

Dreaming of Tenure and IPO's While patient's suffer

October 9th 2013- ZURICH

Stephen H Friend MD PhD
President
Sage Bionetworks
Seattle WA (Non-Profit)



Luis von Ahn

Luis von Ahn



CApTCHa
[captcha]

"Completely Automated Public Turing test to tell Computers and Humans Apart"

THE PLATFORM

You are Here: [Home](#) / The Platform

The Ushahidi Platform was built for information collection, visualization and interactive mapping. Below are some of the countries and projects that are using it:



The image is a composite of three parts. On the left is a portrait of a man with short brown hair and red-rimmed glasses, wearing a brown sweater. The central part is a world map with numerous red location pins, each featuring a white circular icon with a network of lines. The map is labeled with 'North America', 'Atlantic Ocean', 'Europe', 'South America', 'Indian Ocean', and 'Australia'. On the right is a detailed satellite map of Sendai, Japan, with a white callout box. The callout box has the title 'Emergency Supplies' and contains the following text: 'The Japan Emergency Team asking for the following items: g... cans, bottled water, electric water pots, powdered milk, rice, in... canned food tents, sleeping bags Send all items to: The Japar Emergency Team, 3-3-7 Kokubun-cho Aoba-ku Sendai, Miyag... 980-8671 For information, call 0570-000-911 or 090- 7170-471 Telephone connection is not regular at this time.' Below the text is a blue link labeled 'Help Out!'. In the bottom right corner of the map area, there is a blue link labeled 'Terms'.

How does that possibly work?

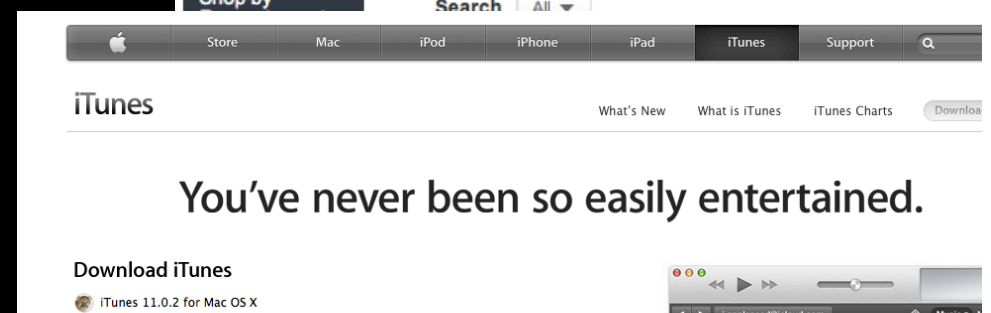
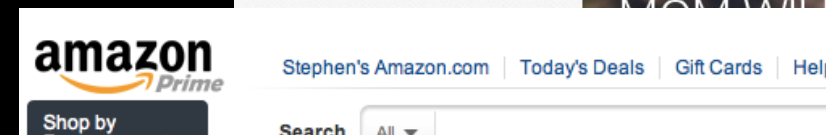
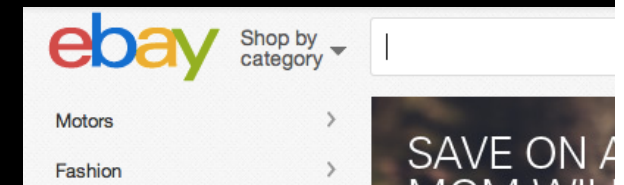
Why not engage in understanding of diseases?



Twentieth Century
Digital Media/internet

Helped people consume

A trillion hours/year
of participatory value
up for grabs





Twenty-First Century
Digital Media/internet

Helping people participate



COGNITIVE SURPLUS

A trillion hours/year
of participatory value
up for grabs

(Clay Shirky)

**ANCIENT
GENEROUSITY**



**MODERN
DIGITAL
TOOLS**



**COGNITIVE
SURPLUS**

A trillion hours/year
Of participatory value
Up for grabs

Twenty-First Century
Digital Media/internet

Helping people participate

(Clay Shirky)

So why can't we engage that power
to help gain better understanding of
health and disease?

