# patient ownership of clinical research data

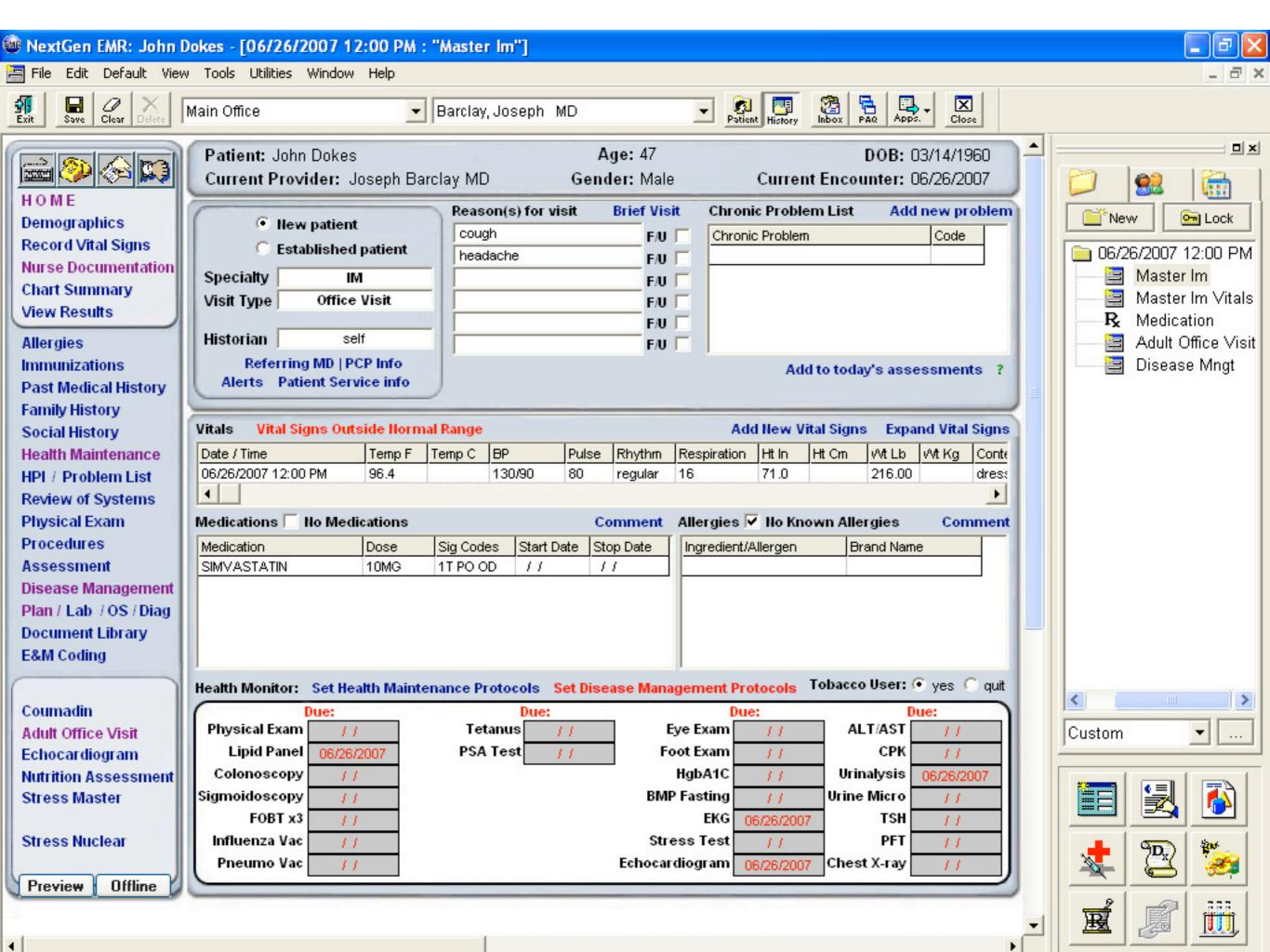
@wilbanks john.wilbanks@sagebase.org

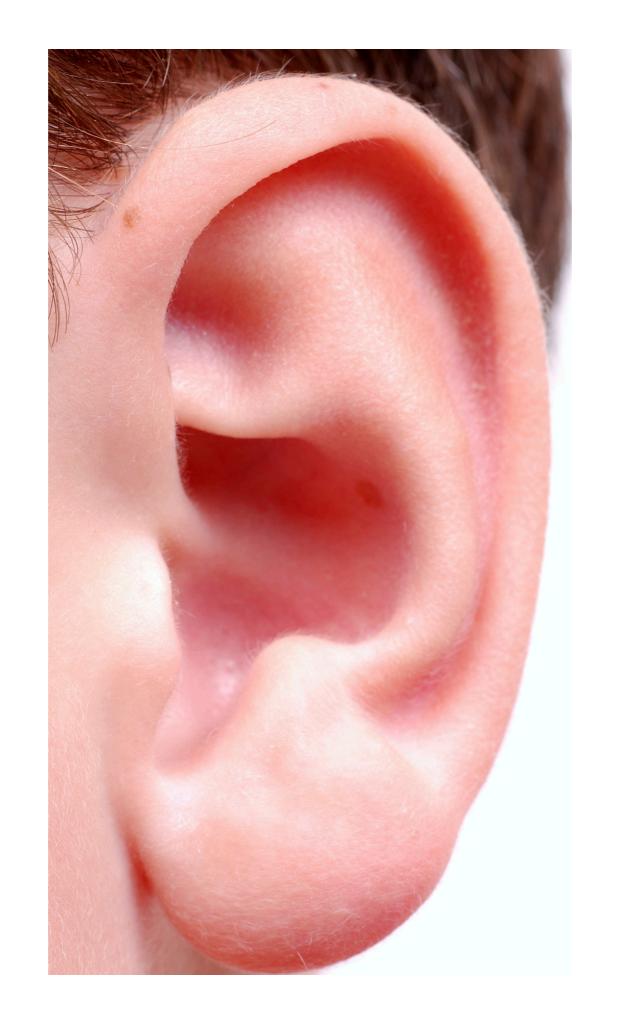
# 1. what do you mean by clinical?

# 1. what do you mean by clinical? research?

# 1. what do you mean by clinical? research? data?

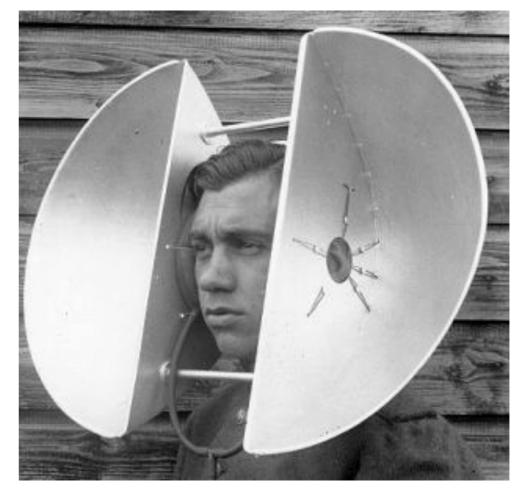
















# 2. we're not very patient.





Inbox (12)

#### 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

Family Tree

Family Inheritance



John, welcome to you.

#### View Your Printable Genetic Health Summary

See your genetic results for all health topics with Established Research in one easy-to-read place! Print the summary for your records or share it with your health care provider.

View Report

Don't show again.



A new survey is available: The Empathy Quotient

2 days ago



#### Cilantro Love and Hate: Is it a Genetic Trait?

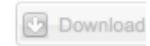
Why do some people love cilantro, while others hate it with every fiber of their being? With the help of customers like you, we've identified a genetic variant associated with disliking cilantro and thinking it tastes soapy.

» Read more



Ever

Home » Self-Contributed Data fo...



### Self-Contributed Data for Common Genomics Research (syn1418121)

Added by: Xavier Schildwachter on: Mon Oct 01 10:16:10 GMT-700 2012 Modified by: Christine Suver on: Mon Oct 01 13:39:47 GMT-700 2012

#### Description

Dataset of self-contributed health and Genomics data available for use in emerging genomics research.

These data were donated through Portable Legal Consent (PLC) by individuals who wish to broadly share their personal information with the Synapse user community for research purposes. Portable legal Consent: http://weconsent.us/about

