



AMERICAN SOCIETY OF
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Big Data for Rehabilitation: Promises, Pitfalls, and Future Potential

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Outline

- 1. Introduction**
- 2. Challenges & Opportunities**
- 3. Resources – Center for Large Data Research & Data Sharing (CLDR)**
- 4. Questions**



Background

Data Discovery

“The march of quantification, made possible by enormous new sources of data, will sweep through academia, business, health care and government. There is no area that is going to be untouched.”

Science 2011



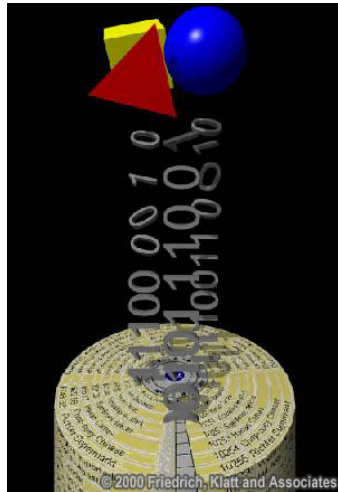
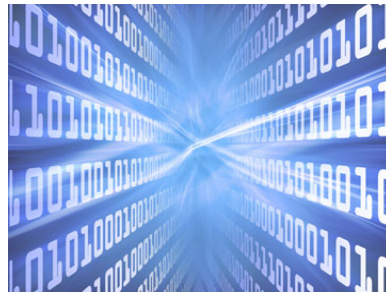
2008



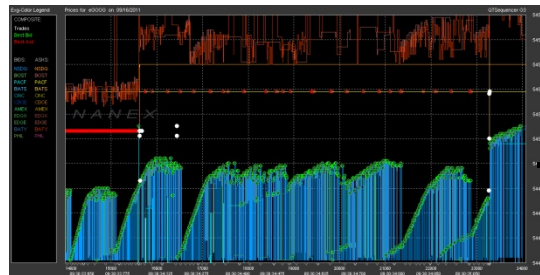
2011

The Challenges

Large datasets can be overwhelming



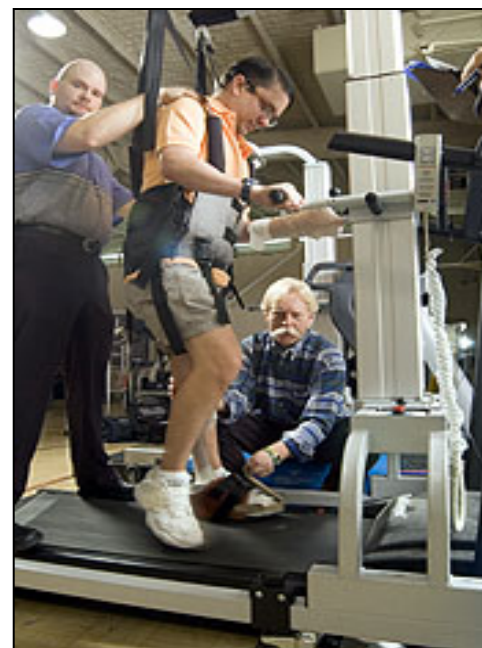
Data



The Challenges

Rehabilitation investigators are trained to conduct (prospective) clinical, patient-oriented research...

not comprehensive or secondary analysis of large data.

