ASNR AMERICAN SOCIETY OF NEUROREHABILITATION

Big Data for Rehabilitation: Promises, Pitfalls, and Future Potential

Kenneth J. Ottenbacher

University of Texas Medical Branch

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CLDR Center for Large Data Research & Data Sharing in Rehabilitation

Outline

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

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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

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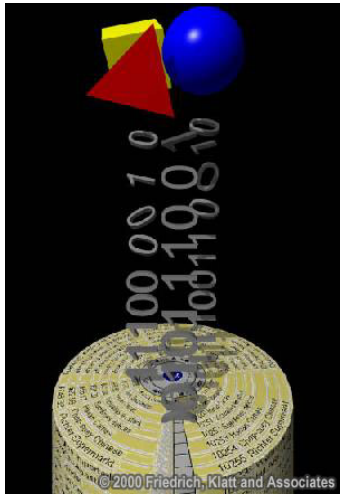
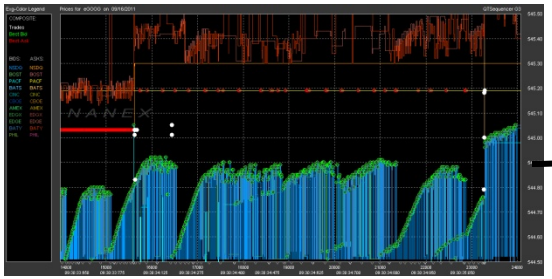
The Challenges

Large datasets can be overwhelming





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The Challenges

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

not comprehensive or secondary analysis of large data.

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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**

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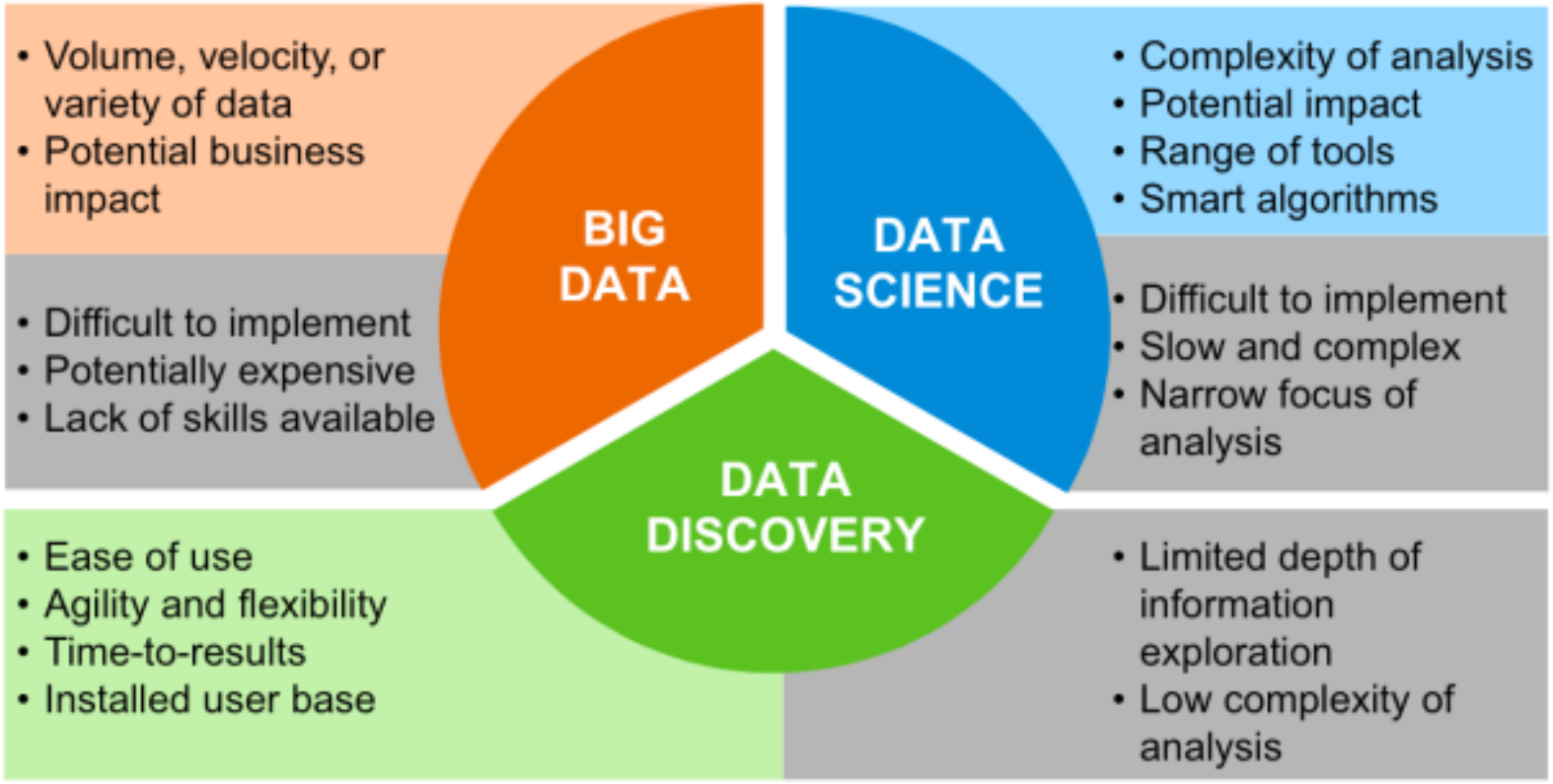
Large Data Analytics is an Evolving Field