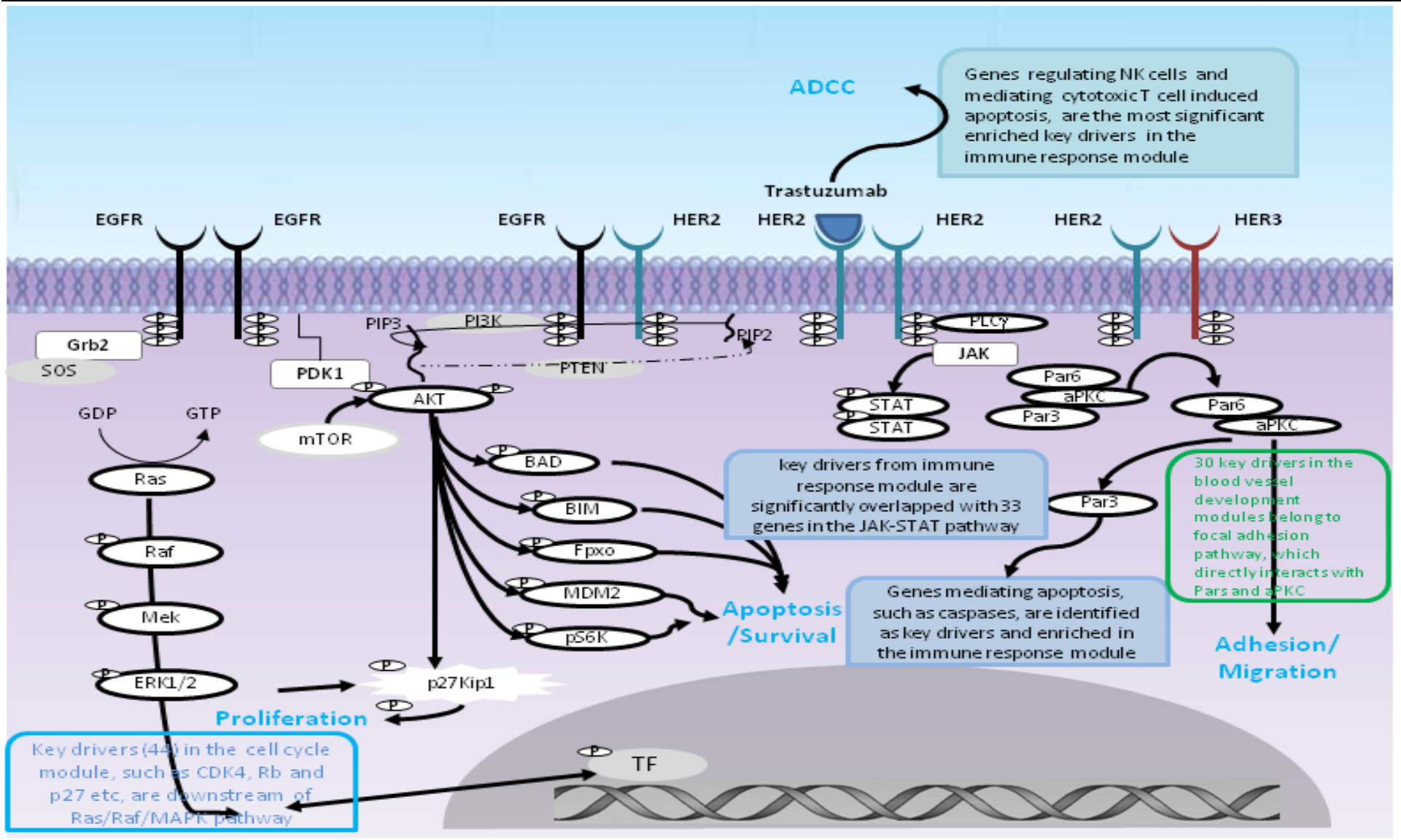
Well maybe there is no need sensed



Human Genome Project



Reality: Overlapping Pathways

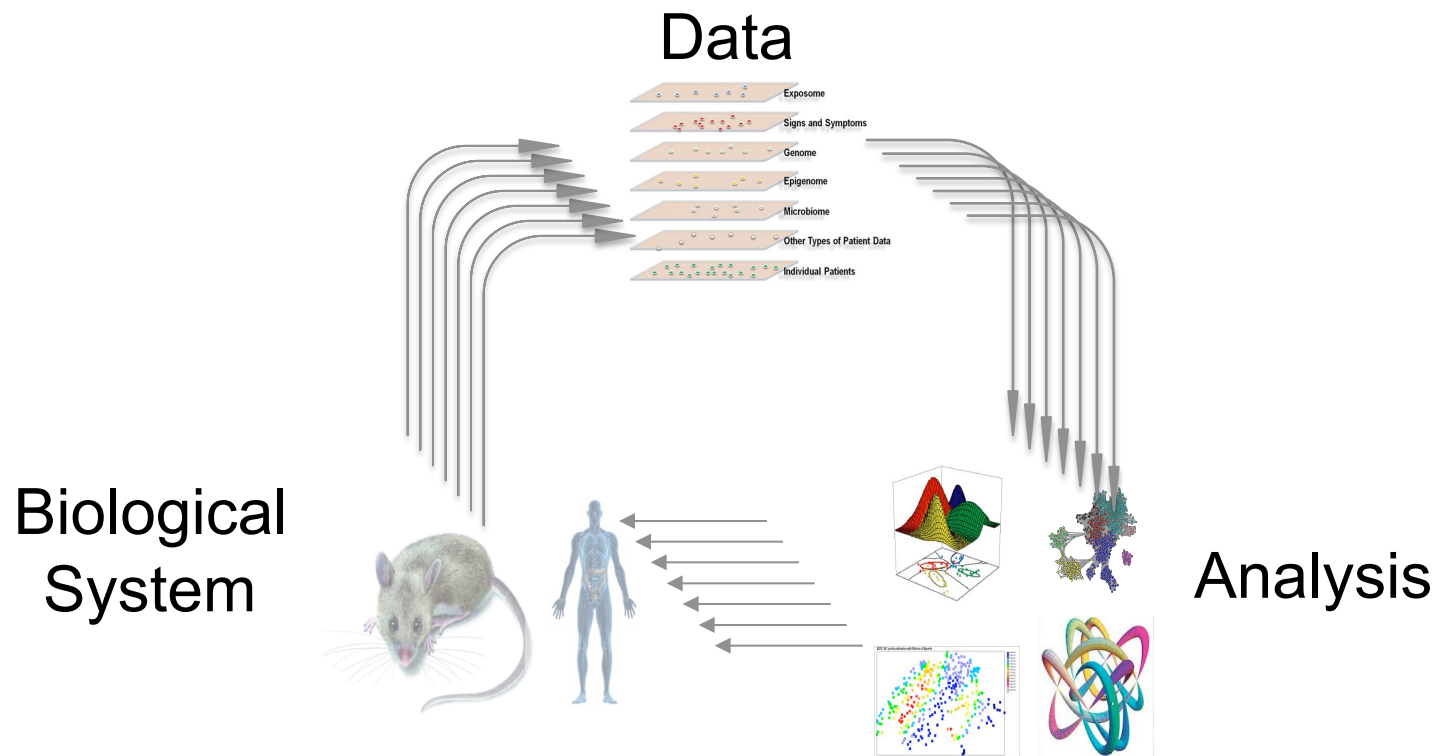




Maybe the system is well set up so no need

Existing Iterative Approaches To Generating Analyzing and Supporting New Models

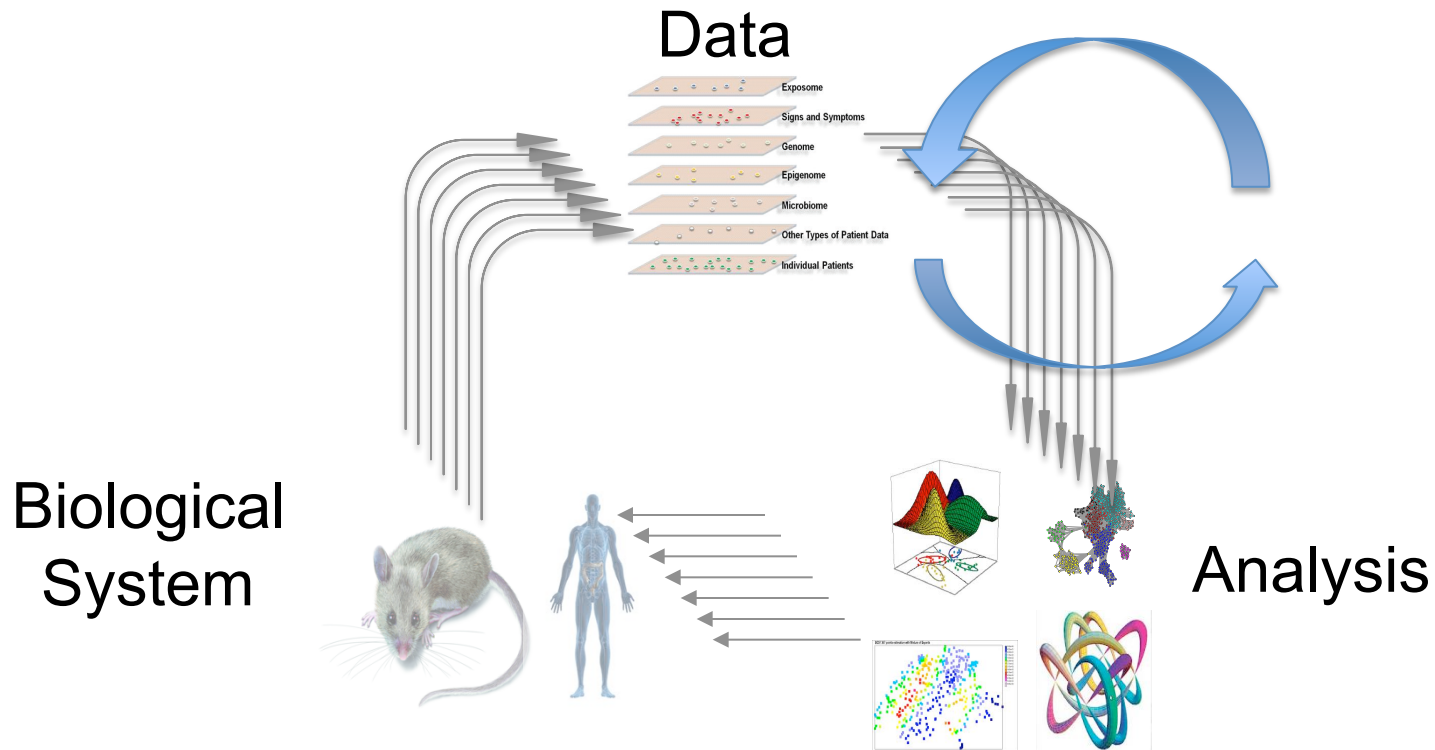
“HYPOTHESIS DRIVEN DATA ANALYSIS”



The automatic linkage between the data generators, analyzers, and validators from the time of hypothesis driven medical research

Beyond Iterative Approaches Generating Analyzing and Supporting New Models

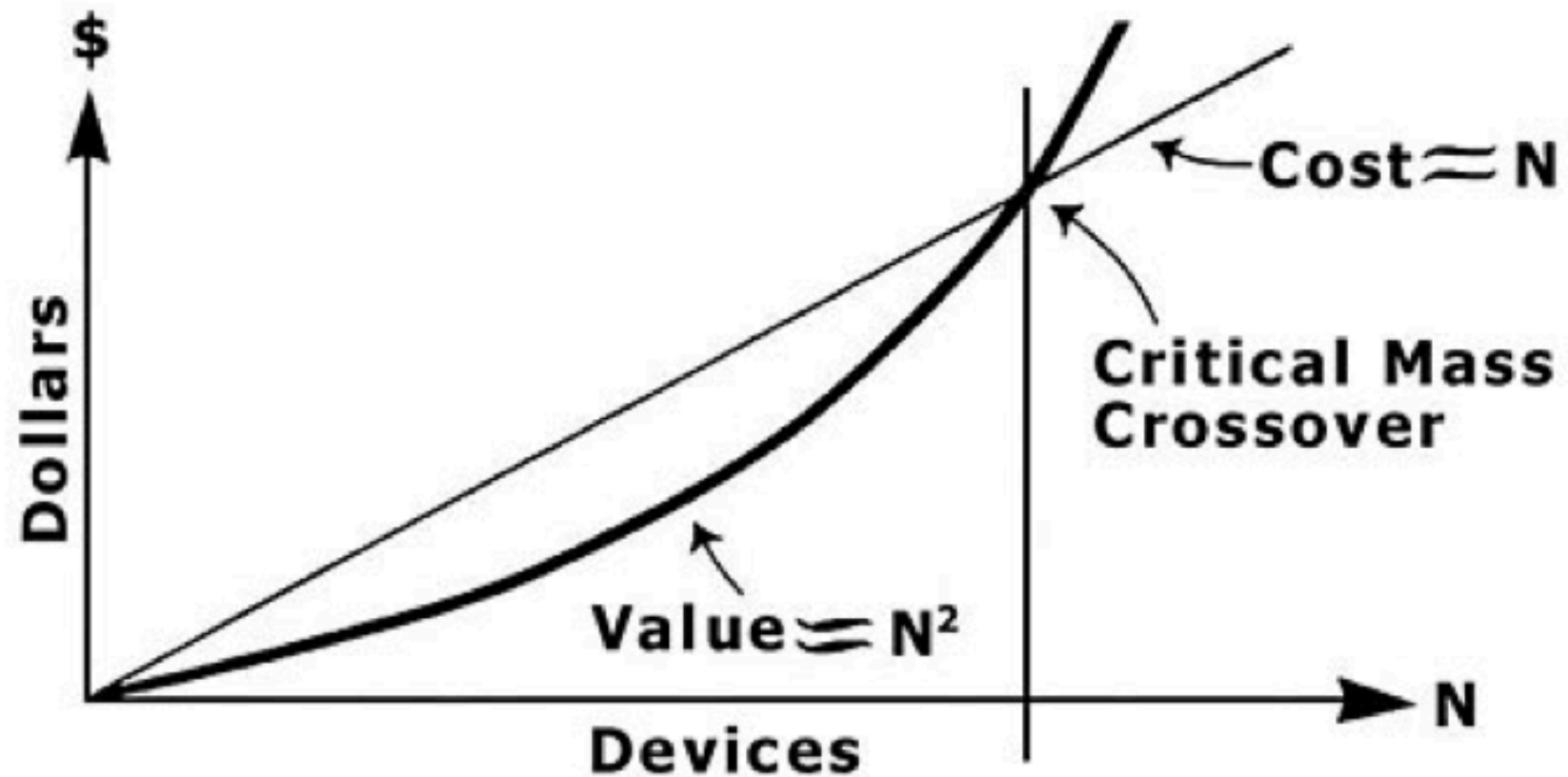
“DATA DRIVEN DATA ANALYSIS”



