

The Personal Data is Political



Bastian Greshake

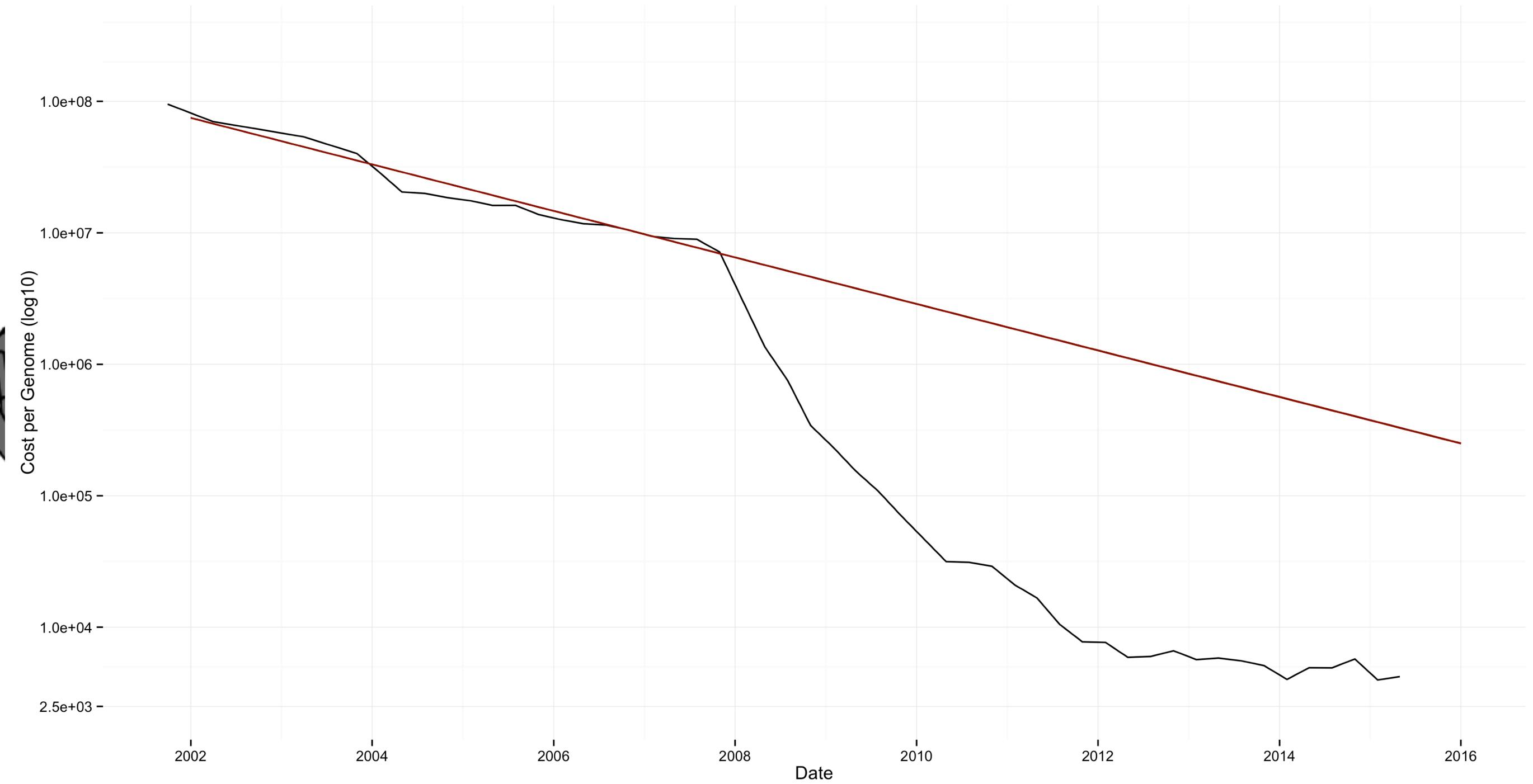


@gedankenstuecke

What will I talk about?! 

my connection to personalized
health

my connection to personalized health



DTC
genetic
testing





Shopping Cart

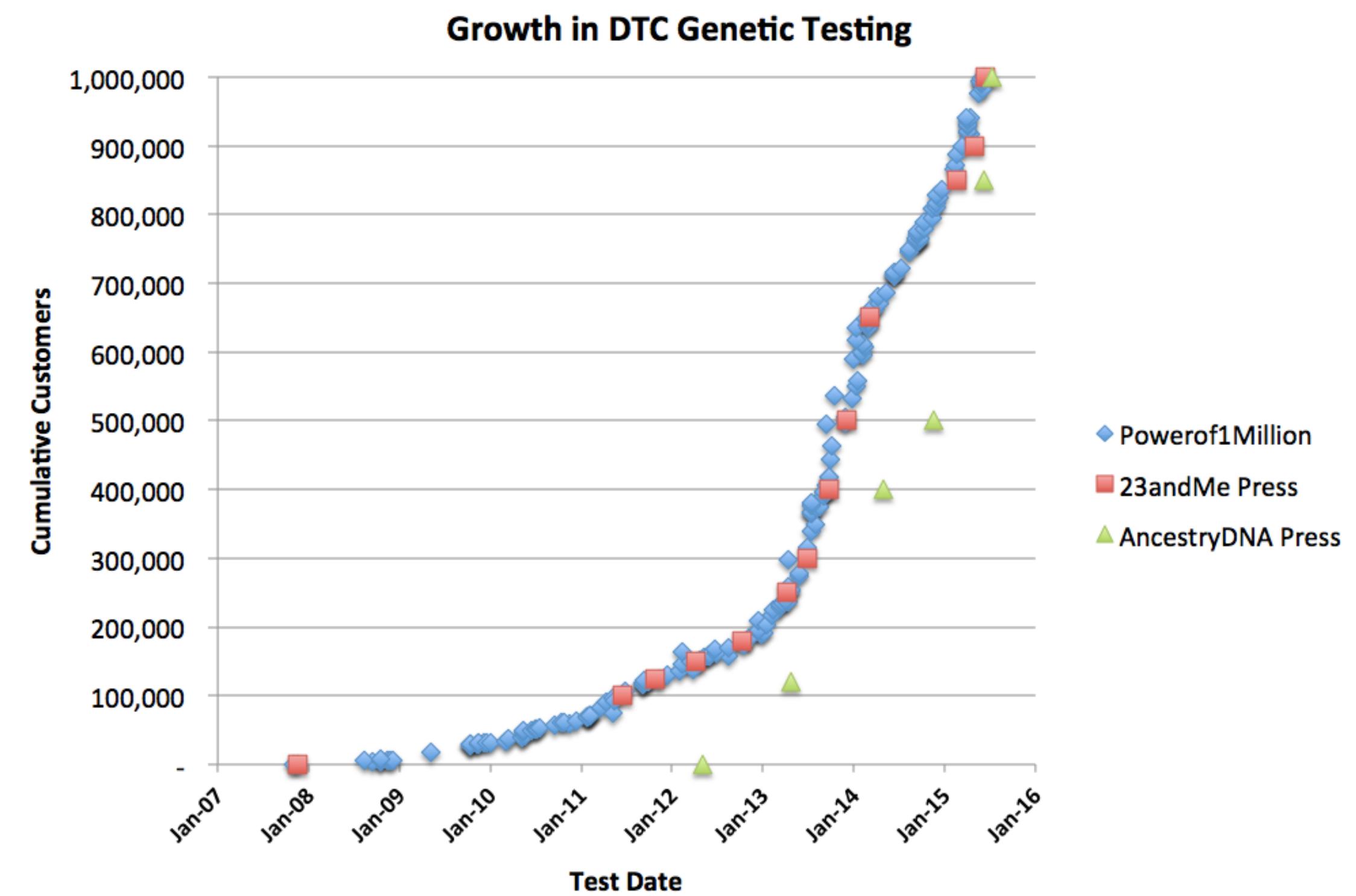
		Price	Quantity
 A photograph of the AncestryDNA test kit box, which is white with a blue circular logo and some text.	AncestryDNA: Genetic Testing - DNA Test by AncestryDNA In Stock Eligible for FREE Shipping Gift options not available. Learn more	\$99.00	<input type="button" value="1"/> 

