1.

tension between data generation and utility.

My Home
Inbox (5)

My Health
Disease Risk
Carrier Status
Drug Response
Traits
Health Labs

My Ancestry
Maternal Line
Paternal Line
Relative Finder
Ancestry Painting
Global Similarity
Ancestry Labs

Sharing & Community
Compare Genes
Family Inheritance
23andMe Community

disease risk

Share my health results with family and friends

Show results for John Wilbanks

See new and recently updated reports »

23andWe Discoveries were made possible by 23andMe members who took surveys.

Elevated Risk

Name	Confidence	Your Risk	Avg. Risk	Compared to Average
Prostate Cancer ♂	★★★★	31.9%	17.8%	1.79x
Psoriasis	★★★★	22.4%	11.4%	1.98x
Alzheimer's Disease	★★★★	14.2%	7.2%	1.98x
Ankylosing Spondylitis	★★★			
Asthma	★★★			
Bipolar Disorder: Preliminary Research	★★★			
Chronic Lymphocytic Leukemia	★★★			
Follicular Lymphoma	★★★			
High Blood Pressure (Hypertension)	★★★			

Table 1. Total Prostate-Specific Antigen for White Males

Men <40 years	<2 ng/mL	<2 µg/L (SI units)
Men 40–50 years	2–2.8 ng/mL	2–2.8 µg/L
Men 51–60 years	2.9–3.8 ng/mL	2.9–3.8 µg/L
Men 61–70 years	4–5.3 ng/mL	4–5.3 µg/L
Men >70 years	5.6–7.2 ng/mL	5.6–7.2 µg/L

Reprinted with permission from Prostate-specific antigen (PSA). Available at: http://www.webmd.com/hw/mens_conditions/hw5522.asp. Accessed August 13, 2006.[7]

JNCI JOURNAL OF THE NATIONAL CANCER INSTITUTE

ABOUT THIS JOURNAL CONTACT THIS JOURNAL SUBSCRIPTIONS CURRENT ISSUE ARCHIVE SEARCH

Oxford Journals › Medicine › JNCI J Natl Cancer Inst › Volume 94, Issue 13 › Pp. 981-990.

Overdiagnosis Due to Prostate-Specific Antigen Screening: Lessons From U.S. Prostate Cancer Incidence Trends

Ruth Etzioni, David F. Penson, Julie M. Legler, Dante di Tommaso, Rob Boer, Peter H. Gann and Eric J. Feuer

