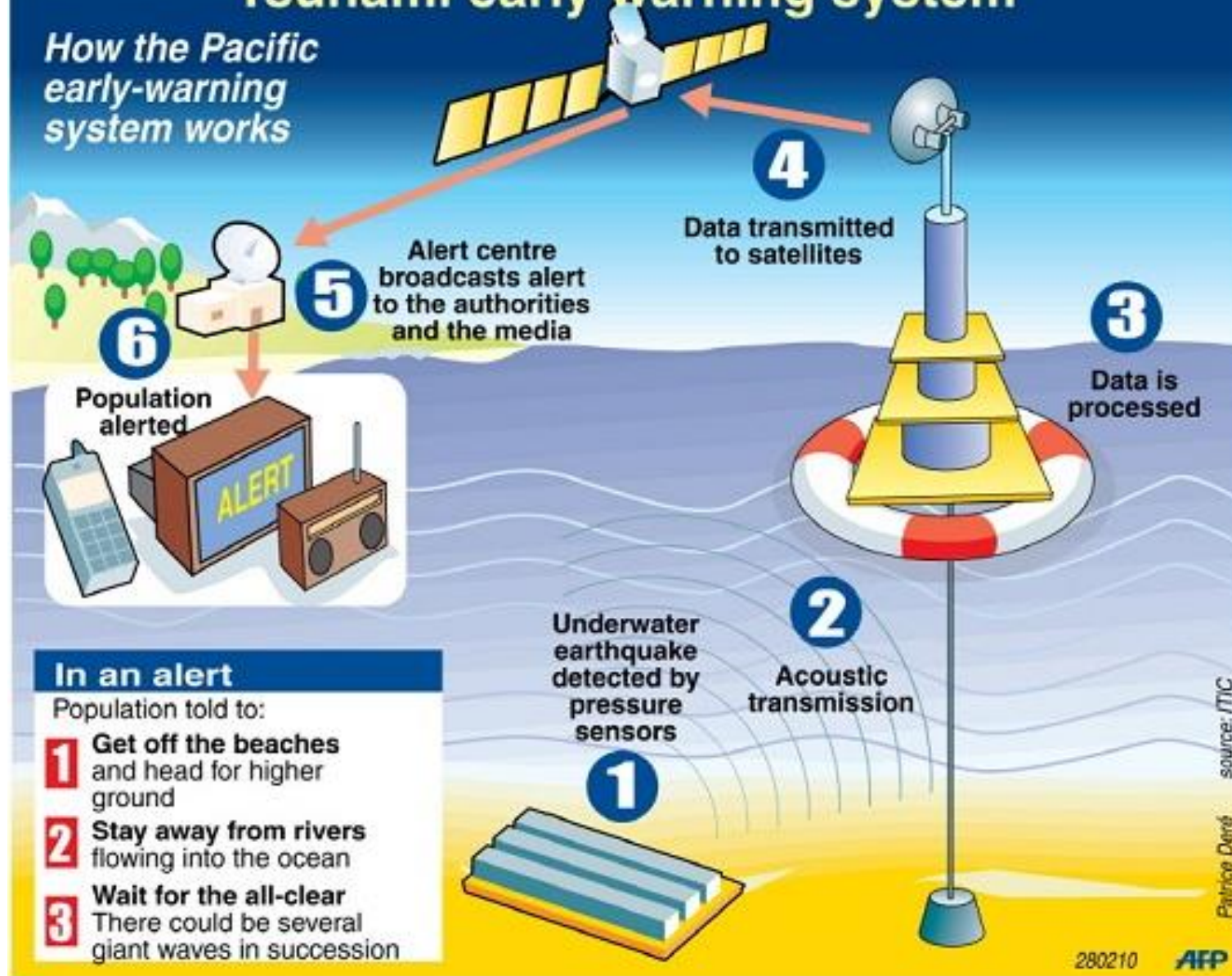
- ❑ Define PGHD and describe current and future trends for collection and exchange.
- ❑ Define Triple Aim initiative and discuss how PGHD will support Triple Aim initiatives.
- ❑ Identify technical challenges for nurses and clinicians using current EMR/EHR software for consuming and reviewing PGHD in a timely and appropriate manner.
- ❑ Discuss nurse considerations for patient/caregiver expectations of PGHD and how PGHD will affect nursing care plans.
- ❑ Identify primary privacy challenges of PGHD exchange.
- ❑ Identify at least 3 use cases of PGHD leading to improved care outcomes.



Japan 2011

Tsunami early warning system

How the Pacific early-warning system works



In an alert

Population told to:

- 1 Get off the beaches** and head for higher ground
- 2 Stay away from rivers** flowing into the ocean
- 3 Wait for the all-clear**
There could be several giant waves in succession

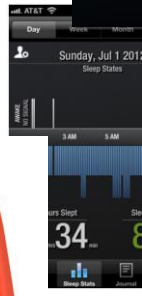
Patrice Deré source: ITIC



Apple WATCH



Bluetooth



23andMe



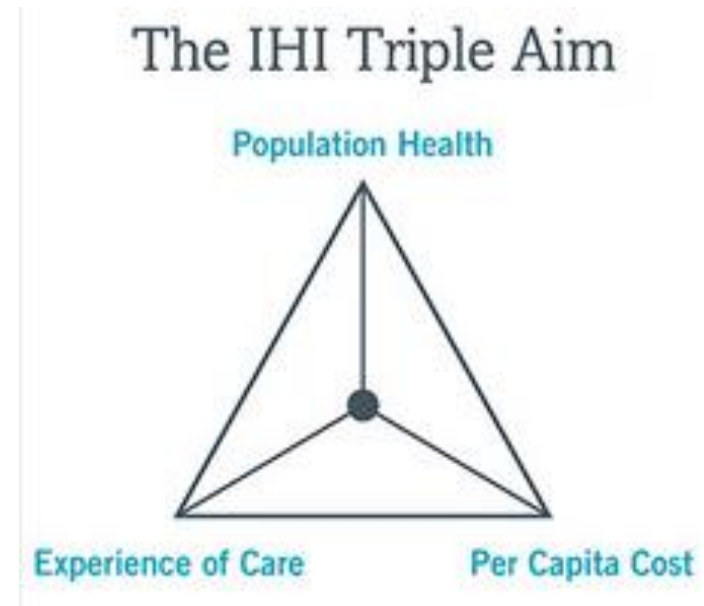
Ginger.io



TRIPLE AIM AND PGHD

Adopted by the Centers for Medicare and Medicaid (CMS), the goals of the *Triple Aim* (Institute for Healthcare Improvement) are defined as:

1. Improving the patient experience of care (including quality and satisfaction)
2. Improving the health of populations
3. Reducing the per capita cost of healthcare





National
eHealth
Collaborative

**Patient-Generated Health
Information**

Technical Expert Panel

FINAL REPORT

December 2013

PGHD

Patient-Generated or Person-Generated

PGHD are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern.

(Technical Expert Panel on Patient-Generated Health Information, National eHealth Collaborative, 2013)

PGHD

PGHD are distinct from data generated in clinical settings and through encounters with providers in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data.

Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders. In these ways, PGHD complement provider-directed capture and flow of health-related data across the health care system.

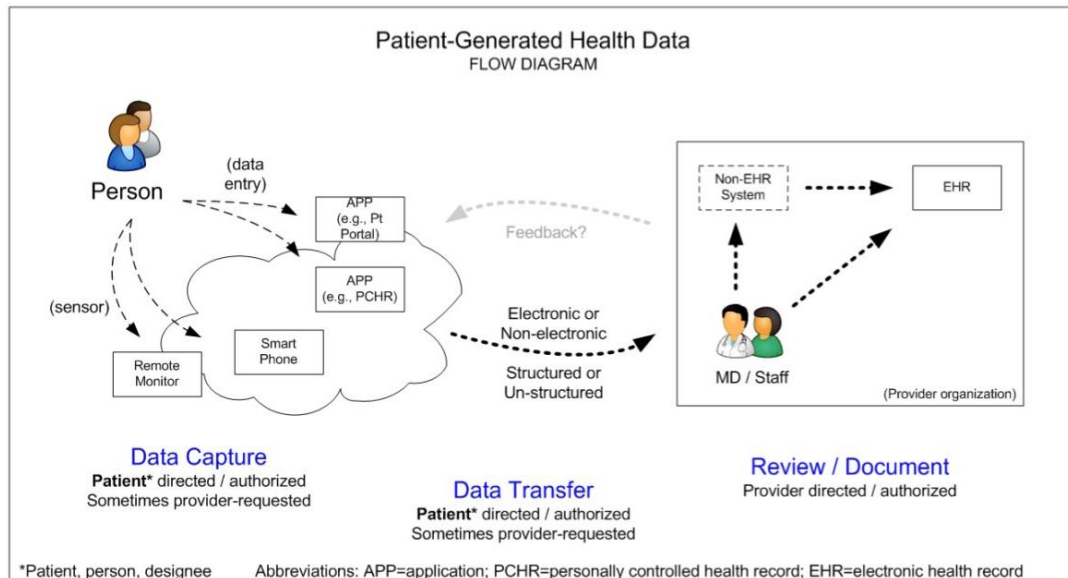
(Technical Expert Panel on Patient-Generated Health Information, National eHealth Collaborative, 2013)

PATIENT-GENERATED OR PATIENT-DIRECTED

Patient-Directed: from a device, patient cannot change or alter data

Patient-Generated: patient can alter or make changes

Figure 1. Patient-Generated Health Data Flow



PGHD can be:

Sensor-derived or manual data entry

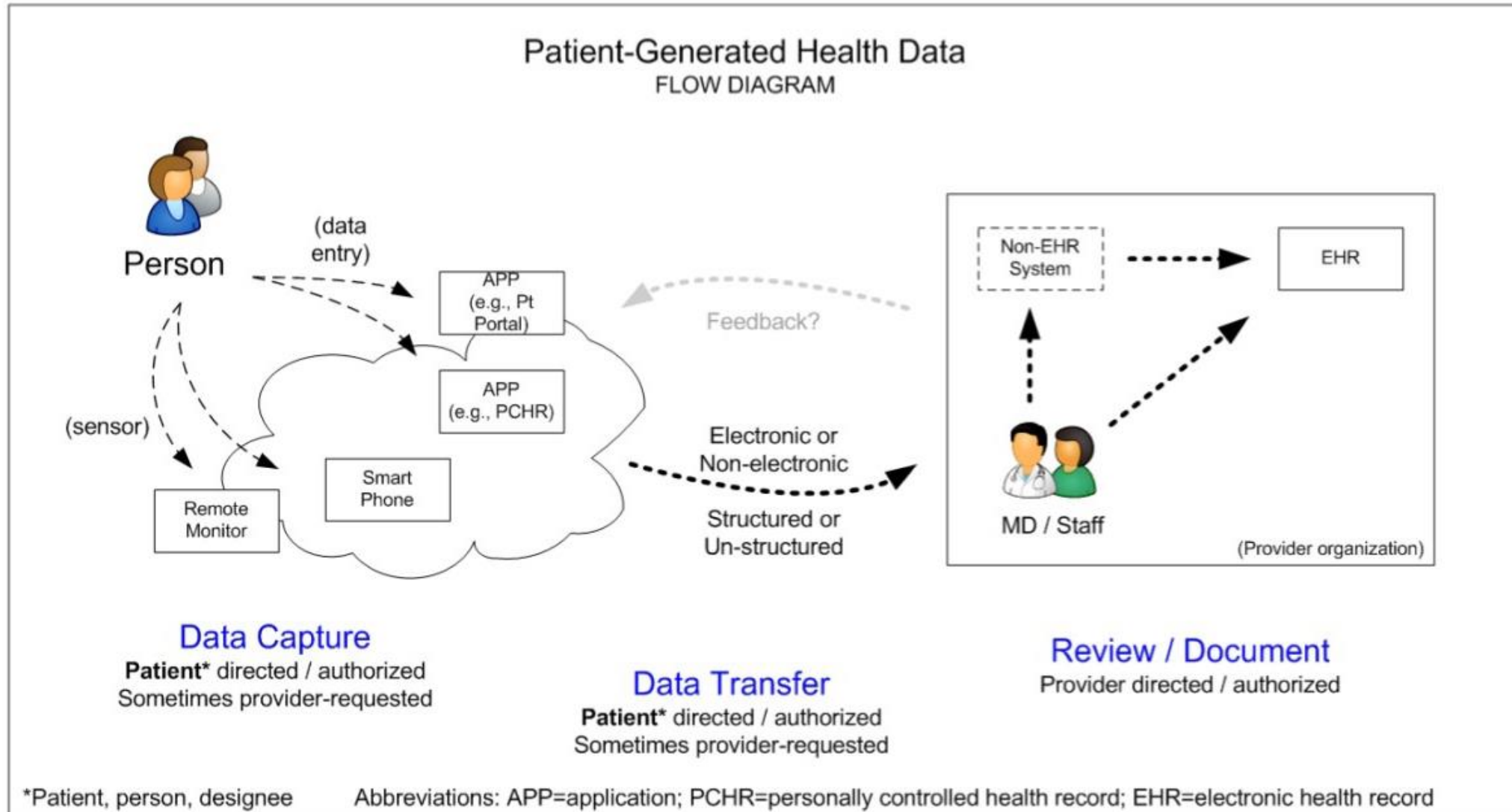
PGHD can be sent:

Electronically or non-electronically

PGHD can be:

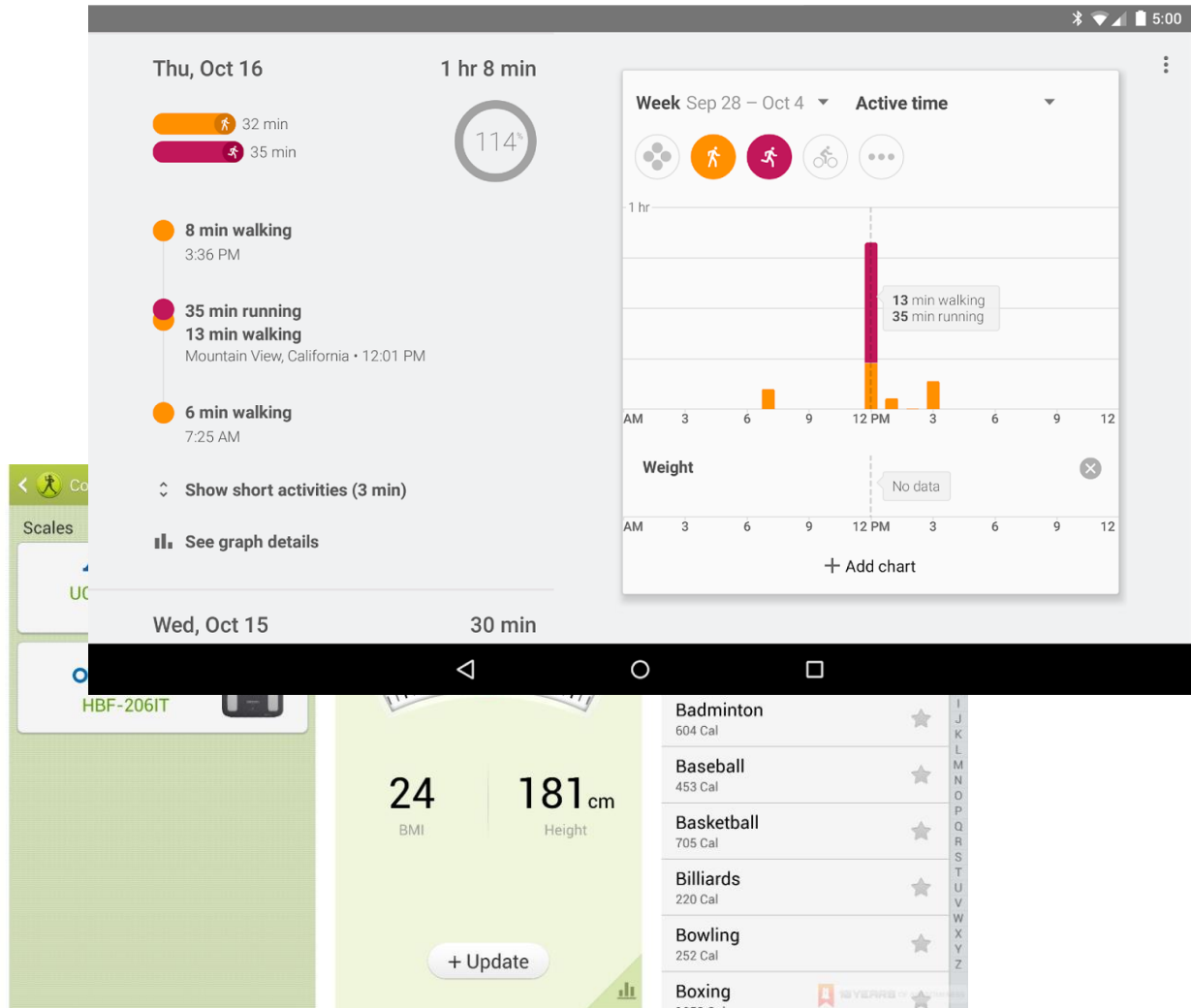
Structured data or unstructured data

Figure 1. Patient-Generated Health Data Flow

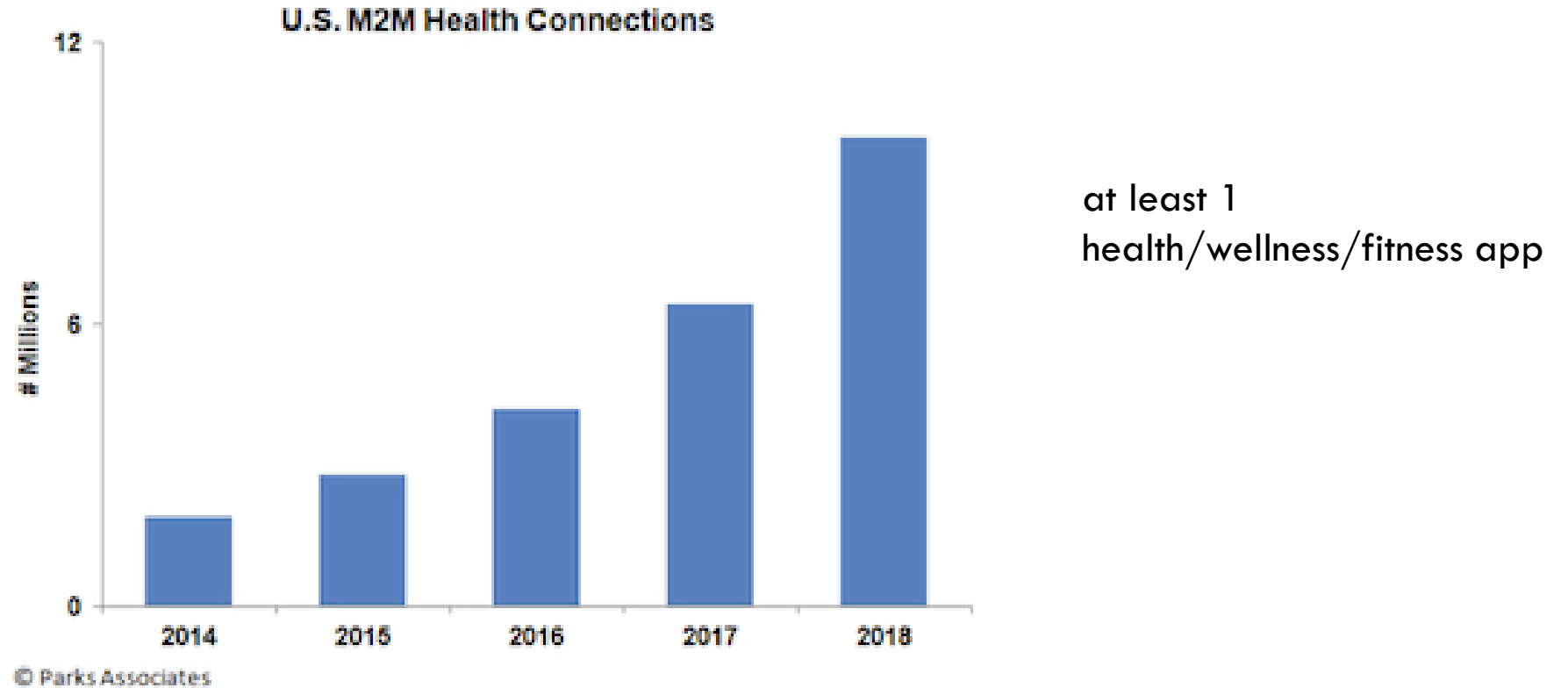