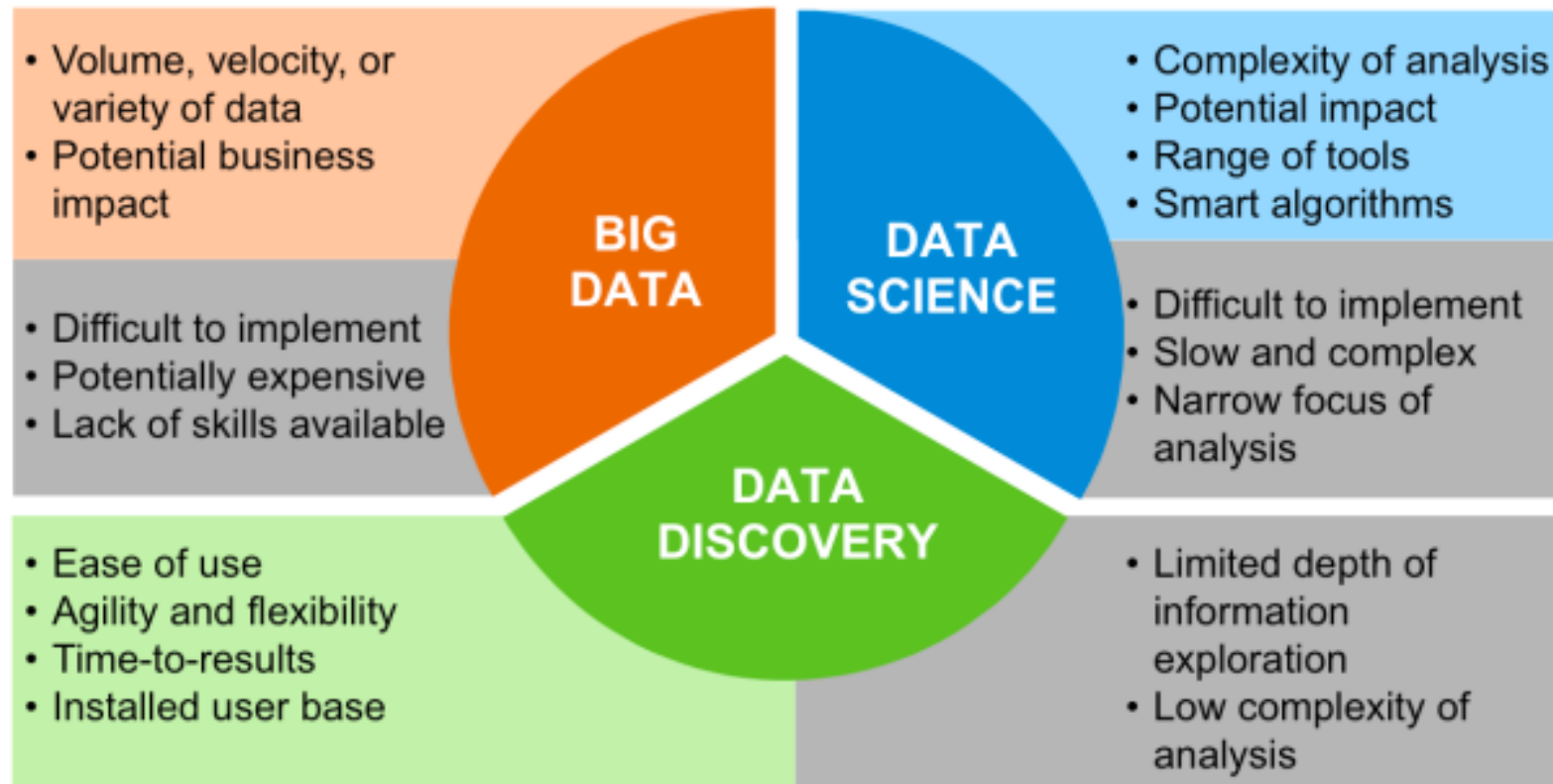


The Opportunities

- **Advances in bioinformatics, statistical computing, information technology and the internet have resulted in access to large amounts of data**
- **Health and biomedical data are available that include information related to rehabilitation, recovery, and disability**



Large Data Analytics is an Evolving Field



EMC Educational Services. *Data Science and Big Data Analytics: Discovering, Analyzing, Visualizing and Presenting Data*. John Wiley & Sons, Hoboken, NJ, 2014. ISBN 9781118876220

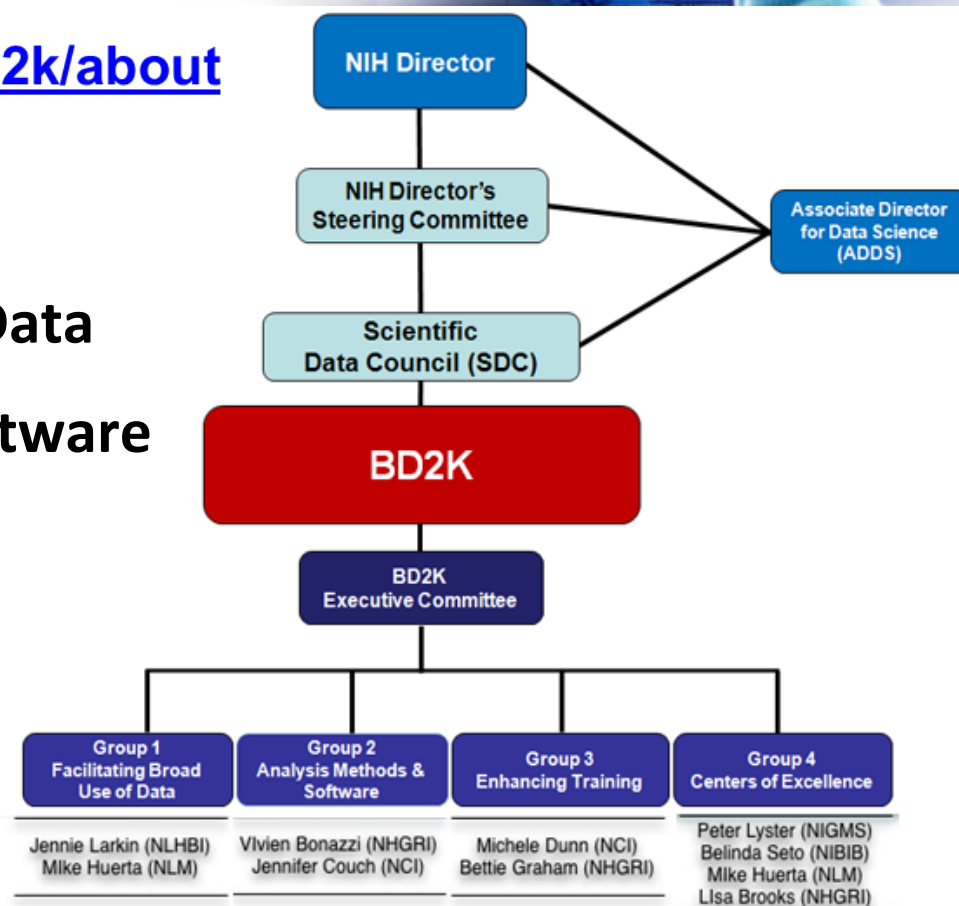
NIH Big Data to Knowledge (BD2K)