#### ProjectContents



Home » Self-Contributed Data fo... » Individual 1418165 » Genotype- 23andme



### 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.

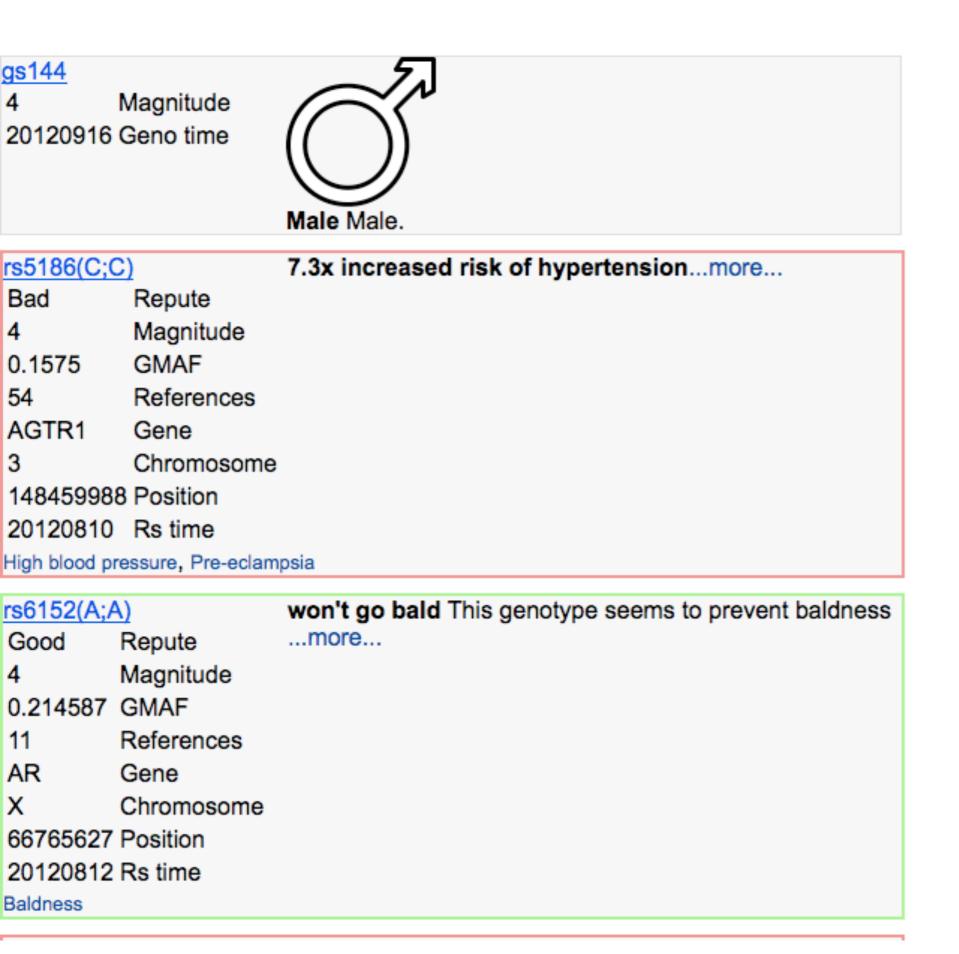
jtw's variations

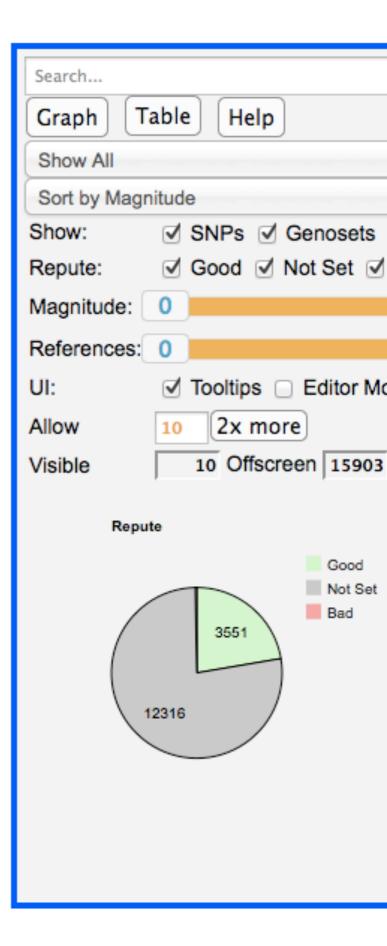
This user has not entered any phenotypes yet.

Contact openSNP: Blog | Twitter | Mail | Privacy Policy | openSNP in the press

The openSNP project is licensed under CC BY SA 3.0. The data is licensed under CC0 1.0. The hand drawn icons were created by one seventy seven and are licensed under CC BY 3.0, the CSS of openSNP is provided by Bootstrap, from Twitter and is licensed under the Apache License v2.0. Tiny white person in the navigational-bar from glyphicons.