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

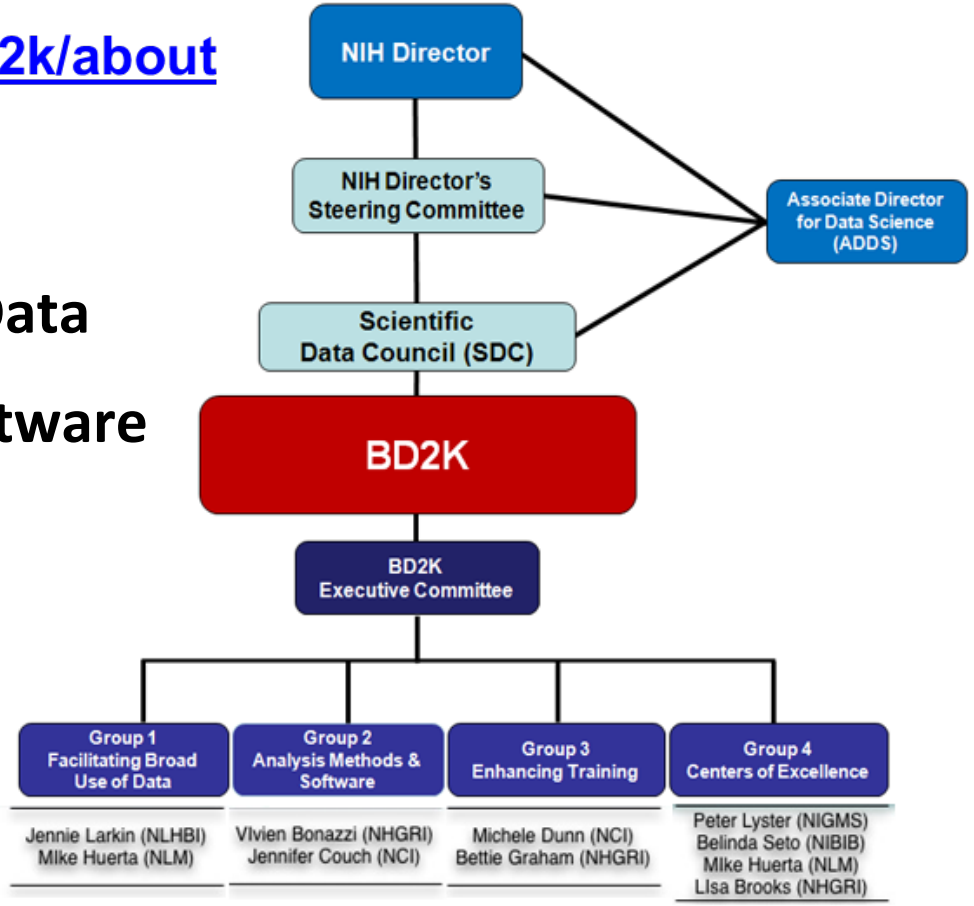
NIH Big Data to Knowledge (BD2K)

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



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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.”

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https://datascience.nih.gov/bd2k/about/what

Characteristics of “Big Data”?