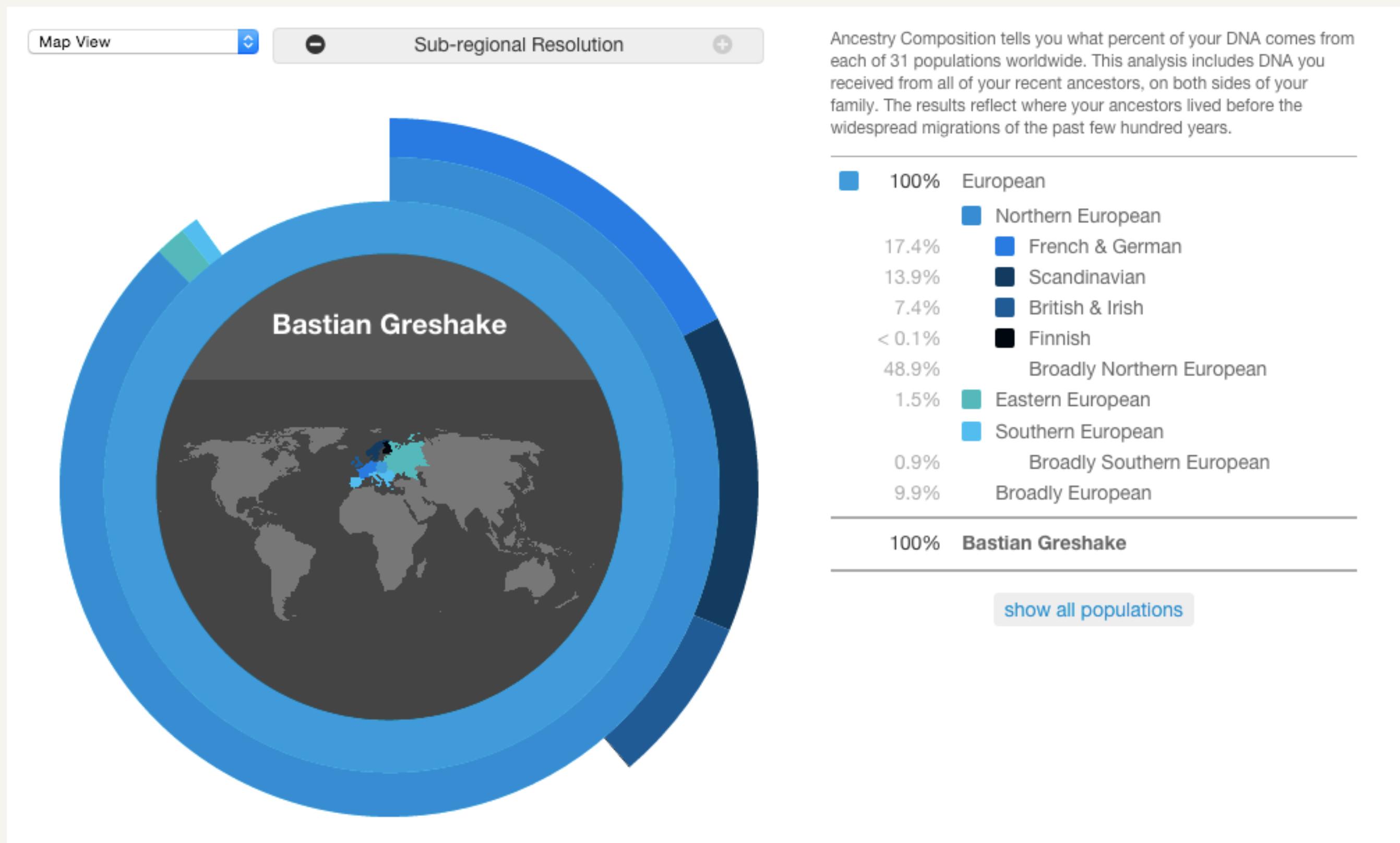
DTC Genetic Testing Numbers



Shopping Cart

	Price	Quantity
AncestryDNA: Genetic Testing - DNA Test by AncestryDNA	\$99.00	1
AncestryDNA		
In Stock		
Eligible for FREE Shipping		
Gift options not available. Learn more		
Delete Save for later		
An Introduction to Genetic Analysis by Anthony J.F. Griffiths	\$221.71	1
An Introduction to Genetic Analysis		
Griffiths		
Hardcover		
Only 9 left in stock (more on the way).		
Eligible for FREE Shipping		
<input type="checkbox"/> This is a gift Learn more		
Delete Save for later		





SHOW RESULTS FOR Bastian Greshake

[SEE NEW AND RECENTLY UPDATED REPORTS »](#)

Health Risks (122) ?

↑ ELEVATED RISKS

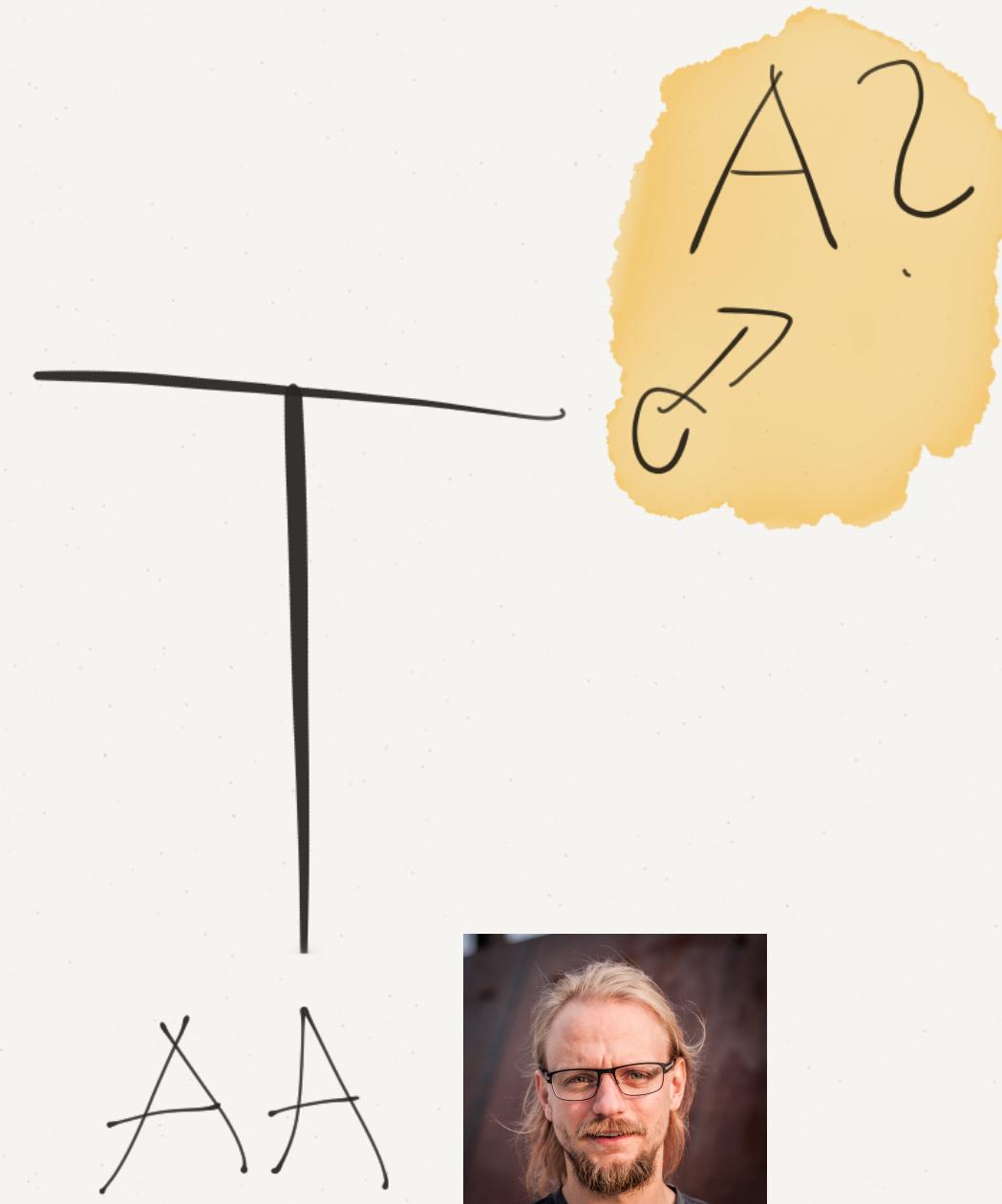
	YOUR RISK	AVERAGE RISK
Prostate Cancer ♂	23.3%	17.8%
Gallstones	11.1%	7.0%
Rheumatoid Arthritis	3.1%	2.4%
Restless Legs Syndrome	2.5%	2.0%
Crohn's Disease	1.2%	0.5%

[See all 122 risk reports...](#)

Inherited Conditions (53) ?

REPORT	RESULT
ARSACS	Variant Absent
Agenesis of the Corpus Callosum with Peripheral Neuropathy (ACCPN)	Variant Absent
Alpha-1 Antitrypsin Deficiency	Variant Absent
Autosomal Recessive Polycystic Kidney Disease	Variant Absent
BRCA Cancer Mutations (Selected)	Variant Absent

what's
next?