Potential benefit of uncoupling the automatic linkage between the data generators, analyzers, and validators

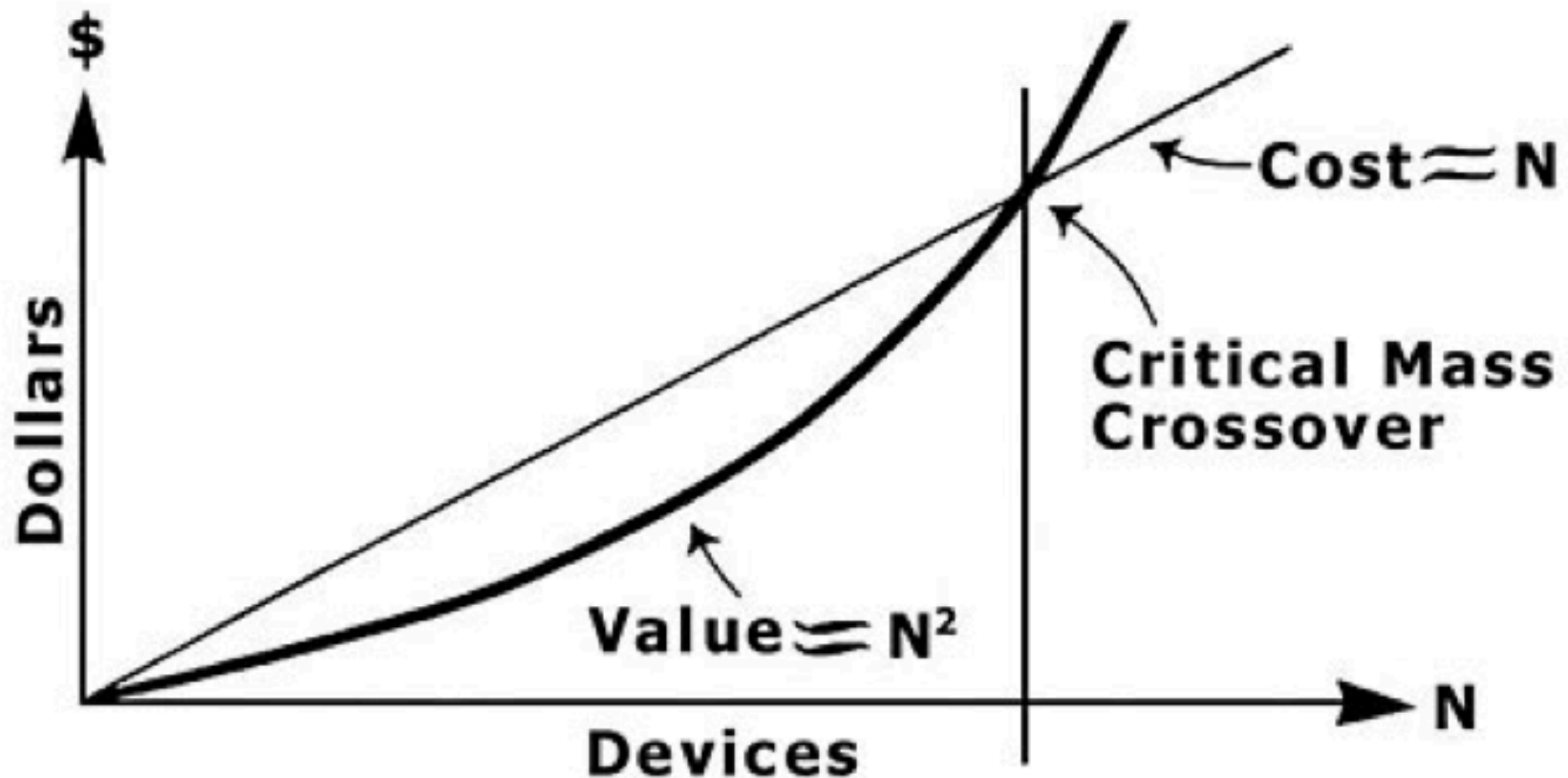
Metcalfe's Law

The Systemic Value of Compatibly Communicating Devices Grows as the Square of Their Number:



Remarkably stalled in Biomedicine where
“communication devices” are primarily articles

**The Systemic Value of Compatibly
Communicating Devices Grows as the
Square of Their Number:**



Unleash cognitive surplus

COMMENTARY

Metcalfe's law and the biology information commons

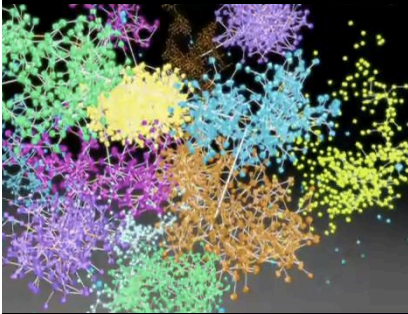
Stephen H Friend & Thea C Norman

Open collaboration on biomedical discoveries requires a fundamental shift in the traditional roles and rewards for both investigators and participants in research.

“Following the light of the sun, we left the Old World.” –*Christopher Columbus*

doctor's diagnosis is based on abnormal threshold measurements, such as broken bones or hemoglobin A1C scores, and provided with-

implicate targets and biochemical pathways. Not surprisingly, drug development statistics confirm what we might expect from such a



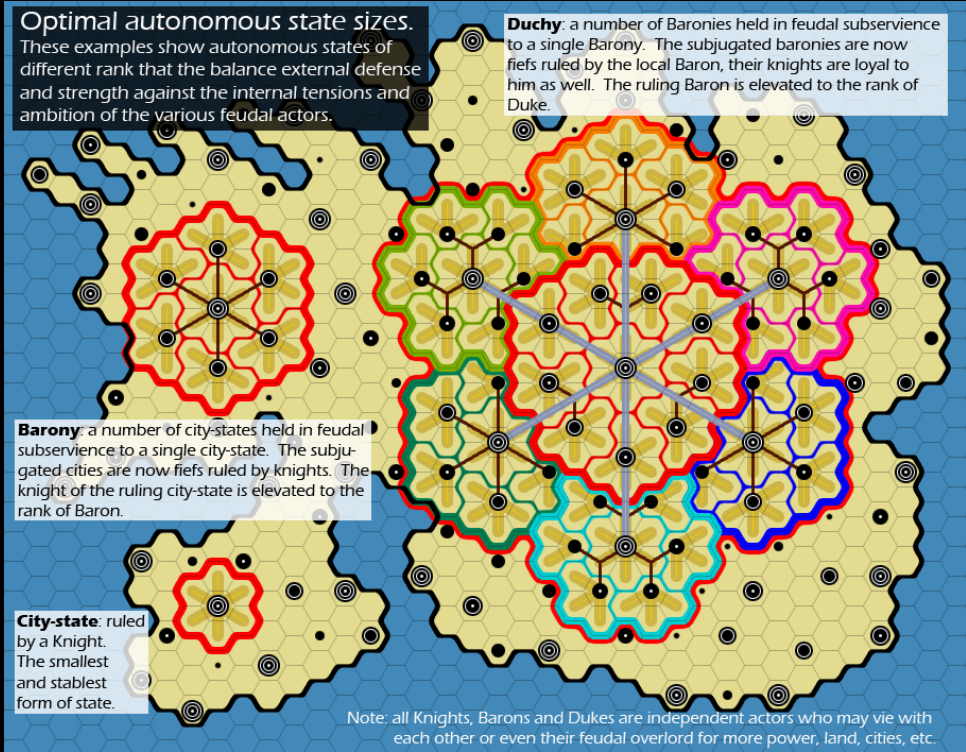
STATE OF THE TECHNOLOGY

STATE OF THE INSTITUTIONS

DISCONTINUITY

TENURE

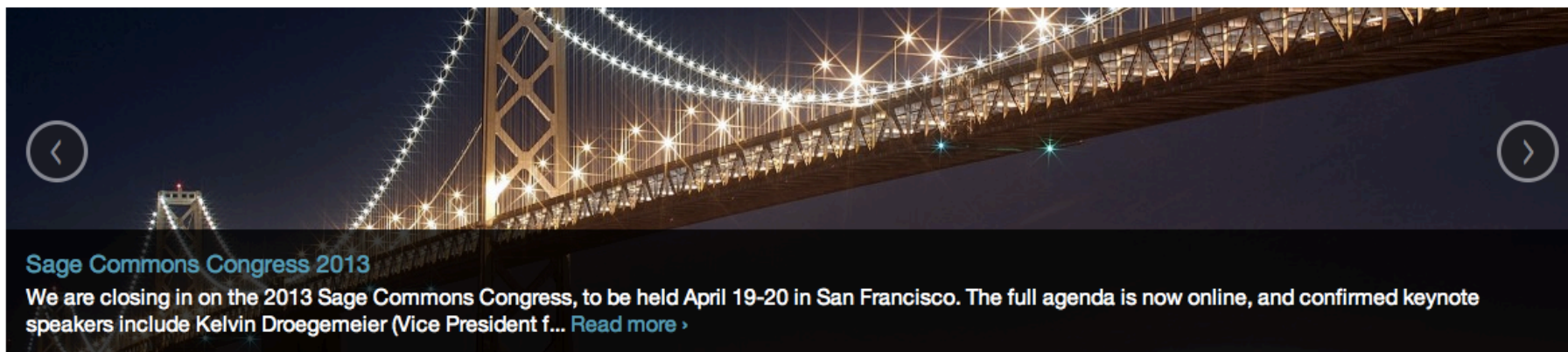
FEUDAL STATES





We focus on a world where **biomedical research** is about to fundamentally change. We think it will be often conducted in an **open, collaborative** way where **teams of teams** far beyond the **current guilds of experts** will contribute to making better, faster, relevant discoveries

Redefining. Challenging. Predicting.



