“Privacy is about context, social situations, and control.”
- danah boyd

1. We are going to get our [genetic, health] data, one way or another.

but we often lack *agency to decide* what is done with data about us…

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My Health
Disease Risk
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Drug Response
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My Ancestry
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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 [redacted]

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)	★★★			

Health Information Privacy

HIPAA
- Understanding HIPAA Privacy
- HIPAA Administrative Simplification Statute and Rules
- Enforcement Activities & Results
- How to File a Complaint
- News Archive
- Frequently Asked Questions

PSQIA
- Understanding PSQIA Confidentiality
- PSQIA Statute & Rule
- Enforcement Activities & Results
- How to File a Complaint

Right to Access Medical Records

If someone has health care power of attorney for an individual, can they obtain access to that individual's medical record?

Can the personal representative of an adult or emancipated minor obtain access to the individual's medical record?

How can family members of a deceased individual obtain the deceased individual's protected health information that is relevant to their own health care?

Does the HIPAA Privacy Rule allow parents the right to see their children's medical records?

If a child receives emergency medical care without a parent's consent, can the parent get all information about the child's treatment and condition?

Does the HIPAA Privacy Rule require a business associate to provide individuals with access to their protected health information or an accounting of disclosures, or an opportunity to amend protected health information?

What does the HIPAA Privacy Rule say about a research participant's right of access to research records or results?

Are the HIPAA Privacy Rule's requirements regarding patient access in harmony with the Clinical Laboratory Improvements Amendments of 1988 (CLIA)?

If patients request copies of their medical records as permitted by the Privacy Rule, are they required to pay for the copies?

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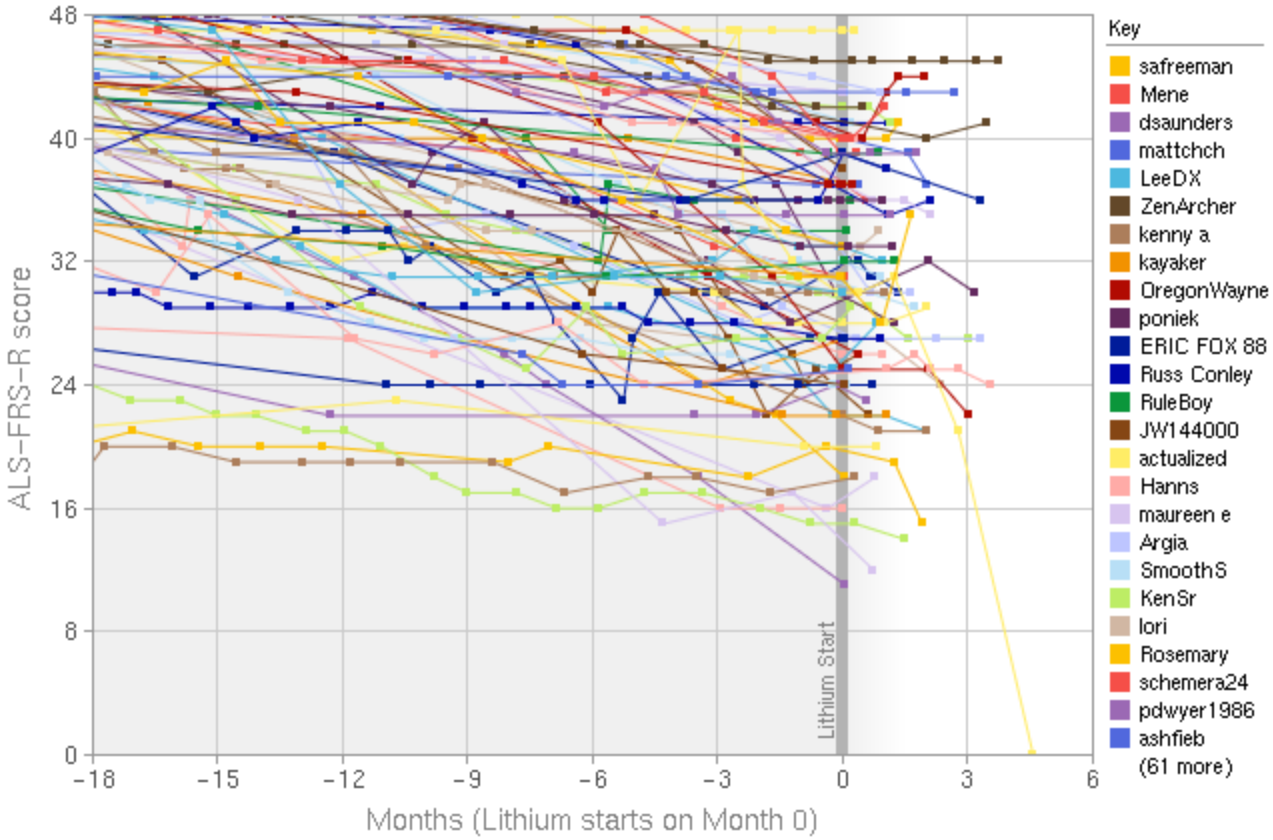
(we are also going to talk about it)