<https://datascience.nih.gov/bd2k/about>

Areas of BD2K

1. Facilitating Broad Use of Data
2. Analysis Methods and Software
3. Enhancing Training
4. Centers of Excellence



What is “Big Data”?

NIH BD2K Definition

“Big Data refers to the complexity, challenges, and new opportunities presented by the combined analysis of data. In biomedical research, these data sources include the diverse, complex, disorganized, massive, and multimodal data being generated by researchers, hospitals, and mobile devices around the world.”

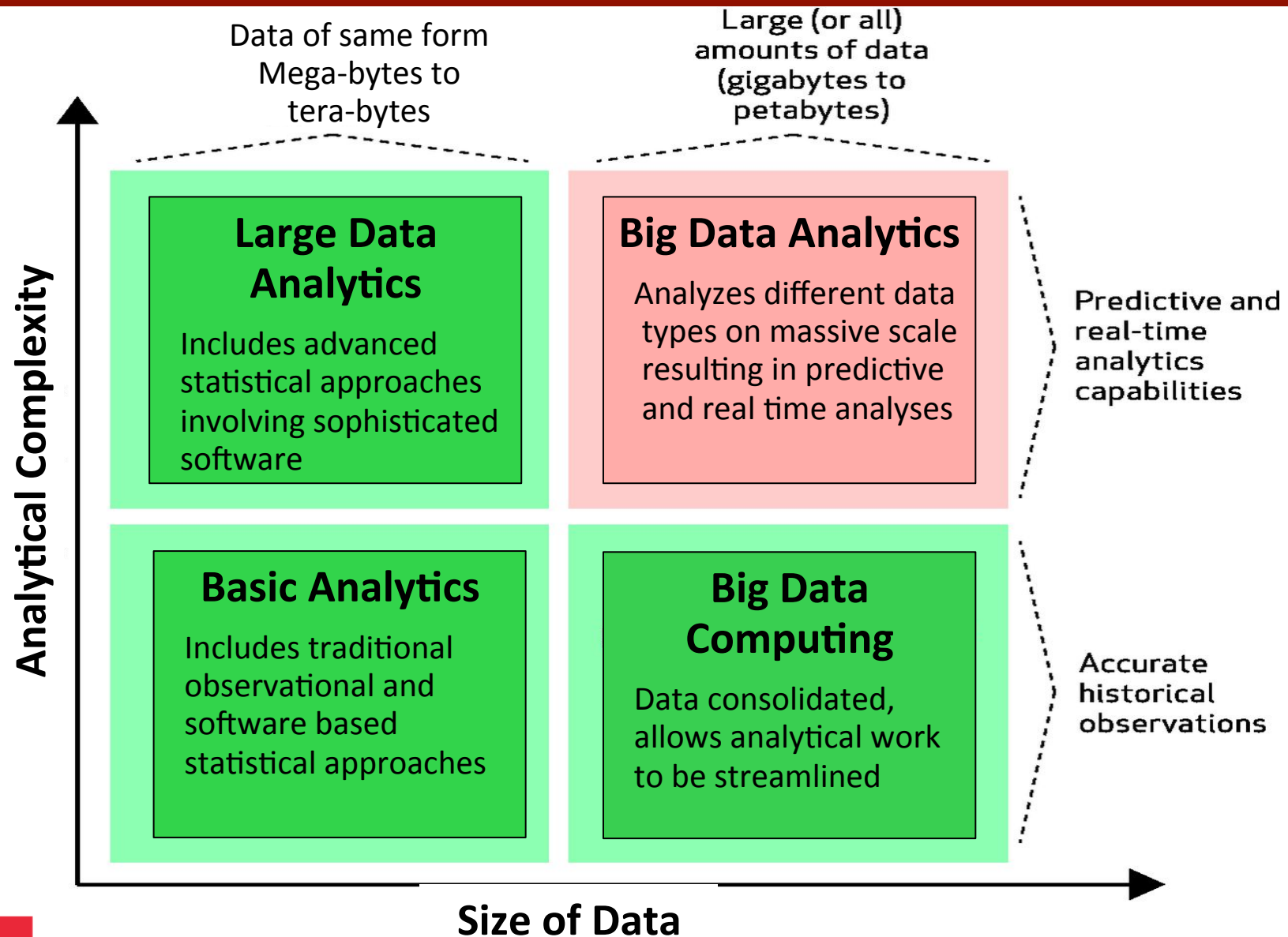


Characteristics of “Big Data”?