Includes everything from Twitter to the Genome

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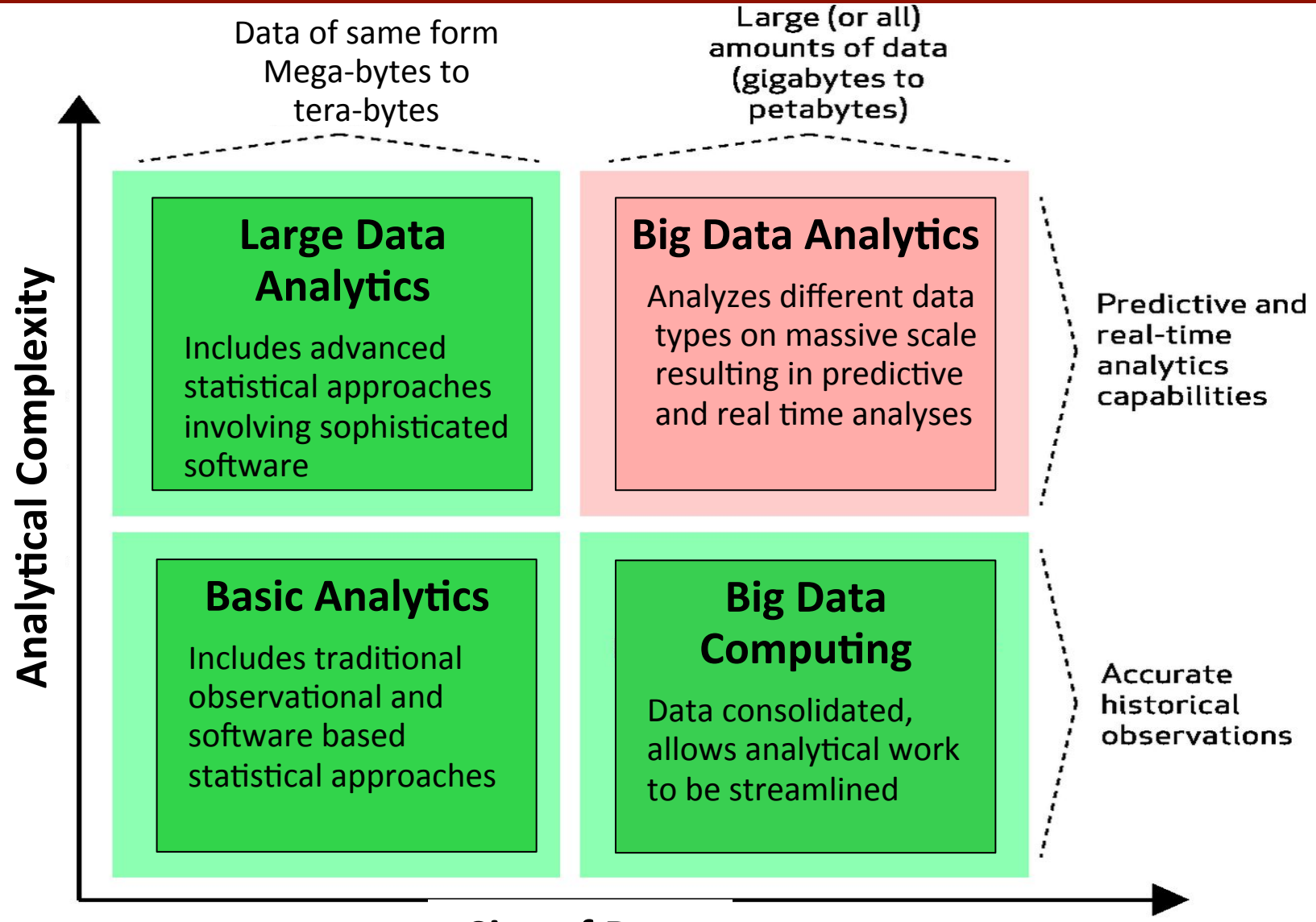
Large Data vs. Big Data