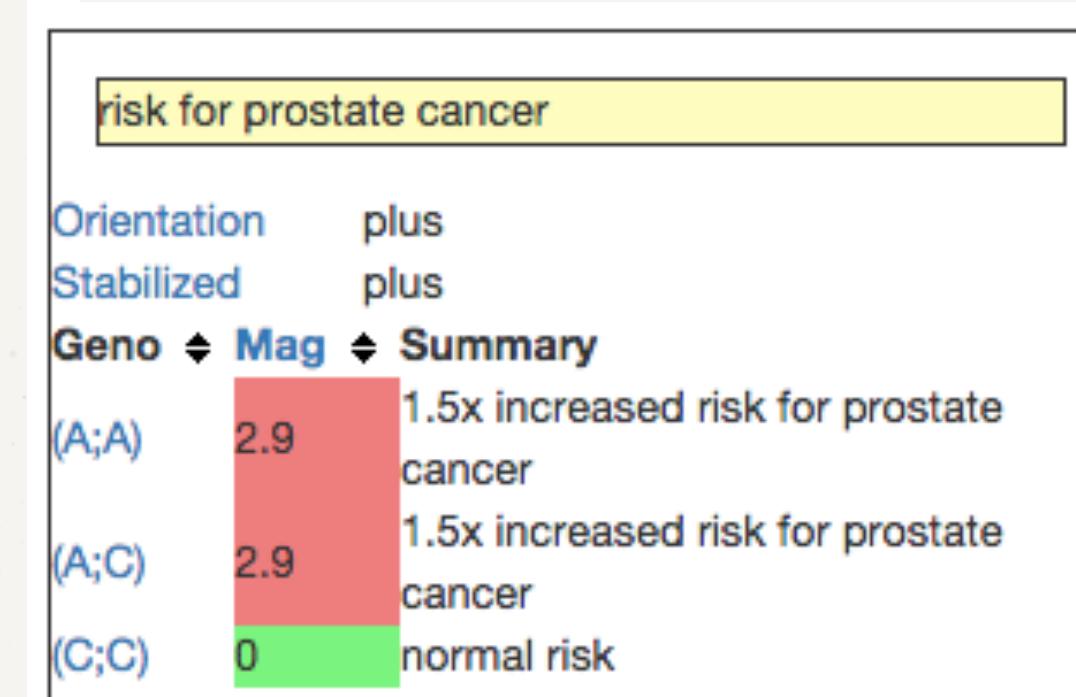
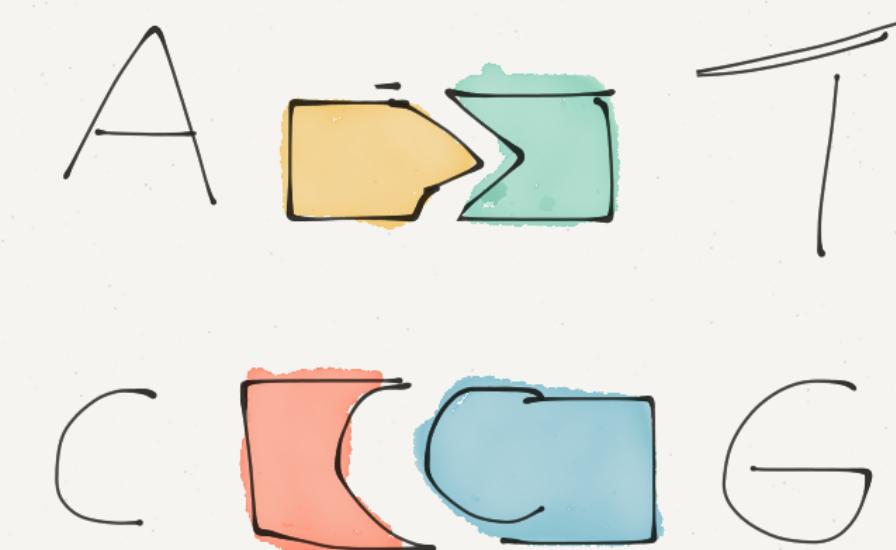
Rs1 A/A

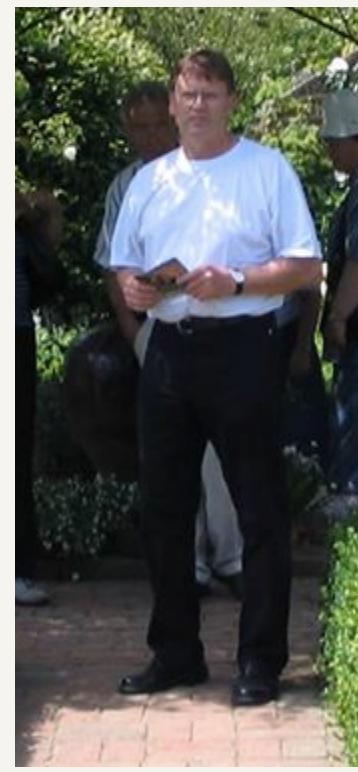
Rs2 G/C

Rs3 T/C

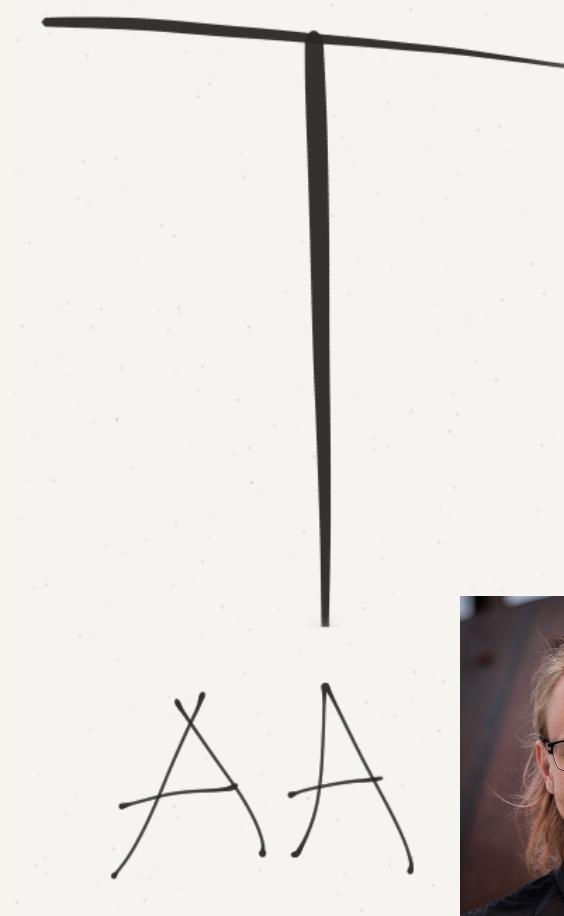
Rs4 G/G

...

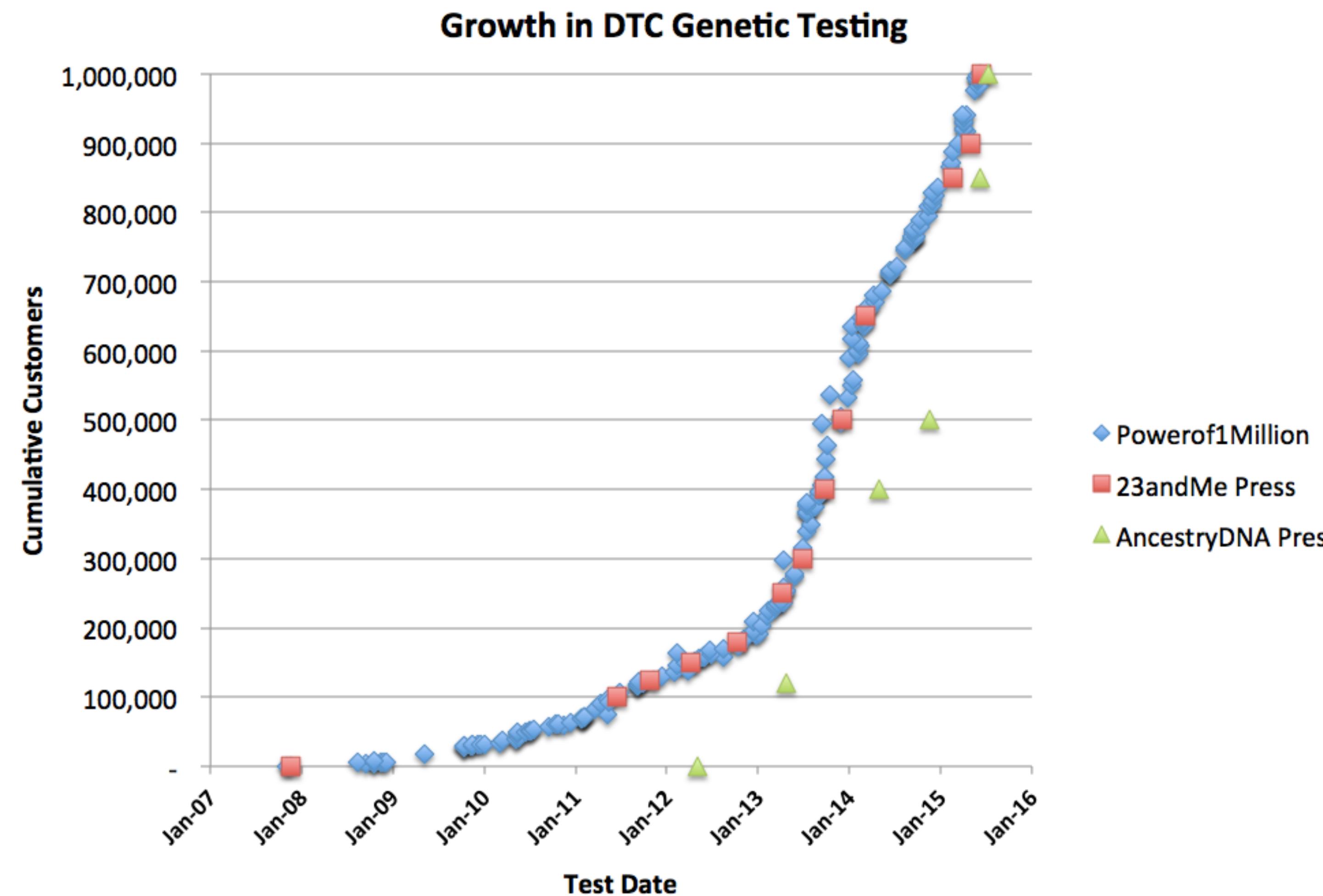




(A;A)	2.9	1.5x increased risk for prostate cancer
(A;C)	2.9	1.5x increased risk for prostate cancer



	(A;A)	2.9	1.5x increased risk for prostate cancer
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Examples

NATURE BIOTECHNOLOGY | COMPUTATIONAL BIOLOGY | ANALYSIS



日本語要約

Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

[Paul Wicks, Timothy E Vaughan, Michael P Massagli & James Heywood](#)

[Affiliations](#) | [Contributions](#) | [Corresponding author](#)

Nature Biotechnology **29**, 411–414 (2011) | doi:10.1038/nbt.1837

[Oxford Journals](#) > [Medicine & Health](#)[Science & Mathematics](#) > [Human Molecular Genetics](#) >

Genetic variants associated with motion sickness point to roles for inner ear development, neurological processes and glucose homeostasis

