

Measuring Individual Privacy

In the Context of Personal Health Big Data

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Justice Scalia's Privacy Legacy



Privacy
of the
home

[Kyllo v. United States](#) (2001)

Held: Where the Government uses a device that is not in general public use, to explore details of a private home that would previously have been unknowable without physical intrusion, the surveillance is a Fourth Amendment "search," and is presumptively unreasonable without a warrant.

TECHNOLOGY

Apple Fights Order to Unlock San Bernardino Gunman's iPhone

By KATIE BENNER and ERIC LICHTBLAU FEB. 17, 2016



Privacy
and
security
trade-offs

Gauging the allure of
designer drugs p. 469

Blown-up brains for a better
inside view pp. 474 & 543

Single-crystal perovskite
solar cells pp. 519 & 522

Science

\$10
30 JANUARY 2015
sciencemag.org

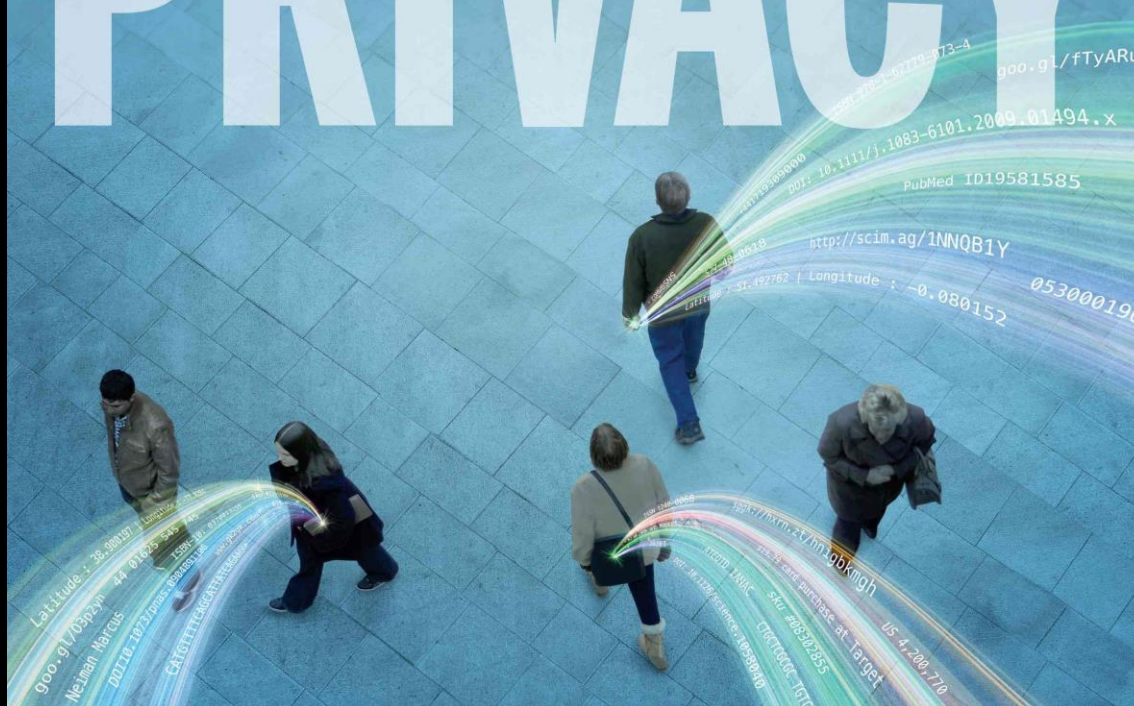


SPECIAL ISSUE

The End of

PRIVACY

Privacy
and big
data



Privacy is discussed a lot, but do we really know what it means?

Samuel Warren and
Louis Brandeis

HARVARD
LAW REVIEW.

VOL. IV.

DECEMBER 15, 1890.

NO. 5.

THE RIGHT TO PRIVACY.

"It could be done only on principles of private justice, moral fitness, and public convenience, which, when applied to a new subject, make common law without a precedent; much more when received and approved by usage."

WILLES, J., in *Millar v. Taylor*, 4 Burr. 2303, 2312.

THAT the individual shall have full protection in person and in property is a principle as old as the common law; but it has been found necessary from time to time to define anew the exact nature and extent of such protection. Political, social, and economic changes entail the recognition of new rights, and the common law, in its eternal youth, grows to meet the demands of society. Thus, in very early times, the law gave a remedy only for physical interference with life and property, for trespasses *vi et armis*. Then the "right to life" served only to protect the subject from battery in its various forms; liberty meant freedom from actual restraint; and the right to property secured to the individual his lands and his cattle. Later, there came a recognition of man's spiritual nature, of his feelings and his intellect. Gradually the scope of these legal rights broadened; and now the right to life has come to mean the right to enjoy life,—the right to be let alone; the right to liberty secures the exercise of extensive civil