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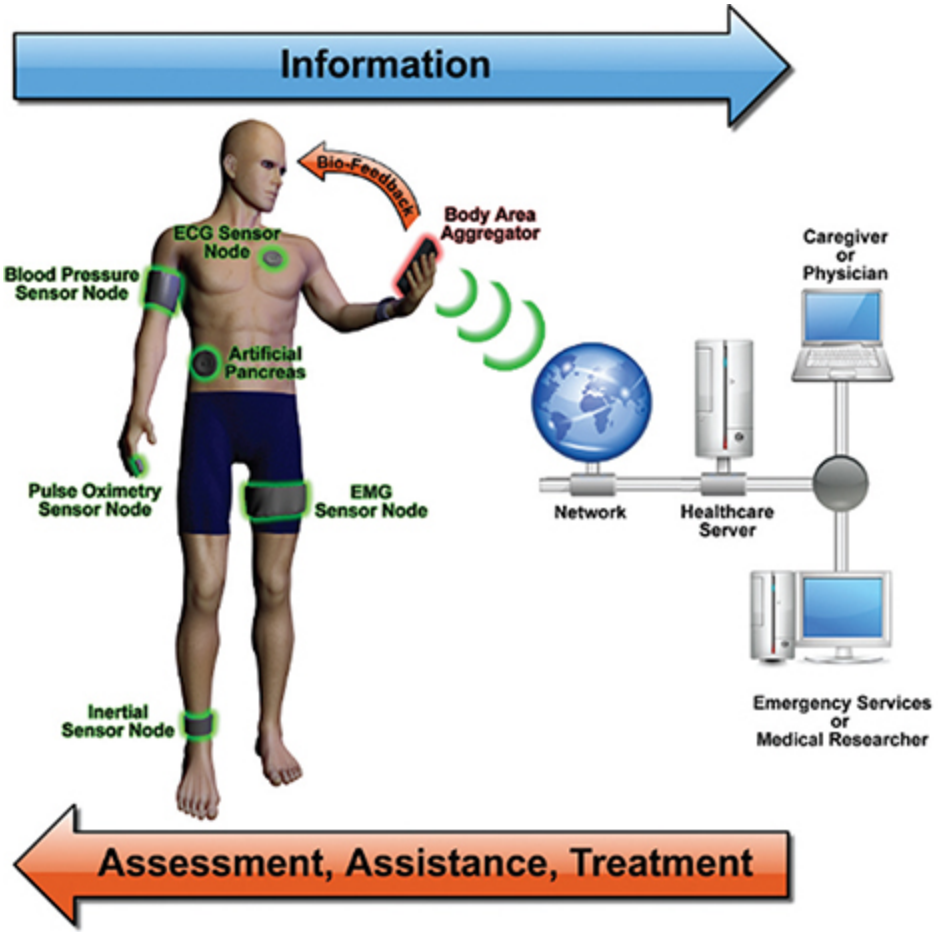
Adapted from: Roski J et al. Health Aff 2014;33:1115-1122

Opportunities (Example)

Personal Motion Technology

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



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Opportunities (Example)

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**

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Example – Large Data Research

Hospital Readmission is a National Quality Indicator for Healthcare Reform

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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.