+ Author Affiliations

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This Article

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Abstract ***Free***

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Article

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Alert me if corrected

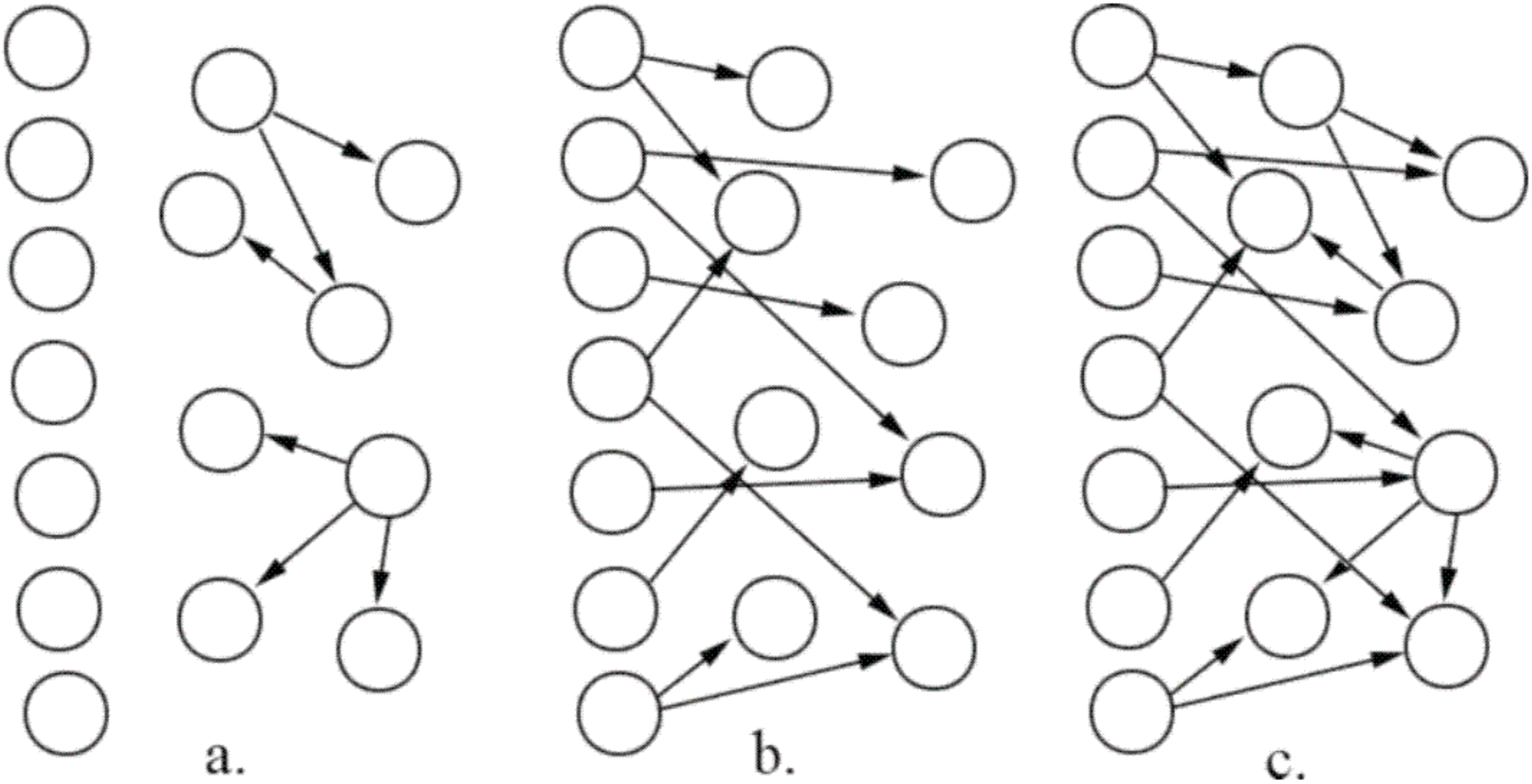
Abstract

“eat less and exercise”

2.

engaging a larger cohort (or, “crowdsourcing”).

crowds of data users


a.
b.
c.

Public Sage/DREAM Modeling Competition Leaderboard

8/28: We have re-run the evaluation due to a bug found in our exactConcordanceIndex calculation. We apologize for any inconvenience.

ID	Name	Submitter	Status	Received	Train Score	Test Score	Detail
syn1123807	Attractor Metagenes Model 090607	317809	complete	2012-09-06 20:45:22	0.7802159106	0.7449735640	Output
syn1123222	SC_TWEEK_SEP4_3	362391	complete	2012-09-04 23:49:26	0.7758041311	0.7443261519	Output
syn1237990	BH0913S7	962237	complete	2012-09-14 05:50:28	0.7793607196	0.7433010826	Output
syn1335448	re-tweaked SC_TWEEK_SEP4_3	362375	deleted	2012-09-18 00:53:12	0.7774088719	0.7427795562	
syn1125638	BH 0911 BL2	962237	complete	2012-09-11 22:48:49	0.7805026511	0.7424018991	Output
syn1123481	Attractor Metagenes Model 090602	317809	complete	2012-09-06 17:49:20	0.7860865453	0.7420422257	Output
