

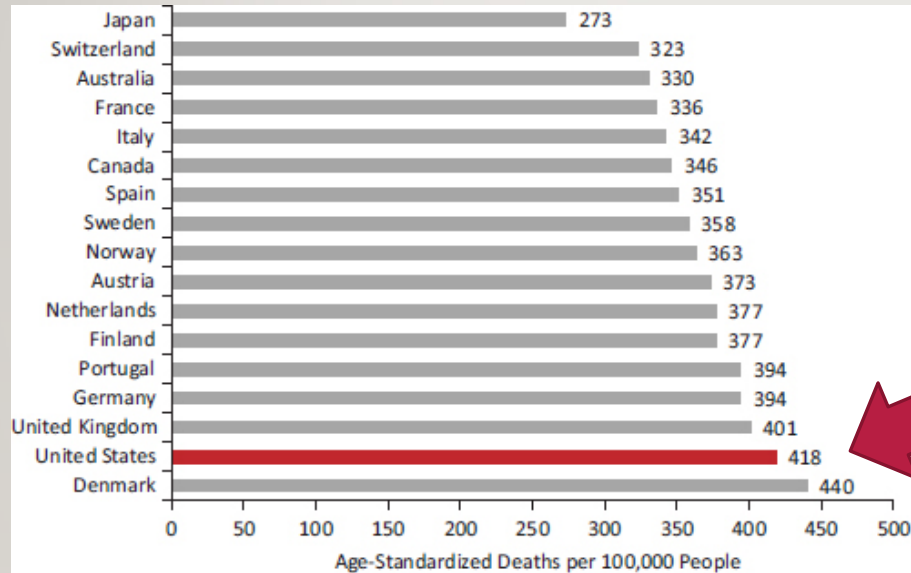


When We Have so Many Trained Professionals & Spend so Much on Health, How Can We Make Health Smarter?

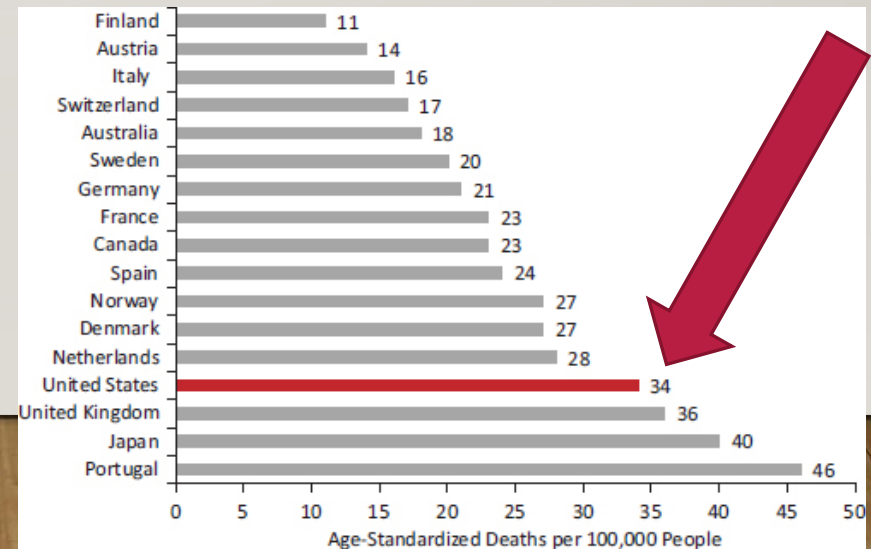
Wendy J. Nilsen, PhD
Program Director, Smart and Connected Health,
Directorate for Computer & Information Systems,
National Science Foundation

U.S. HEALTH: SHORTER LIVES, POORER HEALTH

Mortality from Non-Communicable Disease

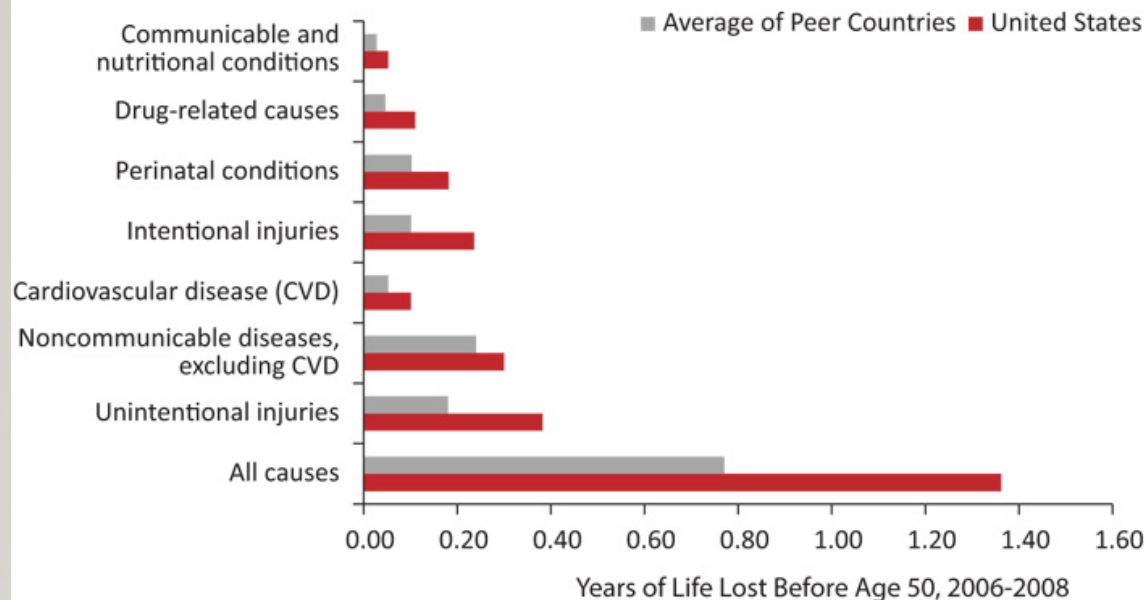


Mortality from Communicable Disease



U.S. HEALTH: SHORTER LIVES, POORER HEALTH

FIGURE: Causes of Death for U.S. Men Before Age 50, Compared with Average of Peer Countries, 2006-2008