patientslikeme™

generated: Mar 31, 2008 03:18PM
by: Visitor

ALSFRS-R Progression of Patients on Lithium

This graph shows the ALSFRS-R scores of ALS patients in the PatientsLikeMe system before and after they started taking lithium. It is an evolving prototype that we are developing to help understand if lithium, and ultimately other treatments, can slow ALS progression. **Source:** http://www.patientslikeme.com/als_lithium



Filters: All patients taking lithium

Caveat: This is a prototype that is attempting to display real-time effects of a treatment in the real world. In contrast to a well controlled double-blind placebo controlled trial, there are many variables, both known and unknown, that suggest significant caution should be used before drawing any conclusions from the results. Known

My Father's Medical Record Fiasco

e-Patient Dave | January 2, 2010

25 TOP ★5K retweet Like 3

Guest post by Alan Viars (@Aviars), CEO of Videntity Systems, Inc.

This past year my father required open heart surgery. This is a short article about the hurdles we (his family) encountered along the way. I've changed the names, because it is not my intention to embarrass particular hospitals or physicians. The issues I raise are systemic within the American healthcare apparatus. My objective is for you to get smart, get mad, and gain control of YOUR medical records.

In July 2009, my father, Charles, had a routine follow up with his primary care physician, "Dr. Smith." Dr. Smith told my father, "Well Charles, your EKG came back the same as last year: abnormal." "Abnormal? What?! Last year was abnormal, too? This is news to me!" My father was stunned.

"Well, you knew you had a heart attack, didn't you?" asked Dr. Smith. "I don't know anything unless you tell me!", my father told Dr. Smith. The doctor changed the subject to treatment: "Let's get you in to see a cardiologist."

Yes, that's right, my father unknowingly had had a heart attack even though he was regularly receiving medical care. A year prior his physician either didn't bother to look at the result of his

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We're in private beta. Want to join us?

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Email

Why do you want to join? What health questions do you want to answer?

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– Melanie Swan

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We start you off with a genotype test, to arm your doctor with extra insight into how your body works. Our genetic counselors are trained to help you and your doctor make the best use of this very newly

« Older

Ethics and Genomic Research: 'Genomethics'

31/01/2012

Categories: ELSI and Guest Posts

Written by Katherine Morley and Guest Author

Dr Anna Middleton is an Ethics Researcher and Registered Genetic Counsellor, based at the Wellcome Trust Sanger Institute. She leads the ethics component of the Deciphering Developmental Disorders study, a collaborative project involving WTSI and the 23 National Health Service Regional Clinical Genetics Services in the UK. This project involves searching for the genetic cause of developmental disorders, using array-CGH, SNP genotyping and exome sequencing, in ~12,000 children in the UK who currently have no genetic diagnosis.

About

Genomes Unzipped is a group blog providing expert, independent commentary on the personal genomics industry.

