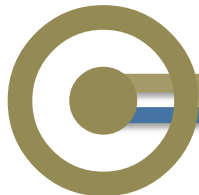




**University of  
Zurich<sup>UZH</sup>**

# The Ethics of Precision Medicine

**Prof. Effy Vayena**  
**Health Ethics and Policy Lab**  
**Institute of Epidemiology Biostatistics and Prevention**  
**University of Zurich**



# Caveat

---

**ethics = constraints**  
**ethics = enablers**

---

# i. Shifting context: goal

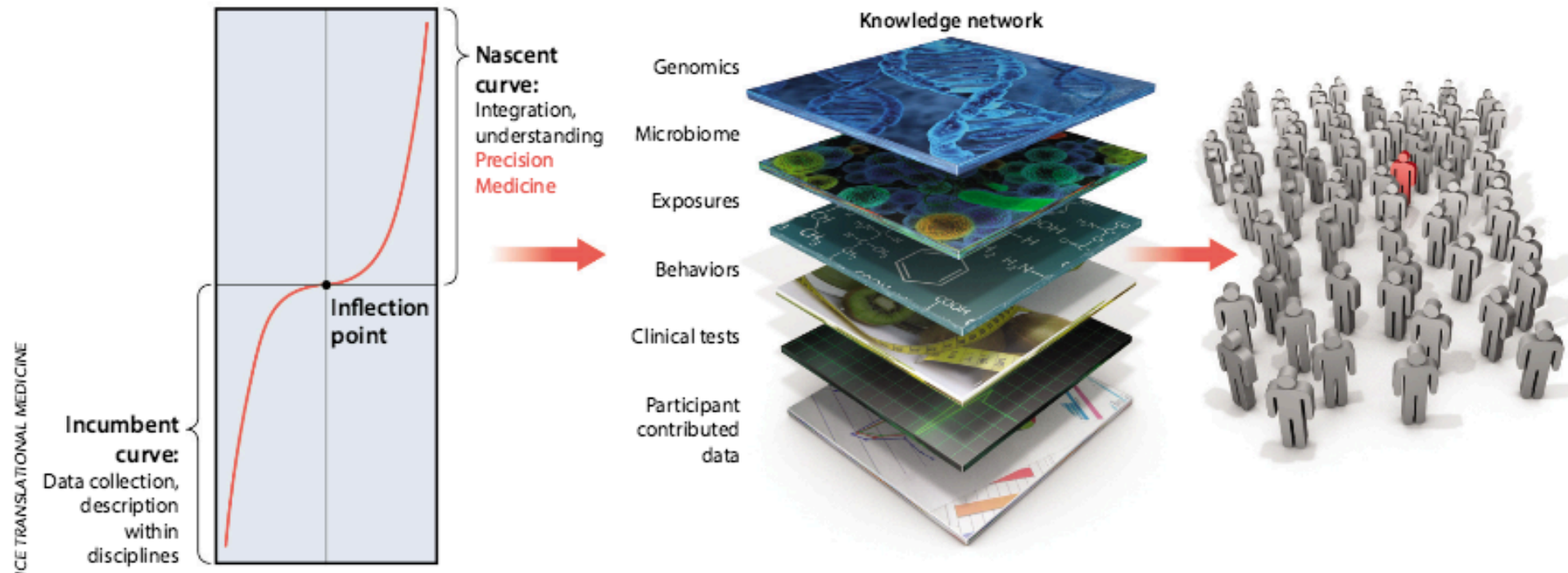
---

“The patient is an **enormous repository** of information [...].