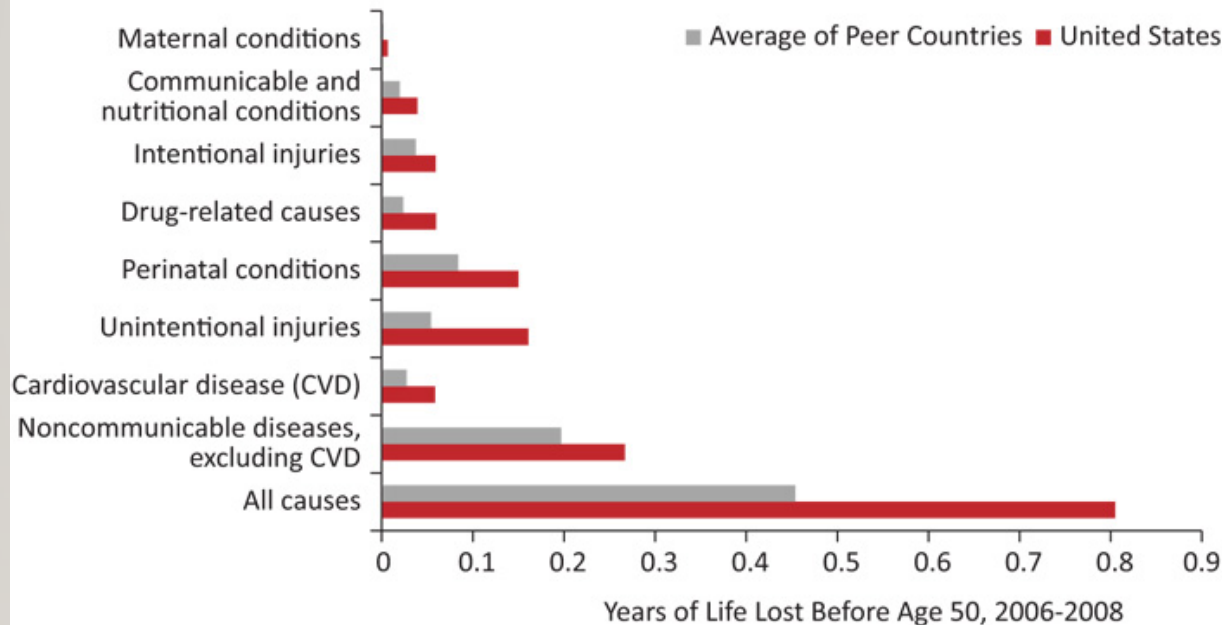
NOTE: CVD is cardiovascular disease

SOURCE: Data from the Human Mortality Database, the World Health Organization Mortality Database, and Statistics Canada, as reported in Ho, J. Y. and S.H. Preston (2011). *International Comparisons of U.S. Mortality*. Data analyses prepared for the National Academy of Sciences/ Institute of Medicine Panel on Understanding Cross-National Health Differences Among High-Income Countries. Population Studies Center, University of Pennsylvania. *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, January 2013

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U.S. HEALTH: SHORTER LIVES, POORER HEALTH

FIGURE: Causes of Death for U.S. Women Before Age 50, Compared with Average of Peer Countries, 2006-2008



NOTE: CVD is cardiovascular disease

SOURCE: Data from the Human Mortality Database, the World Health Organization Mortality Database, and Statistics Canada, as reported in Ho, J. Y. and S.H. Preston (2011). *International Comparisons of U.S. Mortality*. Data analyses prepared for the National Academy of Sciences/ Institute of Medicine Panel on Understanding Cross-National Health Differences Among High-Income Countries. Population Studies Center, University of Pennsylvania. *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, January 2013

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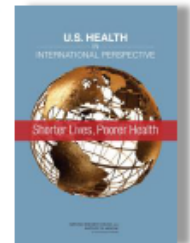
U.S. Children's Health Disadvantage

Children in the US have the **highest probability of dying before age 5** of any of the peer countries.



- In 2004, 11% of US deaths before age 5 were from injuries.
- In 2006, the US had the highest rate of child deaths due to negligence, maltreatment, or physical assault.
- The violent death rate among US boys aged 1-4 has exceeded the OECD average since the late 1960s
- The US is ranked 24th of 30 (OECD) and 21 of 21 (UNICEF) on selected measures of children's well-being.

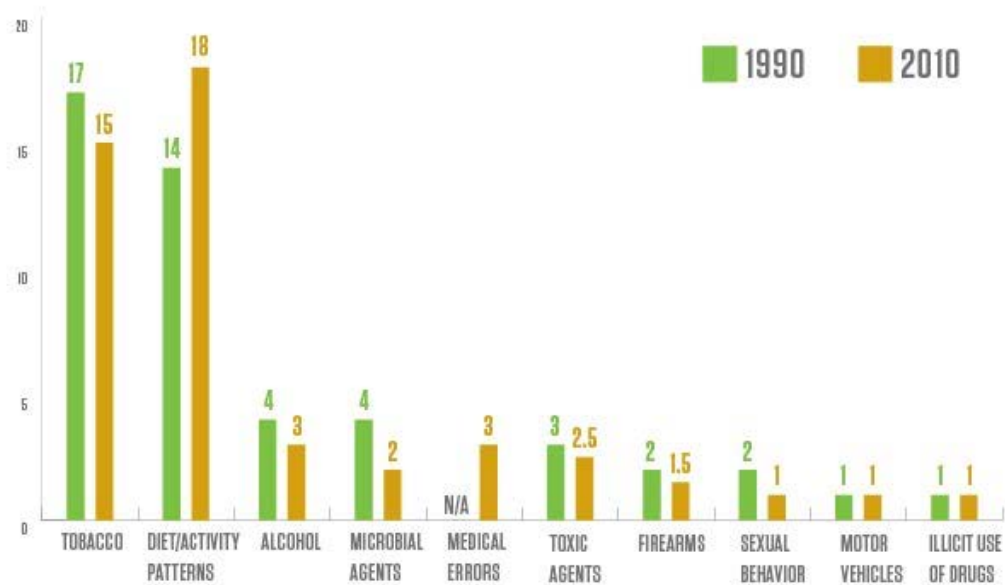
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HALF OF PREMATURE DEATHS ARE PREVENTABLE

Poor Diet, Lack of Exercise Impede Progress on Reducing Early Deaths.