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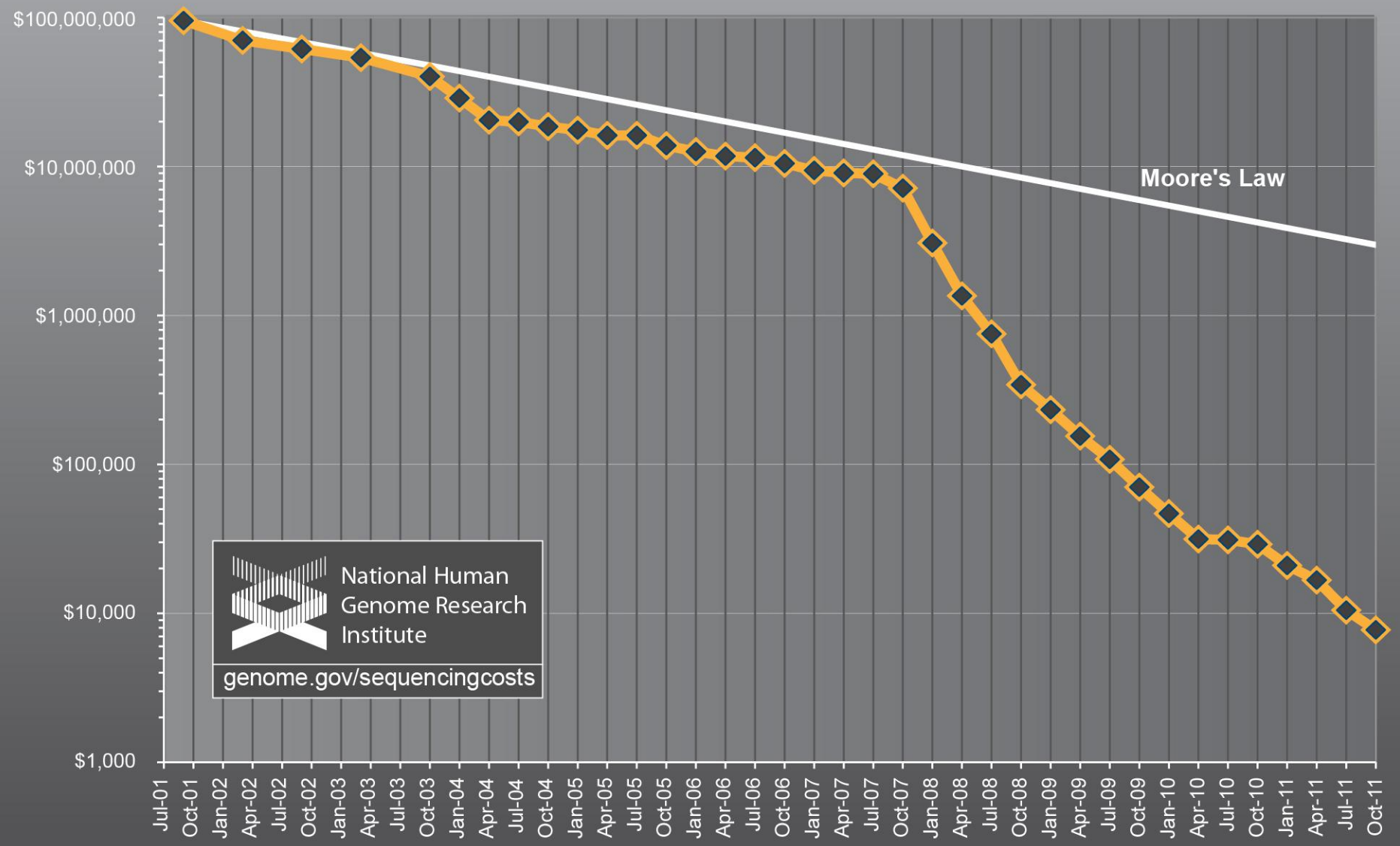
Ethics and Genomic Research: 'Genomethics'

A personal view of genetic

Cost per Genome



in the future, anyone who wants a copy of your genome will probably be able to get it.