syn1199235	BH0913S3	962237	complete	2012-09-13 20:06:22	0.7789783989	0.7416645686	Output
syn1335400	BH0917S7	962237	complete	2012-09-17 22:48:38	0.7825953538	0.7416106176	Output
syn1158570	BH0912S10	962237	complete	2012-09-13 04:43:14	0.7802209411	0.7414307809	Output
syn1123773	Attractor Metagenes Model 090606	317809	complete	2012-09-06 19:42:20	0.7822432163	0.7414127972	Output
syn1123477	Attractor Metagenes Model 090601	317809	complete	2012-09-06 17:42:54	0.7860865453	0.7407114340	Output
syn1189560	BH0913S1	962237	complete	2012-09-13 17:30:21	0.7781131468	0.7381217854	Output
syn1125753	HybridDriverV15	342024	complete	2012-09-12 01:30:15	0.7827261477	0.7379779161	Output
syn1124564	HybridDriverV6	342024	complete	2012-09-08 02:50:45	0.7820872697	0.7363593857	Output
syn1335353	BH0917S5	962237	complete	2012-09-17 20:53:21	0.8030696327	0.7363414020	Output
syn1123270	WarwickSystemsBiology (Wed Sep 5 13.40.37 2012)	362302	complete	2012-09-05 14:11:27	0.8280864850	0.7363234183	Output
syn1123295	WarwickSystemsBiology (Wed Sep 5 15.42.23 2012)	362302	complete	2012-09-05 16:00:58	0.8378004487	0.7358198756	Output
syn1123283	WarwickSystemsBiology (Wed Sep 5 15.11.15 2012)	362302	complete	2012-09-05 15:26:28	0.8321360659	0.7347048880	Output

