NIH Update

Francis S. Collins, M.D., Ph.D.
Director, National Institutes of Health

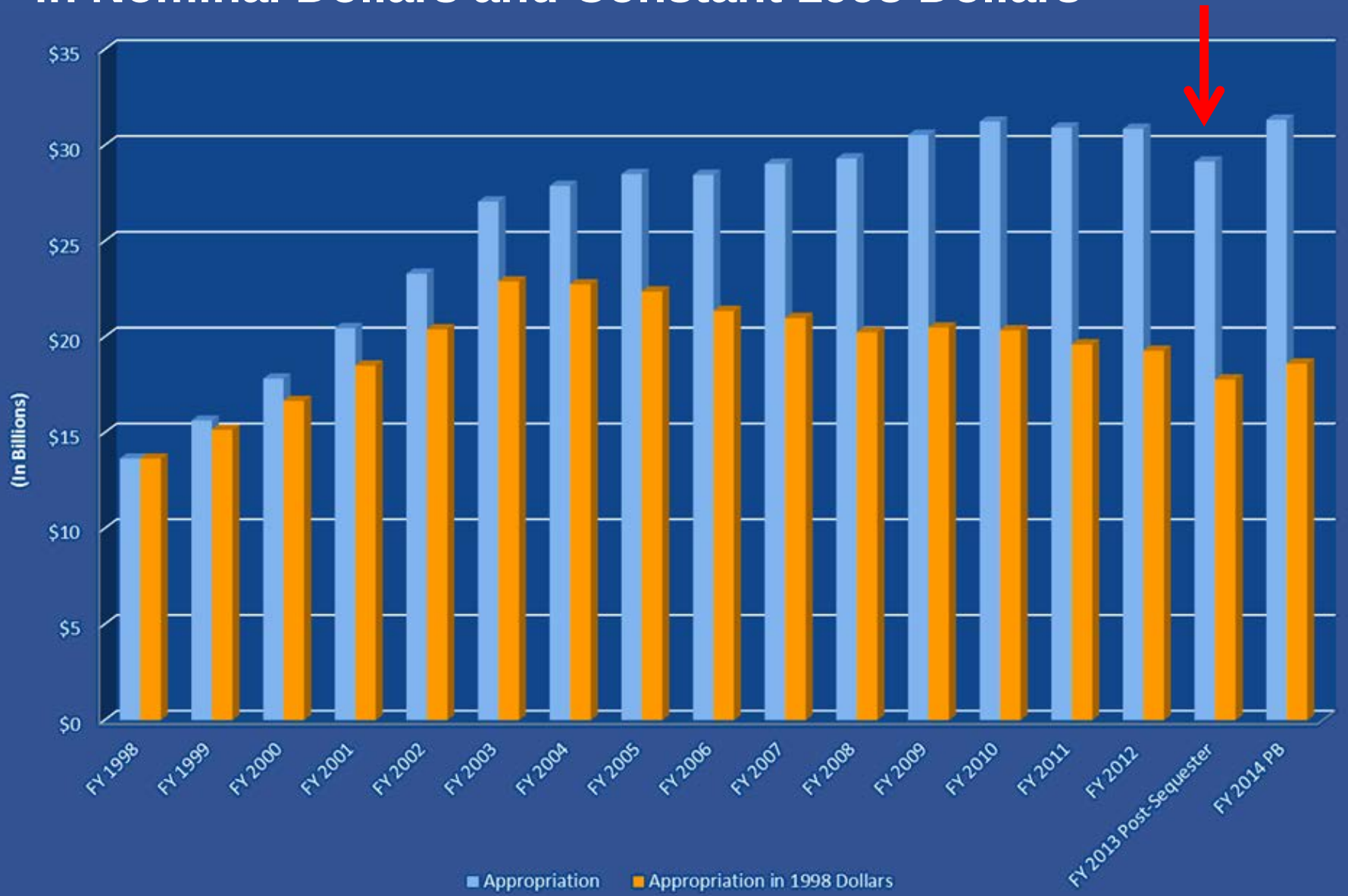
Council of Councils
May 14, 2013

NIH Update: Key Topics

- Budget Update
- Big Data
- Diversity in the Workforce
- BRAIN Initiative
- National Patient-Centered Clinical Research Network