Sage Commons Congress 2013

We are closing in on the 2013 Sage Commons Congress, to be held April 19-20 in San Francisco. The full agenda is now online, and confirmed keynote speakers include Kelvin Droegemeier (Vice President f... [Read more >](#)

Philosophy

Ph

About us

Us

Platforms and Services

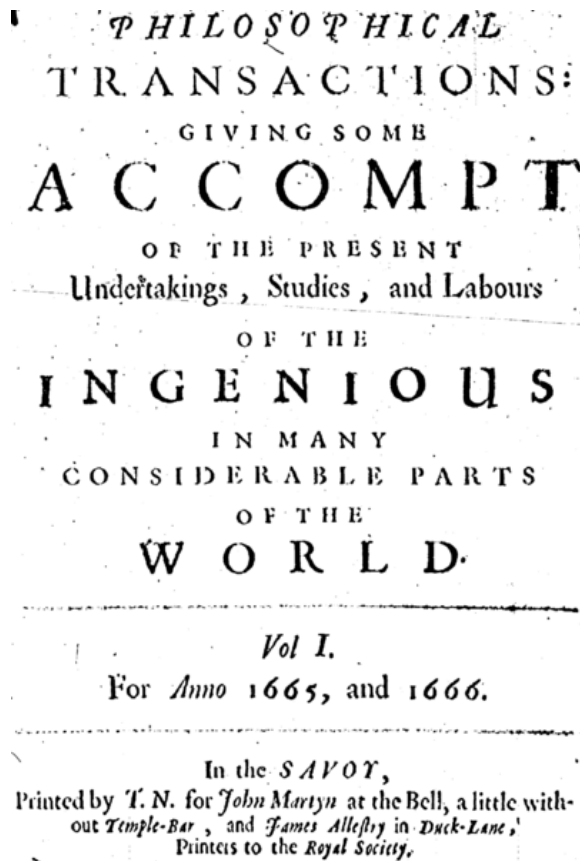
Ps

Research

Re

TECHNOLOGY PLATFORM

two approaches to building common scientific knowledge



Text summary of the completed project
Assembled after the fact

The screenshot shows the GitHub homepage. At the top, it says 'github' with navigation links for 'Signup and Pricing', 'Explore GitHub', 'Features', 'Blog', and 'Login'. A large blue banner states '1,426,936 people hosting over 2,374,350 repositories'. Below this is a search bar with 'jQuery, reddit, Sparkle, curl, Ruby on Rails, node.js, ClickToFlash, Erlang/OTP, CakePHP, Redis, and many more' and a 'Find any repository' button. A row of logos for 'facebook', 'twitter', 'Microsoft', 'vmware', 'redhat', 'LinkedIn', and 'mozilla' is displayed. Two main sections describe 'git' and 'git·hub'. A blue button for 'Plans, Pricing and Signup' is prominent. At the bottom, there are four columns of features: 'Team management', 'Code review', 'Reliable code hosting', and 'Open source collaboration', each with a brief description and a 'More about' link.

Every code change versioned
Every issue tracked
Every project the starting point for new work
All evolving and accessible in real time
Social Coding

Synapse is GitHub for Biomedical Data

The screenshot shows the Synapse website homepage. At the top, there is a navigation bar with the Synapse logo, the tagline "CONTRIBUTE to the CURE", and buttons for "REGISTER" and "LOGIN". Below the navigation bar, there is a "Welcome to SYNAPSE" section with a sub-header "Synapse is a collaborative compute space that allows scientists to share and analyze data together." The main content area is divided into three columns: "Introduction to Synapse" with a video player, "Top Features" with a list of key capabilities, and "We're in Beta" with a note about the current development stage. Below this is a "Search the Commons" section with a search bar and filters. At the bottom, there are sections for "Projects in the Spotlight" and "Top Synapse Contributors" with profile cards for several users.

The screenshot shows the GitHub website homepage. At the top, there is a navigation bar with the GitHub logo and links for "Signup and Pricing", "Explore GitHub", "Features", "Blog", and "Sign in". Below the navigation bar, there is a large banner with the text "2,218,913 people hosting over 3,842,938 repositories". Below the banner, there is a search bar and a list of logos for various companies and organizations, including Facebook, Microsoft, VMware, Red Hat, LinkedIn, and Mozilla. The main content area is divided into two columns: "git /'git/" and "git·hub /'git,hʌb/". Below this is a "Plans, Pricing and Signup" button with the text "Unlimited public repositories are free!". At the bottom, there is a section for "Free public repositories, collaborator management, issue tracking, wikis, downloads, code review, graphs and much more...".

- Data and code versioned
- Analysis history captured in real time
- Work anywhere, and share the results with anyone
- Social/Interactive Science

- Every code change versioned
- Every issue tracked
- Every project the starting point for new work
- Social/Interactive Coding

What is Synapse?

- ✓ *A **private** or **public** workspace that allows you to **aggregate, describe, and share** your research.*
- ✓ *A tool to improve reproducibility of data intensive science, **recording progress as you work** with tools such as **R and Python**.*
- ✓ *A set of **living research projects** enabling contribution to **large-scale collaborative solutions** to scientific problems.*
- ✓ *[Read more about Synapse](#)*

How to Use Synapse

- **Getting Started Guide**
A quick start guide to using Synapse
- **Synapse User Guide**
Using Synapse via the Web and programmatic clients
- **Support Forums**
Help, frequently asked questions and support topics
- **Contact Us**
Other questions about Synapse?

Get Started

Synapse is free to use as a Beta service.

[Login](#)

[Register for a Synapse Account](#)

[DREAM8 Challenges](#)

GBM.annotated.whitelist.maf (syn1331200)

Sharing: Public

Data use conditions: Open [\(info\)](#) [🚩 flag](#)

Added by: Kyle Elliott on: Sat Sep 15 02:25:52 GMT-400 2012

Modified by: Kyle Elliott on: Thu Nov 01 16:12:30 GMT-400 2012

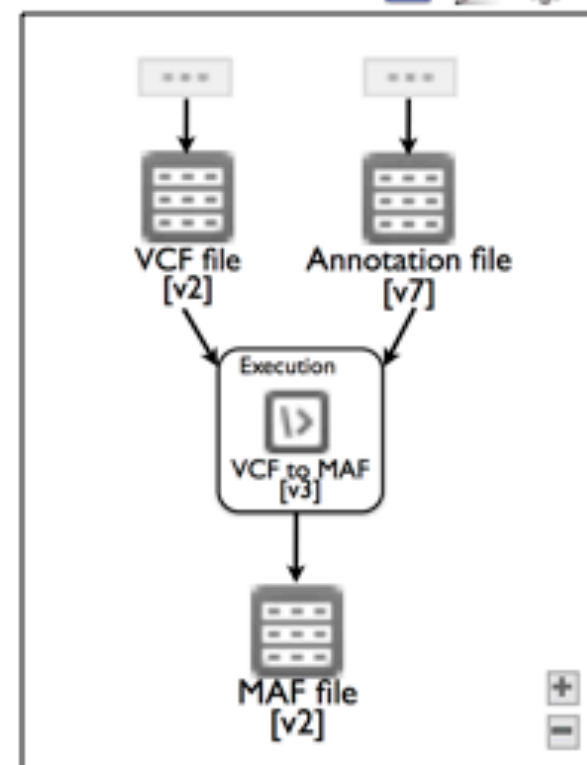
Version: syn2 [\(hide all versions\)](#)

Version	Comment	Modified On	Modified By	
syn2		2012-11-01	Kyle Elliott	viewing
0.0.0		2012-10-21	Kyle Elliott	view

Description

Please add a description by clicking the "Edit" button.

Provenance



Synapse contributions to analyzing Cancers

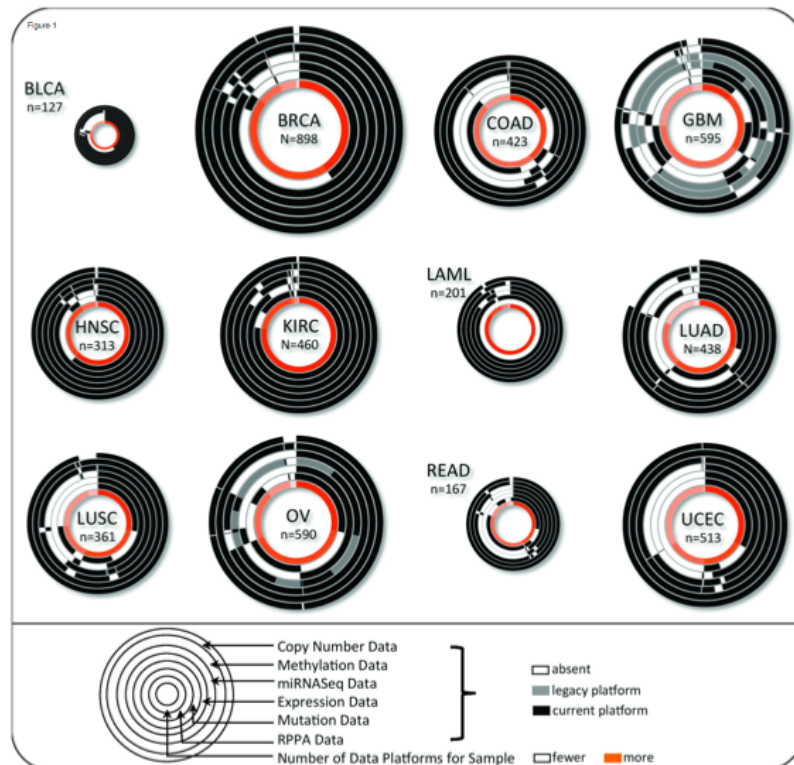


TCGA Pan-Cancer project

- Analysis of: 12 Tumor types, 6 molecular profiling platforms
- Performed by: 150 researchers from 30 institutions.