tension between
anonymity and utility.

⚠ **These are guidelines only. Local regulations may impose a different tier assignment**

- Contact the ACT with any questions (act@sagebase.org)

Open	Restricted	Controlled

• Nonhuman data
• Human data not otherwise restricted. This may be data that is:
  • Anonymized
  • Publicly available elsewhere
  • Genotype data from deceased individuals
  • De-identified, non-genomics data
  • Copy Number Variation (CNV) data
  • Data unambiguously consented for data sharing
	• Human non-genotype data with conditions outlined in informed consent such as:
	  • Research field of use
	  • Type of analysis
	  • Users must be a research partner with data generator
	  • Requirements for return of results
	  • Use affiliations (eg., nonprofit only)
		• Human sequencing and/or genotype data from living individuals
		• Human non-genotype data from sensitive populations

crowds of data donors

tension between
expectation and reuse.

JAMA Internal Medicine
Formerly *Archives of Internal Medicine*

Original Investigation | August 19, 2013

Public Preferences About Secondary Uses of Electronic Health Information ONLINE FIRST

David Grande, MD, MPA[1,2]; Nandita Mitra, PhD[3]; Anand Shah, MD, MSHP[4]; Fei Wan, MS[3]; David A. Asch, MD, MBA[1,2,5]

[+] Author Affiliations

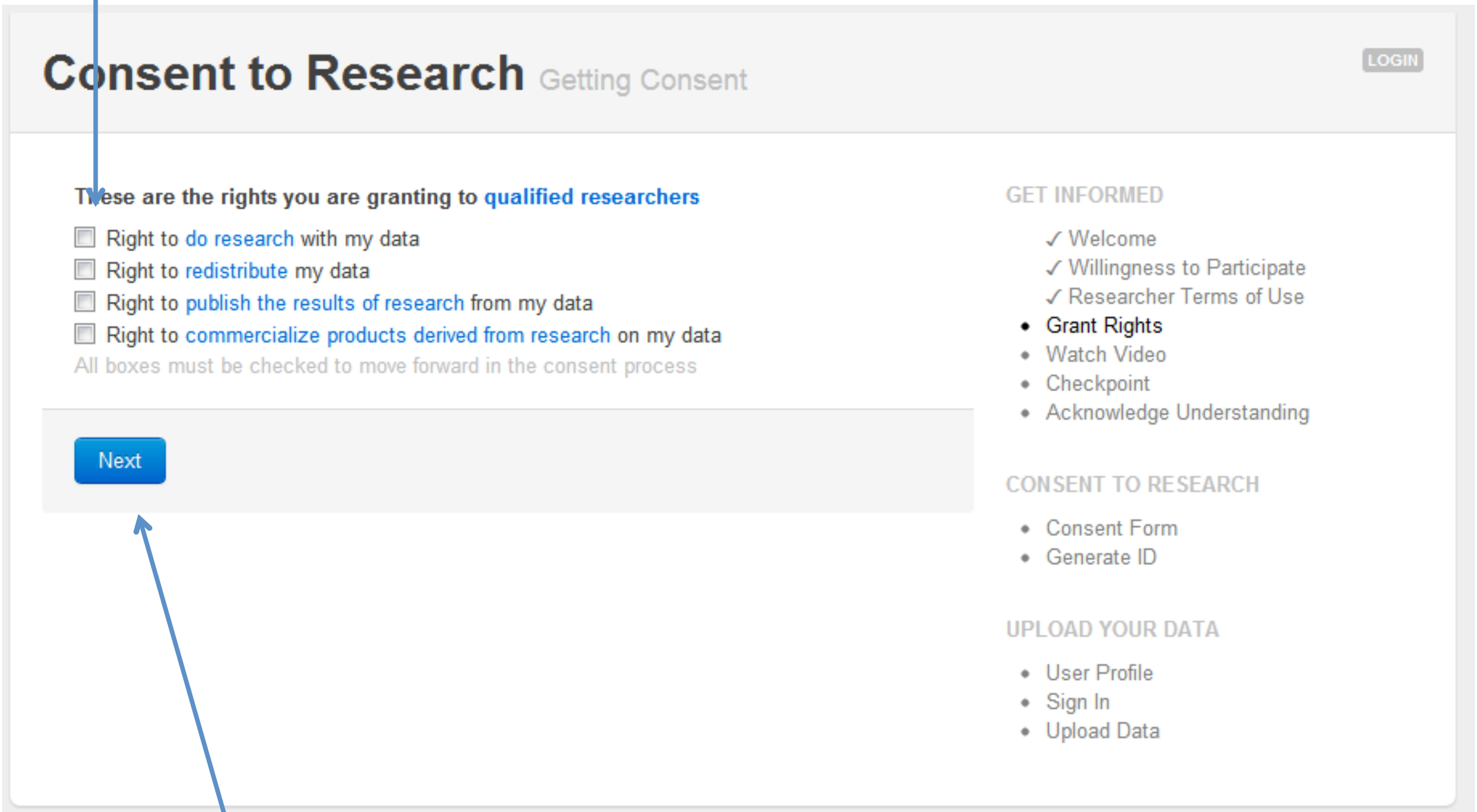
JAMA Intern Med. Published online August 19, 2013. doi:10.1001/jamainternmed.2013.9166

68% ok with sharing in university research.