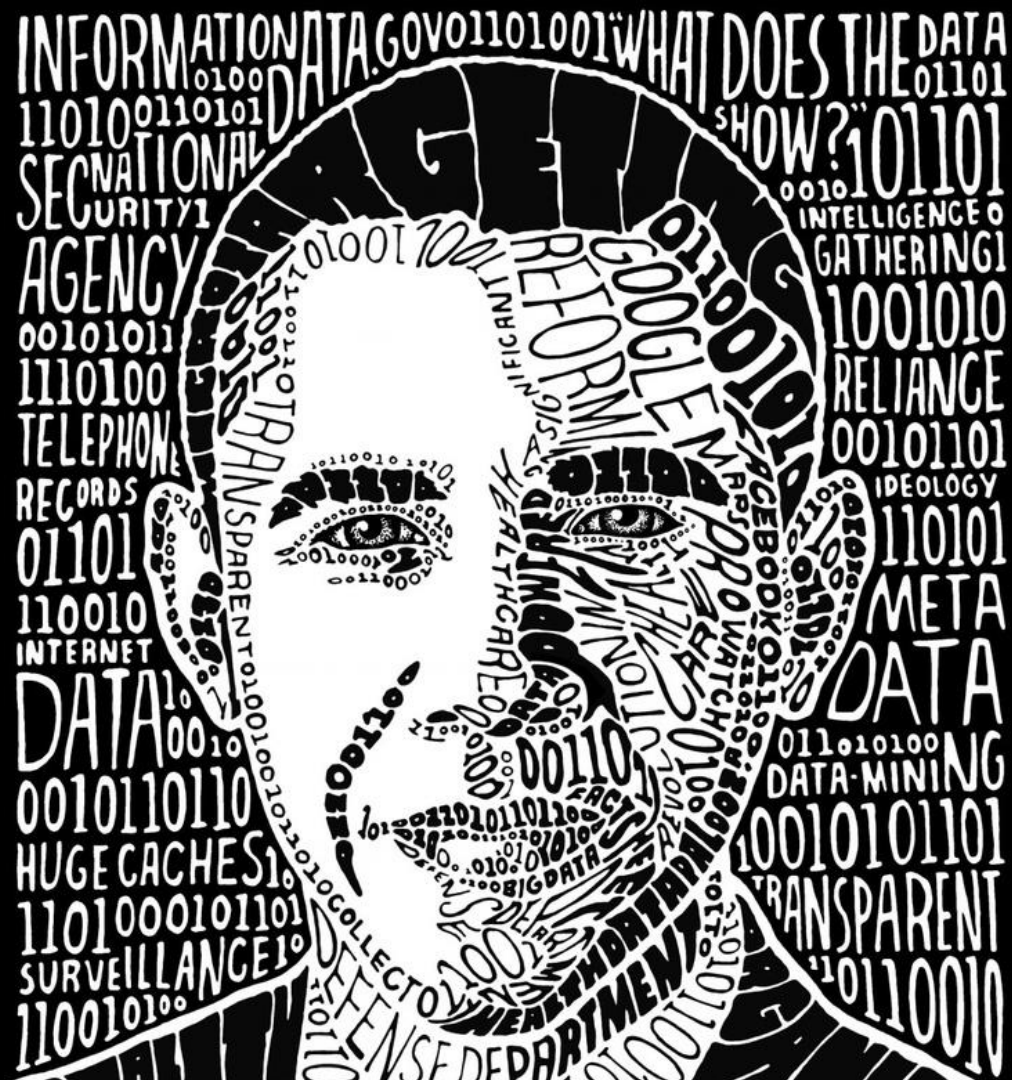
rown to comprise every tangible.

value of sensations, the
s extended to prohibit
the putting another in



first to advocate a right to privacy, or
"right to be let alone"