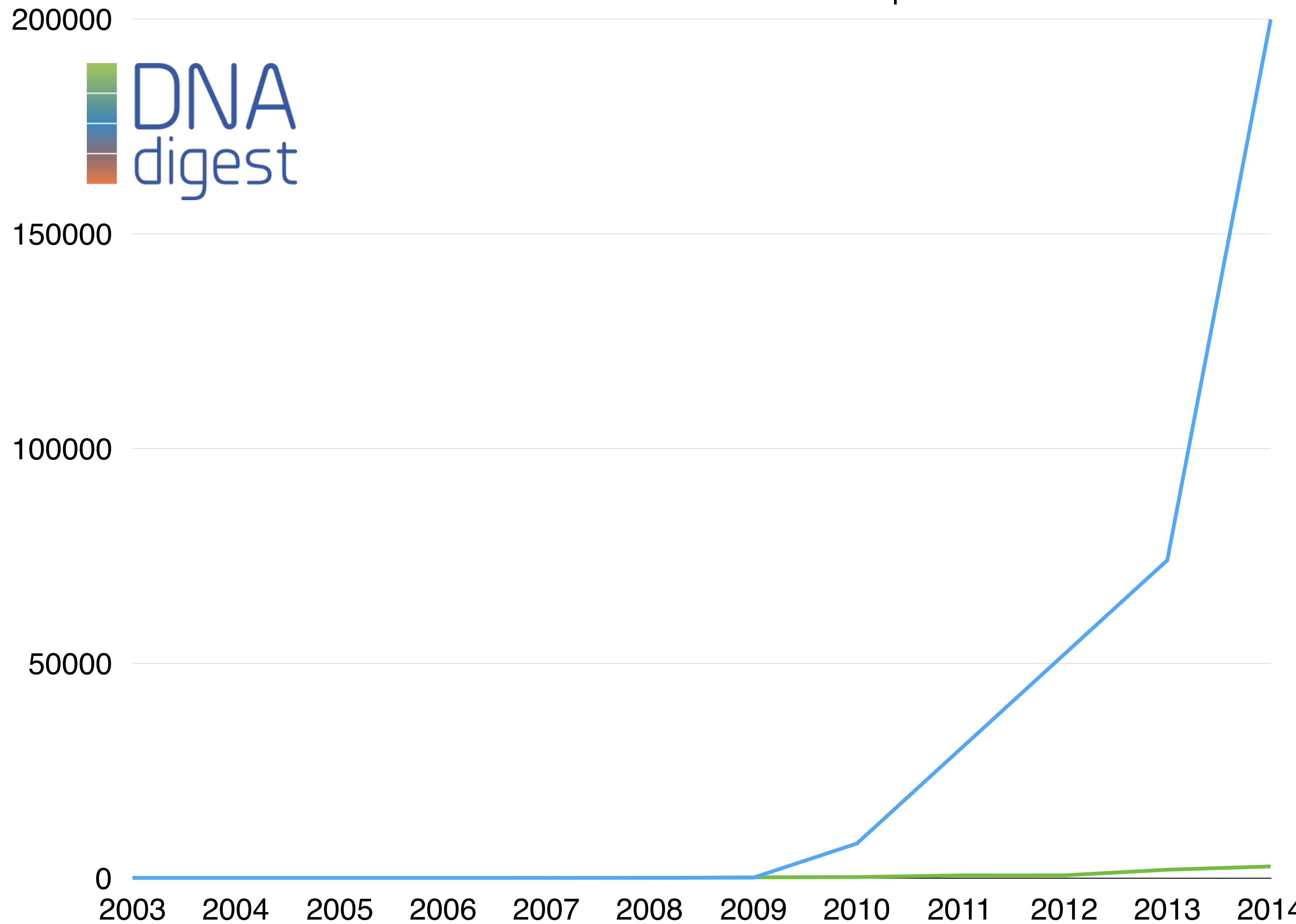
[Bethann S. Hromatka*](#), [Joyce Y. Tung](#), [Amy K. Kiefer](#), [Chuong B. Do](#), [David A. Hinds](#) and [Nicholas Eriksson](#)