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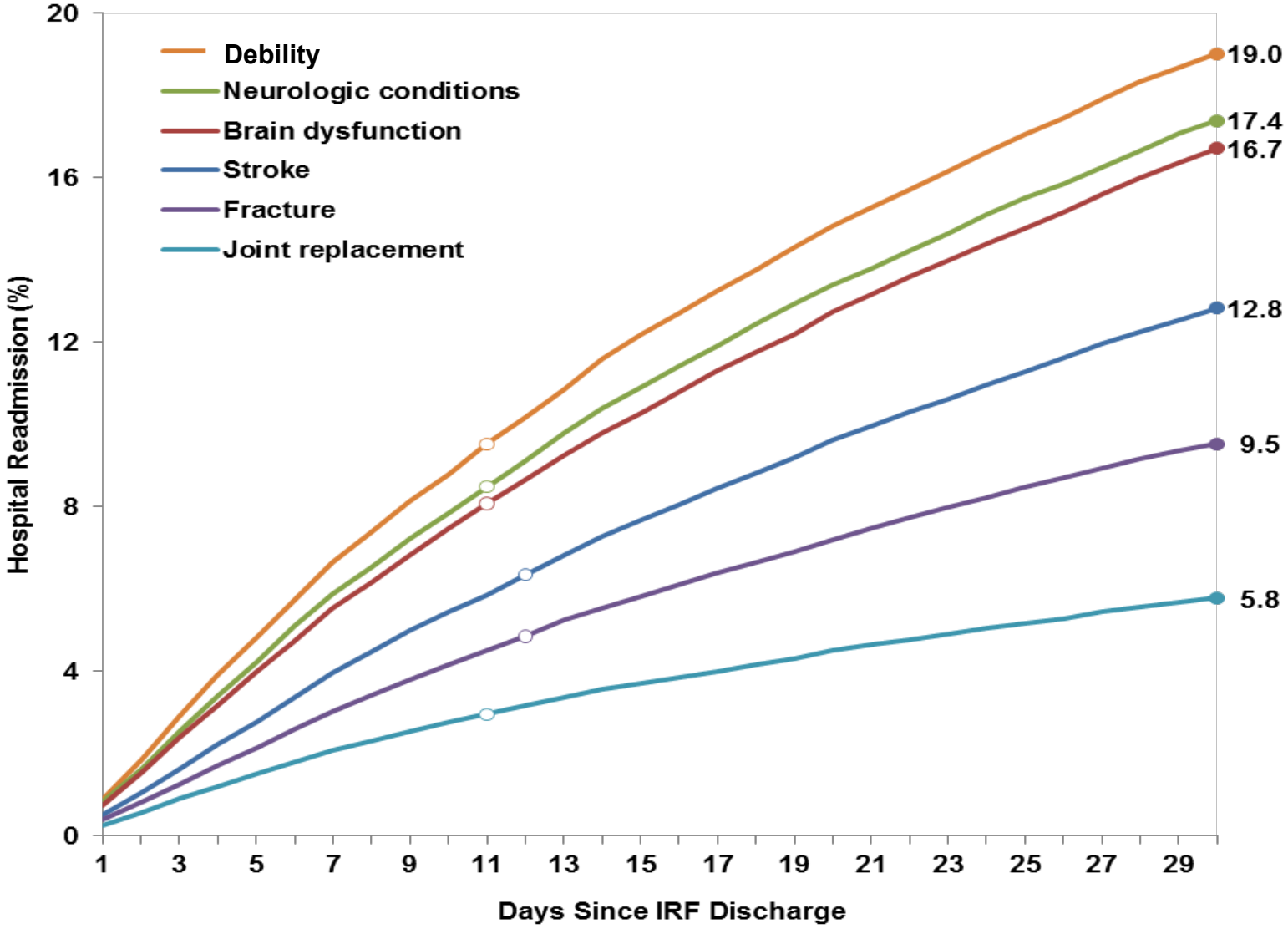
Cumulative 30 Day Readmission after IRF Discharge



JAMA 2014;311(6):604-614

Resources

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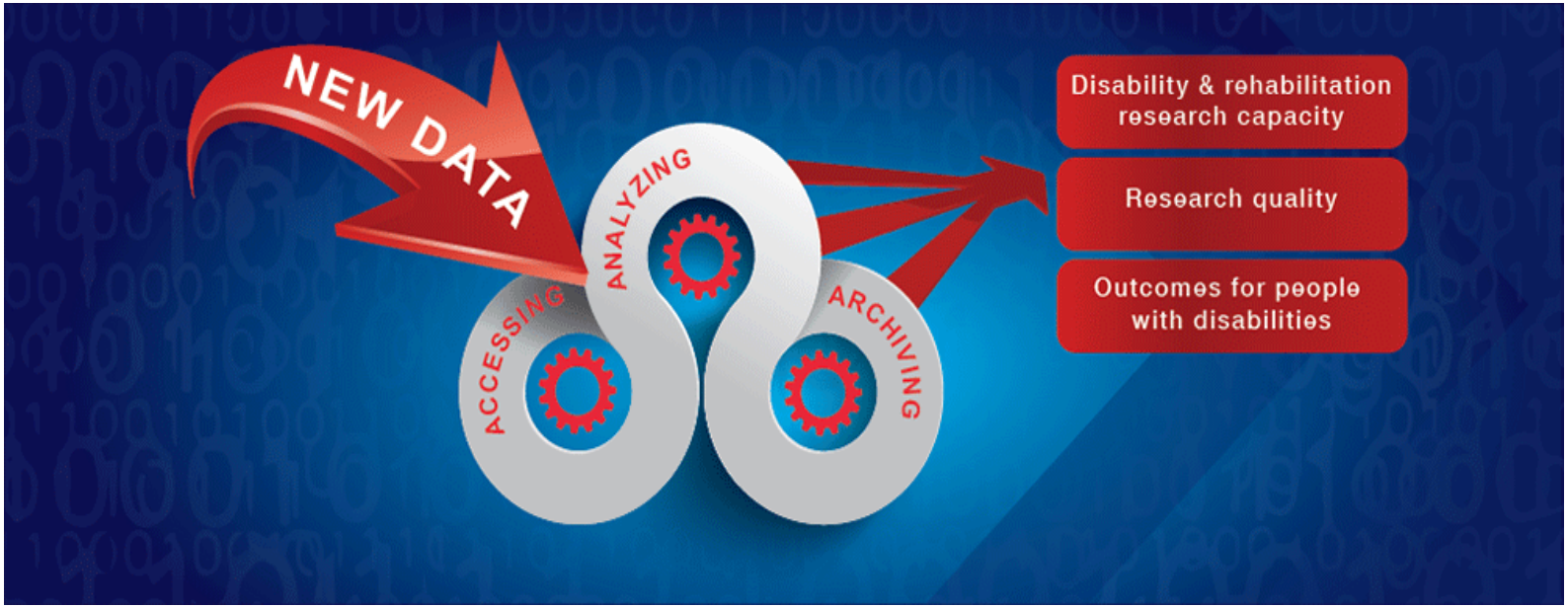