On the heels of
inventions such as
photography &
newspaper



Contemporary inventions enable generation of vast amounts of data

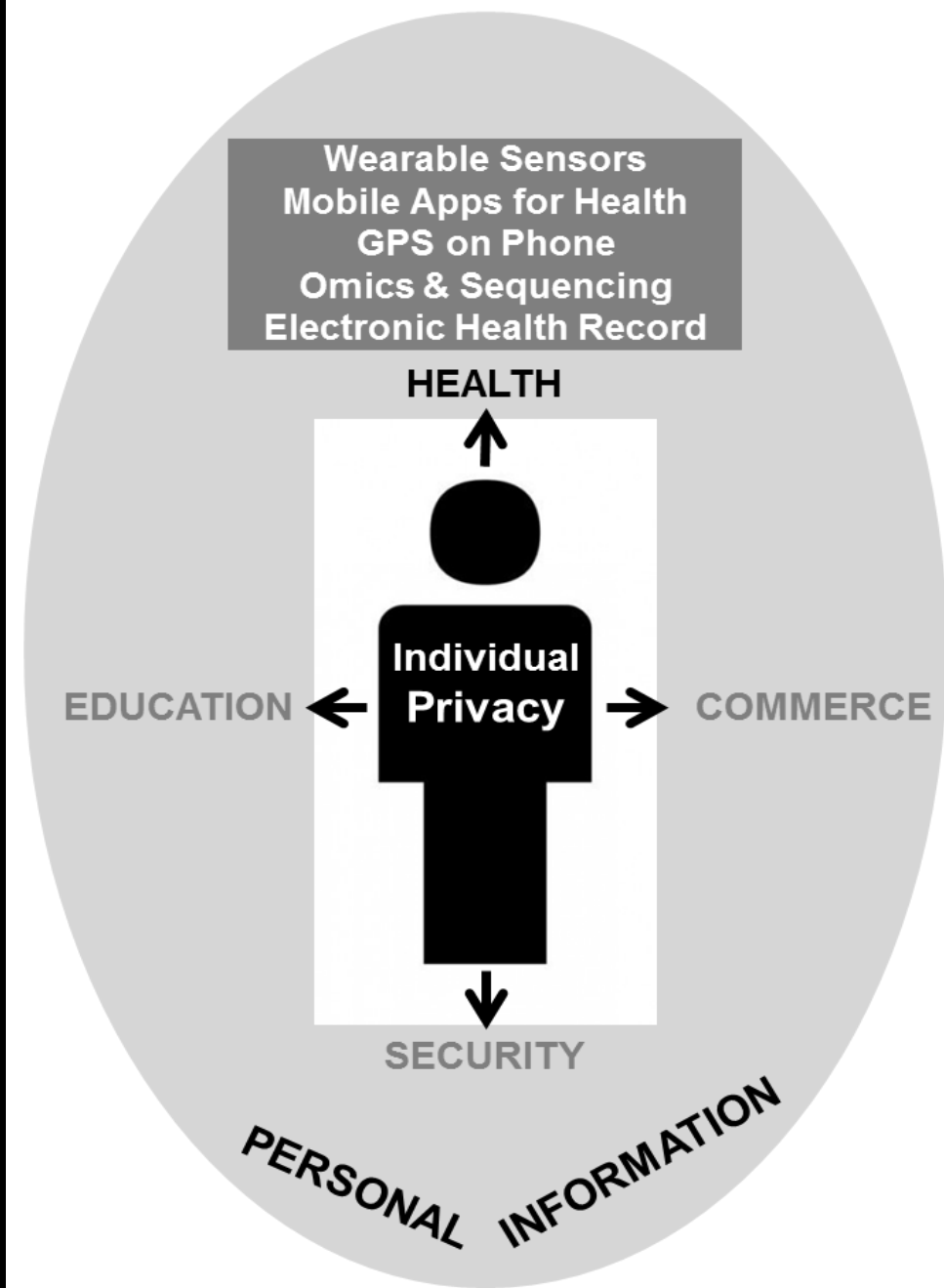
THE BIG DATA PRESIDENT

DRIVEN DECISION MAKING INFORMATION



**Data is highly granular and personal
Currently flows outside of traditional medicine**

Big Data Ecosystem



Meaning of
privacy in this
context?

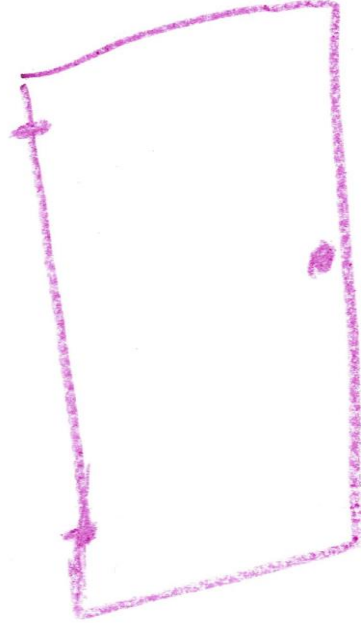
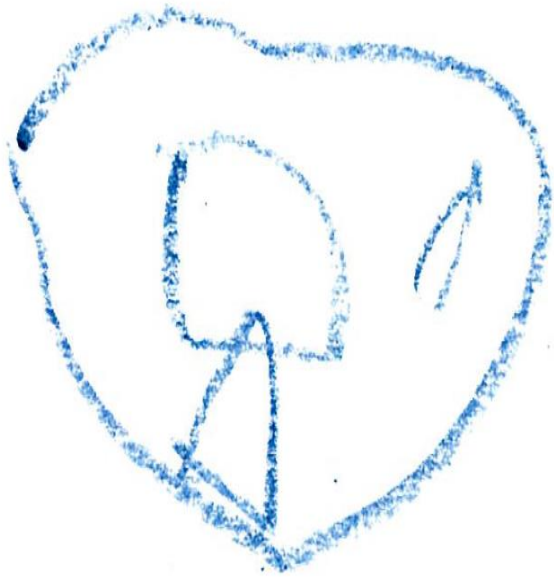
**“a concept in disarray...nobody
can articulate what it means”**

Daniel Solove

**“suffers an embarrassment of
meanings”**

Kim Lane Scheppelle

**Might privacy mean different things
to different people?**



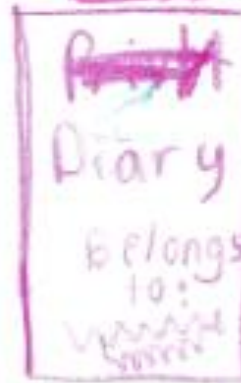
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6th grade

private

~~Private~~



Personal Thoughts  
& Possessions

Female, 6<sup>th</sup> Grade



**“Places where I have a bandaid”**

**Male, 5 years old**



**“What’s in my mind”**

**Male, 12<sup>th</sup> Grade**



“What happens in my house”

Female, 20's



# Internet search history

STAR WARS ep VII fan theories

Doctor WHO episodes

Neil Degrossse Tyson's <sup>ties</sup>

reddit.com/r/food

Clear all  
browsing data?