Product Science, 23andMe, Inc., Mountain View, CA, USA

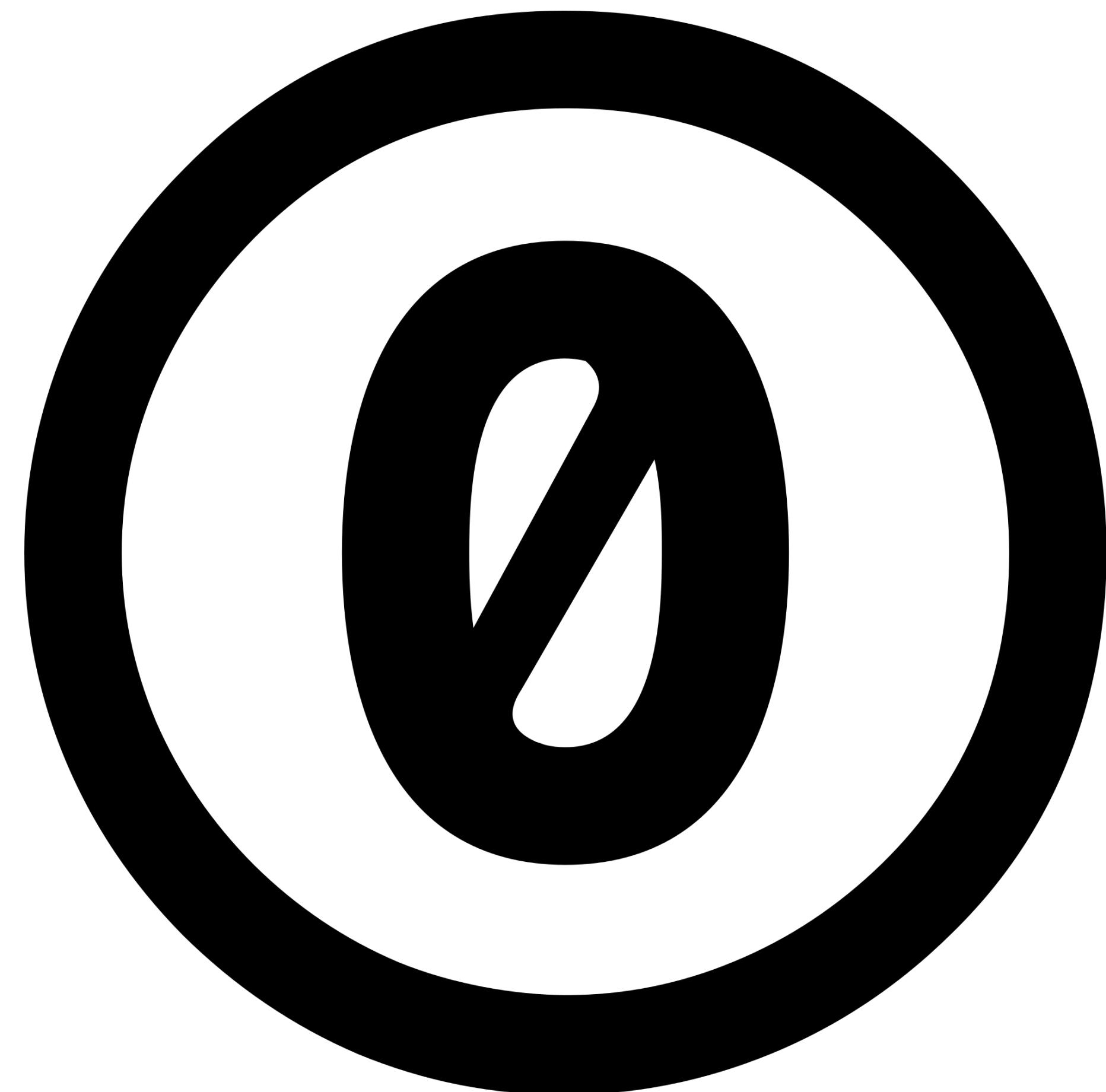
40+ more studies by *23andMe*



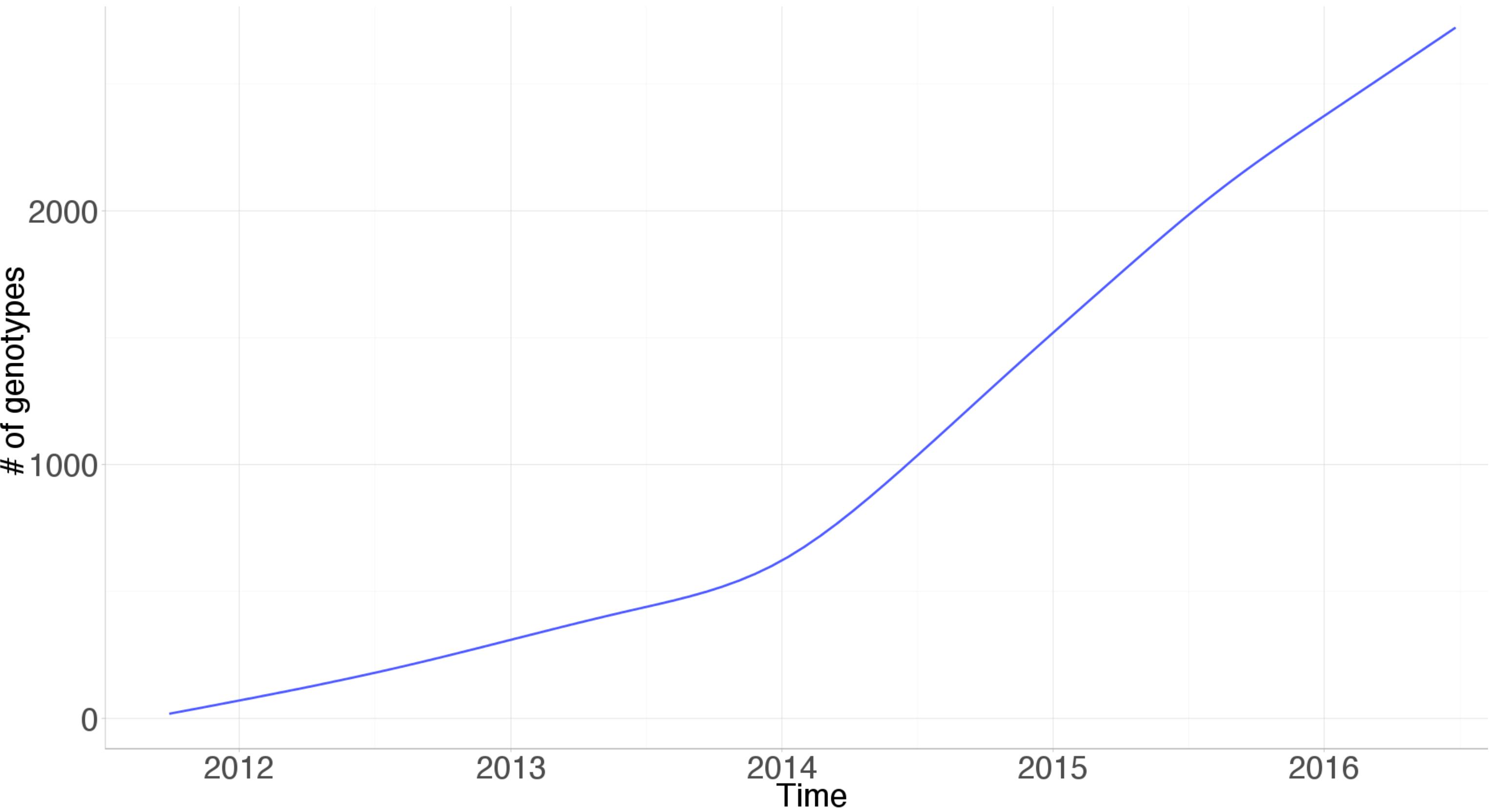
— All — Open



Let's go open



- open data ✓
- open source ✓
- crowdsourced ✓
- crowdfunded ✓



Uses Cases

DE GRUYTER OPEN
Proceedings on Privacy Enhancing 1



Matthias Shapiro
Mar 12 · 10 min read

Mathias Humbert*, Kévin Huguenin, Joachim Hugonot, Erman Ayday, an
**De-anonymizing Genomic Databases:
Phenotypic Traits**

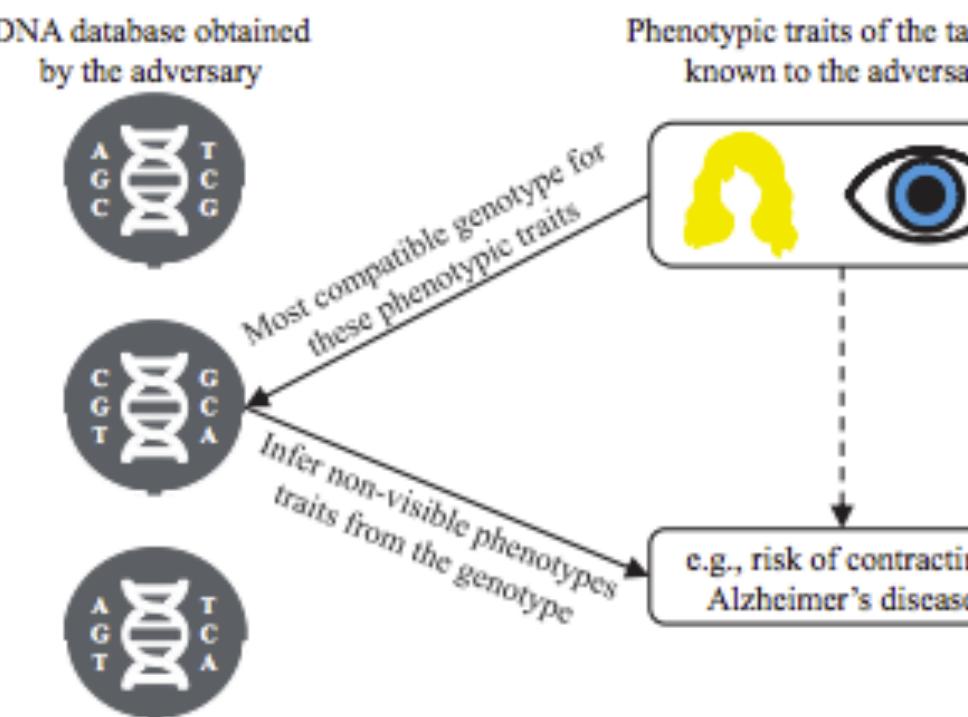


Fig. 1. Illustration of the identification attack: The adversary identifies the genotypes of a target individual from some of her visible phenotypic traits and uses the de-anonymized genotype to infer her susceptibility to Alzheimer's disease.

ALSO,

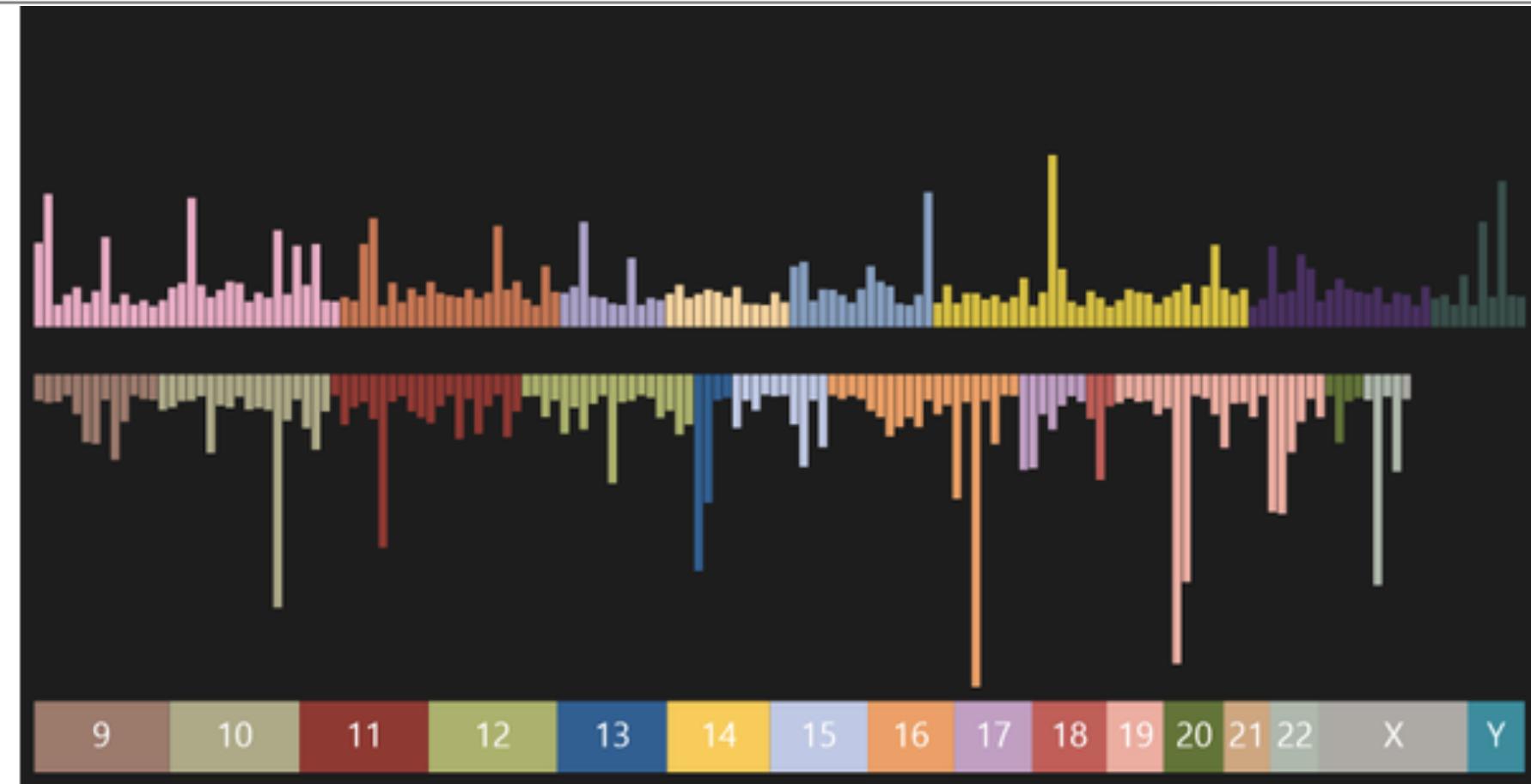
Sasha Laundy and 5 others recommended

The Beginner's Guide to Genetics Hacking

Investigation of methods for machine learning associations between genetic variations and phenotype

[Amanda M. Hartung](#)

Follow



confirms twisted bones

car park confirmed as that of Richard III, as
excavation site

ell.

28) in
e de

igree.