PERCENT OF EARLY DEATHS (BEFORE AGE 80) BY CAUSE, 1990 AND 2010

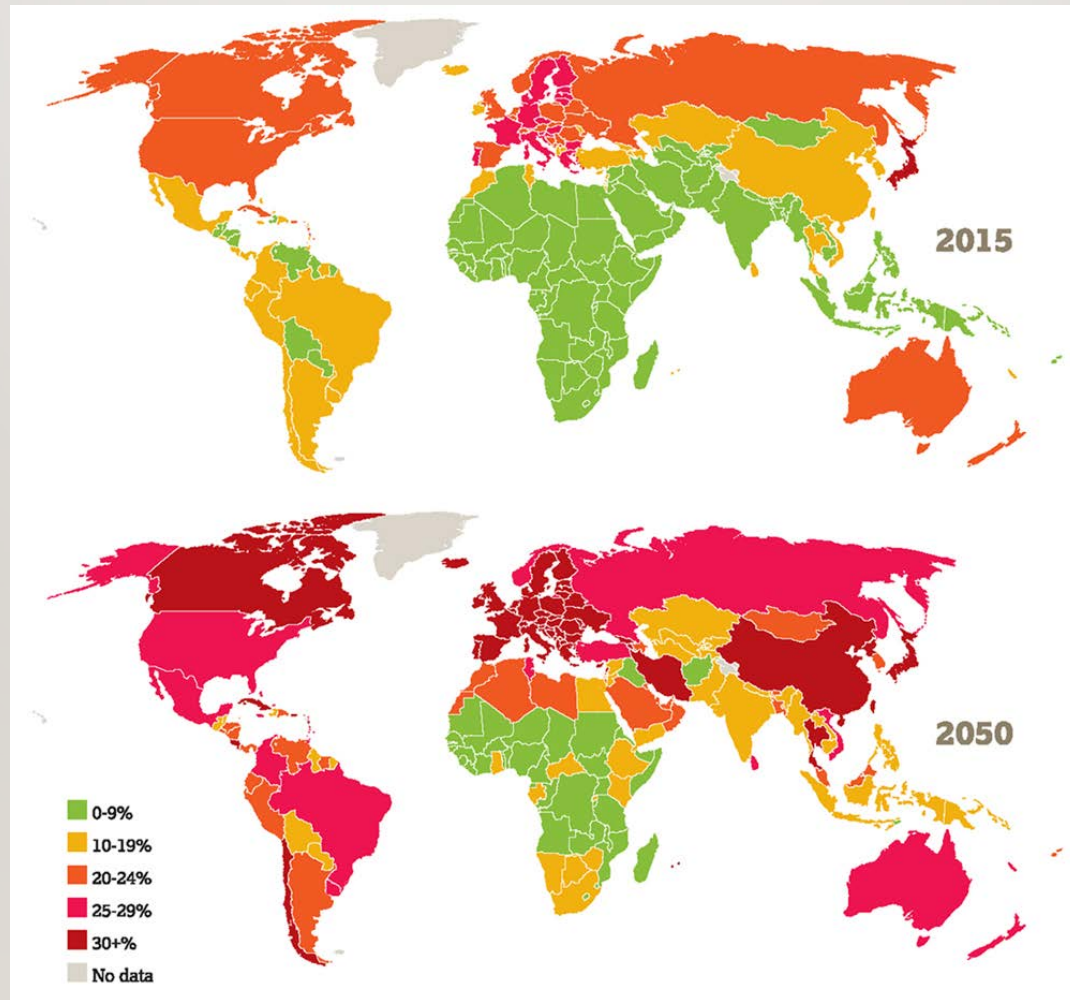


NOTE: Deaths due to medical errors not calculated in 1990.

SOURCE: J. Michael McGinnis, "Actual Causes of Death, 1990-2010," Workshop on Determinants of Premature Mortality, Sept. 18, 2013, National Research Council, Washington, D.C.