Includes everything from Twitter to the Genome

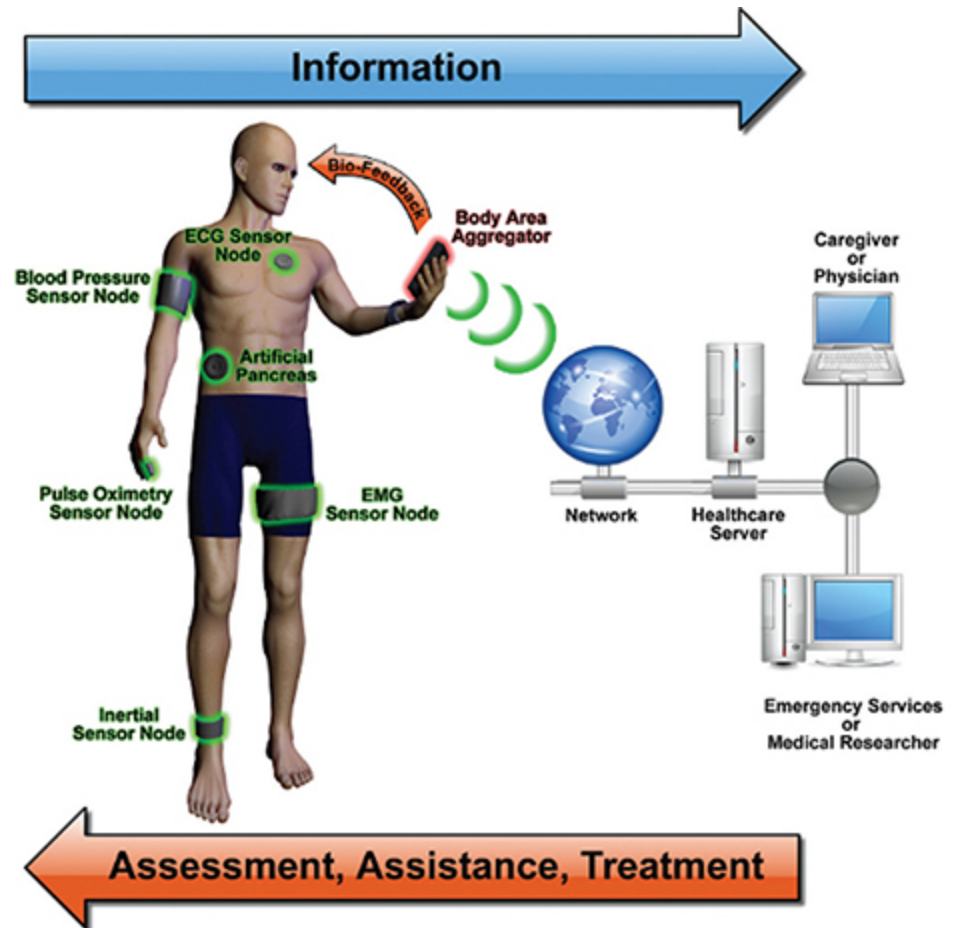
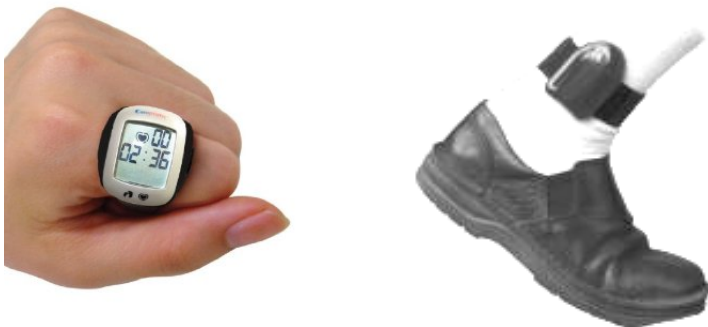
Large Data vs. Big Data



Opportunities (Example)

Personal Motion Technology


Continuous recording of biological or performance information generates large amounts of data.