NIH Program Level

in Nominal Dollars and Constant 1998 Dollars



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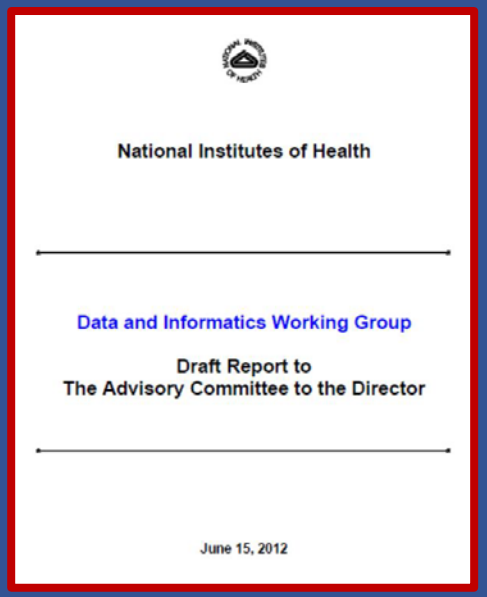
“Big Data”: Challenges for Biomedicine in an Era of Massive Data Sets

Recent explosion of biomedical data

- Challenge: find ways to optimize data that
  - Speed discovery and innovation
  - Improve nation’s health, economy
- NIH responds to the challenge
  - New internal governing/oversight bodies
  - New trans-NIH initiative: Big Data to Knowledge (BD2K)
  - New leadership position: Associate Director for Data Science (Eric Green, current Acting Associate Director)



National Institutes of Health

Data and Informatics Working Group

Draft Report to
The Advisory Committee to the Director

June 15, 2012

Evelyn Hockstein for The New York Times

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Enhancing Diversity in the Biomedical Research Workforce

- BUilding Infrastructure Leading to Diversity (BUILD) program
  - Will assist nationwide consortium of institutions to help diversify students entering graduate programs for biomedical research
- NIH will also:
  - Create a National Research Mentoring Network
  - Recruit a Chief Officer for Scientific Workforce Diversity
  - Conduct studies on potential bias in review, funding of grants
  - Develop better means of tracking trainees

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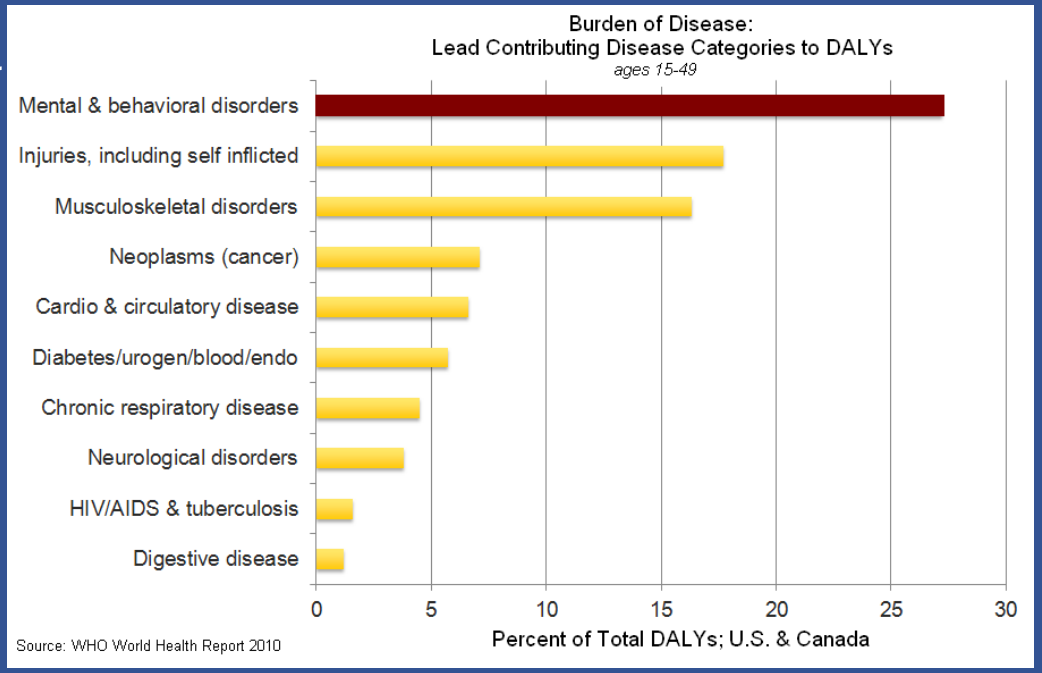
A Bold New Initiative in American science