“...blah blah, **closed data bad**, blah blah, **open data good...**”

–Yours truly

...but... something's WEIRD? 

but... something's WEIRD? 😱

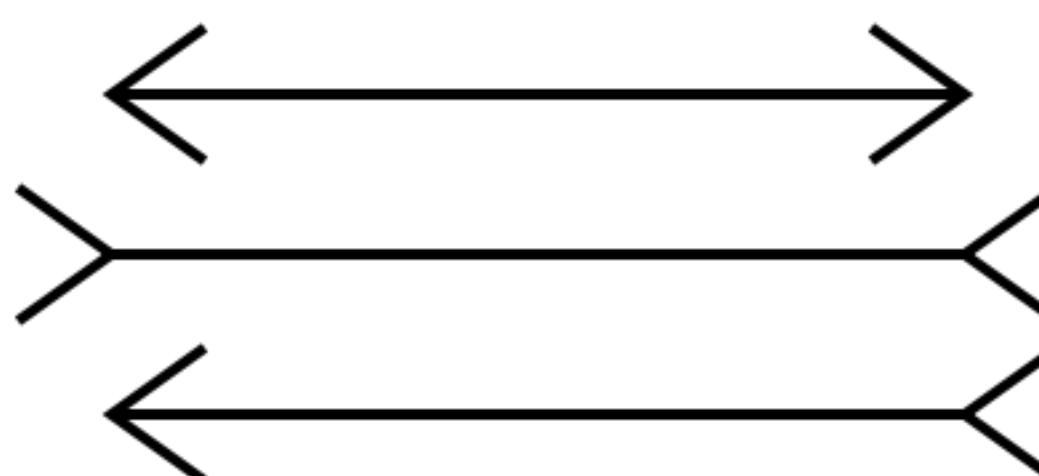
Behavioral and Brain Sciences, Volume 33,

Issue 2-3

June 2010, pp. 61-83

The ^{Western} ^{Educated} ^{Industrialized} ^{Rich} ^{Democratic} ^{weirdest people in the world?}

Joseph Henrich ^(a1), Steven J. Heine ^(a2) and Ara Norenzayan ^(a3) Societies



but... something's WEIRD? 😱

**Behavioral and Brain Sciences, Volume 33,
Issue 2-3**

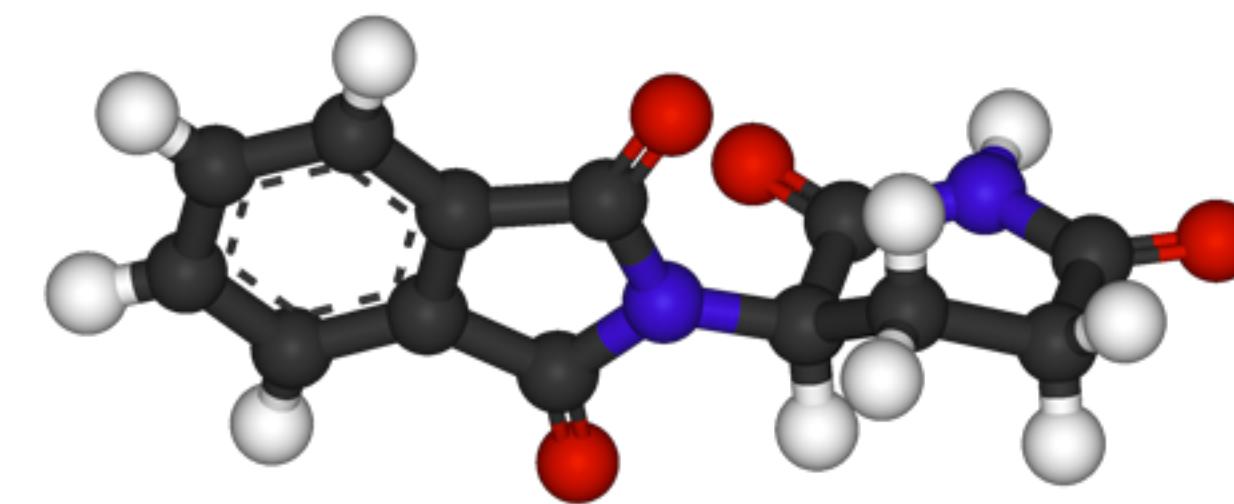
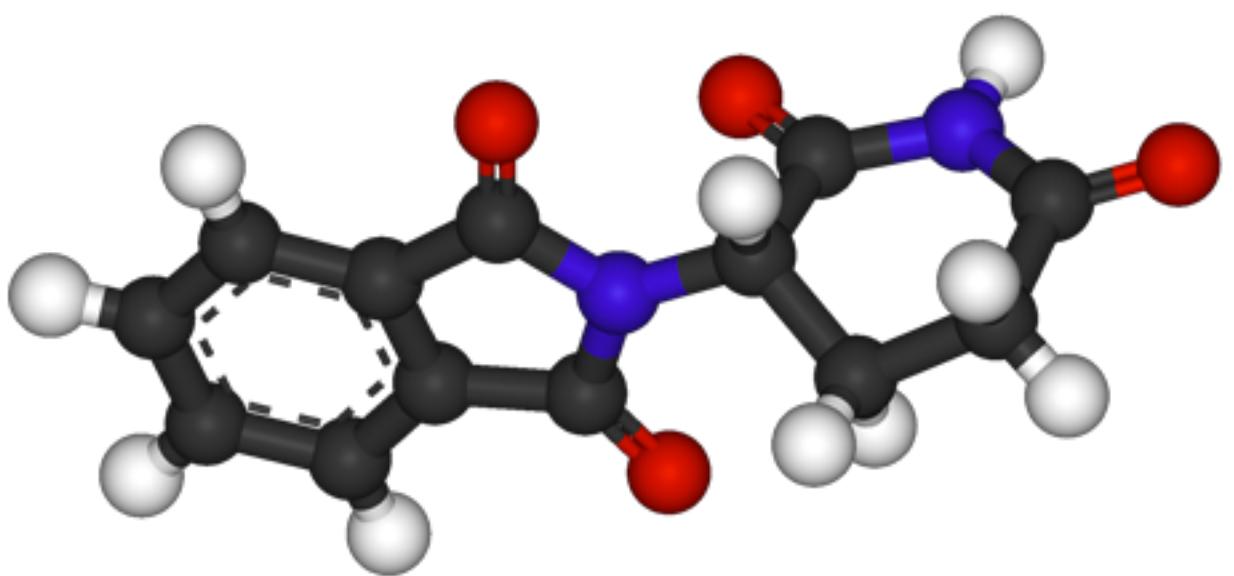
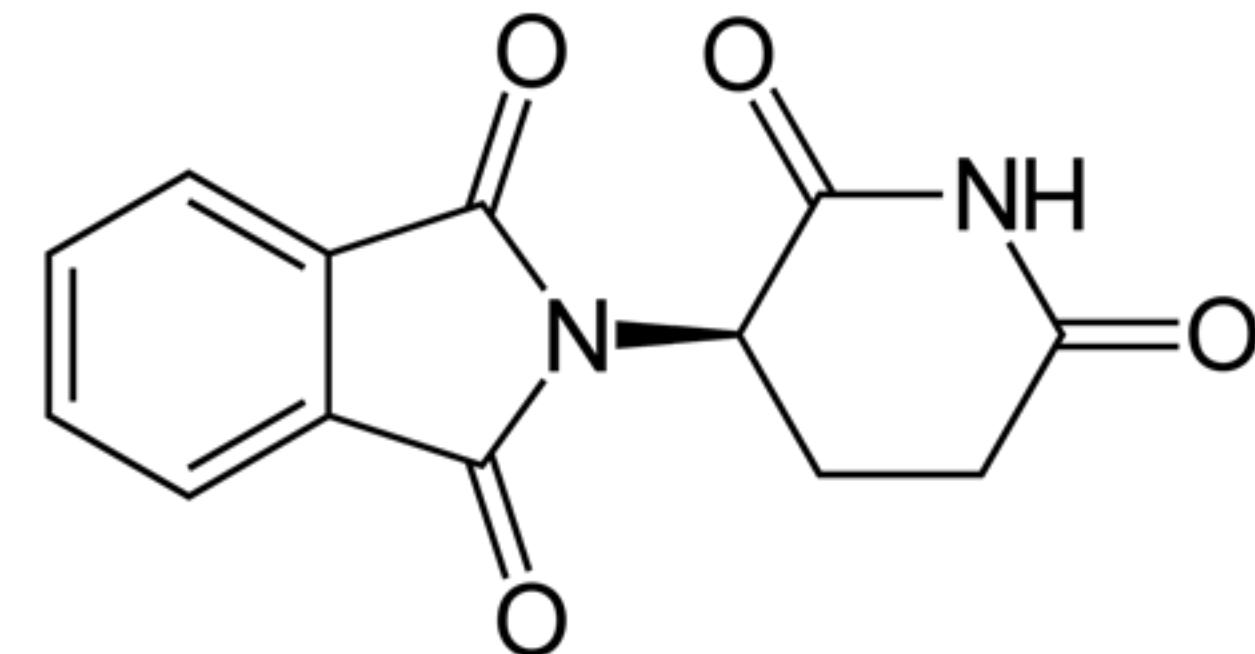
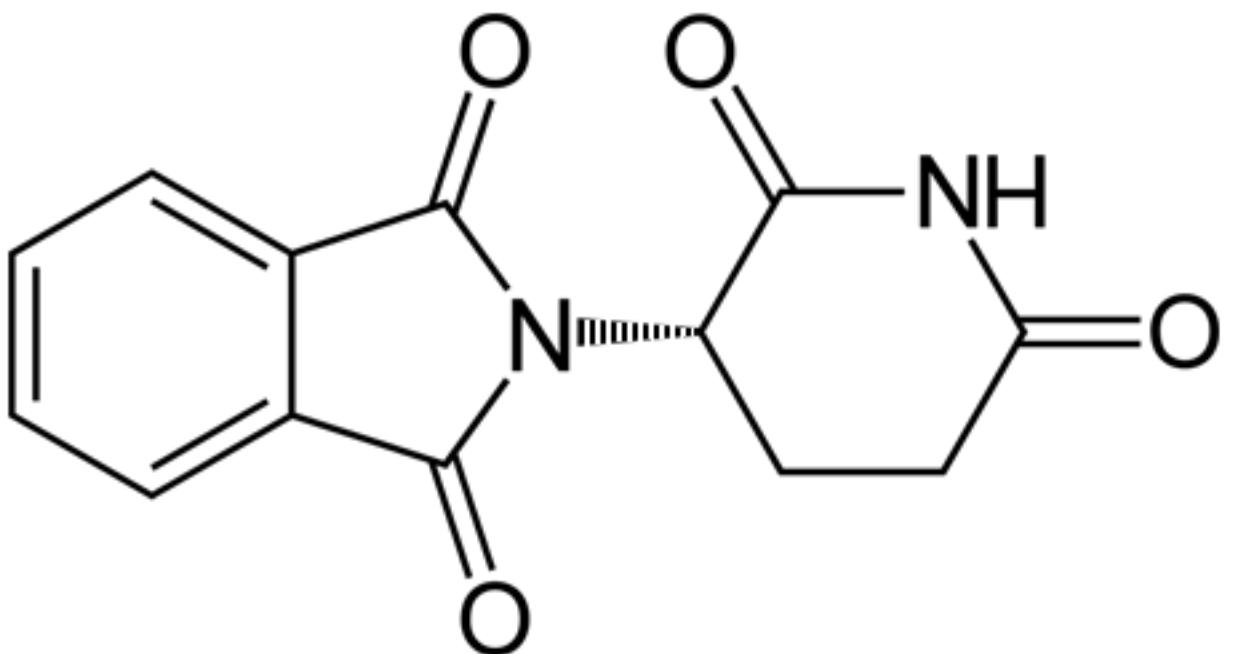
June 2010, pp. 61-83