2. data

> information

> knowledge

> wisdom

ORIGIN

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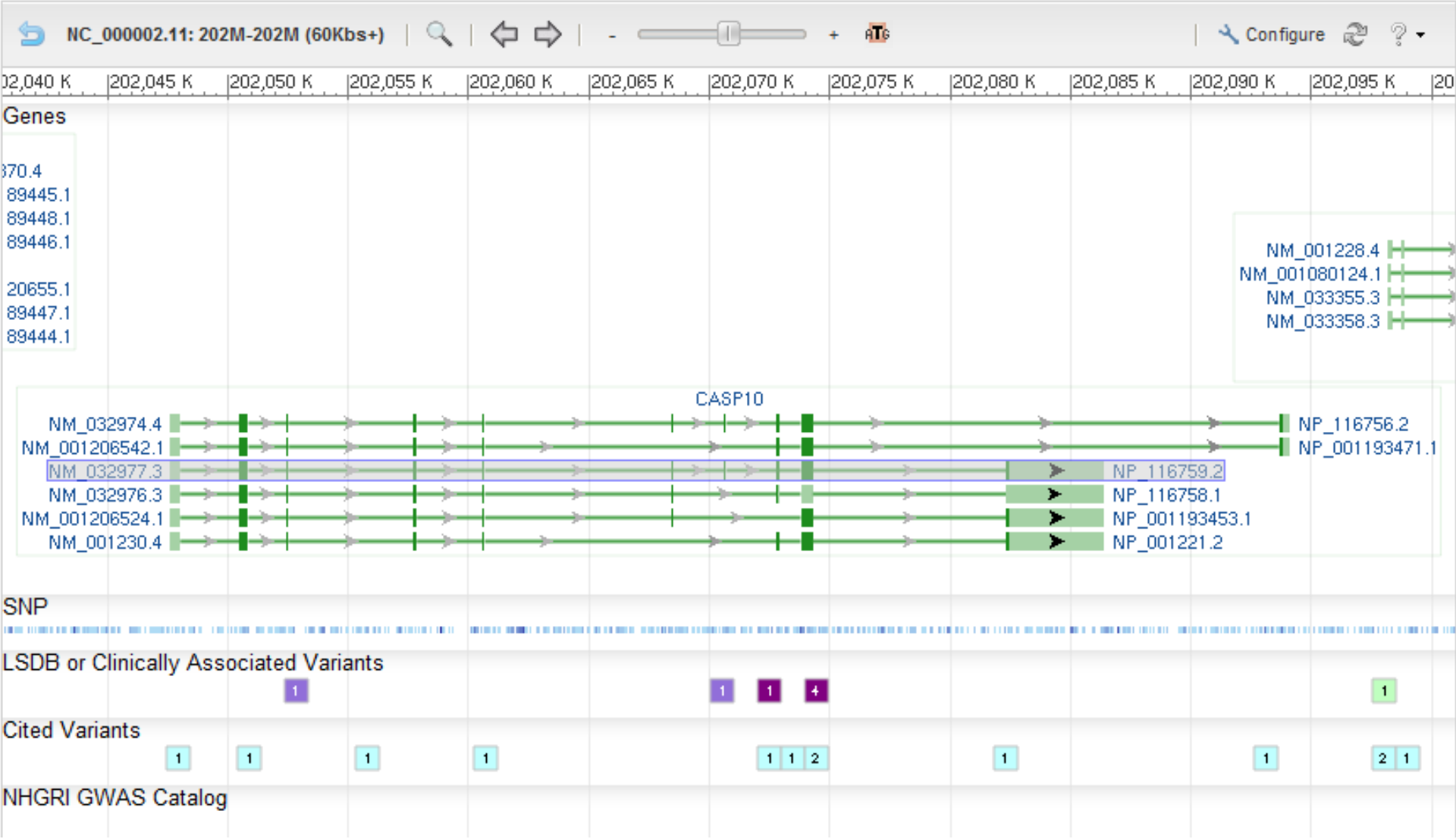
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NP_116759.2
NP_116758.1