(Technical Expert Panel on Patient-Generated Health Information, National eHealth Collaborative, 2013)

MHEALTH AND PGHD



OVER 40 MILLION SMARTPHONE WELLNESS APPS USED ACTIVELY



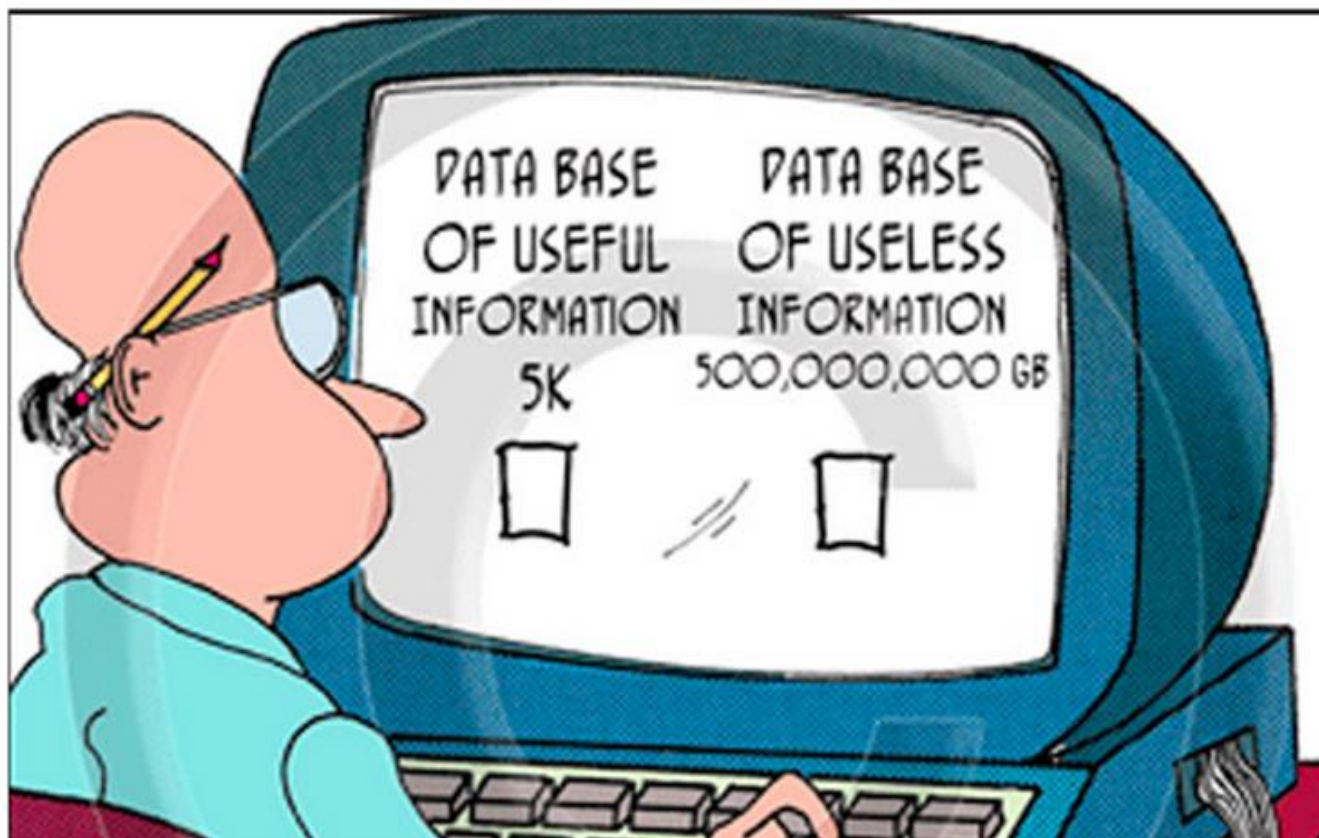
(MobiHealthNews)