Learning the language of the brain

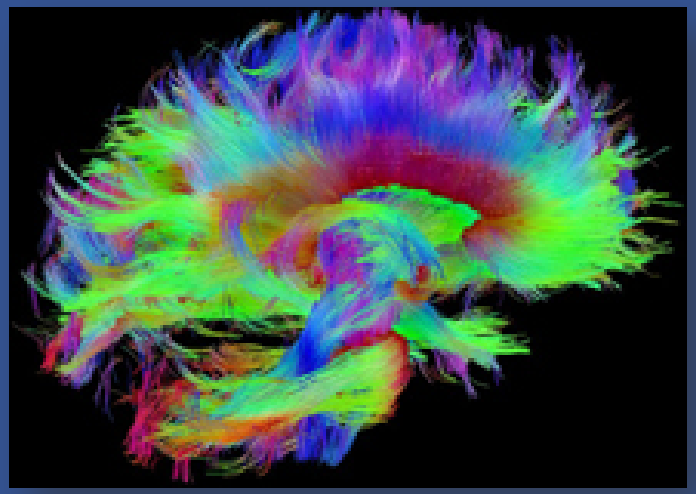
The Need Is Great

- Brain disorders: #1 source of disability in U.S.
  - > 100 million Americans affected
- Rates are increasing: autism, Alzheimer's disease, and in our soldiers PTSD and TBI
- Costs are increasing: annual cost of dementia ~$200B
  - Already equals cost of cancer and heart disease



The Science Is Ready

- Progress in neuroscience is yielding new insights into brain structure, function



- Progress in optics, genetics, nanotechnology, informatics, etc. is rapidly advancing design of new tools

The Vision

"So there is this enormous mystery waiting to be unlocked, and the BRAIN Initiative will change that by giving scientists the tools they need to get a dynamic picture of the brain in action and better understand how we think and how we learn and how we remember. And that knowledge could be – will be – transformative."

~President Obama, April 2, 2013

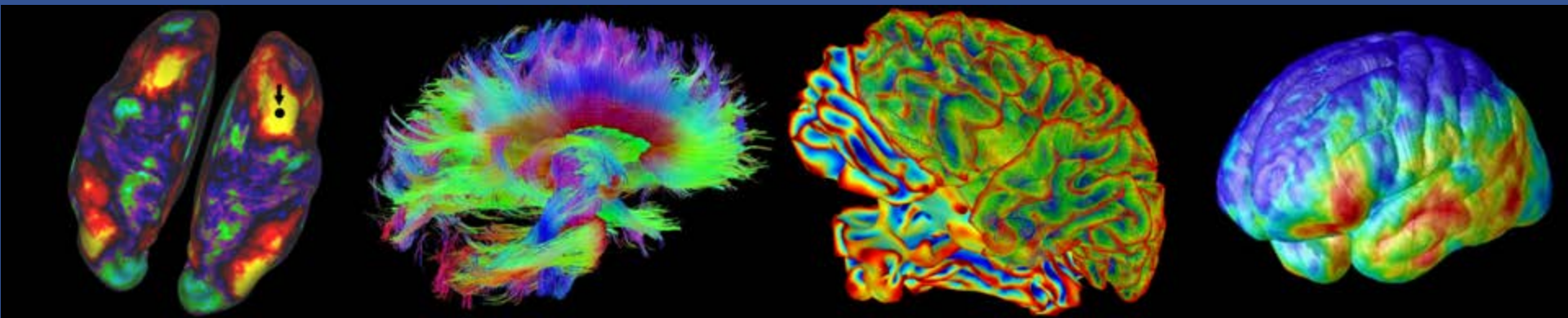
BRAIN Initiative Partners

FY2014 Investments

Government Agencies	$ in Millions
National Institutes of Health	$40
Defense Advanced Research Projects Agency	$50
National Science Foundation	$20
Private Organizations	
Allen Institute for Brain Science	$60
Howard Hughes Medical Institute	$30
Salk Institute for Biological Studies	$28
The Kavli Foundation	$4

Goals of NIH BRAIN

- Accelerate development, application of innovative technologies to construct dynamic picture of brain function that integrates neuronal and circuit activity over time and space
- Build on growing scientific foundation – neuroscience, genetics, physics, engineering, informatics, nanoscience, chemistry, mathematics, etc. – to catalyze interdisciplinary effort of unprecedented scope



NIH Neuroscience BRAIN Team

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National Science Foundation

Stephen Colbert Monitors His Brain Activity

April 4, 2013

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The Trials of Conducting Clinical Research

- Few pre-existing cohorts of substantial size
- Even fewer with broad disease relevance
- Absence of longitudinal follow up
- Paper medical records the norm until very recently
- Lack of population diversity
- Vexing consent issues
- Multiple IRBs
- Privacy and confidentiality challenges
- Chronic difficulty achieving enrollment goals
- Limited data access
- Heavy costs of start-up and shut-down