#### http://opensnp.org/users/615





http://files.snpedia.com/reports/promethease\_data/genome\_itw\_ui2.html

#### 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 Chrla: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	
rs1109918	at Chr1a:67862482	gave 'AG' The minor allele is 'G' with a MAF = 0.	
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	
rs279552	at Chr3a:9976159	gave 'AG' The minor allele is 'A' with a MAF = 0	00630
		<b>3</b>	
rs460965	at Chr3a:10122927	gave 'CT' The minor allele is 'T' with a MAF = 0.	
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/

nor Sample

\$10.00

per Hour

### The Scientific Services Marketplace

The easiest way to get experiments conducted by researchers in top core facilities and institutions.

#### Search All Services

NA Sequencing

IA microarray	\$107.50 per Sample		
IA Commondan	\$2.50		

	persompte
Real Time qPCR	\$3.50 per Sample

Mass Spectrometry	\$10.00 per Sample

mmunomistochemistry	per Sample
Nainfarmatics	\$50.00

#### Featured RNA microarray Providers

Science Exchange has 63 verified RNA microarray providers including the following featured providers.



#### Virginia Bioinformatics Institute

Virginia Polytechnic Institute and State University | Blacksburg, VA, United States

The Core Laboratory Facility (CLF) at VBI functions as a multi-user resource dedicated to the development and application of various high-throughput technologies to aid in the discovery of biological macromolecules.

\$284.00 USD per Sample

REQUEST ESTIMATE









BOSTON

https://www.scienceexchange.com



View all providers for this experiment →



# 3. principles for sharing.

honesty. reusability. portability.



Support

John Wilbanks

Search



#### NARROW RESULTS

#### Node type

data (788)

study (101)

folder (26)

summary (1)

#### Species

Homo sapiens (875)

#### Disease

Cancer (473) cancer (400)

#### Modified on

Any Time

Past 24 Hours

Past Week

Past Month

Past Year

#### Created on

A ....

#### tcga

916 results found

#### 1. FIC Scores For TCGA LUSC huex10stv2

metaGenomics » Precomputed Analysis Objects » FIC Scores For TCGA LUSC huex10stv2

FIC Scores presented as a matrix with genes along the rows and TCGA batches across the top. Row names are entrez gene lds followed by \_eg suffix. Column names are formed by concatenating the entity name and synapse entity id values. We also include an R data frame..

Created by Brig Mecham on 2012-08-30, Updated by Brig Mecham on 2012-08-30

#### 2. FIC Scores For TCGA OV huex10stv2

metaGenomics » Precomputed Analysis Objects » FIC Scores For TCGA OV huex10stv2

FIC Scores presented as a matrix with genes along the rows and TCGA batches across the top. Row names are entrez gene lds followed by \_eg suffix. Column names are formed by concatenating the entity name and synapse entity id values. We also include an R data frame...

Created by Brig Mecham on 2012-08-30, Updated by Brig Mecham on 2012-08-30

#### FIC Scores For TCGA GBM huex10stv2

metaGenomics » Precomputed Analysis Objects » FIC Scores For TCGA GBM huex10stv2

FIC Scores presented as a matrix with genes along the rows and TCGA batches across the top. Row names are entrez gene lds followed by the accustive Column names are formed by concernation the antity name and amongs antity id values. We also include

### <u>tp://synapse.sagebase.org</u>

#### Consent to Research Getting Consent



#### These are the rights you are granting to qualified researchers:

- Right to do research with my data.
- Right to redistribute my data.
- Right to publish the results of research from my data.
- Right to commercialize products derived from research on my data.

All boxes must be checked to move forward in the consent process

Next

#### **GET INFORMED**

- √ Welcome
- √ 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

### http://weconsent.us

#### 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
1122250	Wannel - 1-0	262202	1-4-	2012 00 05 12:26:42	0.7274462000	0.7244171402	0

### WELCOME TO BRIDGE

We believe knowledge sharing is vital for new discoveries. With that in mind, we created Bridge as a platform to accelerate medical research through open-source collaboration.



#### Bridge is currently focused on



http://sagebridge.org

#### **Get Involved**

It will take the efforts of all of us working together in new ways to learn what happens when people affiliate their real names with their data and then have an active voice in determining what hapens with that data. Link below to learn more about how you can best make a difference.



LEARN HOW TO FUND THE **REAL NAMES PILOT** 



I WANT TO CONTRIBUTE MY DATA TO THIS RESEARCH



CONTACT ME WHEN REAL NAMES DATA IS READY FOR RESEARCH

#### **Get Connected**

Patient advocate communities will serve as an importan cornerstone for the success of the Real Names Discovery Pilot. Read more below and link to the sites of two such groups that have already stepped up to help launch Real Names Discovery Pilot.