Opportunities (Example)



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 Search



[ABOUT US](#)

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[RESEARCH & RESULTS](#)

[GET INVOLVED](#)

[MEETINGS & EVENTS](#)

[Research & Results](#)

OUR PROGRAMS

PCORnet: The National Patient-Centered Clinical Research Network



PCORnet, the National Patient-Centered Clinical Research Network, is an initiative of PCORI. It is designed to make it faster, easier, and less costly to conduct clinical research than is now possible by using the power of large health data and patient partnerships.

<http://www.pcornet.org/>

Opportunities

What we have done ... Link research to Federal healthcare legislation & priorities:

- 1. ACA – Hospital Readmission Reduction Program**
- 2. ACA – Bundled Payment for Care Improvement**
 - Comprehensive Care for Joint Replacement**
- 3. ACA – Value-based Healthcare - Quality Measure Reporting**
- 4. MedPAC Reports to Congress**



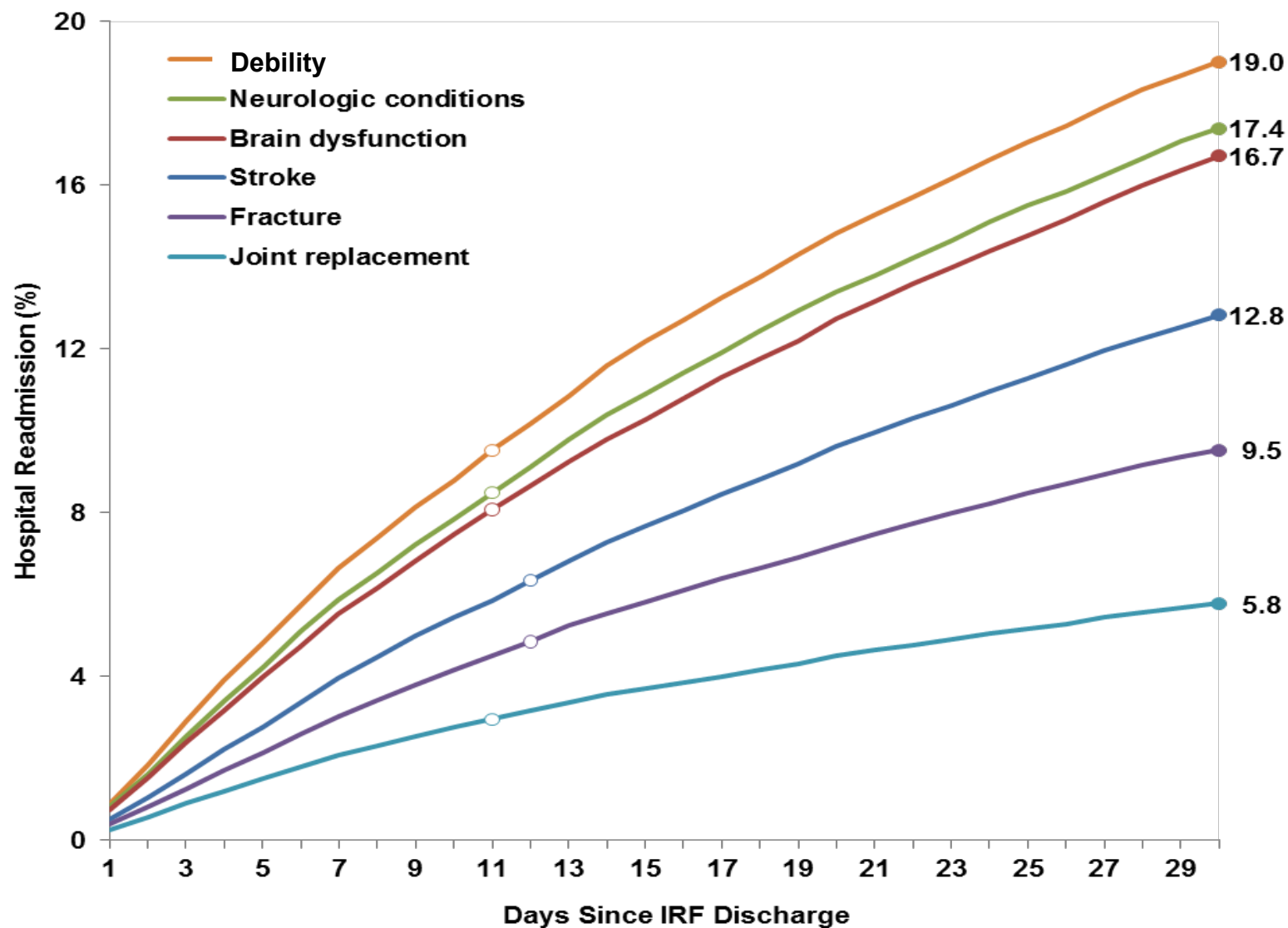
Example – Large Data Research

Hospital Readmission is a National Quality Indicator for Healthcare Reform

We examined national data from 1.7 million Medicare files to determine rates of hospital readmission for the six largest impairment groups receiving inpatient medical rehabilitation in the U.S.