Imagine …

A National Patient-Centered Clinical Research Network

- Bringing together 20–30 million covered lives, with
  - Good representation of gender, geographic, ethnic, age, educational level, and socioeconomic diversity
  - Broad opt-in consents from 80 - 90% of participants
  - Longitudinal follow up over many years
- Offering a stable research infrastructure
  - Including trained personnel in each of the participating health services organizations
  - Making it possible to run protocols with low marginal cost

Imagine …

A National Patient-Centered Clinical Research Network

- Drawing on electronic health records (EHR) for all patients, with
  - Interoperability across all sites
  - Meaningful use for research purposes
- An efficient Biobank
- Promoting data access policies that provide for broad research use but protect privacy and confidentiality
- Providing governance with extensive patient participation in decision making

A National Patient-Centered Clinical Research Network: *Potential Uses*

- Rapidly design and implement observational trials
  - At very low cost
- Quickly and affordably conduct randomized studies
  - Using individual or cluster design
  - In diverse populations and real-world practice settings
- Significantly reduce expenses associated with start-up, shut-down of clinical research studies

Science Translational Medicine

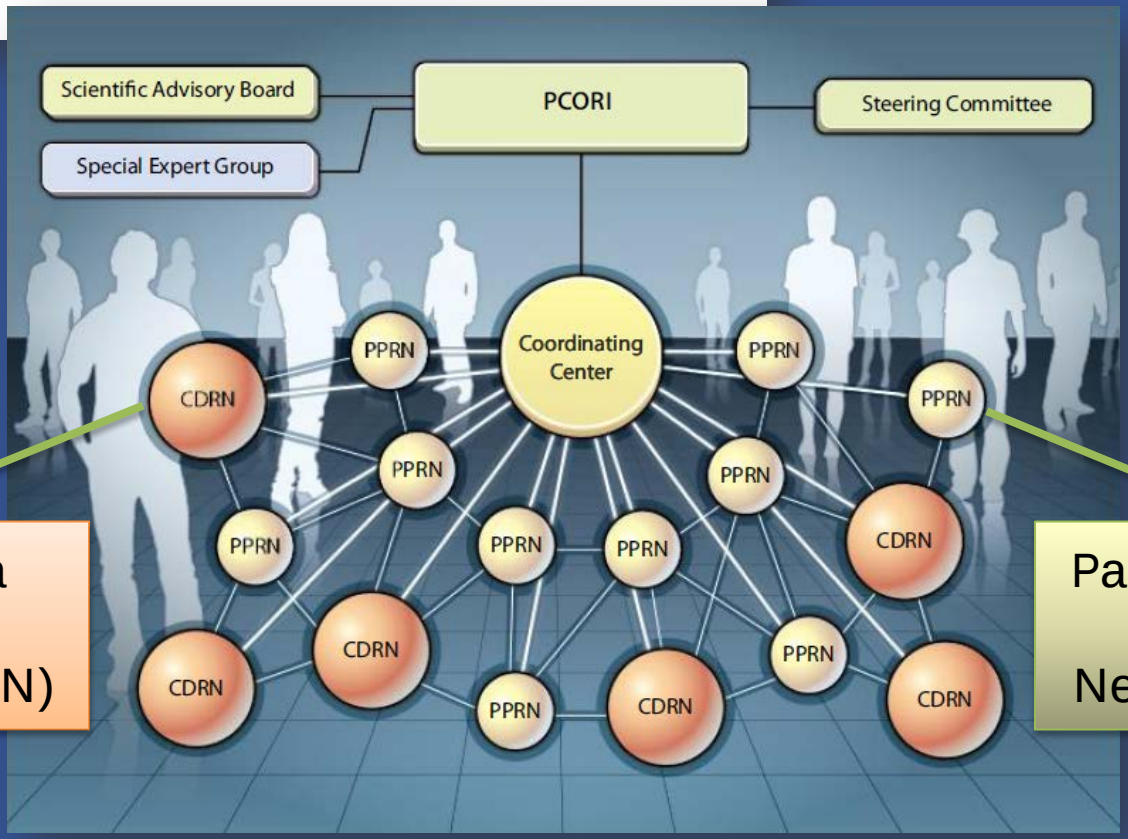
FOCUS

24 April 2013 Vol 5 Issue 182

POLICY

Network News: Powering Clinical Research

Joseph V. Selby,[1] Harlan M. Krumholz,[2,3] Richard E. Kuntz,[3,4]
Francis S. Collins[3,5*]



Clinical Data Research Network (CDRN)

Patient-Powered Research Network (PPRN)

pcori




NIH…

Turning Discovery Into Health