“My Internet Activity”

Female, 20's

# Impact of Privacy Environments for Personal Health Data on Patients

*Conceptualize, measure, and understand individual privacy affinities and responses with respect to PHD information technologies.*

RO1 HG HG008753

**National Human Genome Research Institute**

**Aim 1:** Refine conceptual model of privacy through literature review, individual interviews, focus groups, consultation with experts, and analyses of preliminary data.

**Aim 2:** Develop psychometrically sound instrument to measure individual Privacy Affinities and Privacy Environment Responses to personal health data technologies.

**Aim 3:** Administer scale in a larger population and use it to explore the relationship between privacy and other factors, including propensity to adopt PHD technologies, propensity to share PHD for research, and disease type and stage.

# Why should we seek to understand individual privacy?

Understand people's privacy-related behaviors

Enhance patients' (sense of) control of personal health data

Develop approaches for addressing privacy concerns

Promote user-centered design of health technologies & IT

Enable safe data sharing for biomedical research

Promote rigorous research on an ill-defined topic

# Example from Clinical Depression

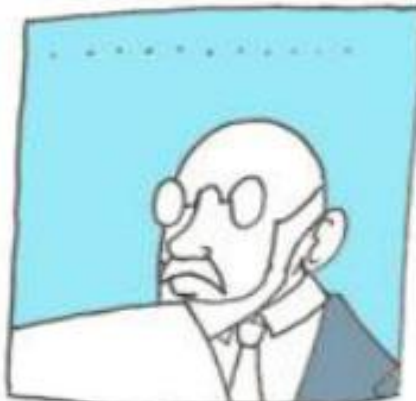
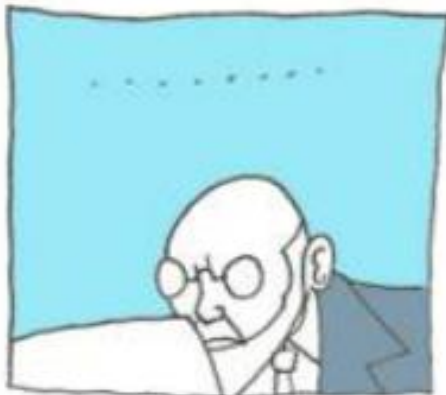
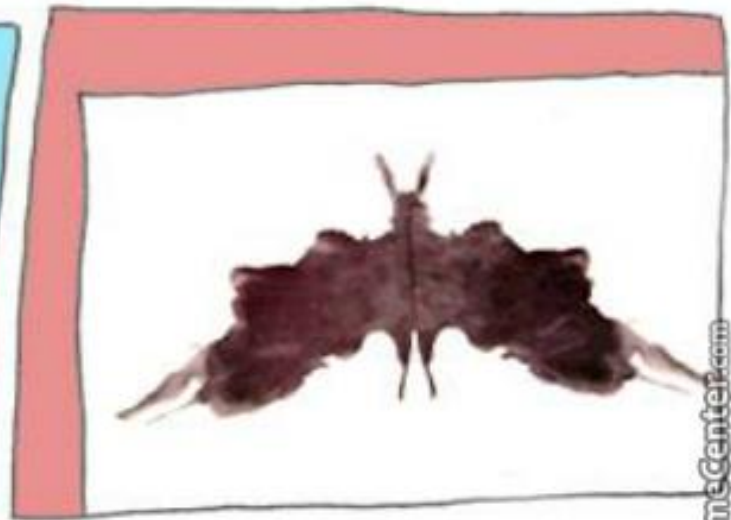
*Freud's Psychoanalytic Theory*



Depression as “inverted hostility toward the self”