QUANTIFIED SELF



<http://quantifiedself.com/>

USEFUL VS. USELESS PGHD?



TECHNICAL CHALLENGES

Information is not easily shared

- On a wearable device – wireless connectivity or data port
- On a non-connected device
- Reliable data? (e.g. Steps on phone vs steps on wearable)
- In a silo not connected to the patients' EHR
- Not standardized or correct format for EHR
- Inconsistent delivery frequencies

BEHAVIORAL CHALLENGES

- Up to 1/3 of wearable users stop using after 6 months ([mobilHealthnews](#))
- PGHD often is manually synched data
- PGHD must be captured at the appropriate time –
all day? all night? during exercise?
- Physicians and clinicians may NOT accept PGHD
- Clinicians are NOT reviewing PGHD when imported

PRIVACY CHALLENGES

- No privacy laws in place to stop gadget/wearable device makers from selling PGHD to 3rd parties (healthitanalytics)

Who reads Terms and Conditions?

- Users identity is often not masked or easy to figure out on PGHD aggregator web pages open to the public
- The “Internet of Things” lacks privacy and security safeguards
- Senator Chuck Schumer (D-NY) working with Federal Trade Commission on regulations to “close the loopholes”.

Consent for sharing, privacy protections (conceal identity)

PGHD WORKS! CASE STUDIES



CASE STUDY #1

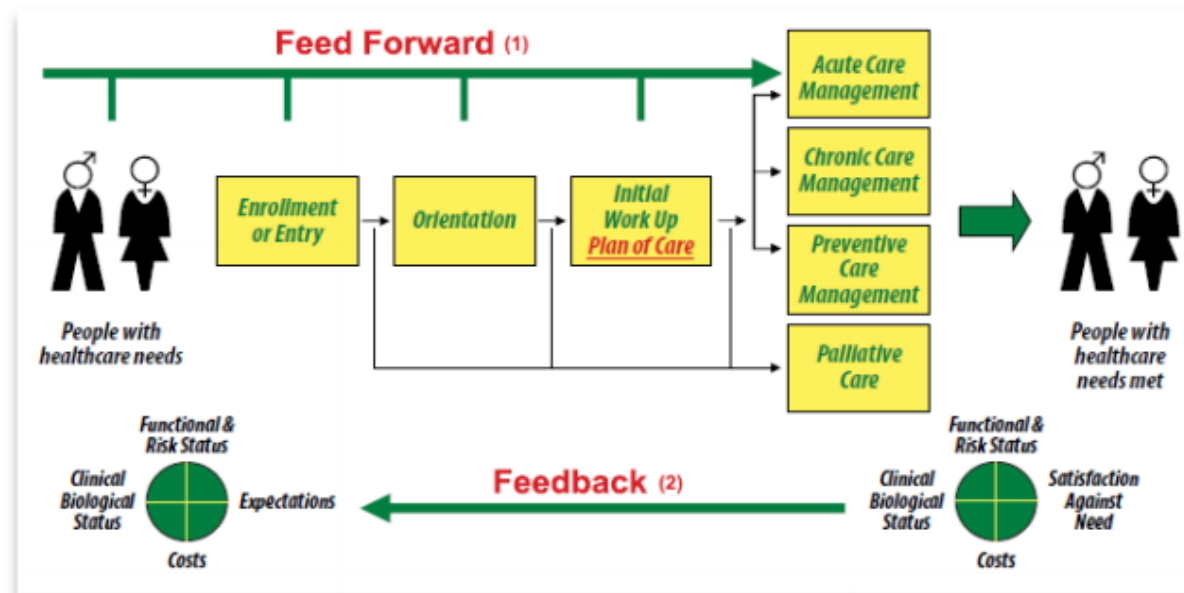
Dartmouth-Hitchcock Spine Center

Online patient survey – can be completed at home or in waiting room (not encouraged or recommended)

Incorporated in scheduling process

Clinical staff must commit to using PGHD and summary from survey in care appointment

CASE STUDY #1 DARMOUTH-HITCHCOCK SPINE



Feed Forward and Feedback Data Flow

Diagram illustrating use of feed forward and feedback data in flow of care for patient care, improvement and research.

1. Feed forward to keep data about the patient with the patient as care is delivered (in multiple settings) over time.
2. Feedback to provide summary data on clinical populations to improve care in individual programs, collaborative networks and to provide research data base.

CASE STUDY #1 DARMOUTH-HITCHCOCK SPINE

- ✓ Survey and summary report of PGHD collected has become a “must have” for clinical staff and process is now the “new normal” for organization.
- ✓ PGHD is now expected and integral part of the care.