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NIH (P2C-HD065702)

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**

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Cornell University ILR School Employment and Disability Institute
PHYSICAL MEDICINE & REHABILITATION UNIVERSITY OF MICHIGAN HEALTH SYSTEM

Education & Training

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Search... Search

TMB Home » Center for Large Data Research and Data Sharing in Rehabilitation » Education-training » Accessing Data Thursday, September 1, 2016

Home | About Us | Data Directory | Variable Catalog | Data Sharing & Archiving | Education & Training | Pilot Projects | Visiting Scholars

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.

Accessing | Analysis & Application | Archiving

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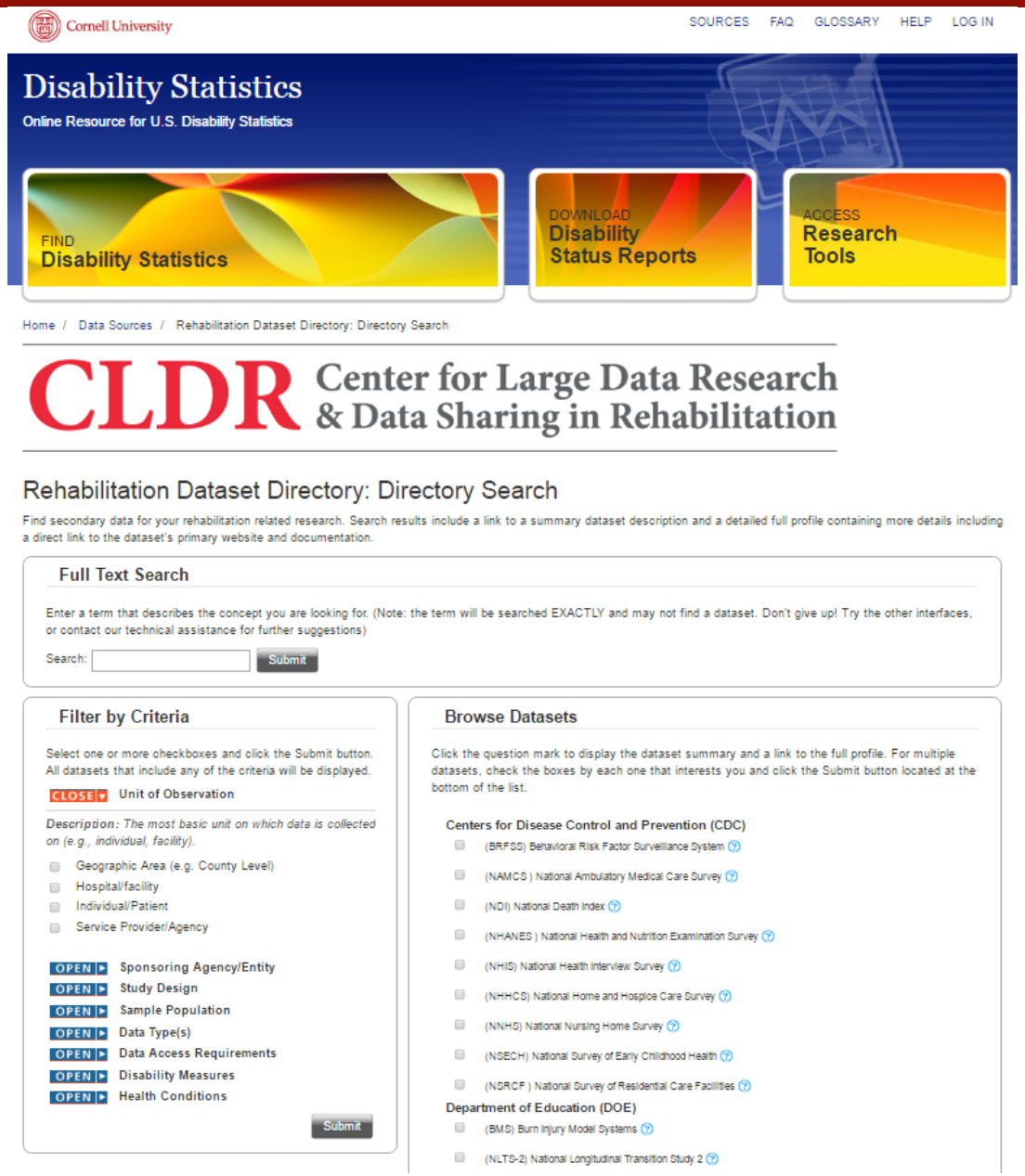
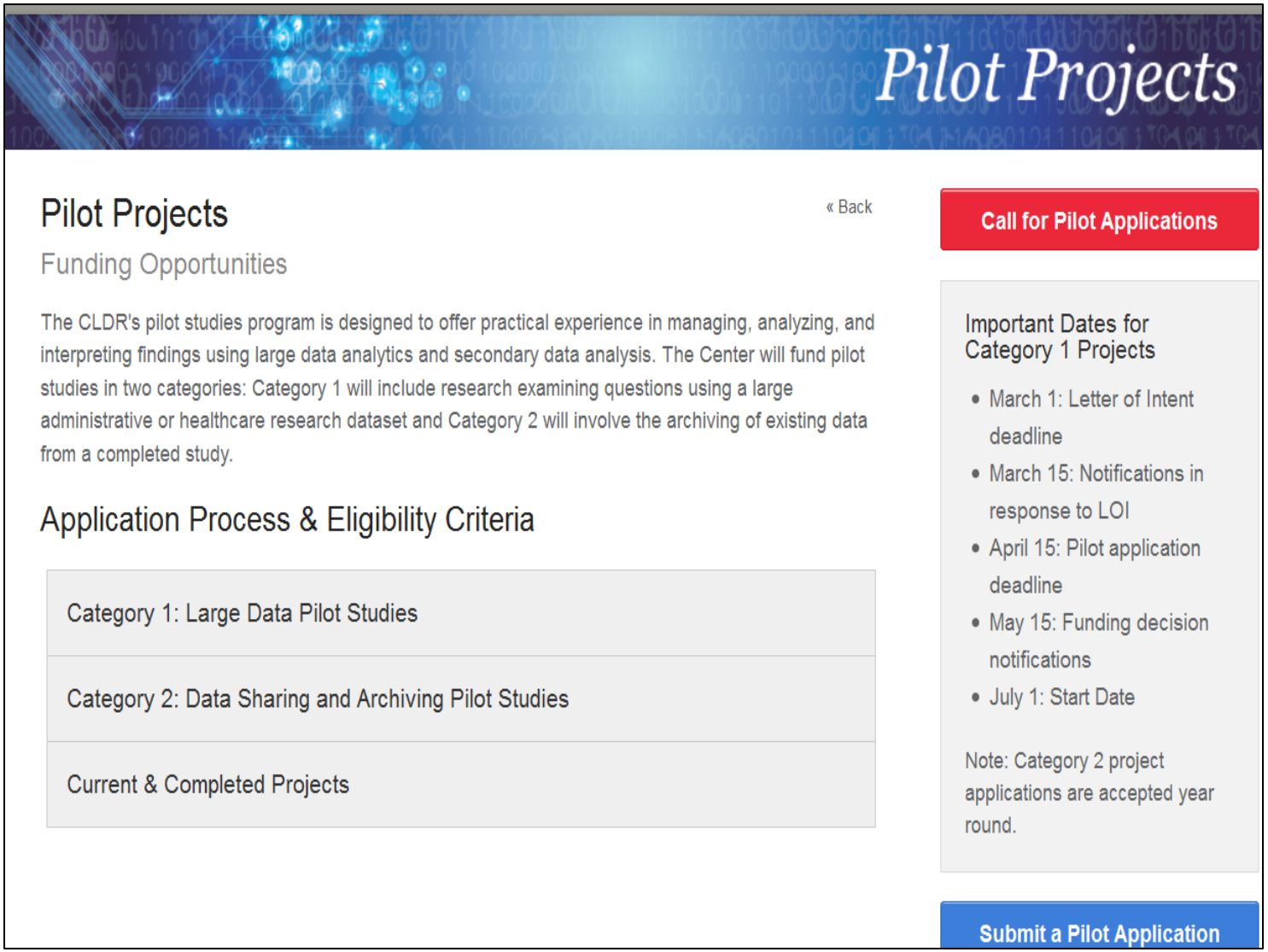
Data Directory