TIME IS NOT ON OUR SIDE: AGING DEMOGRAPHICS

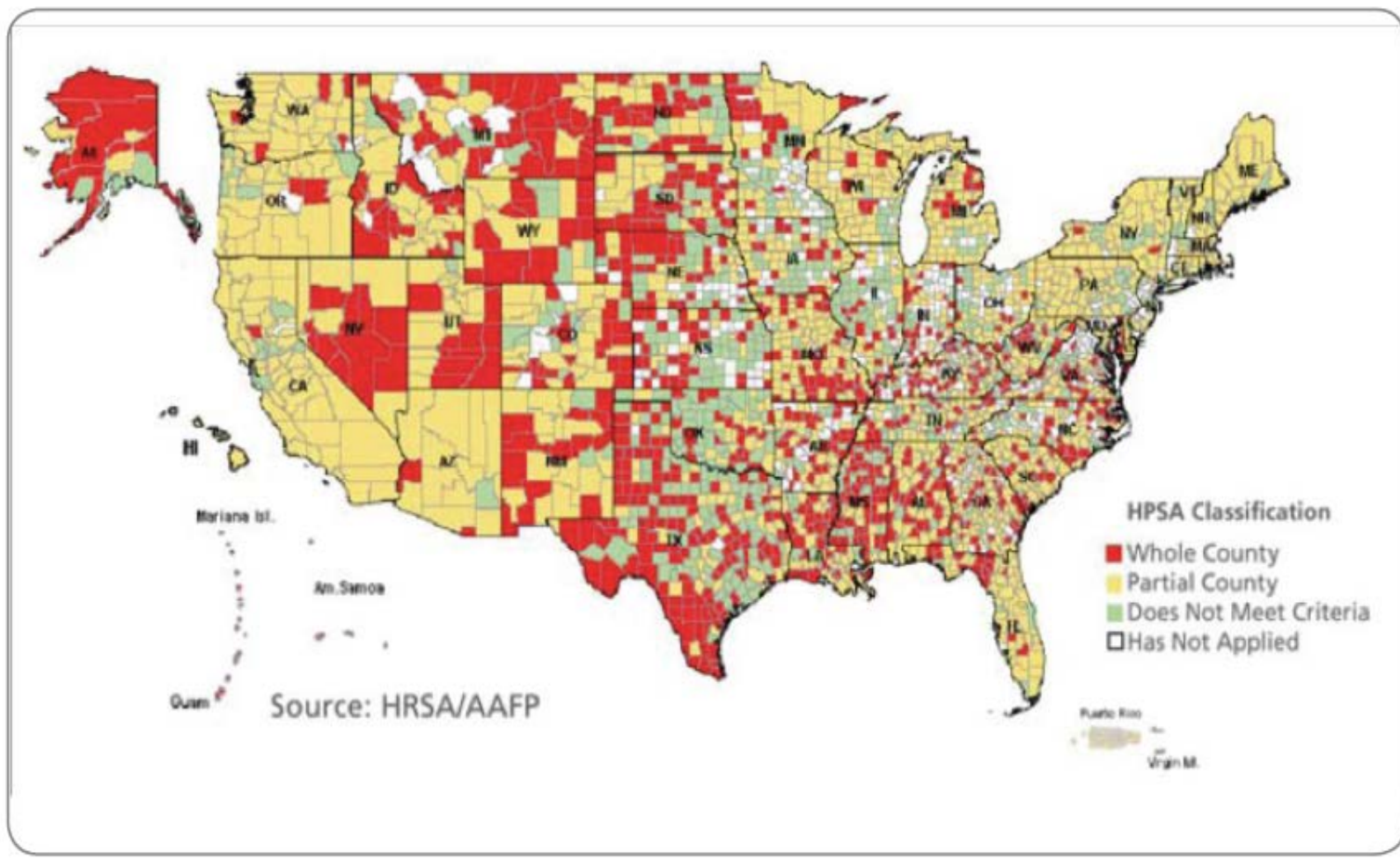
PERCENTAGE OVER AGE 60



UNDESA Population division, World population prospects: the 2015 revision, DVD Edition, 2015.

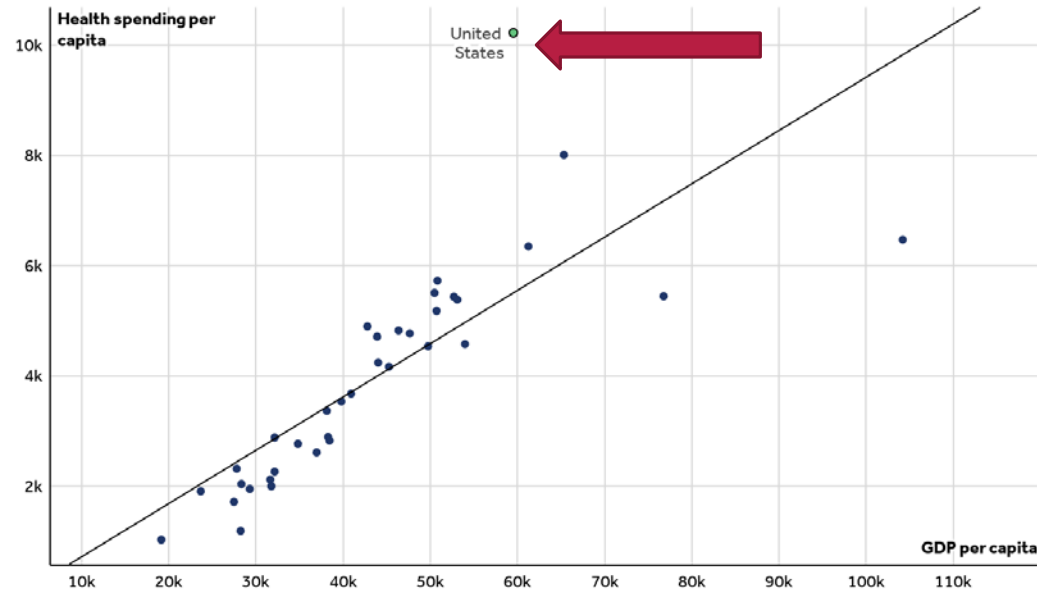
NOR IS THE WORKFORCE

Federally Designated Health Professional Shortage Areas by County



HEALTH COSTS BY GDP

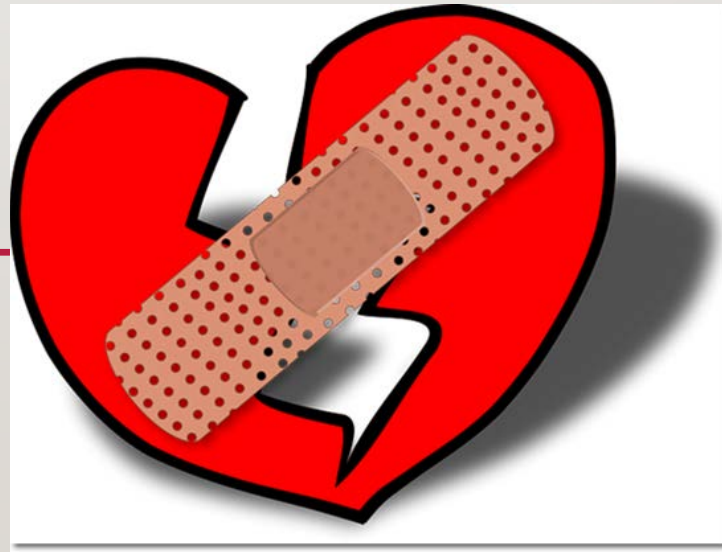
GDP per capita and health consumption spending per capita, 2017 (U.S. dollars, PPP adjusted)



Source: KFF analysis of data from National Health Expenditure Accounts and OECD
• [Get the data](#) • [PNG](#)