CASE STUDY #2 VHA

Veterans Health Administration

Multiple sources of PGHD:

MyHealthVet portal, POS kiosks, Mobile apps, Telehealth, Wearable devices

2003 > Care Coordination/Home Telehealth (CCHT) program

Over 100,000 non-institutional patients – diabetes, CHF, depression – send PGHD via biometric monitors and messaging devices – viewed and monitored by nurses/social workers

CASE STUDY #2 VHA

Over 4 years of CCHT program:

- ✓ 25% reduction in bed days of care
- ✓ 19% reduction in admissions
- ✓ high levels of patient satisfaction

CASE STUDY #3 GEISINGER HEALTH SYSTEM

MyGeisinger patient portal

2011 project to incorporate PGHD via portal feedback regarding medication list

Pharmacist receives and process feedback and updates EHR

Pharmacist also notifies PCP if needed

CASE STUDY #3 GEISINGER HEALTH SYSTEM

Assessed by NORC at University of Chicago:

- ✓ 30% of patients responded to offer to update record
- ✓ 85% processed within 4 days of offer
- ✓ Average patient requested 2 changes
- ✓ Pharmacists accept proposed changes more than 50% of the time

PGHD EXCHANGE: WHAT ARE PROVIDERS THINKING ABOUT?

Provider concerns

- Risk or liability? What about emergencies?
- Financial incentives?
- What is the volume of PGHD heading my way?

PGHD EXCHANGE: WHAT ARE PATIENTS AND FAMILIES THINKING ABOUT?

Patient and Care team

- Will everything be reviewed by a clinician?
- Will everything be in my chart as a permanent record?
- What about future insurance liability? (e.g. gene defects, life insurance)
- What are my incentives for collecting and sending the PGHD?

PGHD — PRACTICAL GUIDANCE

- ❑ Strong leadership and strategy
- ❑ Clear policies – Emergencies, notification loops (example: HealthLoop+)
- ❑ Simple and effective workflows for staff and patients/family
- ❑ Data Provenance – where did this PGHD come from?
- ❑ Encourage active participation for patients and care teams (OpenNotes)

WHERE ARE WE NOW?

Early Apple HealthKit pilots (Mayo, Duke and Oschner)

- ❑ Patients and Clinicians want to collect, exchange and include in EHR
- ❑ EMR (in this case, Epic) is a one-way exchange
- ❑ Current data set of exchange is very limited
- ❑ CMS has CPT codes (999090 and 99091) for PGHD \$56/month
- ❑ Android is not being left behind (Google Fit and Samsung S Health)
- ❑ There will be bugs (Apple's glucometer units issue – fixed with iOS 8.2)
- ❑ HUGE implications for medical research and treatments (ResearchKit iOS 8.2)

MHEALTH, EHR AND PGHD — THE NEXT STEPS (DEMO VIDEO)



WHAT'S NEXT?

PGHD and “Precision Medicine” initiatives Stage 3 Meaningful Use and PGHD

Health

Obama wants funding for research on more precise health care

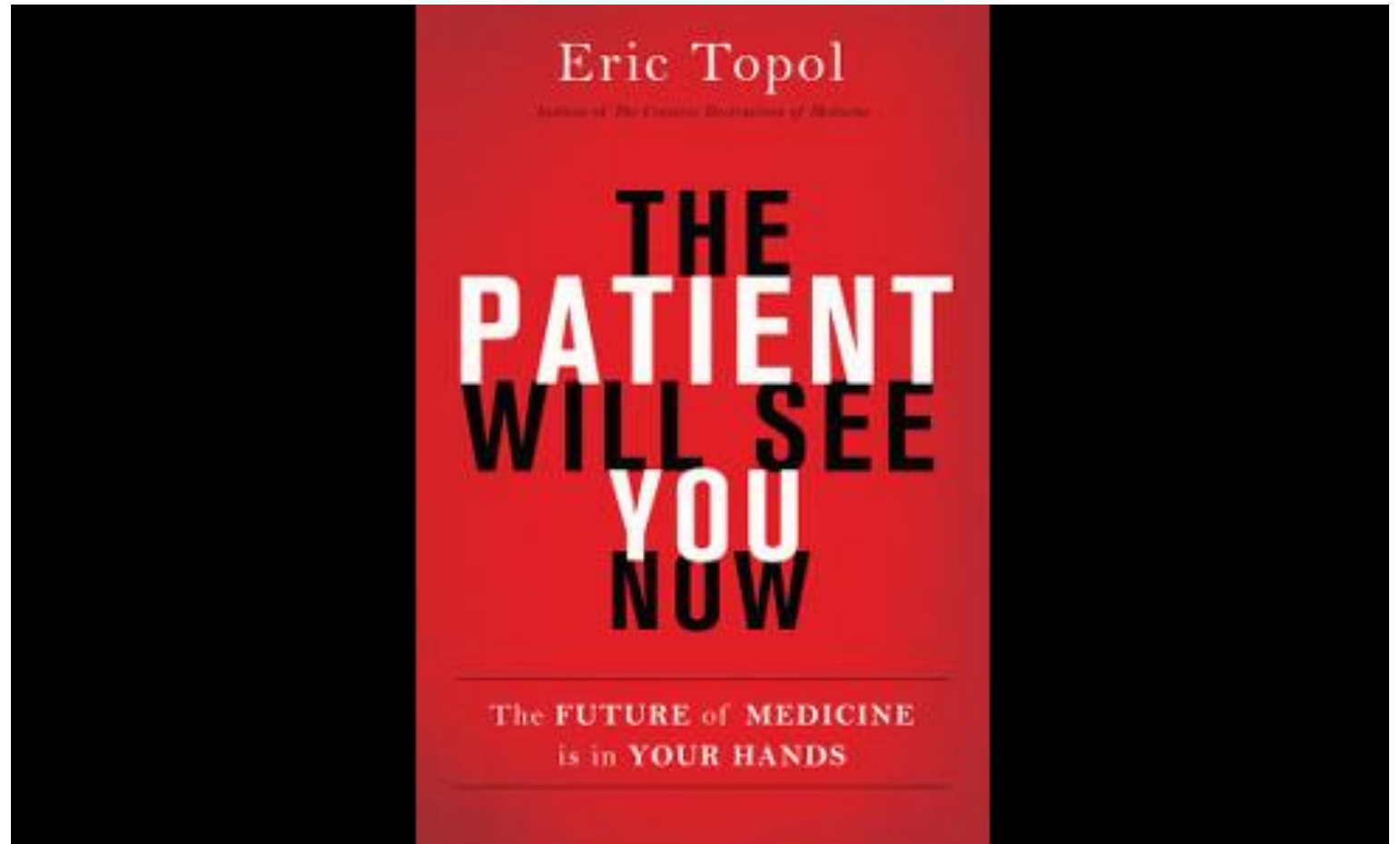
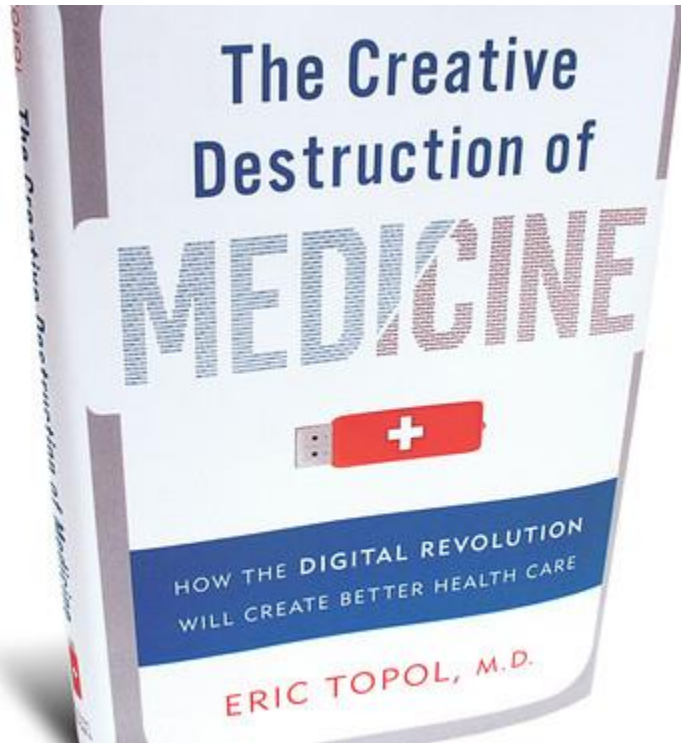
Richard Harris | NPR