Cumulative 30 Day Readmission after IRF Discharge



JAMA 2014;311(6):604-614

Resources

CLDR Center for Large Data Research & Data Sharing in Rehabilitation



Activities - CLDR

- Web Site <http://rehabsciences.utmb.edu/cldr>
- Education & Training
- Data Directory
- Pilot Projects
- Visiting Scholars Program
- Data Archiving & Sharing Program



Education & Training




Center for Large Data Research
& Data Sharing in Rehabilitation

Search... Search

TMB Home » Center for Large Data Research and Data Sharing in Rehabilitation » Education-training » Accessing Data

Thursday, September 1, 2016

HomeAbout UsData DirectoryVariable CatalogData Sharing & ArchivingEducation & TrainingPilot ProjectsVisiting Scholars




Disability & rehabilitation research capacity
Outcomes for people with disabilities
Research quality

Education & Training


CLDR education and training activities cover three fundamental aspects of using large data for rehabilitation research: 1) Identifying and accessing large data sources; 2) Managing and analyzing large datasets; and, 3) Archiving and sharing research data with other investigators.

CoHSTAR Summer Institute on Health Services Research at Boston University - Videos Available



On June 29, 2016 CoHSTAR held its first [Summer Institute on Health Services Research at Boston University](#). Summer Institute sessions were webcast and the archived proceedings are now available for viewing, including a presentation by CLDR Director Ken Ottenbacher, PhD, OTR. Access to the archived webcast proceedings is free with registration.

CLDR Institute on Large Data and Data Sharing Research: Issues, Methods & Opportunities - Videos Available



CLDR Director Ken Ottenbacher, PhD, OTR, and colleagues offered a pre-conference [Institute on Large Data and Data Sharing Research: Issues, Methods & Opportunities](#) co-sponsored by The American Occupational Therapy Foundation (AOTF) and American Occupational Therapy Association (AOTA) at AOTA's national conference in Chicago on April 6th, 2016.

AccessingAnalysis & ApplicationArchiving

Data Directory



[SOURCES](#) [FAQ](#) [GLOSSARY](#) [HELP](#) [LOG IN](#)

Disability Statistics

Online Resource for U.S. Disability Statistics

FIND
Disability Statistics

DOWNLOAD
Disability
Status Reports

ACCESS
Research
Tools

[Home](#) / [Data Sources](#) / [Rehabilitation Dataset Directory: Directory Search](#)

CLDR Center for Large Data Research & Data Sharing in Rehabilitation

Rehabilitation Dataset Directory: Directory Search

Find secondary data for your rehabilitation related research. Search results include a link to a summary dataset description and a detailed full profile containing more details including a direct link to the dataset's primary website and documentation.

Full Text Search

Enter a term that describes the concept you are looking for. (Note: the term will be searched EXACTLY and may not find a dataset. Don't give up! Try the other interfaces, or contact our technical assistance for further suggestions)

Search:

Filter by Criteria

Select one or more checkboxes and click the Submit button. All datasets that include any of the criteria will be displayed.

Unit of Observation

Description: The most basic unit on which data is collected on (e.g., individual, facility).

- ☐ Geographic Area (e.g. County Level)
- ☐ Hospital/facility
- ☐ Individual/Patient
- ☐ Service Provider/Agency

Sponsoring Agency/Entity

Study Design

Sample Population

Data Type(s)

Data Access Requirements

Disability Measures

Health Conditions

Browse Datasets

Click the question mark to display the dataset summary and a link to the full profile. For multiple datasets, check the boxes by each one that interests you and click the Submit button located at the bottom of the list.

Centers for Disease Control and Prevention (CDC)

- ☐ (BRFSS) Behavioral Risk Factor Surveillance System ?
- ☐ (NAMCS) National Ambulatory Medical Care Survey ?
- ☐ (NDI) National Death Index ?
- ☐ (NHANES) National Health and Nutrition Examination Survey ?
- ☐ (NHIS) National Health Interview Survey ?
- ☐ (NHHCSS) National Home and Hospice Care Survey ?
- ☐ (NNHS) National Nursing Home Survey ?
- ☐ (NDECH) National Survey of Early Childhood Health ?
- ☐ (NSRCH) National Survey of Residential Care Facilities ?

Department of Education (DOE)

- ☐ (BMS) Burn Injury Model Systems ?
- ☐ (NLTS-2) National Longitudinal Transition Study 2 ?

Search Type 1:

Search by Criteria

Use the expandable guided selection interface. Select one or more checkboxes and click the Submit button. (all datasets that include any of the criteria will be displayed.)

Unit of Observation

Description: The most basic unit on which data is collected on (e.g., individual, facility).