Peterson-Kaiser
Health System Tracker

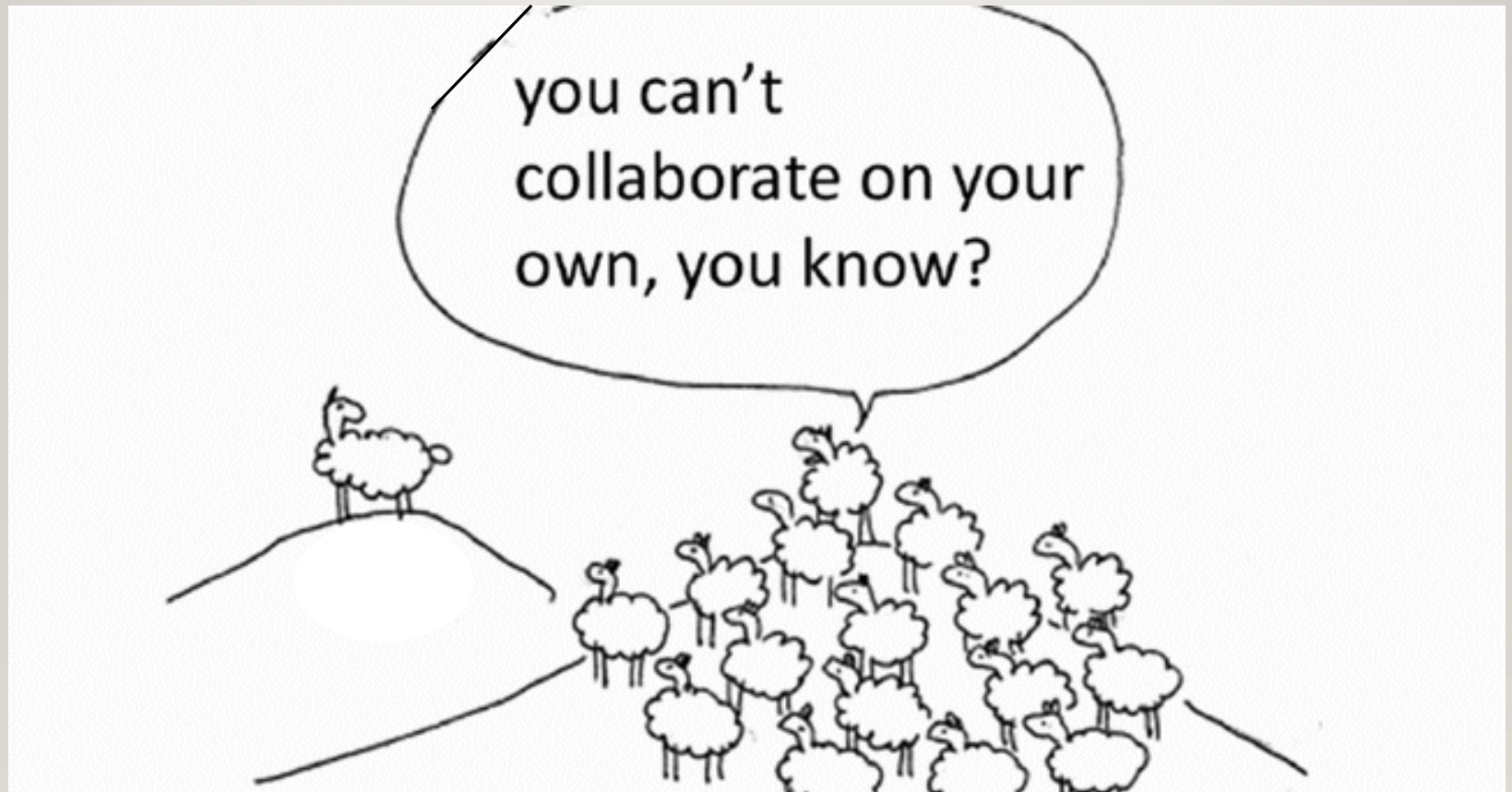
WHAT ARE WE TO DO?



Siloed Sciences



**“YOU CAN’T COLLABORATE ON
YOUR OWN, YOU KNOW?”**



HEALTH - COMMUNITY ARE POORLY CONNECTED



Siloed Incentives and Policy



WHAT TO DO?



Data

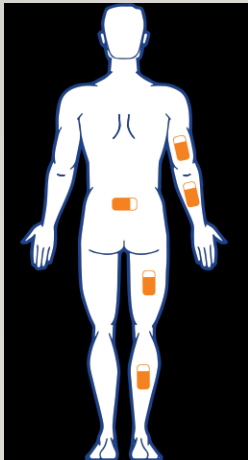
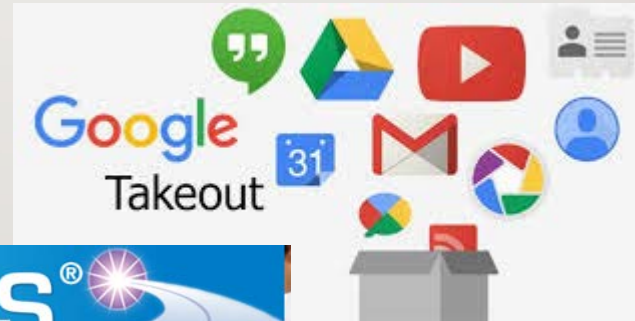
Billions of mobile devices

+ Billions of sensors

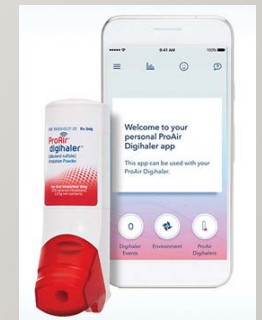
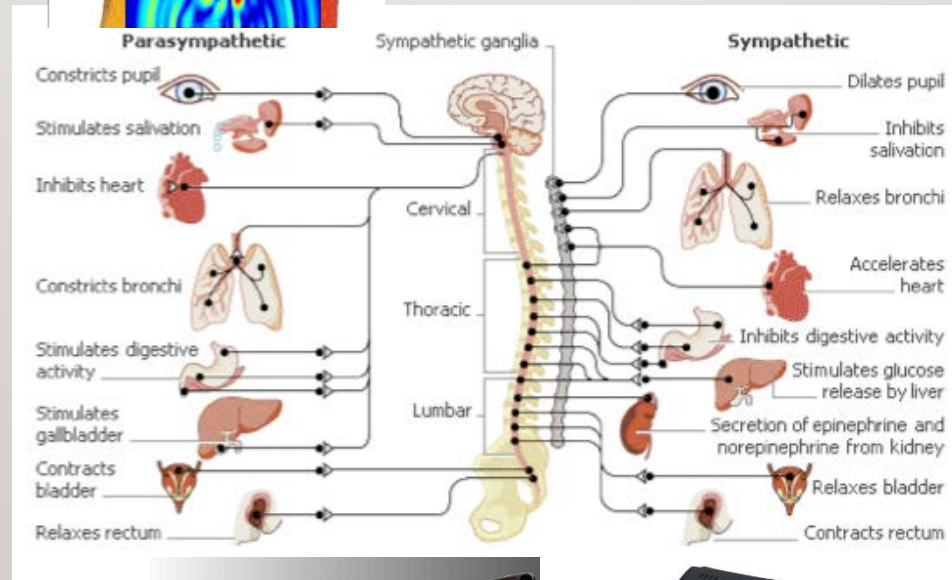
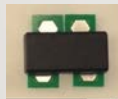
+ Billions using social networks