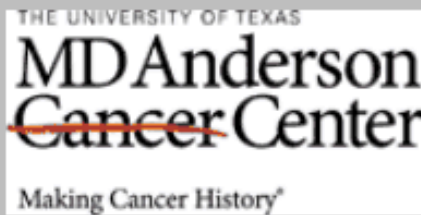


“Synapse is a compute platform for transparent, reproducible, and modular collaborative research.”



Omberg, et al. Enabling collaborative and transparent analysis of 12 tumor types in the cancer genome atlas. S, Nature Genetics (published Oct 2013)

Colorectal Cancer Sub-classification Consortium





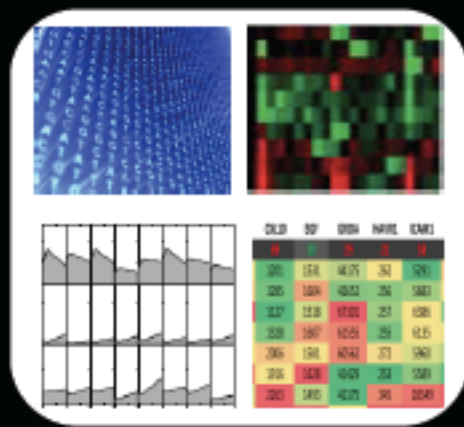
University of Pittsburgh



Disease Models for Neuropsychiatric Disease

Structure of a Challenge

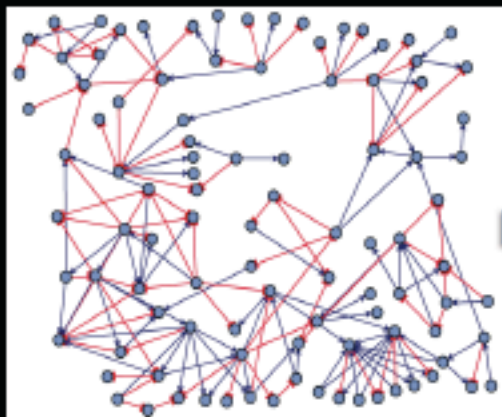
Data



Crowd-sourcing



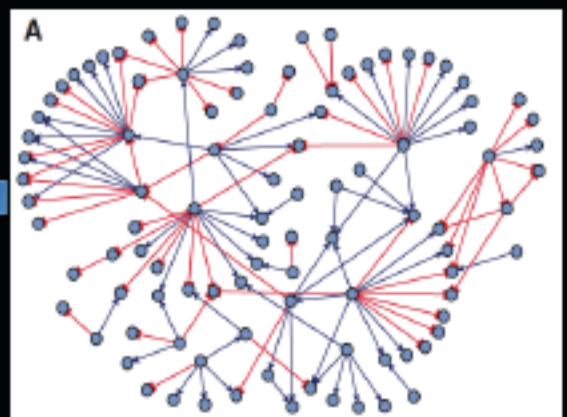
Predictions



Measurements

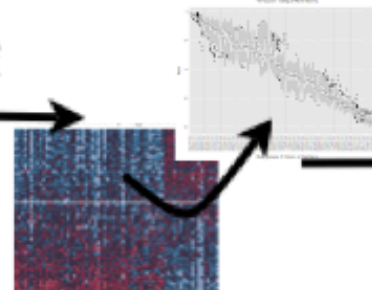
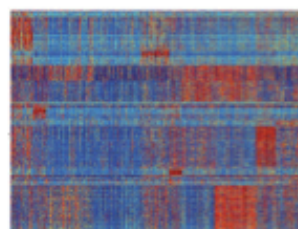
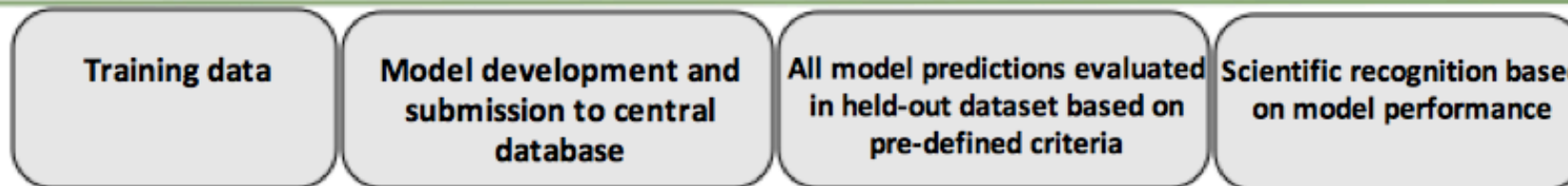


Ground Truth



Unbiased Evaluation
Acceleration of Research
Collaboration

Contributors to the Sage / DREAM breast cancer prognosis challenge



Oslo University Hospital
Rehabiliteringsufstus



Anne-Lise Borresen-Dale
Lars Ottestad
Hans Kristian Moen Volla
Vessela N. Kristensen
Hege G. Russnes
Daehoon Park
Veronica O. Vang
Jorg Tost

Carlos Caldas
Oscar Rueda
Christina Curtis



Samuel Aparicio



Joseph Hellerstein
Tyler Pirtle
Lamia Youseff
Craig Citro



The Sage/DREAM
breast cancer
challenge consortium



Stephen Friend
Adam Margolin
Erich Huang
Thea Norman
Brig Mecham
Ben Sauerwine
In Sock Jang
Michael Kellen
Lara Mangravite
Matthew Furia
Brian Bot
Justin Guinney
Nicole A. Deflaux
Bruce Hoff
Xavier Schildwachter



Gustavo Stolovitzky
Erhan Bilal



Erich Schadt
Gaurav Pandey
Andrea Califano
Mariano Alvarez
Yishai Shimoni
Trey Ideker
Janusz Dutkowsky
Benjamin Logsdon



Kelly LaMarco
Katrina Kelner



Marc Hurlbert



Dinah Singer
Dan Gallahan



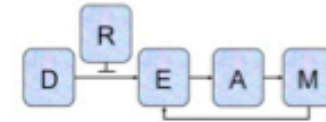
17 APRIL 2013, VOL. 5, #181

COVER STORY | RESEARCH ARTICLE AND REPORT

DREAMING of Biomedicine's Future

An Open Challenge yields fresh insights (Margolin *et al.*), a new prognostic model for breast cancer (Cheng *et al.*), and a modern approach to peer review (Editor's Summary).

All articles free and open access



CROWDSOURCING

Systematic Analysis of Challenge-Driven Improvements in Molecular Prognostic Models for Breast Cancer

Adam A. Margolin,^{1*} Erhan Bilal,^{2†} Erich Huang,^{1,3,4†} Thea C. Norman,¹ Lars Ottestad,⁵ Brigham H. Mecham,^{1,6} Ben Sauerwine,⁷ Michael R. Kellen,¹ Lara M. Mangravite,¹ Matthew D. Furia,^{1,8} Hans Kristian Moen Vollan,^{5,9,10,11} Oscar M. Rueda,¹¹ Justin Guinney,¹ Nicole A. Deflaux,¹ Bruce Hoff,¹ Xavier Schildwacher,¹ Hege G. Russnes,^{9,10,12} Daehoon Park,¹³ Veronica O. Vang,^{9,10} Tyler Pirtle,⁷ Lamia Youseff,⁷ Craig Citro,⁷ Christina Curtis,¹⁴ Vessela N. Kristensen,^{9,10,15} Joseph Hellerstein,⁷ Stephen H. Friend,^{1*} Gustavo Stolovitzky,² Samuel Aparicio,^{16,17,18†} Carlos Caldas,^{11,19,20†} Anne-Lise Borresen-Dale^{9,10†}



RESEARCH ARTICLE

COMPUTATIONAL MODELING

Development of a Prognostic Model for Breast Cancer Survival in an Open Challenge Environment

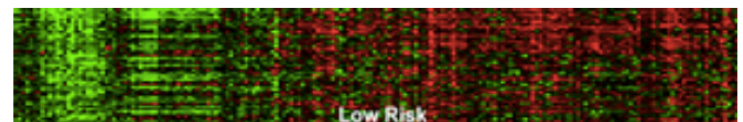
Wei-Yi Cheng, Tai-Hsien Ou Yang, Dimitris Anastassiou*



Breast Cancer: 'Geek Sandbox' Holds Clues to Survival

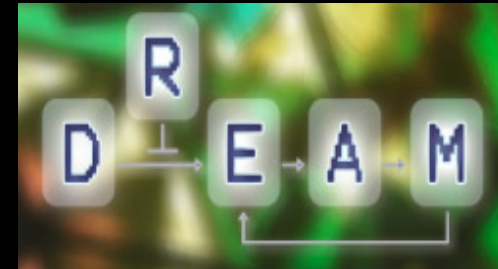
[Download Complimentary Source PDF](#)
By Charlene Laino, Senior Writer, Gupta Guide
Published: April 17, 2013

Sometimes the news is not as important as how the researchers arrived at it.