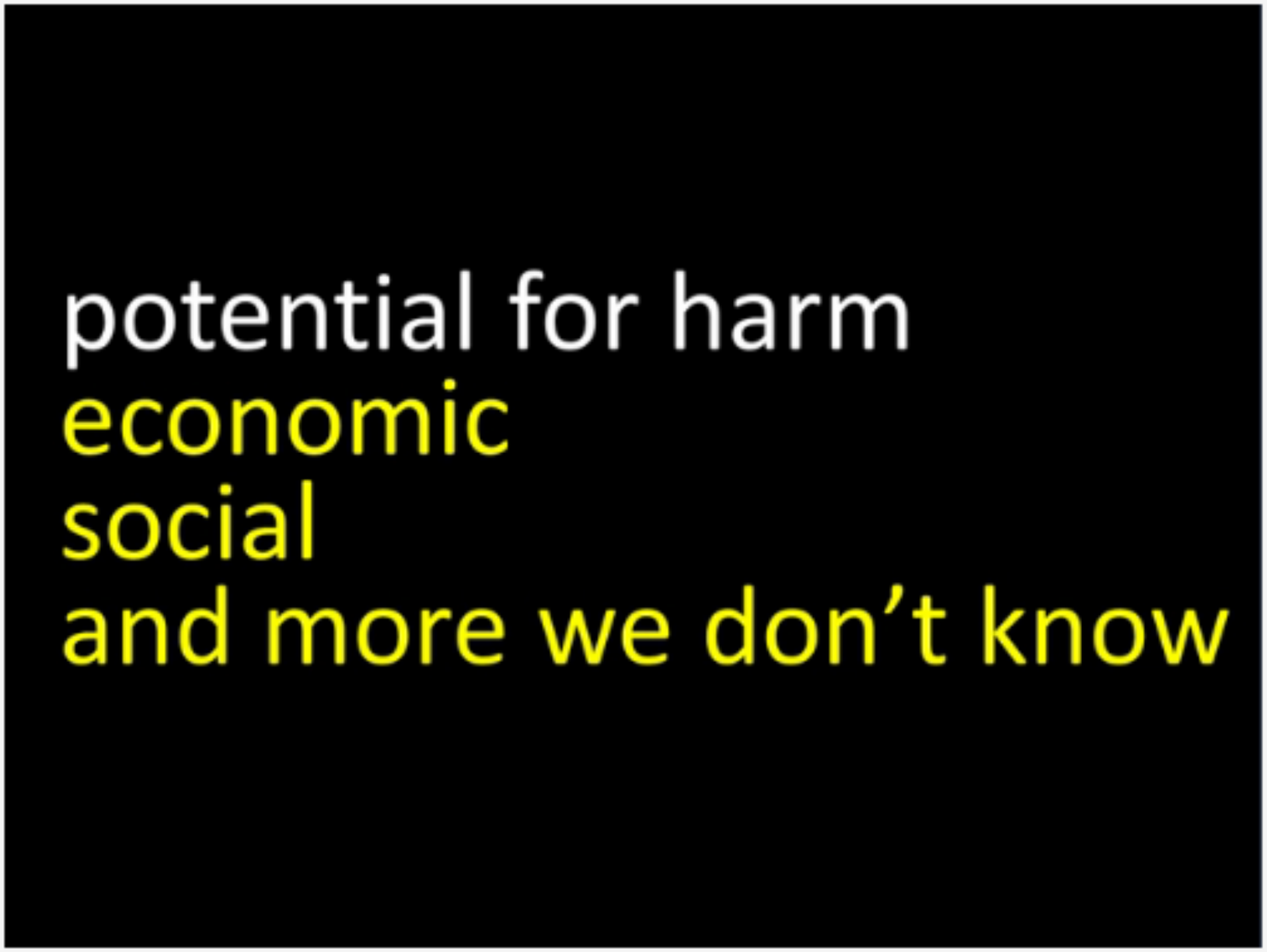
El que suscribe, Antonio Bruno mayor de veinte y cinco años de edad, natural de Cerceda provincia de Coruña hijo de Manuel Bruno y de Josefa Castro hace constar por la presente que, gustoso y ejerciendo su propria y libérrima voluntad, consiente en someterse á los experimentos que con el objeto de determinar las vías de propagacion de la fiebre amarilla, haga en su persone la Comision que para ese efecto ha nombrado el Secretario de la Guerra de los Estados Unidos; que dá su consentimiento para que se lleven á cabo dichos experimentos, por las razones y con las condiciones que abajo se expresan.

El infrascrito comprende perfectamente bien que en el caso de desarrollarse en él la fiebre amarilla, ha de peligrar su vida hasta cierto punto pero siendole completamente imposible evitar el contagio durante su permanencia en esta Isla, prefiere arrostar la posibilidad de contraerla ex-profeso, con la seguridad de que ha de recibir de la Comision yá mencionada, los cuidados mas prolijos y la asistencia médica mas esmerada.

all boxes must be checked



volunteer must click to proceed



You must finish watching the video to advance in the consent process.

volunteer cannot skip video

Consent to Research Getting Consent

LOGIN

Tell us that you understand this informed consent process.

- [x] I understand the uncertainty and risk of public genetic research.
- [x] I provide consent for my data to be used in public genetic research
- [x] I understand that although I can withdraw at any time, I cannot withdraw data that has already been distributed.

All boxes must be checked to create informed consent.