It is the only way we will **define wellness and its progression to disease**, rather **than traditional medicine that defines disease and its progression to death.**”

Dennis Ausiello , Nature Biotech, 2015

# ii. Shifting context: process



### iii. Shifting context: capabilities

---



**Posture**  
Lumo  
Zephyr  
Jins Meme

**Muscle Activity**  
Athos

**Blood Pressure**  
iHealth  
Withings

**Skin Conductance**  
Basis  
Body Media  
Empatica  
Neumitra

**Movement**  
Fitbit  
Nike Fuelband  
Jawbone Up Band

Garmin  
Samsung  
MC10  
Zephyr  
Withings  
Spire  
iHealth  
Jins Meme  
Proteus  
Neumitra  
Body Media  
Empatica  
Owlet

**Oxygen Level**  
iHealth  
Withings  
Owlet

**Hydration**  
Corventis  
MC10

**Temperature**  
Tempdrop  
MC10  
Empatica  
Body Media  
Basis  
Owlet

**Brain Activity**  
NeuroSky  
Melon (acquired by DAQRI)  
Emotiv

**Glucose**  
Google  
Dexcom  
Glysens Incorporated

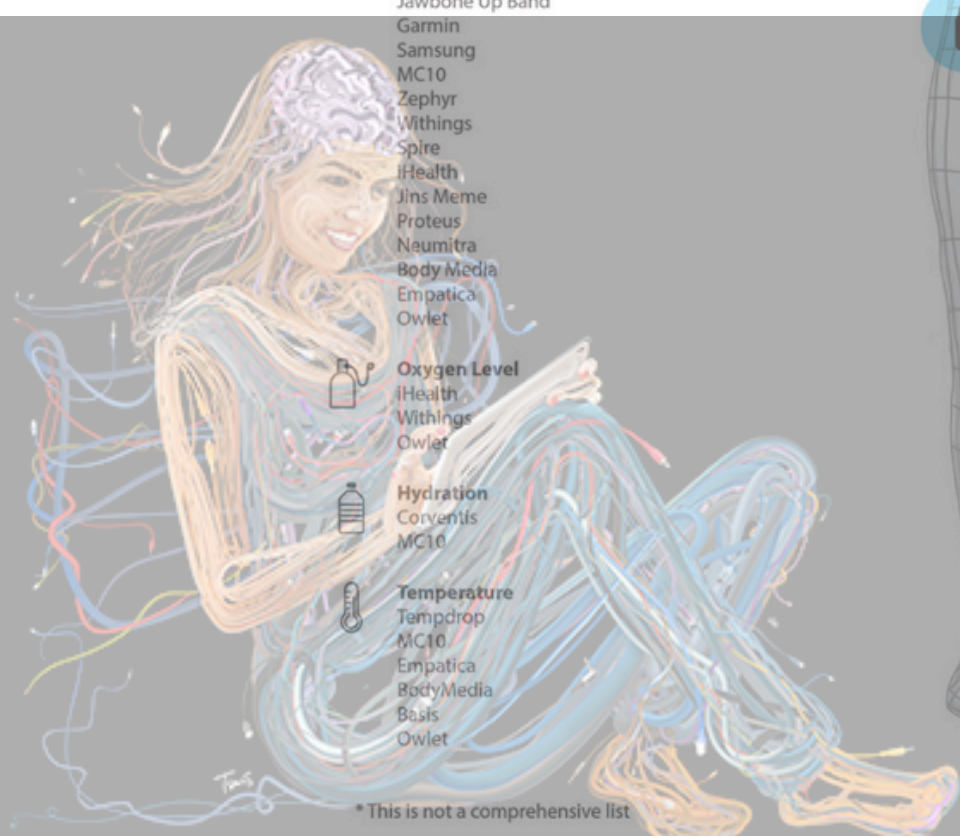
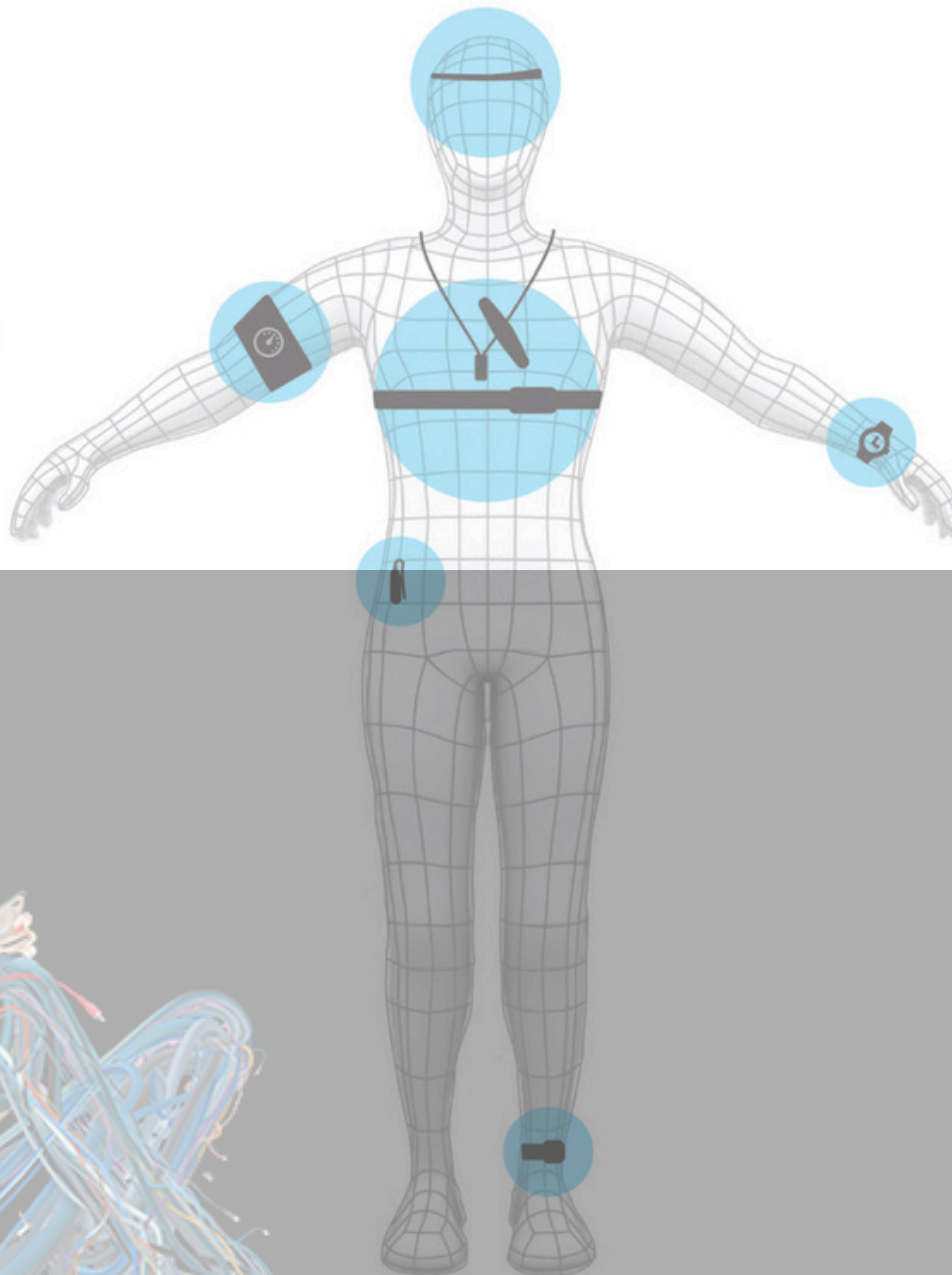
**Eye Tracking**  
Jins Meme

**Sleep**  
FitBit  
Rest Devices  
Garmin  
Nike  
Amigo  
BodyMedia  
Withings  
Samsung  
Misfit  
Jawbone  
iHealth  
Basis  
Owlet