The weirdest people in the world?

Joseph Henrich ^(a1), Steven J. Heine ^(a2) and Ara Norenzayan ^(a3)

Western
Educated
Industrialized
Rich
Democratic

Research
Participants



Policy: NIH to balance sex in cell and animal studies

[**Janine A. Clayton & Francis S. Collins**](#)

14 May 2014

Janine A. Clayton and Francis S. Collins unveil policies to ensure that preclinical research funded by the US National Institutes of Health considers females and males.



Maya Dusenberry [Follow](#)

Executive director of editorial at Feministing.com

Mar 23, 2015 · 11 min read

Is Medicine's Gender Bias Killing Young Women?

by Maya Dusenberry

Heart disease is the number one killer of both men and women in the United States, yet it's long been considered a "man's disease" in the popular imagination. This perception likely stems, in part, from the fact that coronary heart disease, the most common cause of heart attacks, is more prevalent among men—and tends to strike them at a younger age. When younger women do have heart attacks, though, studies have found that they are about twice as likely to die as their male counterparts—and more than 15,000 women under the age of 55 do every year.

than 75 percent of whom are women to receive a proper diagnosis, and that half report being labeled "crazy" in the early stages of their illness. Then there are the diseases, like chronic fatigue syndrome and fibromyalgia, that exist so squarely at the overlap of the Venn diagrams of "affects mostly women" and "unknown etiology" that they've only recently begun to be recognized as "real" diseases at all.

#ResearchParticipantsSoWhite



[Home](#) > Current Issue > vol. 113 no. 16 > Kelly M. Hoffman, 4296–4301

Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

Kelly M. Hoffman^{a,1}, Sophie Trawalter^a, Jordan R. Axt^a, and M. Norman Oliver^{b,c}

...isn't personalization the
solution?

How Self-Tracking Apps Exclude Women

"Self-knowledge through numbers" seems like a genderless goal, yet the actual products out there are anything but.

ET TU, SIRI? 3/19/15 10:35 AM

Apple has a lady problem: the new version of HealthKit still doesn't track periods

By Kashmir Hill

...but maybe technology is?

discriminate on other grounds too. When I looked further into the heart Istvan wrote about, made by French company Carmat, I came across [an astonishing figure](#): While this revolutionary device fits 86 percent of men, it's only suitable for about 20 percent of women.

GADGET POLITICS 3/9/15 2:57 PM

Will the Apple Watch's coolest feature work for people of color?

By Alexis C. Madrigal

How Photography Was Optimized for White Skin Color

169,434 views

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personalization & technology
depends on assumptions

personalized health



collective medicine

genetics to the rescue?

NATURE GENETICS | ANALYSIS



日本語要約

Detection and interpretation of shared genetic influences on 42 human traits

Joseph K Pickrell, Tomaz Berisa, Jimmy Z Liu, Laure Ségurel, Joyce Y Tung & David A Hinds

- Results

[Abstract](#) · [Introduction](#) · [Results](#) · [Discussion](#) · [Methods](#) · [Change history](#) · [References](#) ·

[Acknowledgments](#) · [Author information](#) · [Supplementary information](#)

We assembled summary statistics from 43 GWAS of 42 traits or diseases performed in individuals of European descent (Table 1; 2 of these GWAS were for age at menarche).

Genome-wide association study identifies novel susceptibility loci for cutaneous squamous cell carcinoma

Harvind S. Chahal, Yuan Lin, Katherine J. Ransohoff, David A. Hinds, Wenting Wu, Hong-Ji Dai, Abrar A. Qureshi, Wen-Qing Li, Peter Kraft, Jean Y. Tang, Jiali Han & Kavita Y. Sarin

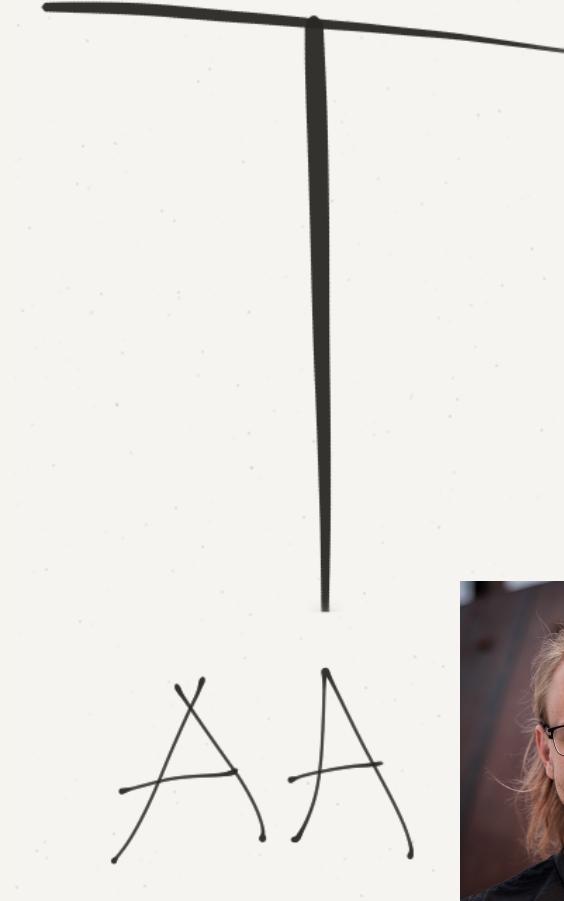
Nature Communications 7,

Received: 30 September 2015

Individuals were only included if they had >97% European ancestry, as determined through an analysis of local ancestry³¹. Briefly, this analysis first partitions phased



(A;A)	2.9	1.5x increased risk for prostate cancer
(A;C)	2.9	1.5x increased risk for prostate cancer



	(A;A) 2.9	1.5x increased risk for prostate cancer
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this only worked because my
dad and I are WEIRDos!



QUARTZ



...

DATA GAP

23andMe has a problem when it comes to ancestry reports for people of color

By Euny Hong

August 26, 2016



23andMe

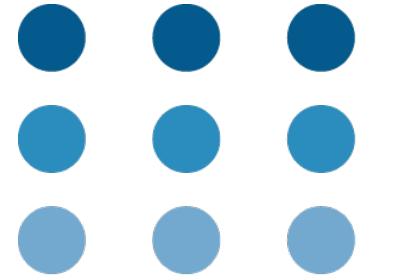
We bring the world of genetics to you. 23andMe.com