I want to give consent

GET INFORMED

- ✓ Welcome
- ✓ Willingness to Participate
- ✓ Researcher Terms of Use
- ✓ Grant Rights
- ✓ Watch Video
- ✓ Checkpoint
- Acknowledge Understanding

CONSENT TO RESEARCH

- Consent Form
- Generate ID

UPLOAD YOUR DATA

- User Profile
- Sign In
- Upload Data

7. You choose what data to upload.

		Response Percent	Response Count
True		100.0%	118
False		0.0%	0
	answered question		118
	skipped question		2

8. You can decide to withdraw at any time.

		Response Percent	Response Count
True		98.3%	116
False		1.7%	2
	answered question		118
	skipped question		2

9. If you withdraw, it's certain that all your data can be cleared from the system.

		Response Percent	Response Count
True		7.6%	9
False		92.4%	109
	answered question		118
	skipped question		2

10. You are guaranteed confidentiality.

		Response Percent	Response Count
True		41.5%	49
False		58.5%	69
	answered question		116
	skipped question		2

11. Researchers have to sign terms of use to access your data.

		Response Percent	Response Count
True		96.6%	114
False		3.4%	4
	answered question		116
	skipped question		2

12. Your data will be redistributed to qualified researchers.

		Response Percent	Response Count
True		97.4%	114
False		2.6%	3
	answered question		117
	skipped question		3

3.

“just put it up and see what happens”

Synapse BETA | CONTRIBUTE to the CURE

Down

Genotype- 23andme (syn1418166)

Added by: Xavier Schildwachter on: Mon Oct 01 18:59:24 GMT-700 2012
Modified by: Christine Suver on: Tue Oct 02 09:07:59 GMT-700 2012
Version: 0.0.0 [1] (show all versions)

Description

Genotype from individual 1418165, generated by 23andme using the Illumina OmniExpress Plus genotyping beadchip.

This is a PLC contributed dataset (http://weconsent.us/about)

jtw's page

jtw has uploaded genotyping rawdata.

- Download this set (23andme)

Description

This user has not entered a description yet.

jtw's variations

This user has not entered any phenotypes yet.

http://opensnp.org/users/615

gs144

4	Magnitude
20120916	Geno time

Male Male.

rs5186(C;C) **7.3x increased risk of hypertension**...more...

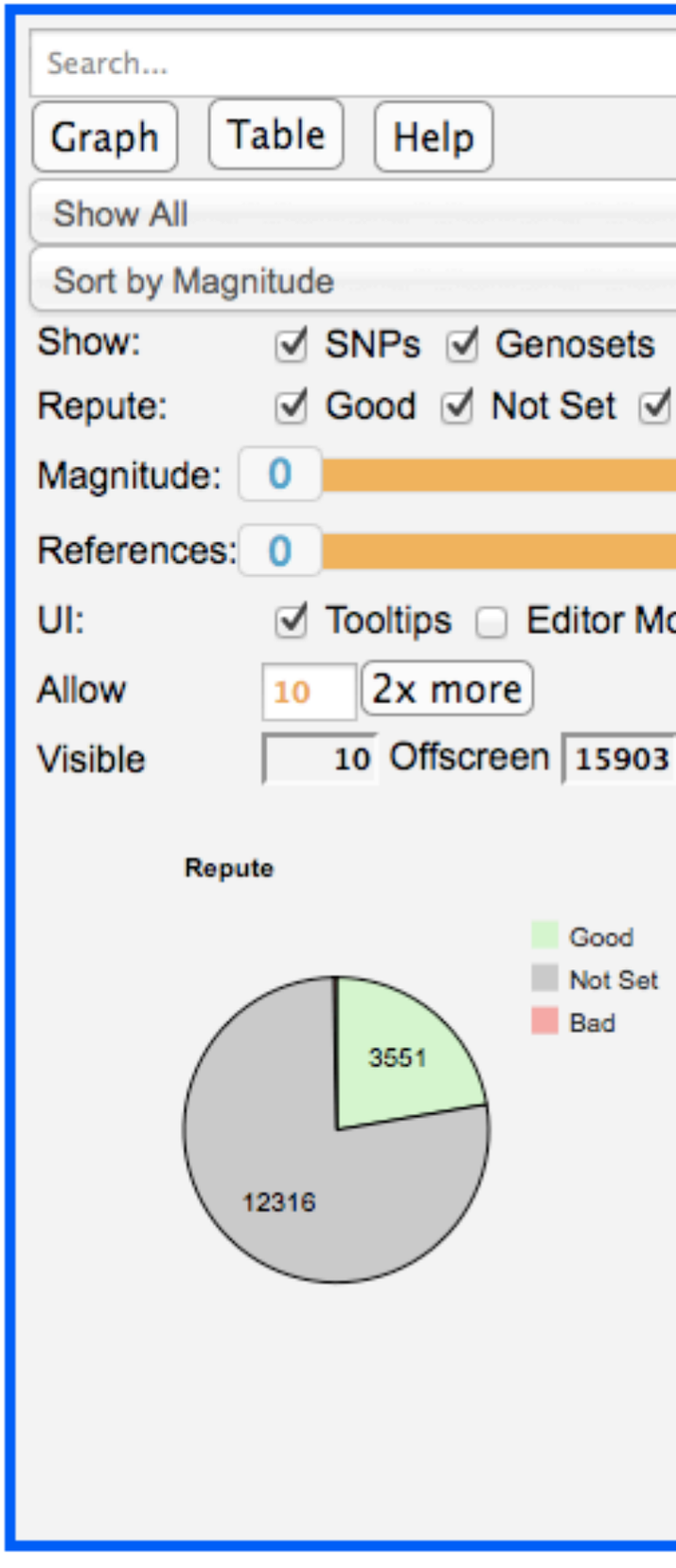
Bad	Repute
4	Magnitude
0.1575	GMAF
54	References
AGTR1	Gene
3	Chromosome
148459988	Position
20120810	Rs time