January 30 2015

Harvard University student Elana Simon introduces President Obama before he spoke at the White House Friday about an initiative to encourage research into more precise medicine. [MANDEL NGAN/AFP/GETTY IMAGES](#)



PGHD = PATIENT-LEAD HEALTH



DO IT YOURSELF HEALTH (DYI)

<http://healthcarediy.com/>




The screenshot shows the homepage of HealthcareDIY.com. At the top left is a logo with four icons: a fork, a heart, a pill, and a Wi-Fi symbol. The text 'HealthcareDIY' is prominently displayed, with 'DIY' in a larger, green font. To the right of the logo is a 'LOG IN OR REGISTER' link. Below the logo is a navigation bar with links for 'Healthcare Essentials', 'Live well', 'Eat right', 'Shop smart', 'Use technology', and 'Blog'. A search bar is located on the right side of the navigation bar. The main content area features a large '#hackinghealth' hashtag in a dark grey box. Below this is a link to 'DIY basics for #hackinghealth' with a 'READ MORE FROM JANE' button. A social sharing bar includes 'Share', 'Recommend' (113), 'Tweet' (122), and 'G+1' (+28). Below the sharing bar is a section titled 'FROM THE BLOG' with two article teasers: 'It's National Nutrition Month: how's your food IQ?' (EATING) and 'The Quantified Family: what the 2015 Consumer Electronics Show featured for tracking your kids, your parents, your pets, and your self' (TECH). On the right side of the page, there is a red heart graphic with the text 'DON'T MISS A BEAT' and a 'REGISTER NOW' button. Below this is a 'Socially accessible' section with social media icons for Facebook, Google+, and Twitter, and links to 'HEALTHCAREDIY ON TWITTER', 'HEALTHCAREDIY ON FACEBOOK', and 'HEALTHCAREDIY ON GOOGLE+'. At the bottom right is a 'Meet the HealthcareDIY experts' section with a 'VIEW NOW' button.

HEALTH POPULI

<http://healthpopuli.com/>



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The Internet of Things in health care – technology for good in HuffPo

by Jane on MARCH 10, 2015 in [CONNECTED HEALTH](#), [DESIGN AND HEALTH](#), [DIGITAL HEALTH](#), [FITNESS](#), [HEALTH AT HOME](#), [HEALTH CARE INFORMATION TECHNOLOGY](#), [HEALTH CONSUMERS](#), [HEALTH LAW](#), [HEALTH REGULATION](#), [HEALTH SOCIAL NETWORKS](#), [HEALTHCARE DIY](#), [HEALTHCAREDIY](#), [HEALTHDIY](#), [HIPAA](#), [ICTS](#), [INTERNET AND HEALTH](#), [INTERNET OF THINGS](#), [MEDICATION ADHERENCE](#), [MHEALTH](#), [MOBILE HEALTH](#), [PREVENTION](#), [PREVENTION AND WELLNESS](#), [PRIVACY AND SECURITY](#), [REMOTE HEALTH MONITORING](#), [SENSORS AND HEALTH](#), [SOCIAL MEDIA AND HEALTH](#), [TRUST](#), [WEARABLES](#)

As sensors begin to proliferate our “Things,” from refrigerators to cars, toasters to t-shirt, our health could benefit mightily. Approaching this weekend’s South-by-Southwest Interactive meet-up in Austin, several authors have crowdsourced views on using technology for good in ImpactX, a special section in the Huffington Post sponsored by Cisco. I was asked to develop a [...]