4 days ago · 6 min read

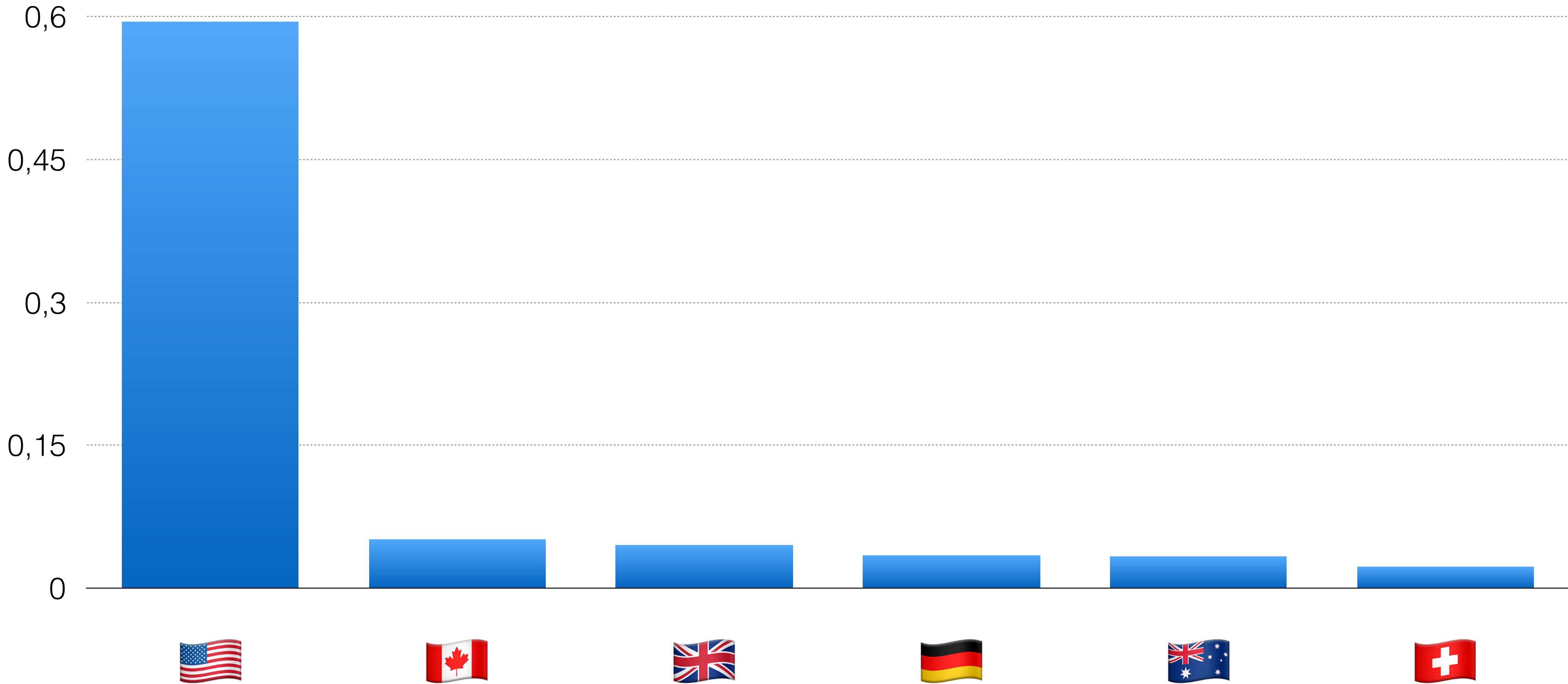
The Real Issue: Diversity in Genetics Research

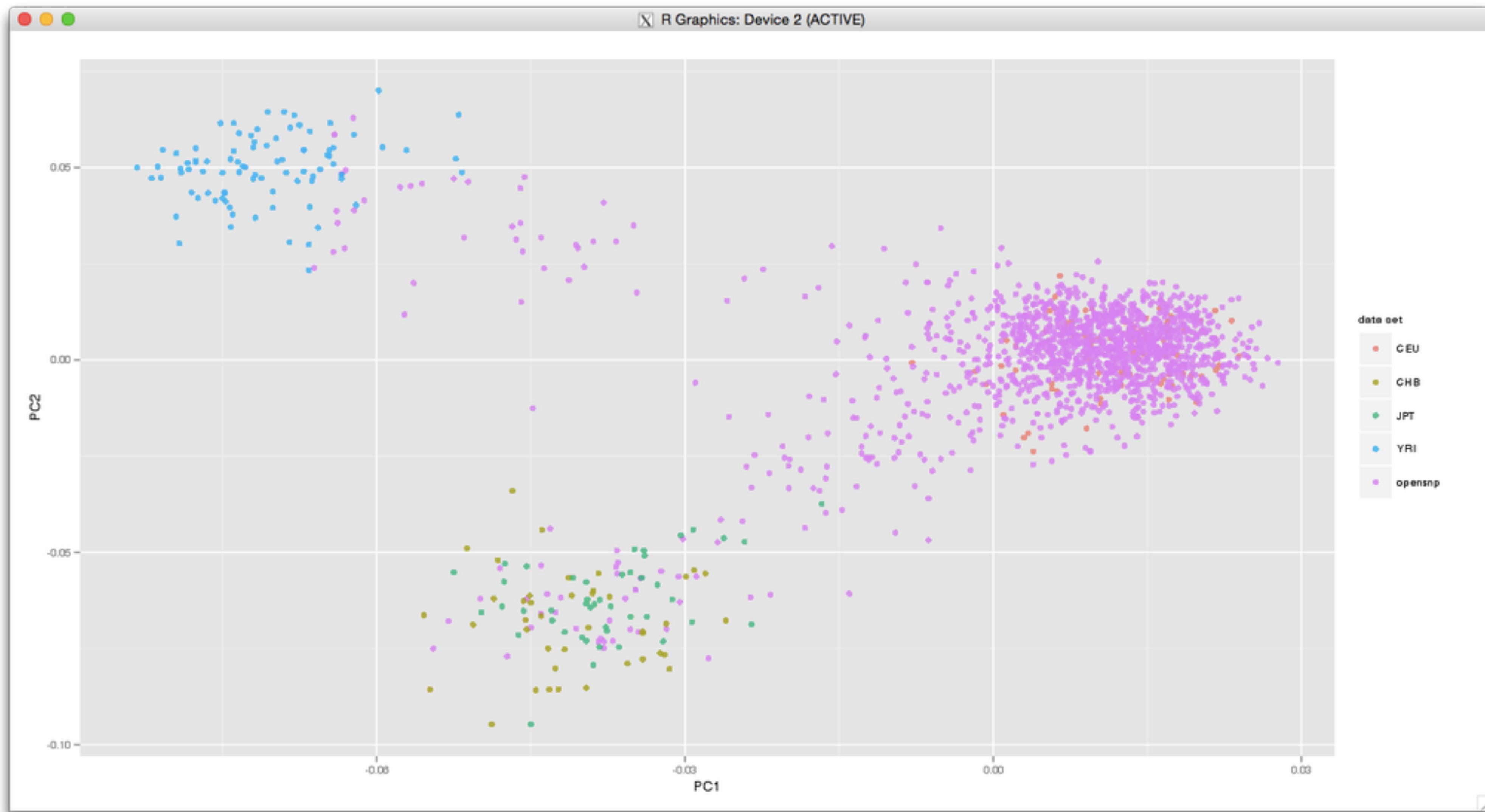
“ I firmly believe that the next great breakthrough in bioscience could come from a 15-year-old who downloads the human genome in Egypt.

– Thomas Friedman (2005, WIRED)



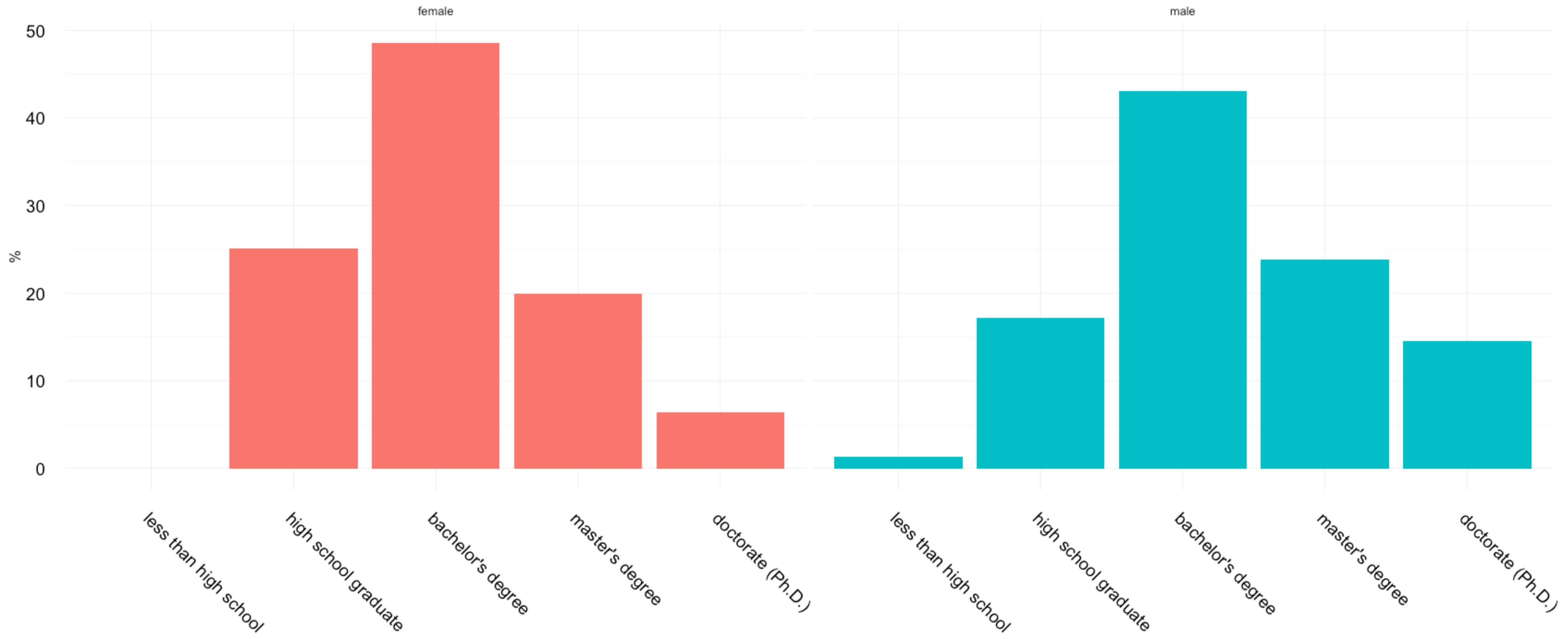
openSNP: ?







openSNP :  ?



So what now?

Personalized medicine still focusses
on people that look like me

The public™ is rightfully demanding
to take a long hard look at our
underlying assumptions

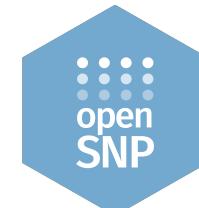
Instead of doing outright WEIRD
research we need diverse research.

(oh, and closed data == bad,
open data == good)



“There are no personal solutions at this time. There is only collective action for a collective solution.”

–Carol Hanisch



Bastian Greshake



@gedankenstuecke