High blood pressure, Pre-eclampsia

rs6152(A;A) **won't go bald** This genotype seems to prevent baldness ...more...

Good	Repute
4	Magnitude
0.214587	GMAF
11	References
AR	Gene
X	Chromosome
66765627	Position
20120812	Rs time

Baldness



http://files.snpedia.com/reports/promethease_data/genome_jtw_ui2.html

'JTW'

MINOR ALLELE PROGRAM REPORT
==========

'JTW' 'jw' '615' 23andMe Results Chromosomes 1-22 4 October 2012

The program finds about 60 'rare/uncommon' SNPs from the 900,000+ tested by 23andMe.

There is just a single 'homozygous-recessive' result:

'AA' rs11869580 Intergenic

but as this occurs in an Intergenic region it is unlikely to be of significance.

There are no SNPs of special note.

==========

RESULTS
=======

==========

rs56367069 at Chr1a:17326767 gave 'CT' The minor allele is 'T' with a MAF = 0.00776.
rs4949212 at Chr1a:31961711 gave 'GT' The minor allele is 'G' with a MAF = 0.00959
rs1181088 at Chr1a:54563039 gave 'AG' The minor allele is 'G' with a MAF = 0.00959
rs1109918 at Chr1a:67862482 gave 'AG' The minor allele is 'G' with a MAF = 0.00822.
rs12751479 at Chr1b:98056007 gave 'GT' The minor allele is 'T' with a MAF = 0.00228
rs35669708 at Chr1b:156851382 gave 'AG' The minor allele is 'A' with a MAF = 0.00999
rs35698797 at Chr1c:229665958 gave 'CT' The minor allele is 'T' with a MAF = 0.00502

rs45471294 at Chr2a:31600017 gave 'CT' The minor allele is 'T' with a MAF = 0.00914.
rs17776702 at Chr2b:103317676 gave 'AG' The minor allele is 'G' with a MAF = 0.00868
rs17760364 at Chr2c:189631806 gave 'AG' The minor allele is 'G' with a MAF = 0.00959

rs279552 at Chr3a:9976159 gave 'AG' The minor allele is 'A' with a MAF = 0.00639
rs460965 at Chr3a:10122927 gave 'CT' The minor allele is 'T' with a MAF = 0.00594.
rs2067466 at Chr3a:11300780 gave 'CG' The minor allele is 'C' with a MAF = 0.00319

“Also there is no suggestion of consanguinity in your pedigree.”

http://www.ianlogan.co.uk/


No Service
3:24 PM
AliveECG
00:04
bpm
68
N
N
N

we’re not so anonymous.

john.wilbanks@sagebase.org
wilbanks@nitrd.gov
@wilbanks