=

Unprecedented opportunities for health data science



MOBILE SENSING DATA



PATIENT SHARED DATA

HMO Collaboratory

Vivli.org

FDA Sentinel

All of Us

VIEWPOINT

The Pathway to Patient Data Ownership and Better Health

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Digital health data are rapidly expanding to include patient-reported outcomes, patient-generated health data, and social determinants of health. Measurements collected in clinical settings are being supplemented by data collected in daily life, such as data derived from wearable sensors and smartphone apps, and access to other data, such as genomic data, is rapidly increasing. One projection suggests that a billion individuals will have their whole genome sequenced in the next several years.¹ These additional sources of data, whether patient-generated, genomic, or other, are critical for a comprehensive picture of an individual's health.

Enabling access to personal health data, clinical or patient-generated, may benefit patients and health care professionals. Research is beginning to show that providing patients with their complete health data may help improve their health. For example, timely access to laboratory results can increase patient engagement.² Access to physician notes after appointments appears to encourage individuals to improve their health and participate in decision-making, with electronically engaged patients demonstrating more successful medication adherence, quality outcomes, and symptom management.³ Economic benefits may include the avoidance of duplicative imaging or laboratory tests.⁴ Clinicians may also benefit from more informed patients. For example, they may score higher in quality performance programs because patients who are more informed may better adhere to treatment plans and hence may improve clinician

Patients need and deserve the opportunity to control their health data.

scores. Despite growing evidence of such benefits, al-

health data. For this to proceed, control of health data must be transferred to the patient or the patient's authorized representative.

More specifically, to obtain active patient engagement and health system improvement, 3 components are necessary: (1) common data elements that enable the sharing and merging of health data from multiple sources; (2) a patient encounter data receipt, comprised of relevant health data from each health care encounter, automatically pushed to the patient's complete digital health record; and (3) a contract between patients and third-party health data managers (eg, health care organizations and commercial entities) that enables individuals to control their longitudinal digital health record. Most of these components already exist in some form, requiring only minor adjustments to effect health system transformation.

Clinicians, patients, and health care systems need a way to efficiently receive, integrate, understand, compute, and use digital health data from other practitioners and health encounter locations. This requires the merging of what is often disparate data from multiple sources, and the most effective way to do this is to establish common data elements agnostic of any particular vendor's electronic health record (EHR) system.

With widespread implementation of common data elements and value sets, semantic and clinical interoperability can be achieved, and health information can be merged, while maintaining data integrity. New initiatives, such as the Standard Health Record,⁷ that focus on standardizing data within health records instead of solely on exchange standards enable the development of one complete, digital health record per patient containing health data merged from all of a patient's clinicians and related health data sources.

PCOR Net

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TECHNOLOGY AND HEALTH

Table. The Digitally Connecting World 2010-2020

	2010	2015 ^a	2020 ^a
World population, billion	6.8	7.2	7.6
No. connected			
Devices, billion	12.5	25	50
Devices per person	1.8	3.5	6.6
No. of smartphone subscriptions, billion	0.5	3.0	6.1
No. of wireless hotspots, million	3	47	500
No. of transistors, million/chip, nm	16/40	19/16	22/8
No. of sensors	20 Million	10 Billion	1 Trillion
No. of individuals sequenced	<10	400 000	5 Million

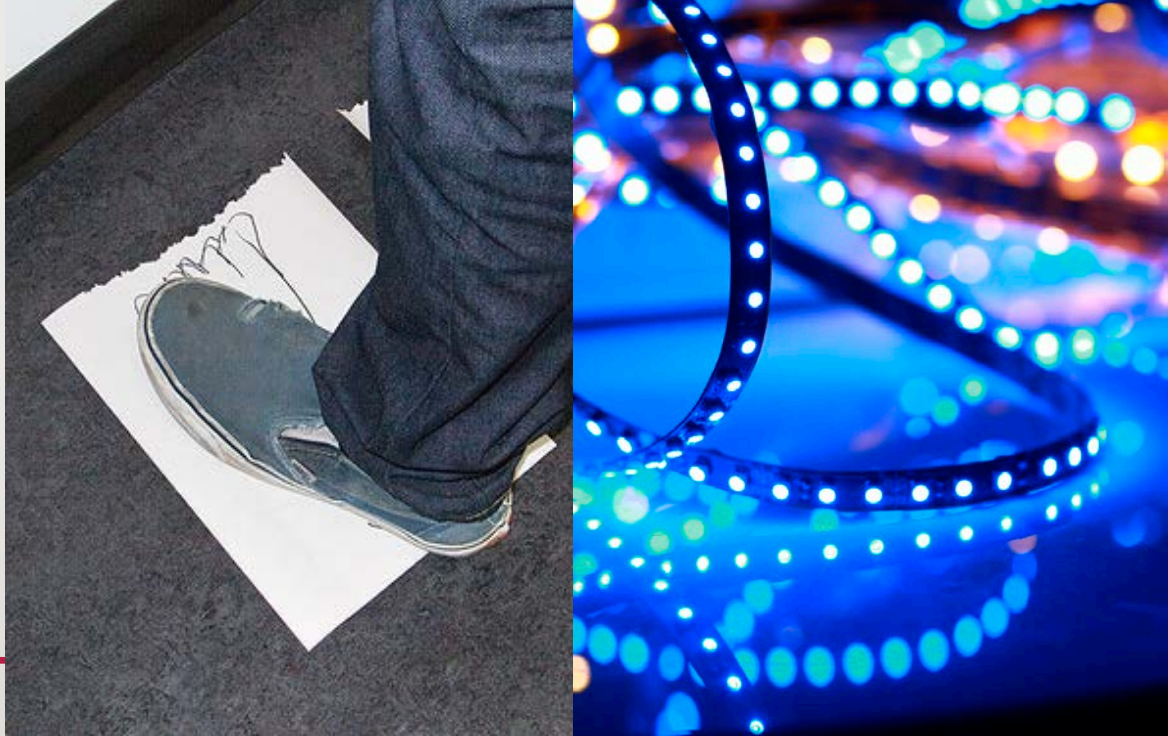
Digital Medical Tools and Sensors: Topol, Steinhubl and Torkamani, JAMA, 2015