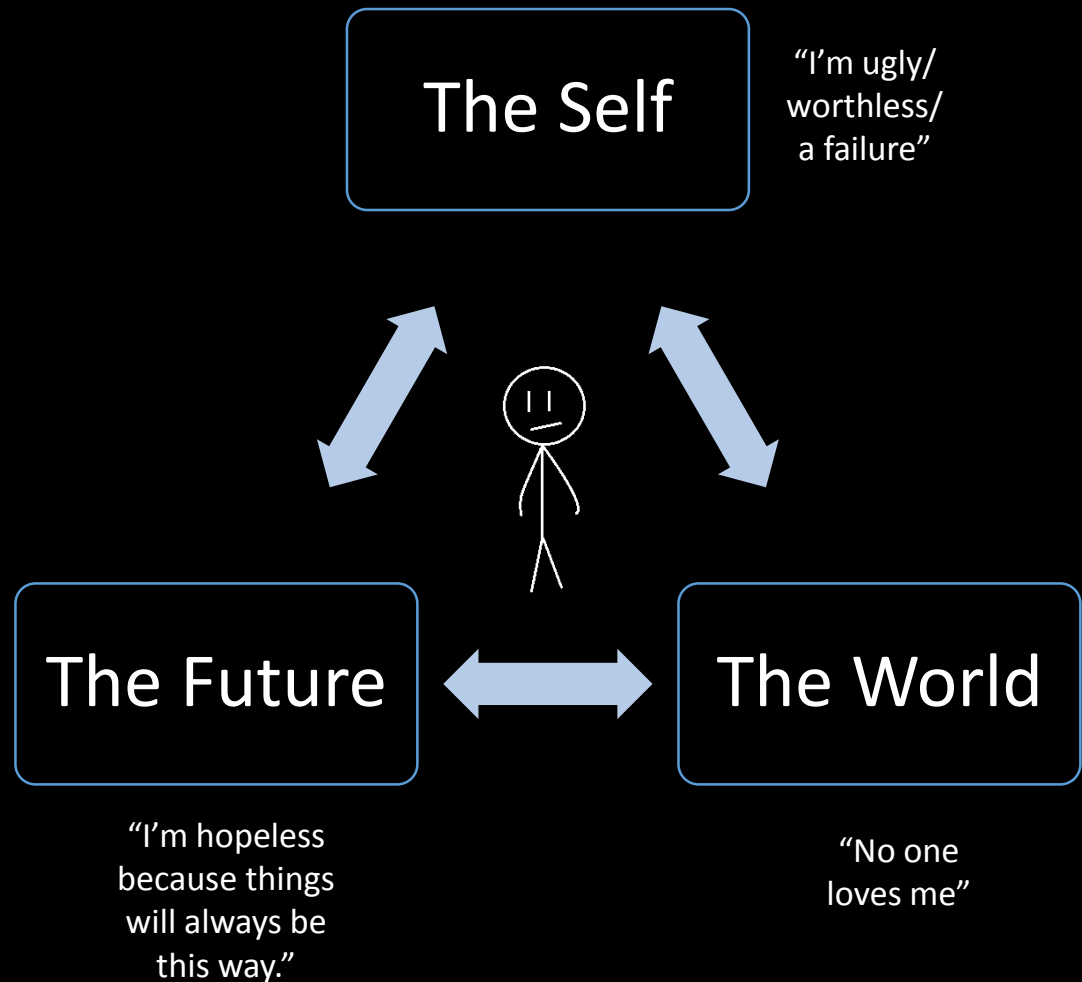
# Original Measurement Tools

(REACTION OF THE RORSCHACH BLOT TEST



# Beck Depression Inventory (1961)

- Aaron T. Beck: regarded as the father of Cognitive Behavioral Therapy (CBT)
- Depression caused by negative cognitions about self and present/future experiences



## Beck's Depression Inventory

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.

- 0 I do not feel sad.
- 1 I feel sad
- 2 I am sad all the time and I can't snap out of it.
- 3 I am so sad and unhappy that I can't stand it.

2.

- 0 I am not particularly discouraged about the future.
- 1 I feel discouraged about the future.
- 2 I feel I have nothing to look forward to.
- 3 I feel the future is hopeless and that things cannot improve.

3.

- 0 I do not feel like a failure.
- 1 I feel I have failed more than the average person.
- 2 As I look back on my life, all I can see is a lot of failures.
- 3 I feel I am a complete failure as a person.

4.