**Respiration**  
Spire  
Zephyr  
Rest Devices

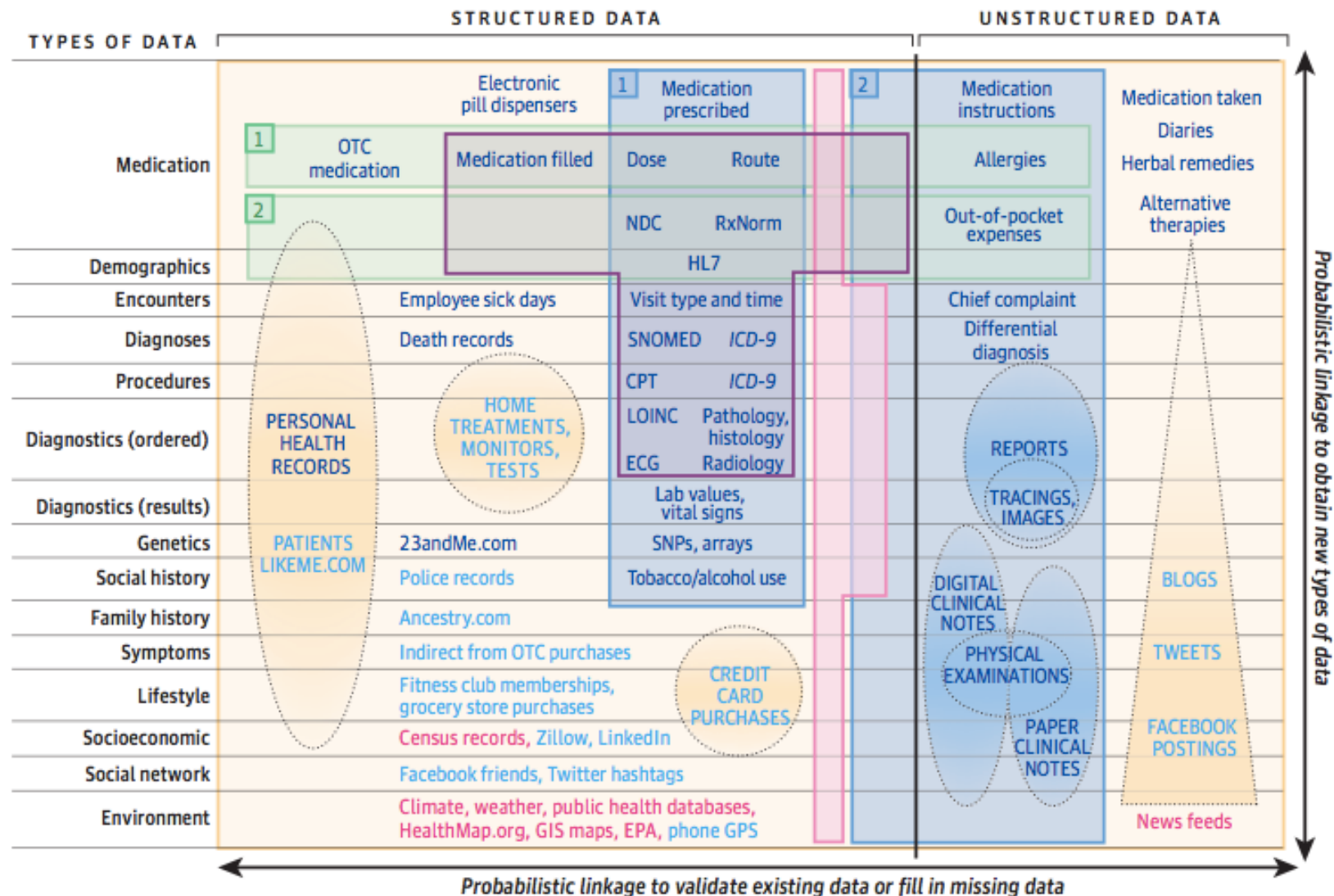
**Ingestion**  
Proteus

**Heart Tracking**  
Zephyr  
Withings  
Sprouting  
Proteus  
iHealth  
Basis  
Corventis  
AliveCor  
Samsung  
Garmin  
Empatica  
Owlet