- ☐ Geographic Area (e.g. County Level)
- ☐ Hospital/facility
- ☐ Individual/Patient
- ☐ Service Provider/Agency

Sponsoring Agency/Entity

Study Design

Description: Design of study: longitudinal (repeated observations over time), cross sectional (observation at a single point in time).

- ☐ Cross-sectional
- ☐ Longitudinal

Sample Population


Data Type(s)

Data Access Requirements

Disability Measures

Health Conditions

Pilot Projects



Pilot Projects

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Call for Pilot Applications

Funding Opportunities

The CLDR's pilot studies program is designed to offer practical experience in managing, analyzing, and interpreting findings using large data analytics and secondary data analysis. The Center will fund pilot studies in two categories: Category 1 will include research examining questions using a large administrative or healthcare research dataset and Category 2 will involve the archiving of existing data from a completed study.

Application Process & Eligibility Criteria

Category 1: Large Data Pilot Studies
Category 2: Data Sharing and Archiving Pilot Studies
Current & Completed Projects

Important Dates for Category 1 Projects

- March 1: Letter of Intent deadline
- March 15: Notifications in response to LOI
- April 15: Pilot application deadline
- May 15: Funding decision notifications
- July 1: Start Date

Note: Category 2 project applications are accepted year round.

Submit a Pilot Application

CLDR Pilot Projects

Category 1: Large Data Pilot Studies

These include traditional pilot studies examining a research question using large data (e.g., survey or administrative dataset) that address an issue related to rehabilitation, recovery, or disability.

Funding up to \$25,000



CLDR Pilot Projects

Category 2: Data Sharing and Archiving Pilot Studies

Category 2 projects are focused on archiving data from a completed rehabilitation study with support being given to either the PI or a member of their research team.

- **Funding up to \$10,000**
- **Applications accepted year-round**

Visiting Scholars

Visiting Scholars Program

Investigators can be supported for periods of up to six months at one of the consortium institutions to work with experienced investigators using large datasets.



Archiving & Data Sharing

New CLDR activity related to federal mandates for data sharing

White House Office of Science and Technology Policy (February 22, 2013)

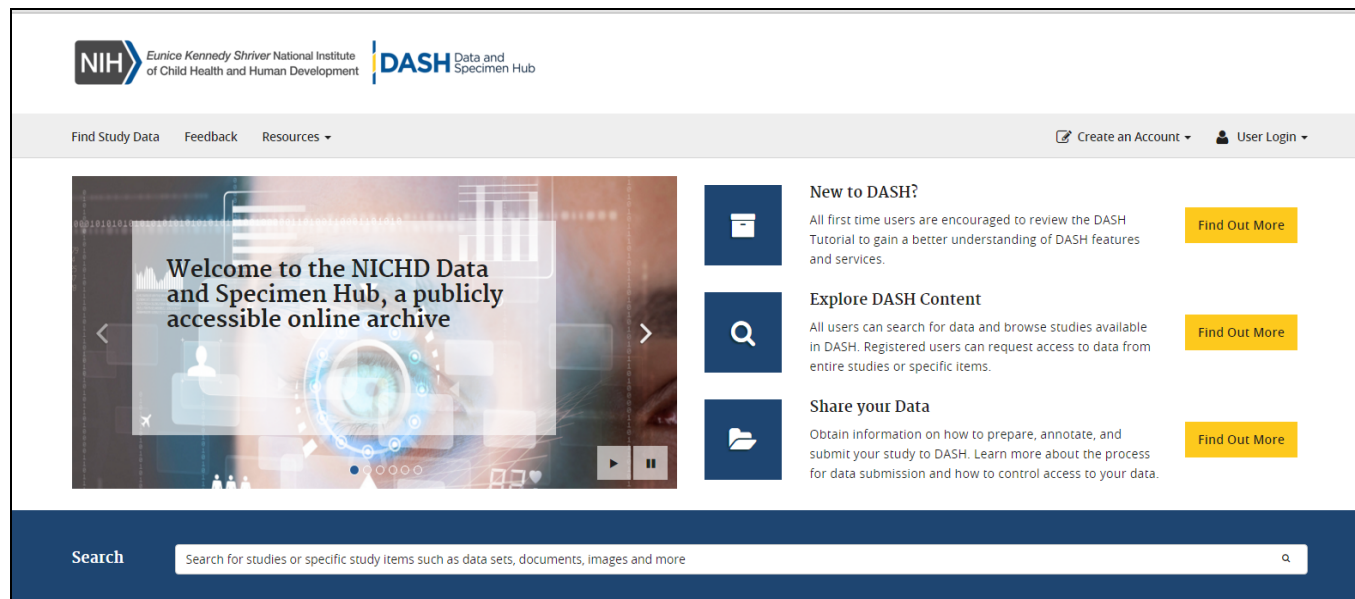


IOM Report: Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk.
National Academies Press,
Washington, DC 2015



NICHD Data and Specimen Hub (DASH)

DASH is a resource to store and access de-identified data from NICHD-funded research studies for secondary research use.