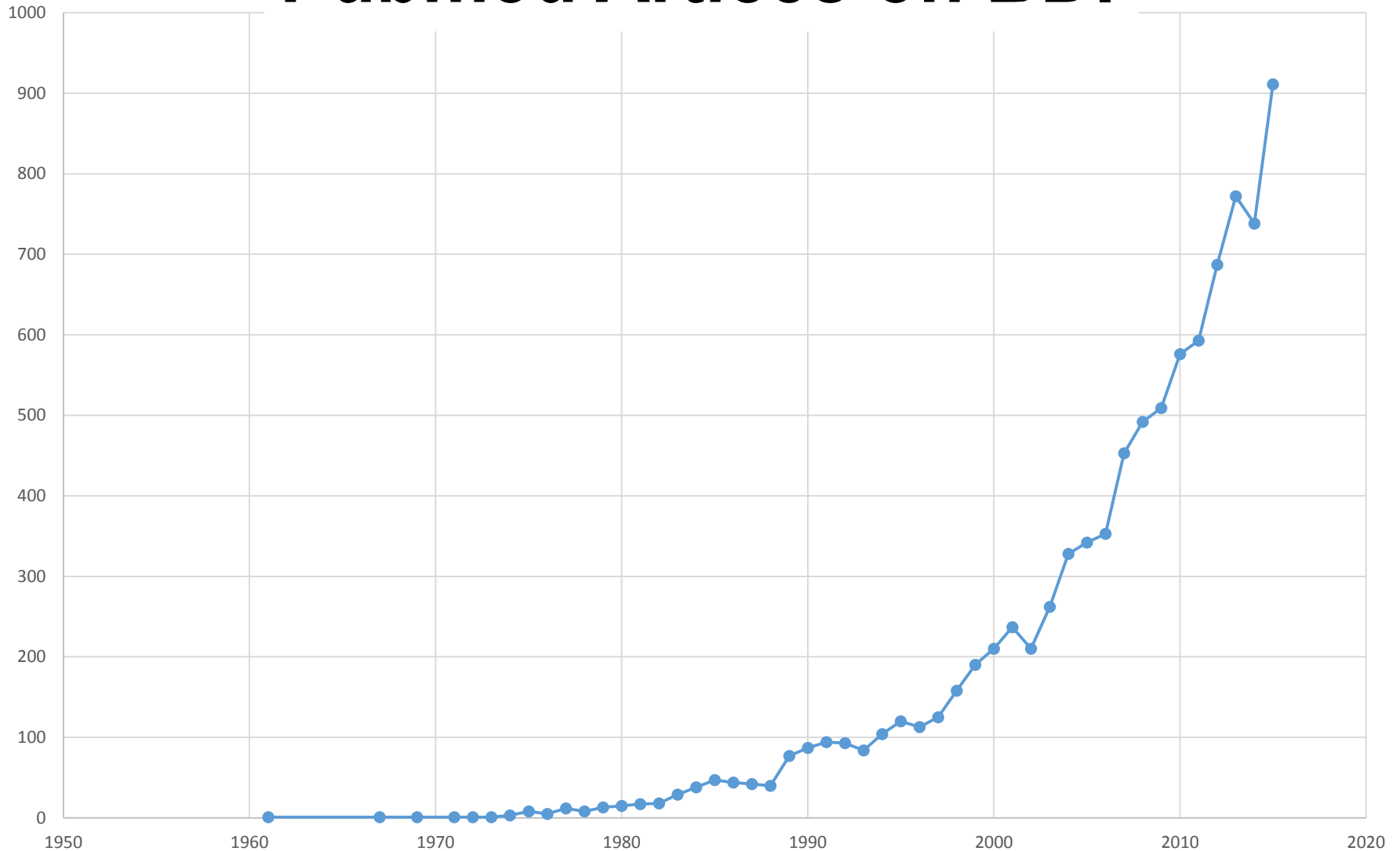
- 0 I get as much satisfaction out of things as I used to.
- 1 I don't enjoy things the way I used to.
- 2 I don't get real satisfaction out of anything anymore.
- 3 I am dissatisfied or bored with everything.

5.

- 0 I don't feel particularly guilty
- 1 I feel guilty a good part of the time.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

BDI items were informed by patients' own descriptions of symptoms vs. description of symptoms by non-depressed individuals

# Pubmed Artices on BDI





# Privacy Study

## Recruitment and Sample Size

### Population

### Recruitment Source/Cohort

Early Adopters

Health Data Exploration Phase 1

Personal Genomes Project

Patients

**Pediatric Chronic Disease,**  
*Rady Children's Hospital*

**Cancer**

*UCSD Moores Cancer Center*

**PatientsLikeMe (PLM)**

*Online Patient Network*

Community-  
Based

**Under-represented/Under-served Community Members**

*SD Community Health Advisor Executive Committee*

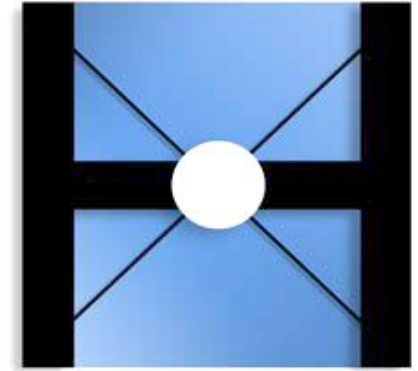
**Public School-based Adolescents**

*High Tech High (public charter school)*



patientslikeme®

Carnegie Mellon University



HIGH TECH HIGH



UCIRVINE



UC San Diego



STANFORD

CENTER

FOR BIOMEDICAL ETHICS

Rady Children's

Hospital San Diego



San Diego Community Liaison Committee



MOORES CANCER CENTER

## Individual Characteristics

Culture/Race/Ethnicity  
Education/SES  
Generation/Age  
Health Status (e.g., disease & disease stage)  
Prior Relevant Experiences

## Privacy Environment Characteristics

Entity Popularity  
Privacy Conditions Accessibility (e.g., readability)  
Entity Privacy Conditions (e.g., policy content)

## PRIVACY AFFINITY (*Trait*)

Dispositional Trust  
Risk Aversion  
Technology Acceptance/Innovativeness  
Introversion/Extroversion

## PRIVACY PERCEPTIONS (*State*)

Perceived Transparency  
Perceived Risk/Exposure  
Familiarity with Entity  
Other Perceived Incentives/Disincentives

## PRIVACY-RELATED PROPENSITIES

EHR/Traditional Technology Use  
Big Data/Non-Traditional Technology Use  
Personal Health Data Sharing for Research

# *Privacy Conceptualizations Among Early Adopters*

- Interview data
  - Health Data Exploration
  - Personal Genome Project
- 18 in-depth, semi-structured interviews
- Qualitative data analysis of transcripts in Dedoose 6.2.21
- Research question: how do early adopters of public health data technologies conceptualize privacy?