\* This is not a comprehensive list

Figure. The Tapestry of Potentially High-Value Information Sources That May be Linked to an Individual for Use in Health Care



<b>Examples of biomedical data</b> 1 2 Pharmacy data    1 2 Health care center (electronic health record) data Claims data    Registry or clinical trial data Data outside of health care system		<b>Ability to link data to an individual</b> ■ Easier to link to individuals ■ Harder to link to individuals ■ Only aggregate data exists	<b>Data quantity</b>  More      Less
---	--	--	--

# Tension:

---

- ① Data taxonomies (all data)
- ② New methods (black box)
- ③ Research/ clinic boundary (genomics)
- ④ Public / private distinction (big data)
- ⑤ New actors (data companies)
- ⑥ New roles (partnerships)



**Are existing  
ethical and regulatory frameworks  
fit for  
precision medicine?**

## Questions :

---

“ We've got to figure out how do we make sure that if I donate my data to this big pool that it's not going to be **misused**, that it's not going to be **commercialized** in some way that **I don't know about**.

And so we've got to set up a series of structures that make **me confident** that if I'm making that contribution to science **that I'm not going to end up getting a bunch of spam** targeting people who have a particular disease I may have.”

President Obama, **Precision Medicine Initiative**

February 2016

Maleficence

Autonomy

Trust

Fair benefit-sharing

Exploitation

Mismatch of motivation

“... privacy issues. We've got to figure out how do we make sure that if I donate my data to this big pool it's not going to be **misused**, that it's not going to be **commercialized** in some way that I **don't know about**.

And so we've got to set up a series of structures that make **me confident** that if I'm making that contribution to science **that I'm not going to end up getting a bunch of spam** targeting people who have a particular disease I'm interested in.

President Obama, Precision Medicine

February 2016

## Questions :

---

“And I would like to think that if somebody does a test on me or my genes, that **that's mine**. But that's not always how we define these issues, right?”

President Obama, **Precision Medicine Initiative**

February 2016

## Questions :

Ownership

Control

“And I would like to think that if somebody does a test on me or my genes, that **that's mine**. But that's not always how we define these issues, right?”