NEW MODES OF MOBILE SENSING

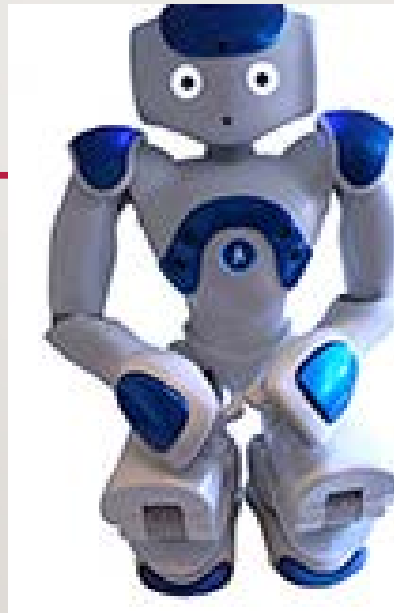
Wifi

Light

Vibration



wifi



DIGITAL DEVICES

AND MORE DEVICES



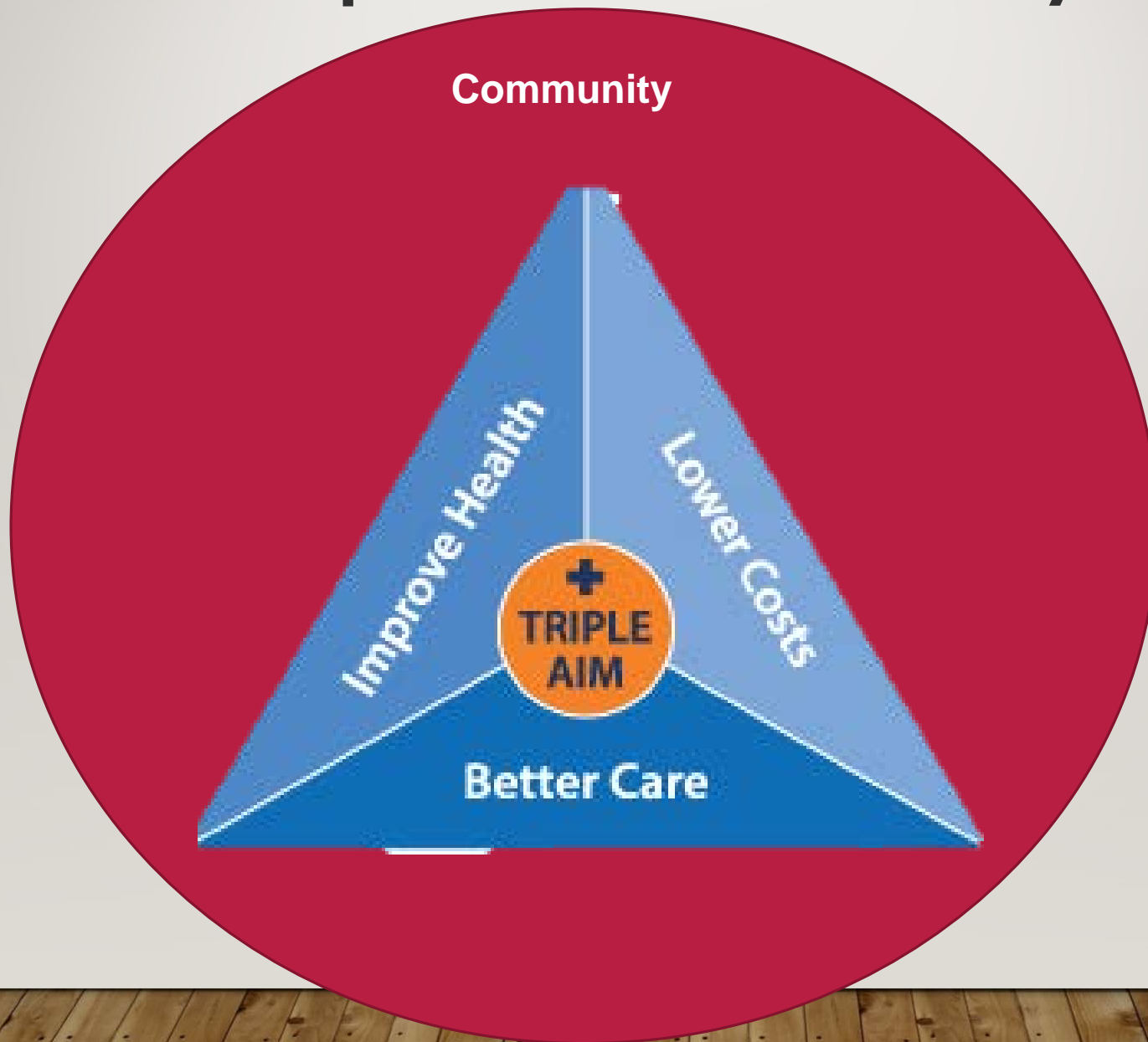
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NEXT STEPS FOR TRANSFORMATION

TIMES THEY ARE A CHANGING

The Walmart logo, featuring the word "Walmart" in blue and a yellow six-pointed starburst icon.

Triple Aim + Community



SUCCESSFUL TECHNOLOGY SHOULD:

- Be safe and trustworthy
- Recognize that multiple approaches are needed to address individual needs
- Create more personalized technology to serve diverse populations, while creating evidence-based, generalizable solutions from which to adapt.
- Create solutions with the principles of 'future' proofing.
- Design technologies to empower patient, caregivers and providers with timely and actionable information.
- Ensure technology does not create a 'digital' divide or disadvantages among groups.
- Have an evidence base to support usage

USER-CENTERED

Consumer technology provides opportunities for engagement that rival unhealthy competition

Want it to talk, be playful or friendly?