# Overall Findings

The majority express 'pragmatic' privacy beliefs  
(privacy as a tradeoff)

~10% were completely privacy 'unconcerned'

However, most participants still voiced privacy concerns despite being early adopters

# Pragmatic

“Science isn’t always the best, but in general I’m an absolute scientist and believe in evidence –based medicine. I think there’s too much out there that’s not really scientific. I think if the motives are good, and if the scientists...they’re honest people really trying to learn something as good scientists are....I think the good far outweighs the possible negative things that could happen.”

# Unconcerned

“I don't care about privacy. There's no such thing. Anything you put out there on a system is available to somebody else at some point at some level in some way. I just assume there is no privacy. I don't care about privacy. I really don't. I just don't put anything out there that I don't want people to have.”

# Fundamentalist Concerns

“I am concerned about privacy and who has access to my information. Then Google shares that information as a result of a financial relationship they might have....I don't trust them to share my information with companies they acquire without telling me about it.”

“In all honesty, I have no desire to have my weight information, or any of my health information hosted by a private company that I don't control access to.”



# Frequently Cited Specific Concerns

Discrimination

Data Security

Re-identification

Big Brother

## Individual Characteristics

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## POLITICS

# Obama Calls on Congress to Fund 'Precision Medicine' Studies

By THE ASSOCIATED PRESS JAN. 30, 2015, 7:00 A.M. E.S.T.

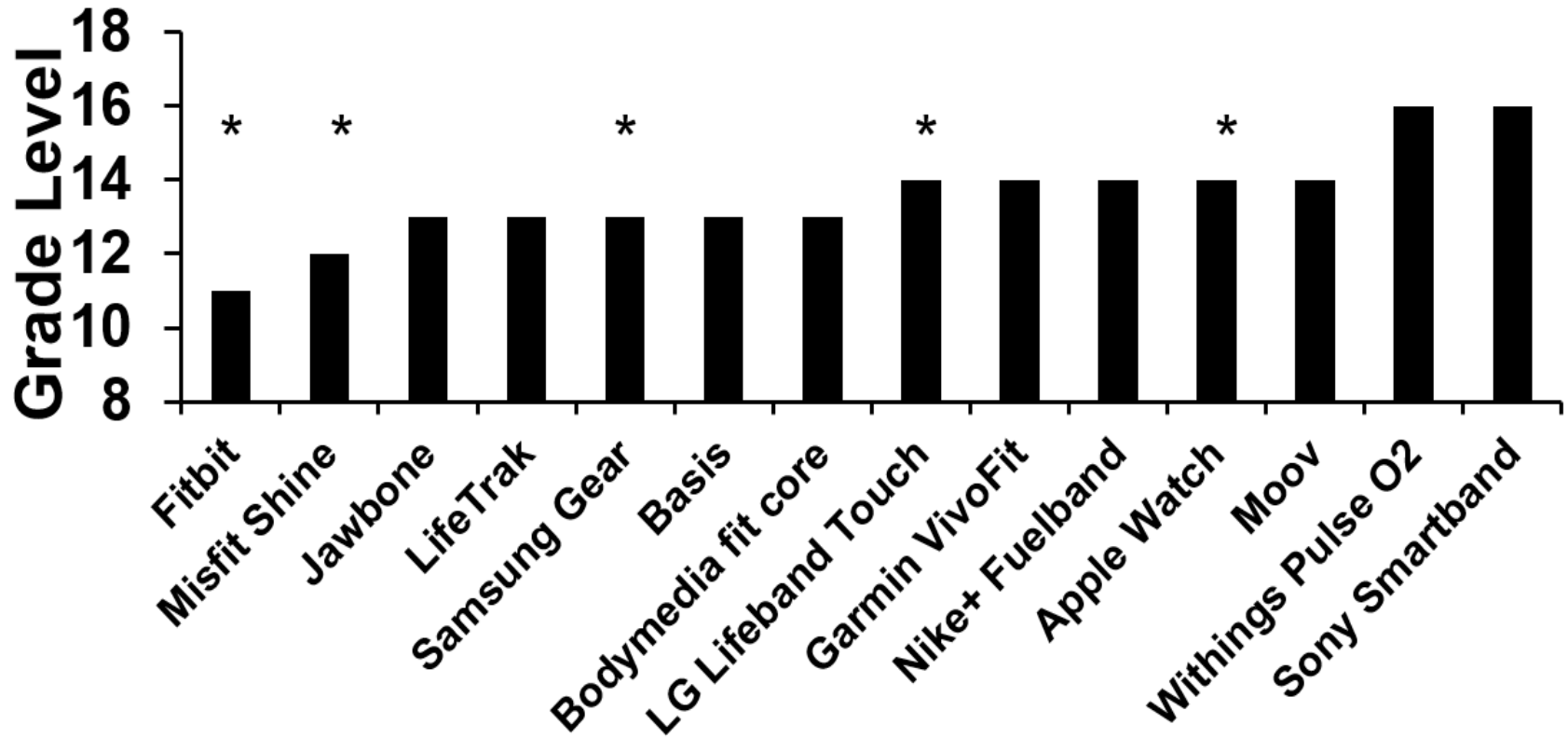
WASHINGTON — Holding out the promise of major medical breakthroughs, President Barack Obama on Friday called on Congress to approve spending in medical research that tailors treatment to an individual's genes.