NP_001193453.1
NP_001221.2
SNP
LSDB or Clinically Associated Variants
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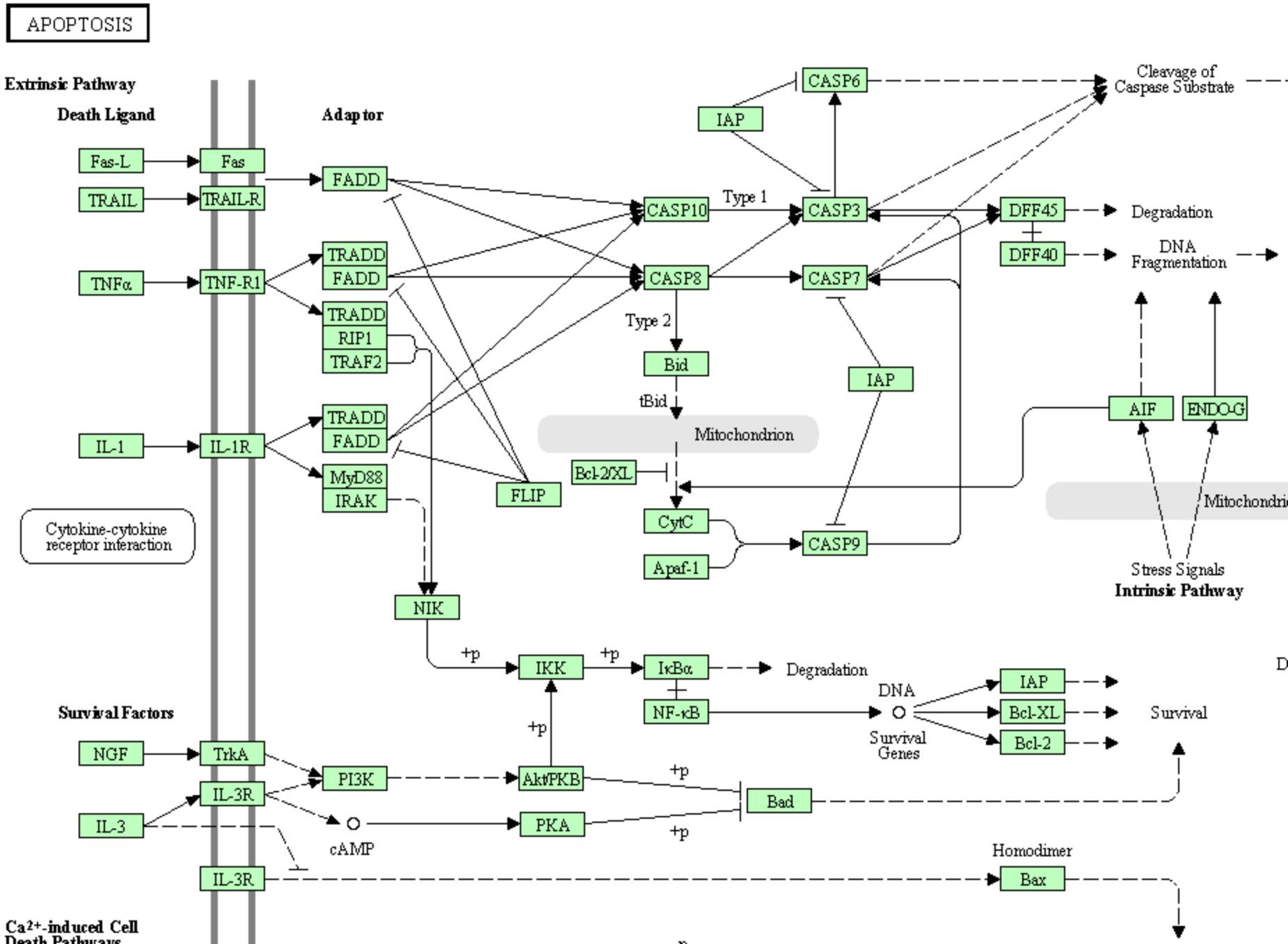
CASP10 caspase 10, apoptosis-related cysteine peptidase [*Homo sapiens*]