Feb 2013



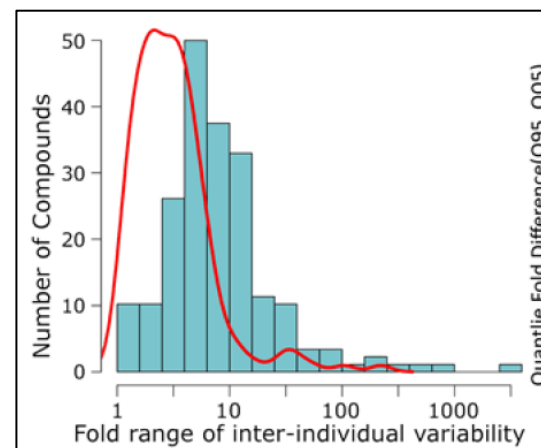
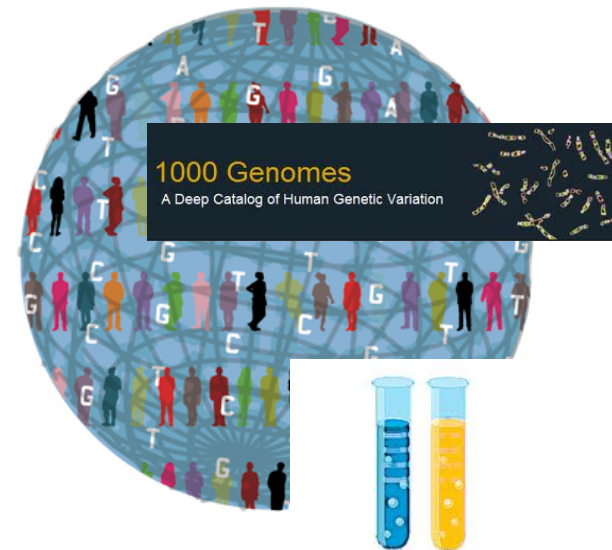
Sage-DREAM
Challenges



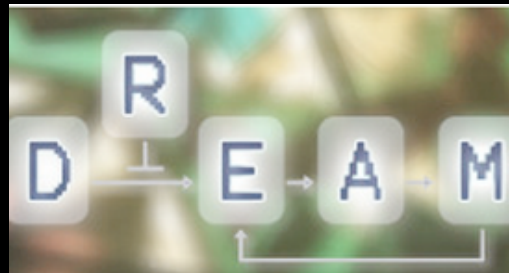
DREAM 8.0
NIEHS/NCATS/UNC DREAM
Toxicogenetics Challenge

NIEHS-NCATS-UNC DREAM Toxicogenetics Challenge

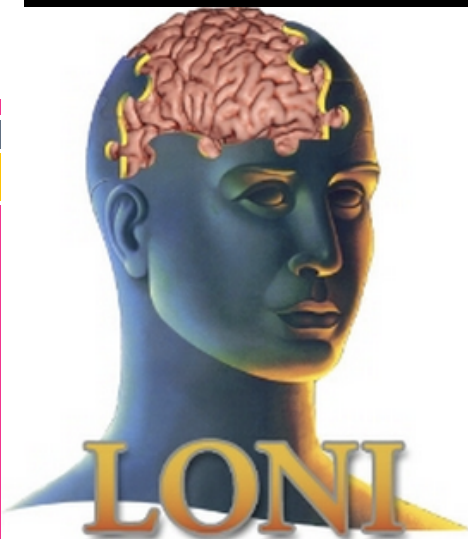
Predict cytotoxic response to environmental compounds across a genetically diverse human population with the goal of Enhancing our capacity to predict what individuals or groups are most sensitive to chemical exposures.



DREAM 8.5



ADNI
ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE



alzheimer's  association™

the compassion to care, the leadership to conquer



Open Source Data – ADNI

Imaging

Clinical

Multiple Cognitive Testing

Whole Genome Sequencing

SAB- Co-Leads

Robert Green (Harvard)

Peter St. George-Hyslop (U Toronto)

Launch Fall 2013

Ending 2014

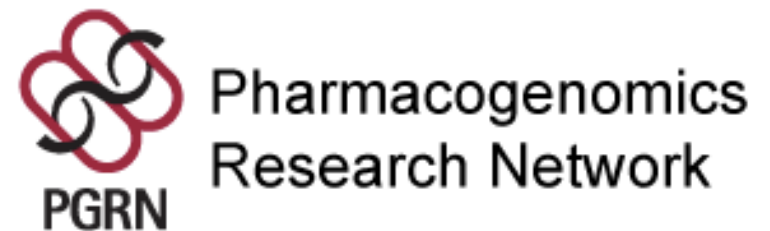
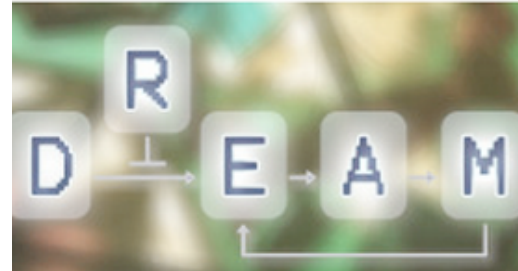
Prime Question: What model best predicts AD cognitive scores recording in ADNI using all Available imaging, genomic, biomarker data including any outside data sets

It is essential that we develop a global framework that unites government and business in a coordinated effort to increase innovation through real-time data sharing so that we may discover a means of treatment and prevention for Alzheimer's and dementia.”

- George Vradenburg CEO Initiative/ Chairman USAgainstAlzheimer's

DREAM 8.5

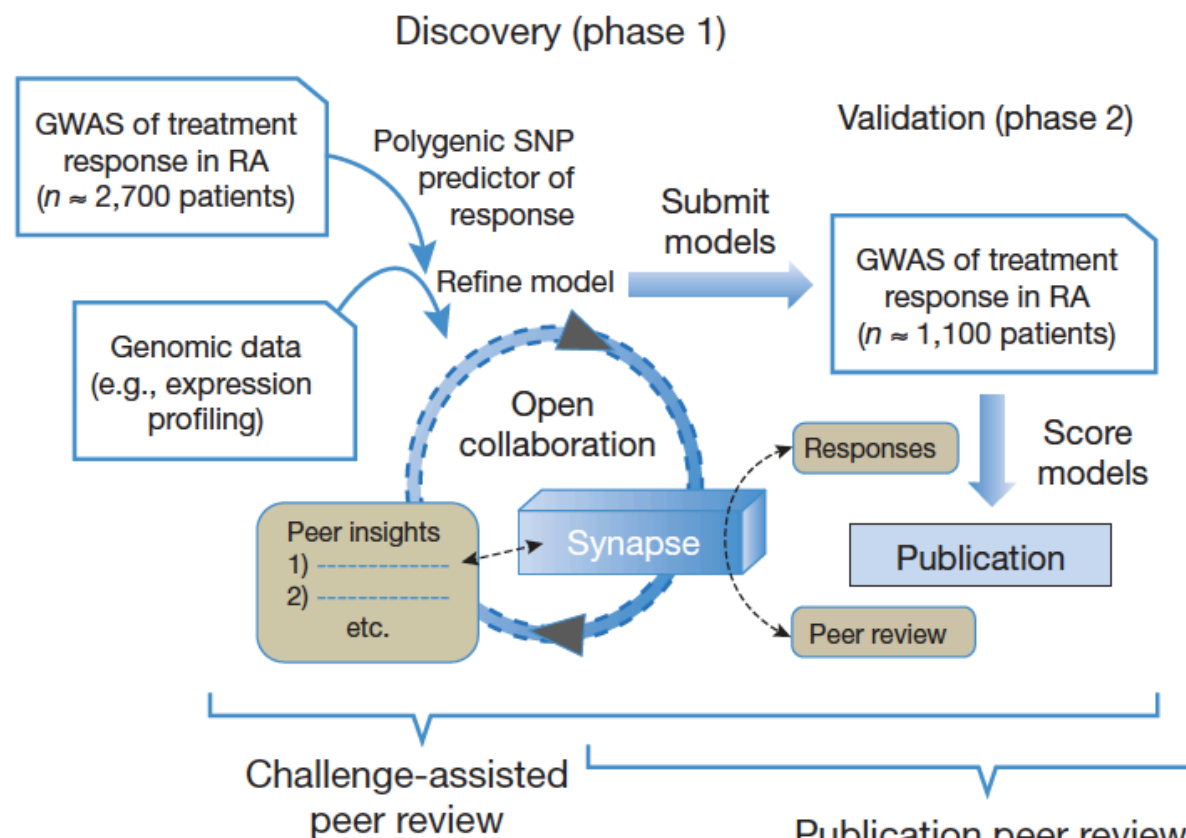
RHEUMATOID ARTHRITIS RESPONDER CHALLENGE



Crowdsourcing genetic prediction of clinical utility in the Rheumatoid Arthritis Responder Challenge

To the Editor:

The ability to translate large-scale genetics and genomics data into biological knowledge has not kept pace with our ability to generate these data sets. As a consequence, a major bottleneck in biomedical research has become access to data within a computational workspace that allows for robust, collaborative analyses. One innovative solution is to bring together scientific data, code, tools and disease models into an open commons or workspace, for example, the Synapse platform of Sage Bionetworks¹. This environment allows for real-time sharing of large genomic data sets, continuous peer review and rapid learning within a system constructed to provide data access in a manner aligned with the informed consent provided by patients and research participants.