Federal Interagency Traumatic Brain Injury Research

FITBIR functions as a repository for data from TBI studies and supports a free web-based application with an interface that allows investigators to contribute and access data.

<https://fitbir.nih.gov/>



The screenshot shows the FITBIR website homepage. At the top, there is a Google Custom Search bar and a 'LOG INTO FITBIR' button. The navigation bar includes links for Home, Defining Data, Contributing Data, Accessing Data, Policies & Procedures, and About FITBIR. The main content area features a large image of two scientists in a lab, with a text overlay asking 'Need help getting started?' and providing a 'LEARN MORE' button. Below this, there is a section titled 'Our Vision' and another titled 'Working with FITBIR' which is divided into three columns: 'Define Data', 'Contribute Data', and 'Access Data'. Each column has a brief description and a 'LEARN MORE' button. On the right side, there is a section titled 'The Federal Interagency Traumatic Brain Injury Research (FITBIR) informatics system' followed by a list of links for 'FITBIR One-Page Brochure', 'ProFORMS One-Page Brochure', and 'FITBIR Imaging One-Page Brochure'. Below this, there is a section for 'Latest News' with links to 'Notice of Modification of the Data Sharing Policy for FITBIR Informatics System' and 'Research Biomarkers Laboratory Guidelines for FITBIR'. At the bottom, there is a 'Participating Organizations' section with logos for DMRDP, MRMC, and NINDS.

Need help getting started?
FITBIR has a fully-staffed operations team to help you along the way.
[LEARN MORE](#)

Our Vision
The Federal Interagency Traumatic Brain Injury Research (FITBIR) informatics system was developed to share data across the entire TBI research field and to facilitate collaboration between laboratories, as well as interconnectivity with other informatics platforms. Sharing data, methodologies, and associated tools, rather than summaries or interpretations of this information, can accelerate research progress by allowing re-analysis of data, as well as re-aggregation, integration, and rigorous comparison with other data, tools, and methods. This community-wide sharing requires common data definitions and standards, as well as comprehensive and coherent informatics approaches.

Working with FITBIR

Define Data	Contribute Data	Access Data
To achieve its vision, FITBIR implements the interagency Common Data Elements for TBI research and provides tools and resources to extend the data dictionary. LEARN MORE	FITBIR has established a two-tiered submission strategy to ensure high quality and to provide maximum benefit to investigators. LEARN MORE	Qualified researchers can request access to data stored in FITBIR. To gain access to shared data, an investigator must obtain data access privileges. LEARN MORE

The Federal Interagency Traumatic Brain Injury Research (FITBIR) informatics system is an extensible, scalable informatics platform for TBI relevant imaging, assessment, genomics, and other data types

- [FITBIR One-Page Brochure](#)
- [ProFORMS One-Page Brochure](#)
- [FITBIR Imaging One-Page Brochure](#)

It is a free resource to the TBI community designed to accelerate comparative effectiveness research on brain injury diagnosis and treatment.
[Learn More](#)

- [Frequently Asked Questions \(FAQs\)](#)
- [Relevant Publications](#)
- [PubMed Articles on TBI](#)
- [NINDS TBI Research Program](#)

Policies and Procedures

- [Policy Overview](#)
- [Standards](#)
- [FITBIR Data Submission Standards](#)

Latest News

- [Notice of Modification of the Data Sharing Policy for FITBIR Informatics System](#)
March 27, 2014
- [Research Biomarkers Laboratory Guidelines for FITBIR](#)
January 27, 2014
- [NIH and NFL Tackle Concussion Research](#)
December 16, 2013

[ALL NEWS](#)

Participating Organizations

- [DMRDP](#)
- [MRMC](#)
- [NINDS](#)

Large/Big Data Caveat

Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information?

T.S. Eliot (The Rock)

Where is the information we have lost in data?



Information



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Rehabilitation Sciences Academic Division & Research Center

Phone: (409) 747-1637

Email: rehab.info@utmb.edu

<http://rehabsciences.utmb.edu/cldr>



Cornell University
ILR School
Employment and Disability Institute



ASNR Disclosures & Acknowledgements

Disclosures (PI or core leader)

• *Research*

P2C-HD065702 (PI, NIH)
R01-HD069443 (PI, NIH)
R01 MD-010355 (PI, NIH)
H133G140127 (PI, NIDILRR)
R24-HS022134 (Core, AHRQ)
P30-AG024832 (Core, NIH)

• *Training*

K12-HD055929 (PI, NIH)
H133P110012 (PI, NIDILRR)

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