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ABOUT JANE & HEALTH POPULI



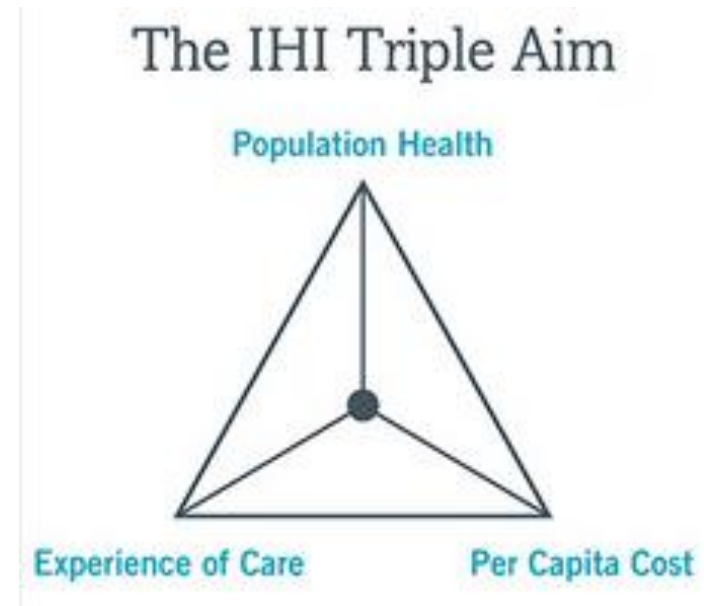
Jane Sarasohn-Kahn is a health economist and management consultant that serves clients at the intersection of health and technology.

Her clients include all stakeholders in health, including providers, payors and plans; companies in biopharma, medical devices, financial services, technology and consumer goods; non-profits and NGOs. Jane’s lens on health was best described by Dr. Regina Benjamin, U.S. Surgeon General, who says that health is where we live, work, play and pray.

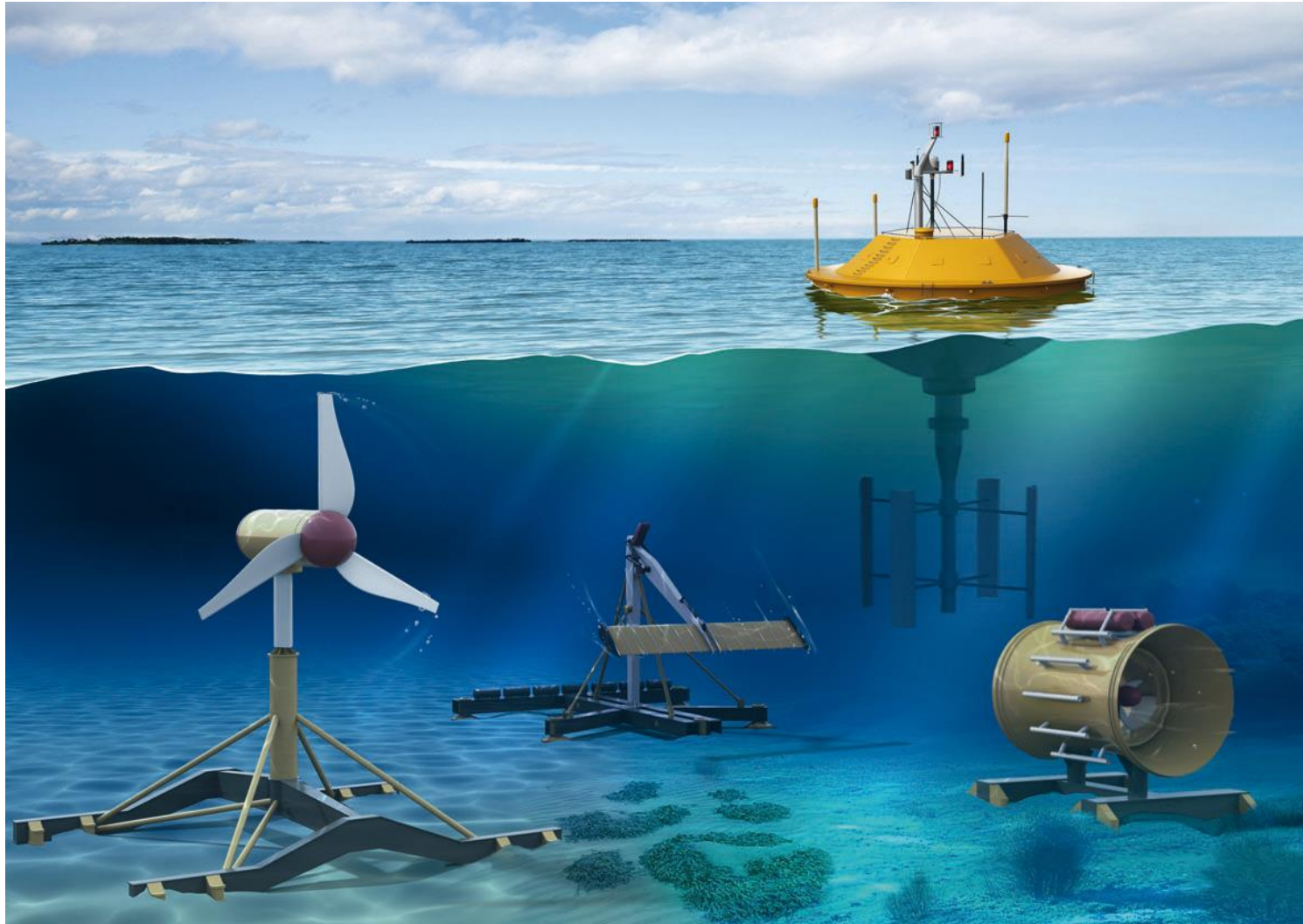
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CAPTURE THE POWER OF THE TIDES



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