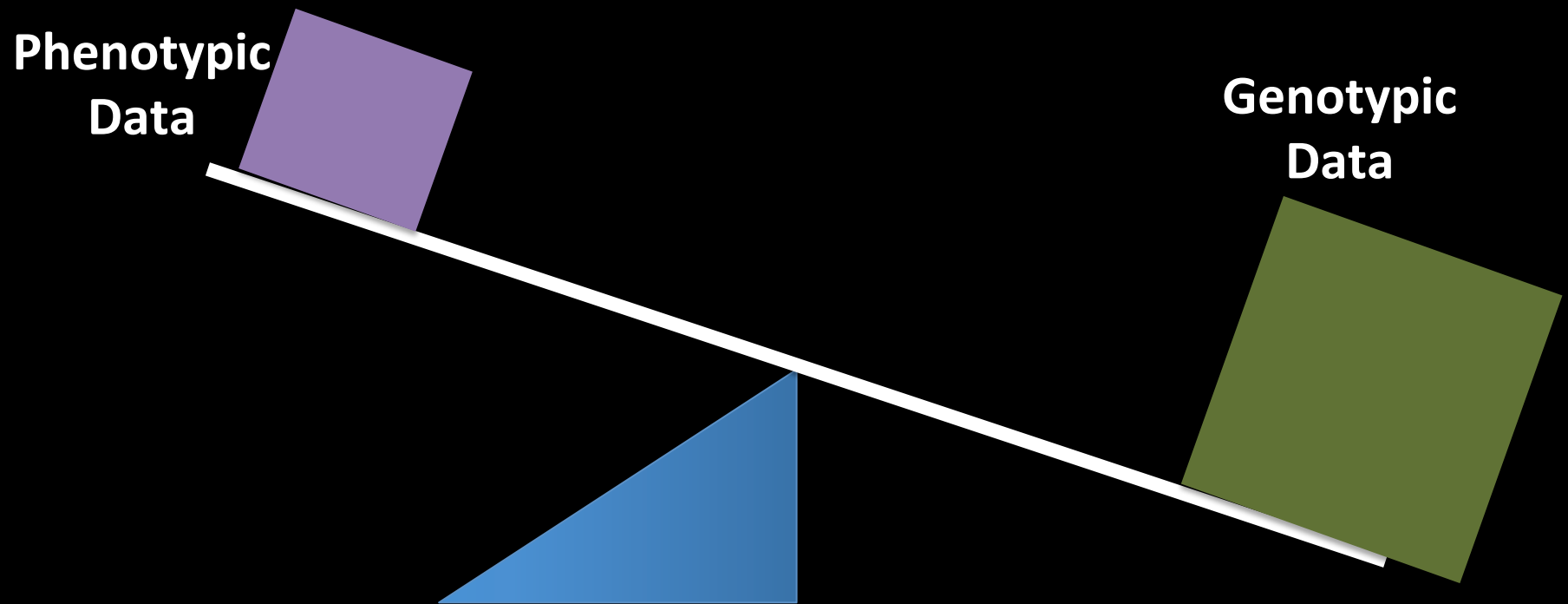
Robert Plenge (Harvard Medical School) Lara Mangravite (Sage Bionetworks)
Gustavo Stolovitszy (DREAM) Thea Norman (Sage Bionetworks)

Jeff Greenberg (CORRONA) Anne Barton (UK, Manchester) Marieke Coenen (Netherlands)
Peter Gregersen (New York) Eli Stahl (Mt. Sinai, New York) Lars Klareskog (Sweden)

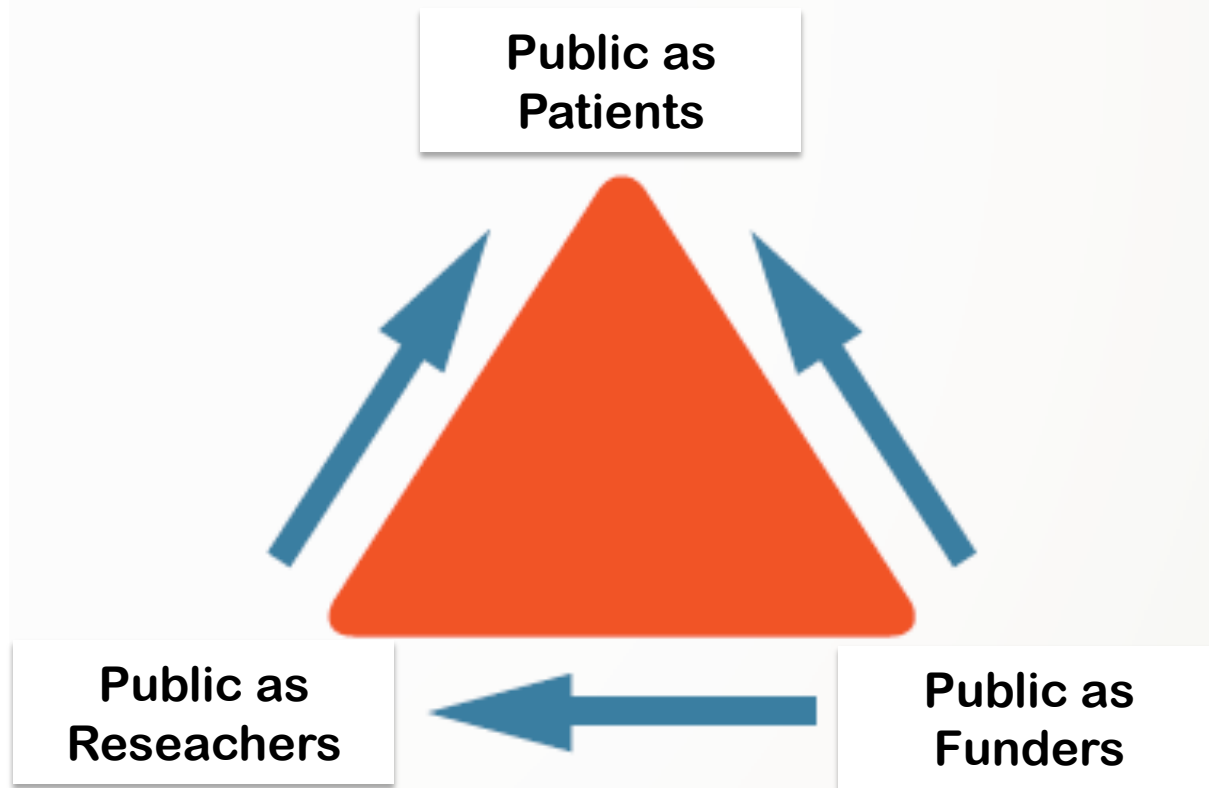
Limited Options As A Citizen



Asymmetry of Data: The public can help with this

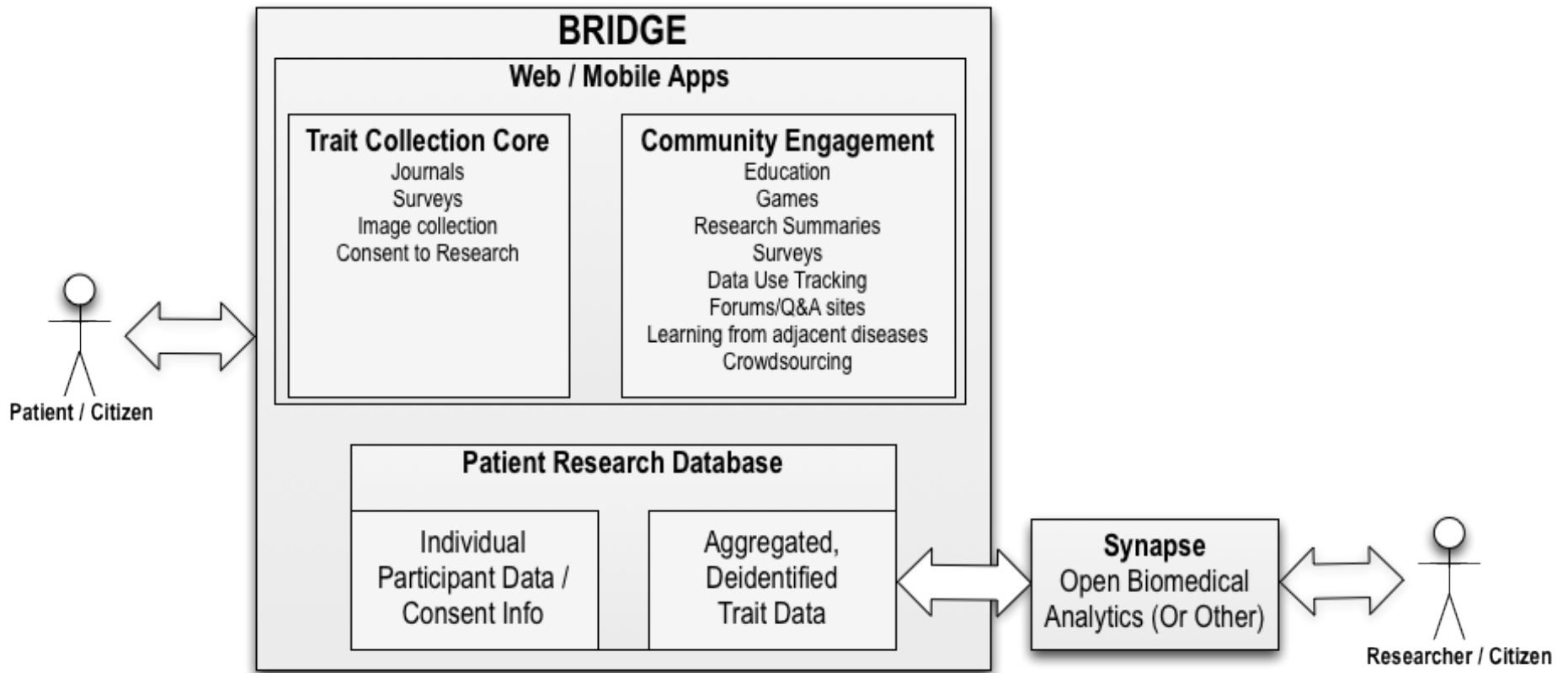


DEMOCRATIZATION OF BIOMEDICAL RESEARCH



BRIDGE

BRIDGE CONCEPTUAL ARCHITECTURE



Diabetes
Breast-Cancer
Chronic-Fatigue-Syndrome
Rare-Genetic-Disorders
Fanconi-Anemia
Multiple-Myeloma
Fragile-X
Melanoma
AML
Parkinsons