#### PATIENTS LIKE ME

PatientsLikeMe is committed to putting patients first. We do this by providing a better, more effective way for you to share your real-world health experiences in conditions.



#### **PARKINSONNET**

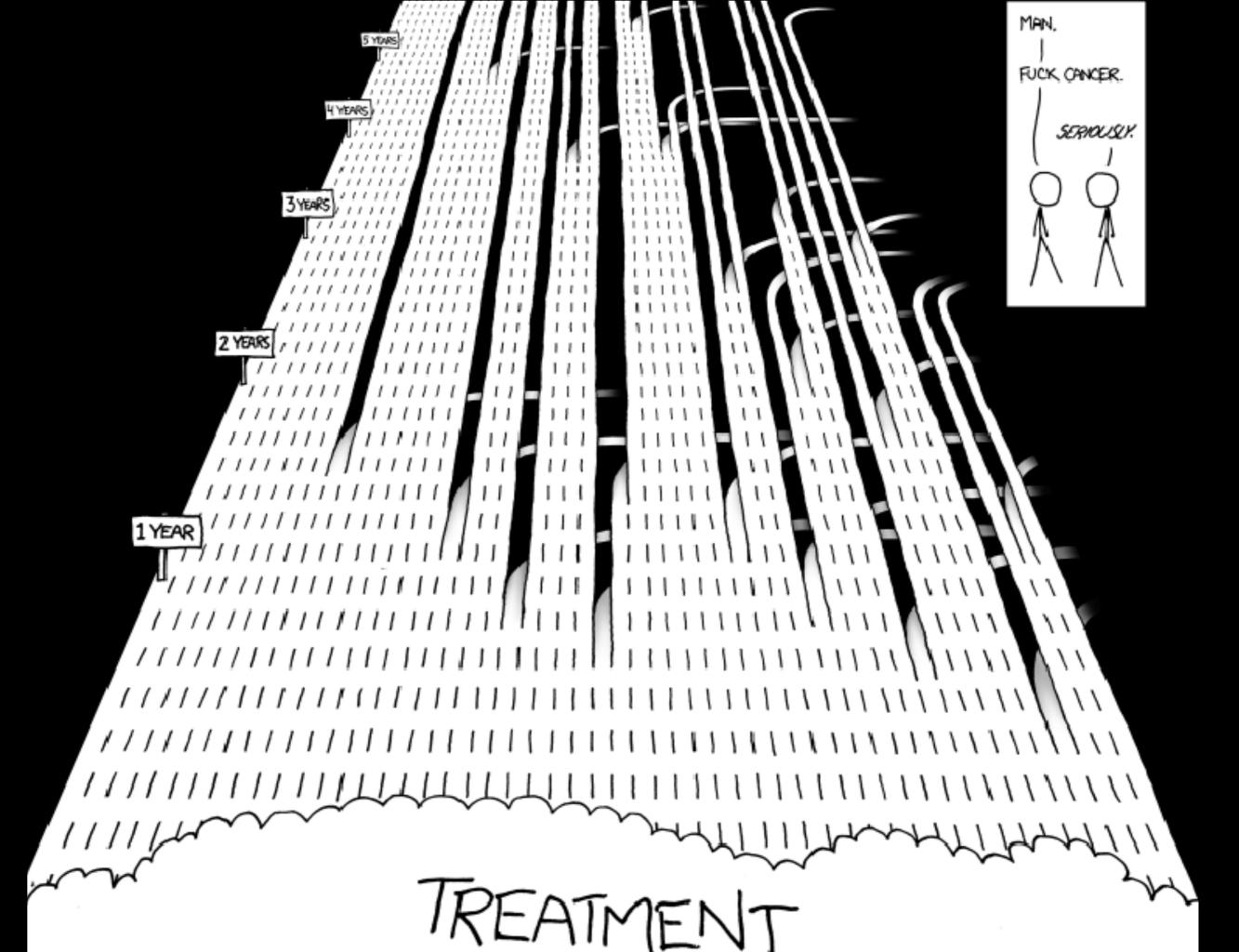
The ParkinsonNet consists of regional networks of care providers in the Netherlands who specialize in treating and managing patients with Parkinson's order to help yourself, other patients like you and organizations that focus on your disease or Parkinson-like disorders (parkinsonisms). The networks are centered around one or more partnerships neurology of the regional hospitals.





# if we scale...

# honesty, reusability, and portability will change a clinical outcome.



# thank you