Gene ID: 843, updated on 8-Jan-2012

Summary

Official Symbol	CASP10 provided by HGNC
Official Full Name	caspase 10, apoptosis-related cysteine peptidase provided by HGNC
Primary source	HGNC:1500
See related	Ensembl:ENSG00000003400; HPRD:03458; MIM:601762; Vega:OTTHUMG00000132818
Gene type	protein coding
RefSeq status	REVIEWED
Organism	Homo sapiens
Lineage	Eukaryota; Metazoa; Chordata; Craniata; Vertebrata; Euteleostomi; Mammalia; Eutheria; Euarchontoglires; Primates; Haplorrhini; Catarrhini; Hominidae; Homo
Also known as	MCH4; ALPS2; FLICE2
Summary	This gene encodes a protein which is a member of the cysteine-aspartic acid protease (caspase) family. Sequential activation of caspases plays a central role in the execution-phase of cell apoptosis. Caspases exist as inactive proenzymes which undergo proteolytic processing at conserved aspartic residues to produce two subunits, large and small, that dimerize to form the active enzyme. This protein cleaves and activates caspases 3 and 7, and the protein itself is processed by caspase 8. Mutations in this gene are associated with type IIA autoimmune lymphoproliferative syndrome, non-Hodgkin lymphoma and gastric cancer. Alternatively spliced transcript variants encoding different isoforms have been described for this gene. [provided by RefSeq, Apr 2011]