PVI

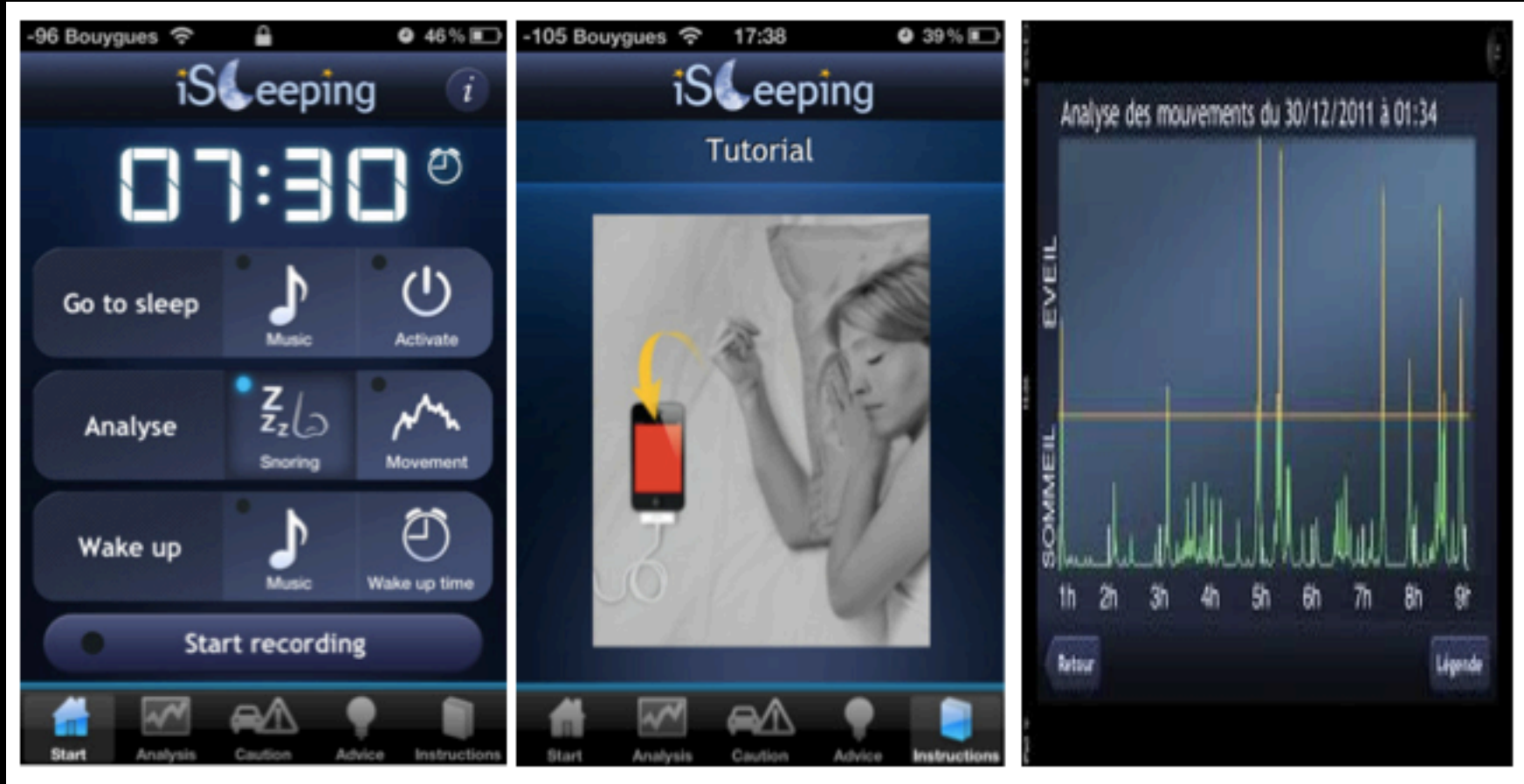
Parkinson's Voice Initiative

[Home](#) [Vision](#) [FAQ](#) [Request feedback](#) [Team](#)

Whether you are healthy or living with Parkinson's, help provide the voice information needed to build a system to screen for and monitor the symptoms of this debilitating disease. All you need to do: make a low-cost, anonymous, three-minute phone call.

 USA	1-857-284-8035
 Brazil	11 3957-0683
 Mexico	55-41703631
 UK	01865 521168
 Spain	91 123 4793
 Argentina	11.5252.8741
 Canada	1-647-931-5776

iSommeil



2013

**ENABLE TEAMS OF TEAMS
TO EVOLVE IDEAS IN REAL TIME**

SYNAPSE with
PROVENENCE

CONSORTIA

OPEN
DREAM CHALLENGES

**EMPOWER THE PUBLIC
NURTURE AS FULL PARTNERS**

BRIDGE

PORTABLE LEGAL
CONSENT

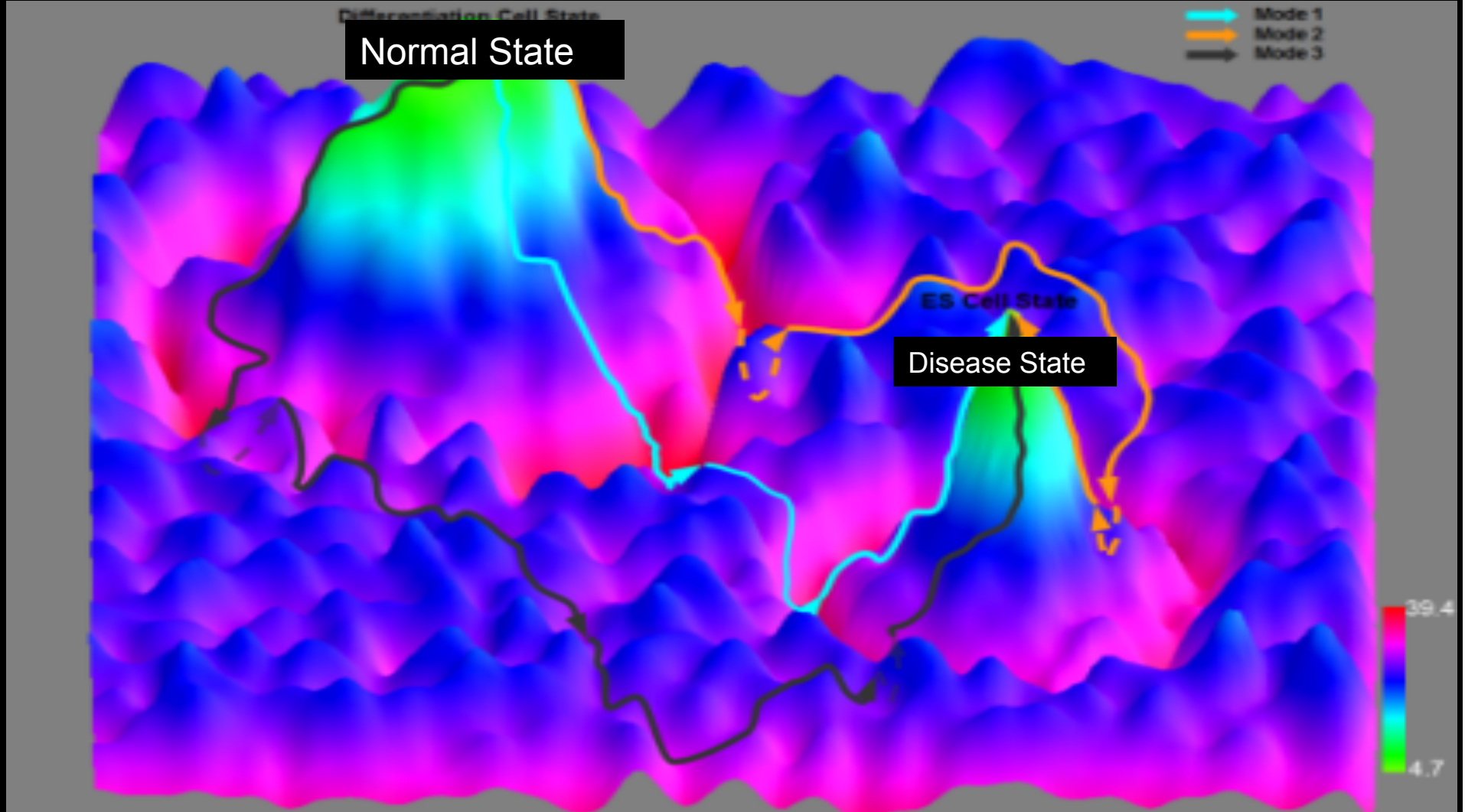
NextGen
Biomedical
Research

The Potential for a Distributed Network of Experts and Non-Experts working in a Generative Rapid Learning Space as an Alternative to Current Biomedical Research

Building a next generation model of biomedical research

NextGen
Biomedical
Research

Navigating between states of wellness



*To avoid mismatch between State of the Institutions and States of the Technology
To avoid siloed problem solving by those gaming the system for tenure
To bring in citizens with their insights, data and funding
We need to fundamentally change the current guilds of experts approaches*