Obama wants \$215 million for what he's calling a precision medicine initiative that moves away from one-size-fits-all treatments. The ambitious goal: Scientists will assemble databases of about a million volunteers to study their genetics — and other factors such as their environments and the microbes that live in their bodies — to learn how to individualize care.

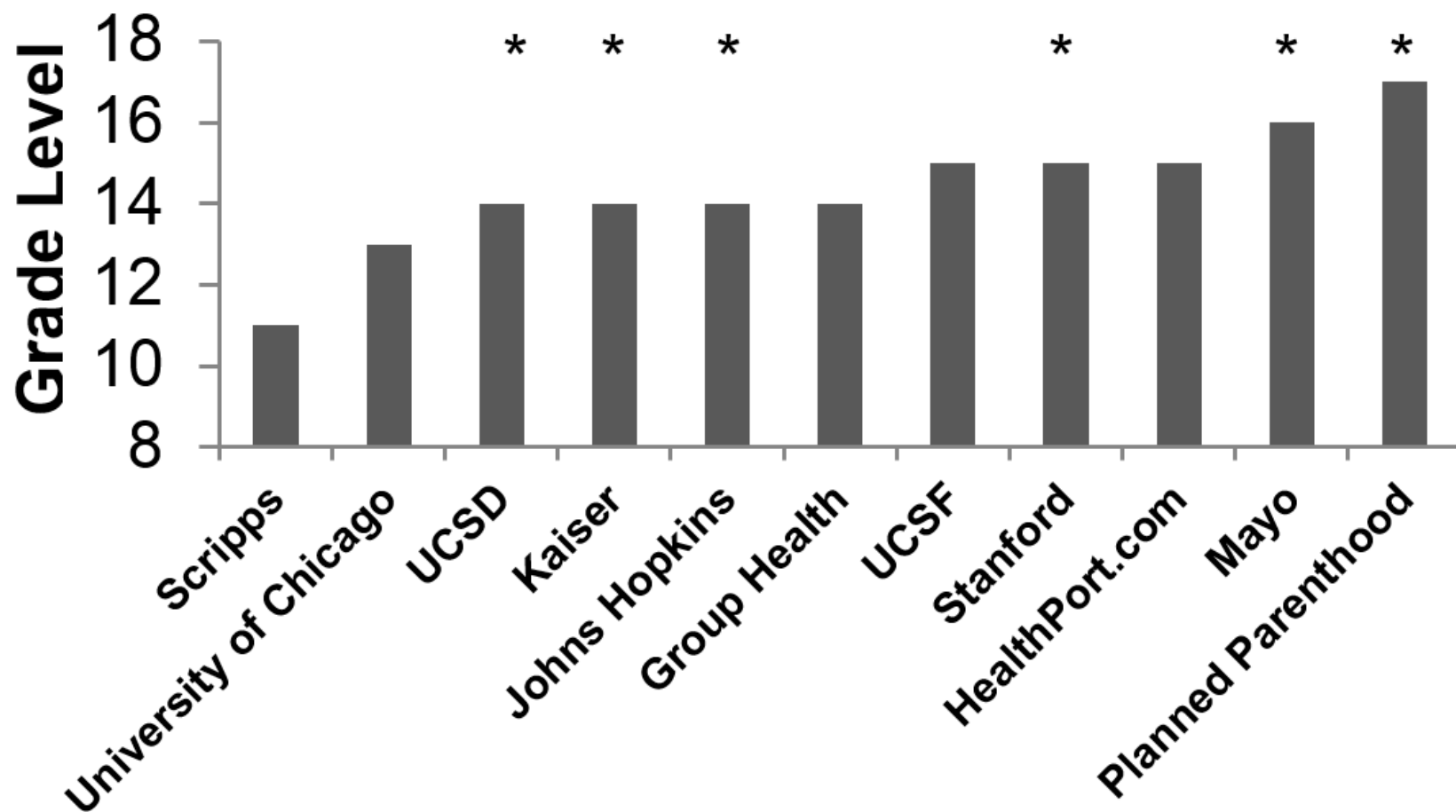


**“We’re going to make sure that protecting patient privacy is built into our efforts from Day 1,” Mr. Obama said.**

# Health and Fitness Sensor Privacy Policy Readability



# Electronic Medical Record Portal Privacy Policy Readability



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"Before I write my name on the board, I'll need to know how you're planning to use that data."

**Need Trust**

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