APOPTOSIS
Extrinsic Pathway
Death Ligand
Adaptor
Fas-L
Fas
TRAIL
TRAIL-R
TNFα
TNF-R1
IL-1
IL-1R
Cytokine-cytokine receptor interaction
FADD
TRADD
FADD
TRADD
RIP1
TRAF2
TRADD
FADD
MyD88
IRAK
FLIP
NIK
IAP
CASP6
Cleavage of Caspase Substrate
CASP10
Type 1
CASP3
DFF45
Degradation
DFF40
DNA Fragmentation
CASP8
CASP7
Type 2
Bid
tBid
IAP
Mitochondrion
Bcl-2/XL
CytC
Apaf-1
CASP9
AIF
ENDO-G
Mitochondri
Stress Signals
Intrinsic Pathway
+p
IKK
+p
IκBα
Degradation
NF-κB
DNA
Survival Genes
IAP
Bcl-XL
Bcl-2
Survival
Survival Factors
NGF
TrkA
IL-3
IL-3R
PI3K
Akt/PKB
+p
Bad
PKA
+p
cAMP
IL-3R
Homodimer
Bax
Ca2+-induced Cell Death Pathways

```
# This data file generated by 23andMe at: Thu Feb  2 09:45:37 2012
#
# Below is a text version of your data. Fields are TAB-separated
# Each line corresponds to a single SNP.  For each SNP, we provide its identifier
# (an rsid or an internal id), its location on the reference human genome, and the
# genotype call oriented with respect to the plus strand on the human reference
# sequence.     We are using reference human assembly build 36.  Note that it is possible
# that data downloaded at different times may be different due to ongoing improvements
# in our ability to call genotypes. More information about these changes can be found at:
# https://www.23andme.com/you/download/revisions/
#
# More information on reference human assembly build 36:
# http://www.ncbi.nlm.nih.gov/projects/mapview/map_search.cgi?taxid=9606&build=36
#
# rsid  chromosome      position        genotype
rs4477212       1       72017   AA
rs3094315       1       742429  AA
rs3131972       1       742584  GG
rs12124819      1       766409  AA
rs11240777      1       788822  GG
rs6681049       1       789870  CC
rs4970383       1       828418  AC
rs4475691       1       836671  CT
rs7537756       1       844113  AG
rs13302982      1       851671  GG
rs1110052       1       863421  GT
rs2272756       1       871896  AG
rs3748597       1       878522  CC
rs13303106      1       881808  AG
rs28415373      1       883844  CC
rs13303010      1       884436  AA
rs6696281       1       892967  CC
rs28391282      1       894028  GG
rs2340592       1       900798  GG
rs13303118      1       908247  TT
rs6665000       1       914761  AA
rs2341362       1       917172  CC
rs9777703       1       918699  TT
rs1891910       1       922320  GG
rs9697457       1       924208  GG
rs35940137      1       930066  GG
rs3128117       1       934427  TT
rs2465126       1       936897  AA
rs2341365       1       938555  AA
rs15842 1       938784  CC
rs6657048       1       947503  CC
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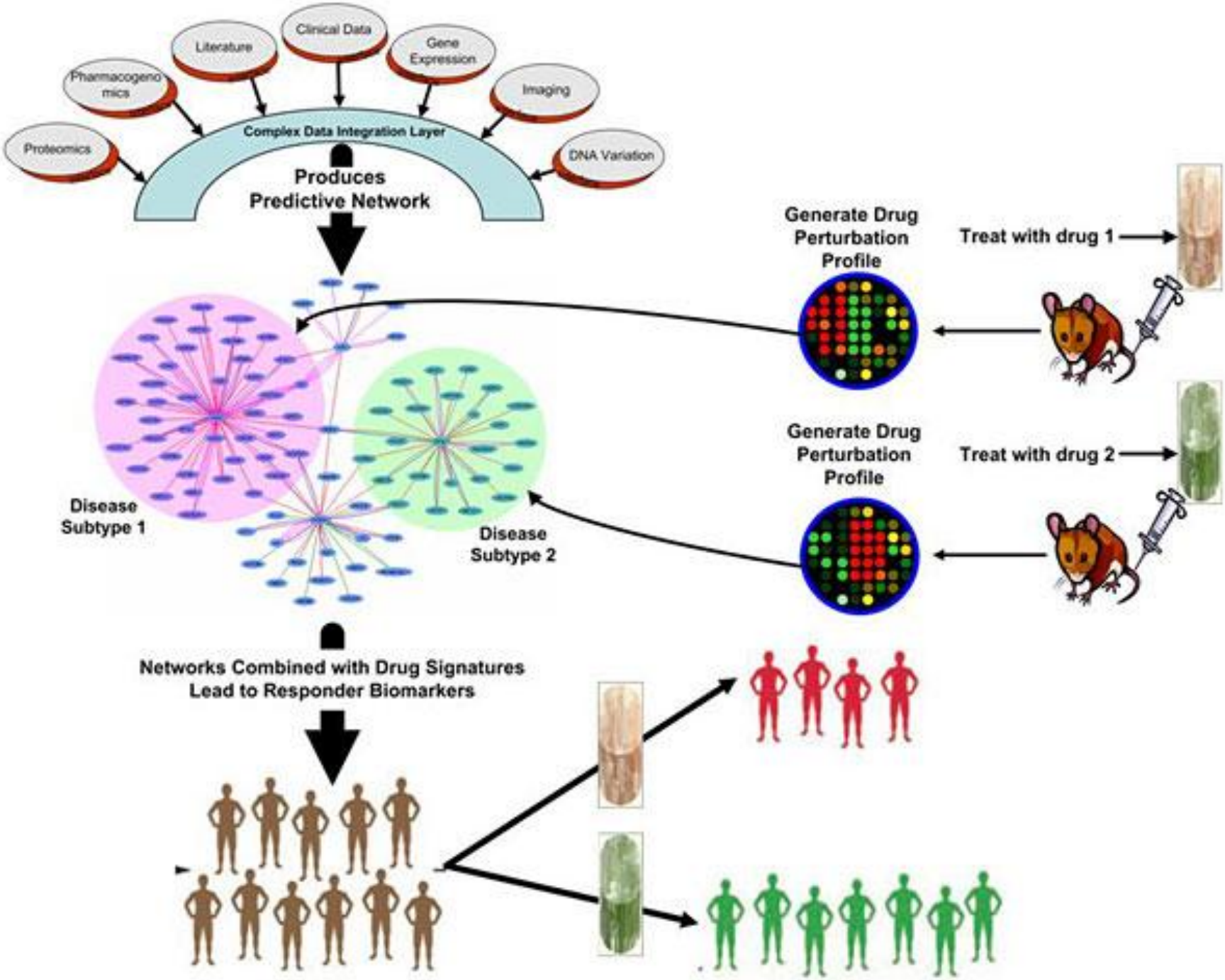
how do we ensure our data gets turned into knowledge?


Literature
Clinical Data
Gene Expression
Pharmacogenomics
Imaging
Proteomics
DNA Variation
Complex Data Integration Layer
Produces Predictive Network
Generate Drug Perturbation Profile
Treat with drug 1
Generate Drug Perturbation Profile
Treat with drug 2
Disease Subtype 1
Disease Subtype 2
Networks Combined with Drug Signatures Lead to Responder Biomarkers

3. the infrastructure is just emerging.

4 reasons patients aren't managing their care

12

Febru

"technology doesn't support patient engagement"

It's
Bu
re

Stev

outlines four reasons why patients aren't managing their healthcare.

1. Patient engagement theories haven't been proven. According to Krupa, being able to engage patients is a largely unproven theory. "And the second piece [is that] health plans will be able to reduce their costs and improve the usability of care that's out there," he said. "Generally, this idea has been proven difficult because, what we've found through research is, a majority of patients don't have interest in being engaged." Instead, Krupa continued,