Personalized for optimal engagement



<https://www.interaction-design.org>

JUST IN TIME



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Flexibility of delivery:

- ▶ When wanted
- ▶ When needed
- ▶ How best conveyed

Real time information

- ▶ Support/information when and where it is needed
- ▶ Information/Support that develops with my needs

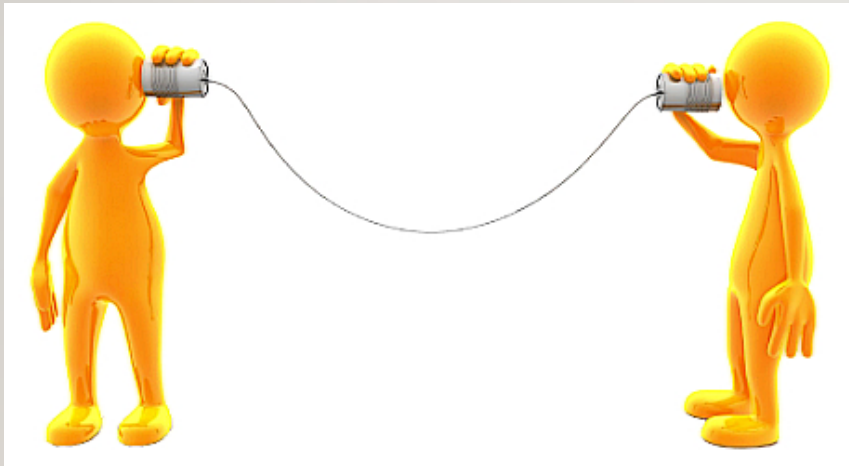
CONTEXT AWARE

- Integrated into real life



<https://www.youtube.com/watch?v=PXgBWsaYCSk>

COMMUNICATION CENTRAL

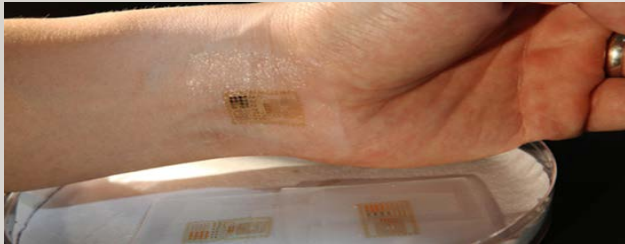


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- Digital devices can act as a health “hub”
- Collecting sensed and patient-generated data
- Providing communication with care team (incl. Patient & caregivers)
 - Photos
 - To ask or do lists
 - Messaging
- Intervention and support programs

PERSONALIZED

- Unobtrusive and minimally invasive
- Capitalize on the Internet of Things
- Capture new modalities – such as dynamic imaging



TRUSTWORTHY

- Methods that would allow real-time assessment of problematic data
- Dealing with biases
- Does the data represent what we think it does?
- Is the variance signal or noise?
- Cause and effect



SAFE

- Access control and authentication
- Confidentiality and anonymity
- Trustworthy control
- Accountability
- Medical device security



BUSINESS / Technology

Hollywood hospital pays \$17,000 in bitcoin to hackers; FBI investigating



The Hollywood Presbyterian Medical Center in 2004. The hospital was recently the target of a ransomware extortion plot in which hackers seized control of its computer systems and then demanded that directors pay in bitcoin to regain access. (Ricardo DeAratanha / Los Angeles Times)



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In Case You Missed It



Ancient beasts roamed this secret spot in Death Valley, but you probably can't go

NOV. 16, 2016



'I can't help you anymore': What it's like to rack on and leave

Evidence

- Validating the effectiveness and reliability of technologies by developing methods of rapidly generate evidence.
- Developing ‘testbeds’ to efficiently, economically and systematically explore the use of technologies and involve the community in the research.
- Thinking about technologies more broadly.
- Creating new robust methods of analysis and sensing-driven decision analysis to create predictive, personalized models of health.



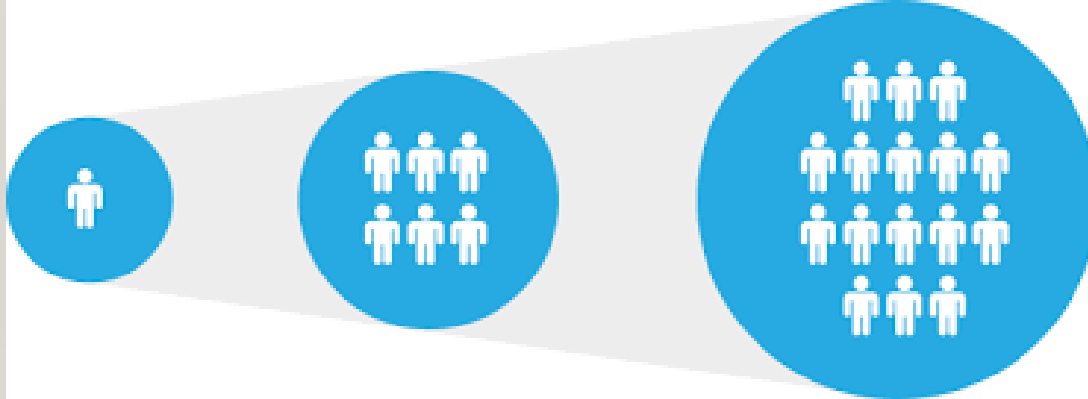
REPRESENTATIVE



Green LA, Miller RS, Reed FM, Iverson DC, Barley GE. How Representative of Typical Practice are Practice-Based Research Networks? Arch Fam Med, 1993; 2:939-949.

SCALABLE

-
- Moving from the individual to the population
 - Robust
 - Usable, trustworthy and safe



BRIDGING ECOSYSTEMS

BRIDGES BETWEEN COMMUNITIES



Bridges between behavioral, biomedical, computing, information, communications and engineering disciplines, patients, providers and health care systems



Bridges are hard, but worthwhile

“Wicked problems” – can’t be solved by a single discipline

Access to expertise or particular skills

Access to equipment, resources, or funding

Enhance trainee education

Impact

Effective Research is a **Relay** between basic and applied science



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The message is case sensitive; so capitalize as indicated!

- ➡ Don't include the brackets.
- ➡ The Subject line should be blank
- ➡ For example, for Robin Smith to subscribe, the message would read
- ➡ *Subscribe SMARTHEALTH_COMMUNITY Robin Smith.*

You will receive a confirmation of your subscription along with instructions on using the listserv.



Questions or Comments?

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