Competing  
interests

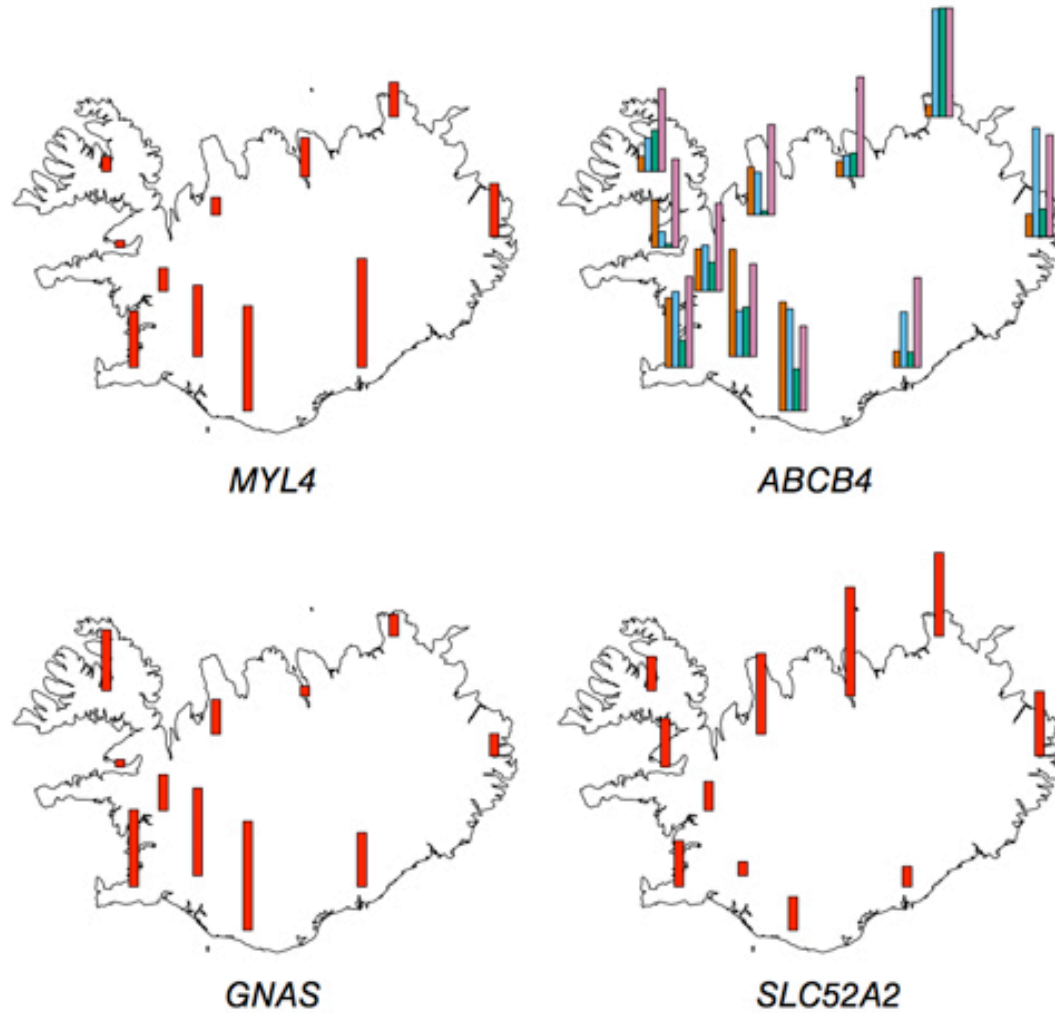
President Obama, Precision Medicine Initiative  
February 2016

# Consent

- Necessary but is it sufficient?
  - Unknown uses, immense possibilities
  - Digital trail (authorization, not consent)
  - Public-private fuzziness



# More than it meets the I ?



<http://www.technologyreview.com/news/536096/genome-study-predicts-dna-of-the-whole-of-iceland/>

# Privacy

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

AAAS

SPECIAL ISSUE

The End of

# PRIVACY



Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

Latitude: 36.898197  
Longitude: 118.111111  
g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC

g00-g1103p24  
+ Newman MarC06  
DOI: 10.1126/science.1258514  
CAGCTTTCAGCATTTCAGC  
PubMed ID19581585  
http://scim.ag/1NNQB1Y  
053000196  
Longitude: -0.080152





About Us

Reports

Key Issues

News


**HOT TOPICS:** [Medical Identity Theft](#) [Health Privacy](#) [Biometrics](#) [Mobile Privacy](#) [Patient's](#)

## New WPF Report – The Precision Medicine Initiative and Privacy: Will Any Legal Protections Apply?



# “From privacy to trust”

## Redefining Genomic Privacy: Trust and Empowerment

Yaniv Erlich , James B. Williams, David Glazer, Kenneth Yocum, Nita Farahany, Maynard Olson, Arvind Narayanan, Lincoln D. Stein, Jan A. Witkowski, Robert C. Kain

Published: November 4, 2014 • DOI: [10.1371/journal.pbio.1001983](https://doi.org/10.1371/journal.pbio.1001983) • Featured in PLOS Collections

**Transparency** creates trust

Increased **control** enhances trust

**Reciprocity** maintains trust

# Can there be trust without privacy?

“The value of privacy is both to be defended and to be enhanced.” (L. Floridi)

# Some solutions

## Consent innovation

- General
- Granular
- Dynamic
- Portable

## New privacy tools

- Encryption
- Differential privacy
- Data Tags

# Partnership

The patient

The citizen

The public

Empowerment

Governance

Accountability



<http://www.sa-pathways.com/new-health-consumer/the-rise-of-the-empowered-patient>

# The ethics of PM