CEOs in 2012

- 5 steps to consider for making the most of telehealth
- 6 points to note about the updated IRS healthcare reporting

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Washington Partner Program
Public - Private Partnerships
Supporters
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Enter a Synapse Id... G

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Adve Sea

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- Learn new Tools and run powerful analysis in the cloud
- Explore cutting edge Network Models
- Find People to collaborate with
- Start new research Projects, with anyone working anywhere

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Development Update

Synapse is currently in Alpha development. This prototype has been developed to demonstrate our vision for the technology and solicit feedback from the community. The ability to create accounts and download Sage-hosted data is operational now. Some of the other functionality of the site is still under development.

Call for ALPHA USERS

Are you interested in working with Sage to start a pilot project on Synapse? Please let us know at synapseinfo@sagebase.org

Example of an EXPERIENCE IN SYNAPSE:

75 x 75 | 75 x 75 | 75 x 75 | 75 x 75 | 75 x 75 | 75 x 75 | 75 x 75

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Featured PROJECT

The Federation Aging project is exploring th large effect of age on human gene express by exploring a set of genes whose express levels are tightly associated with age.

» Learn more...

Top Synapse CONTRIBUTOR

Charles Sawyers et al, MSKCC
DNA copy number, mRNA expression profiles, candidate gene resequencing, and clinical traits from 218 prostate tumors.

Amanda Myers, University of Miami
Genotypes, mRNA expression profiles, and clini traits from 176 Alzheimer disease and 188 non-diseased brain samples.

Beatriz Carvalho & Gerrit Meijer, VUMC
DNA copy number, mRNA expression, and tumo traits from 36 colorectal adenocarcinoma and 33 adenoma tumors.

» See all contributors...

Synapse NEWS

12-Apr-2011: A new analysis method for normalizing data was published by Brig Mecham. » Learn more...

08-Apr-2011: Eric Schadt and colleagues have published an a on a new model for diabetes. » Learn more...

CONSENT TO RESEARCH

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COMMON GENOMIC RESEARCH
FREQUENTLY ASKED QUESTIONS
GLOSSARY OF TERMS
CONTACT US

Standard legal and technical systems for common genomic research and public genomic research.

Use the red arrows at the top of the panes to navigate.

VID

Post-launch chat on Consent to Research with John Wilbanks and Stephen Friend.

2 months ago | 0 notes

TXT

ALPHA TESTING

We're opening up for
on why we're here at

Systematic clinical
medicine. Despite al
learn about biology
lines, or molecular
treatment has to be
This is inherently r
that somebody (or re
Informed consent doc
patients understood
before entering a cl
what the particular
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protection to patient

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Browser Window

Freedoms you are granting

- ✔ Right to do research with your data
- ✔ Right to redistribute your data
- ✔ Right to publish results of research from your data
- ✔ Right to commercialize products derived from research on your data

my wish list

- Remove uncertainty, create incentives, training
- Safe harbor for IRB-approved experimentation with new models for consent (i.e. portable, fully identified, etc)
- Clear guidelines that harm lies in the act of reidentification, not act of distributing data with risk of reidentification (as long as done under safe harbor with consent)
- Matching grants for infrastructure (inarguable role for government)