Pilot Projects



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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

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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**

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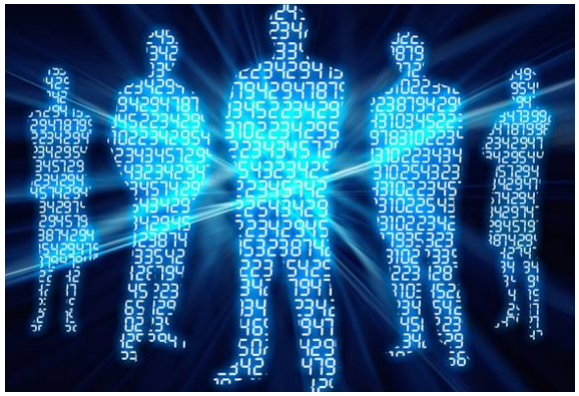
Visiting Scholars

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.



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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

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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.

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https://dash.nichd.nih.gov/

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/

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Large/Big Data Caveat

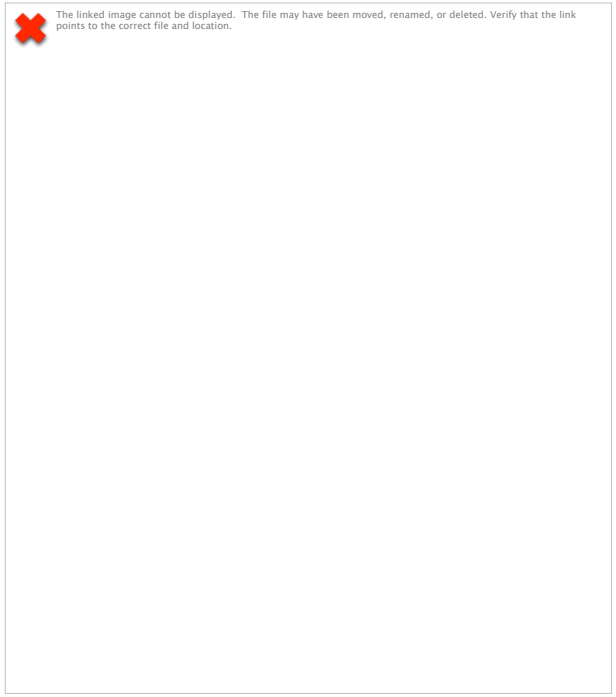
Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information?

T.S. Eliot (The Rock)

Where is the information we have lost in data?

Information



Rehabilitation Sciences Academic Division & Research Center

Phone: (409) 747-1637
Email: rehab.info@utmb.edu

http://rehabsciences.utmb.edu/cldr

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AT THE UNIVERSITY OF MICHIGAN

Cornell University
ILR School
Employment and Disability Institute

PHYSICAL MEDICINE & REHABILITATION
UNIVERSITY OF MICHIGAN HEALTH SYSTEM

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- ***Training***

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H133P110012	(PI, NIDILRR)

Large Data Research Team

Soham Al Snih, MD, PhD
Winston Chan, PhD
Nai-Wei Chen, PhD
Anne Deutsch, RN, PhD, CRRN
Brian Downer, PhD
Karl Eschbach, PhD
James Goodwin, MD
James Graham, PhD
Ickpyo Hong, PhD, OTR*
Bret Howrey, PhD
Jessica Jarvis, MS*
Amol Karmarkar, PhD, MPH
Amit Kumar, PT, PhD, MPH*
Yong-Fang Kuo, PhD
Chih-ying (Cynthia) Li, PhD, OTR*
Yi-Li Lin, MS
Addie Middleton, PT, DPT, PhD
Tim Reistetter, PhD, OTR
Jie Zhou, MS

** Postdoc or Graduate Student*