



ZUCKERBERG
SAN FRANCISCO GENERAL
Hospital and Trauma Center

UCSF Weill Institute for
Neurosciences
Brain and Spinal
Injury Center

The Burden and Benefits of 'Long-tail' data sharing

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Brain and Spinal Injury Center (BASIC)
Department of Neurological Surgery
Weill Institute for Neurosciences, UCSF
Principal Investigator, SFVAHCS

Disclosures

Grants:

US National Institutes of Health: R01NS088475, R01CA213441, R01AG056770, R01MH116156, U01NS086090, P30AR066262, UG3NS106899

US Veterans Affairs: 1I01RX002245, I01RX002787

US Department of Defense: SC150198, SC150177

US Department of Energy

Craig H. Neilsen Foundation

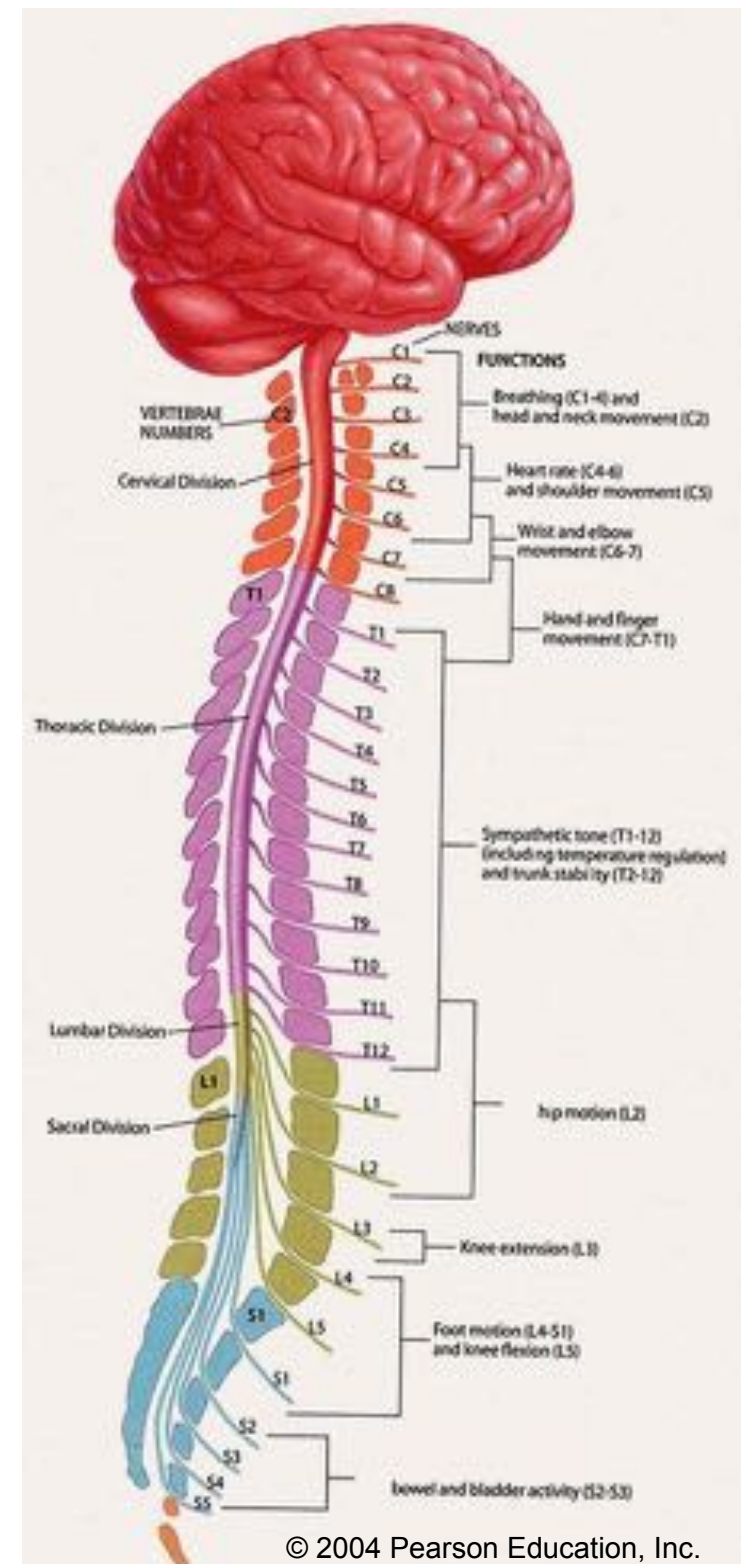
Wings for Life Foundation

Data Science Consulting (noncommercial):

Moody Project for Translational TBI

Santa Clara Valley Medical Center

Central Nervous System (CNS) Injury is Complex!



A Vitals from handwritten surgical notes

B Data Curation and Digital Entry

C Vitals During SCI Surgery (N=11)

D Average Weight (N=18)

E External anal sphincter EMG

F Treadmill and Kinematics

G Forelimb Locomotion

H Hindlimb Locomotion

I Climbing

J Cups

K Animal Observation

L Open-Field and Chair Behavior

M Treadmill and Kinematics

N Treadmill and Kinematics

O Treadmill and Kinematics

P Treadmill and Kinematics

Q Treadmill and Kinematics

R Treadmill and Kinematics

S Treadmill and Kinematics

T Treadmill and Kinematics

U Treadmill and Kinematics

V Treadmill and Kinematics

W Treadmill and Kinematics

X Treadmill and Kinematics

Y Treadmill and Kinematics

Z Treadmill and Kinematics

100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0%

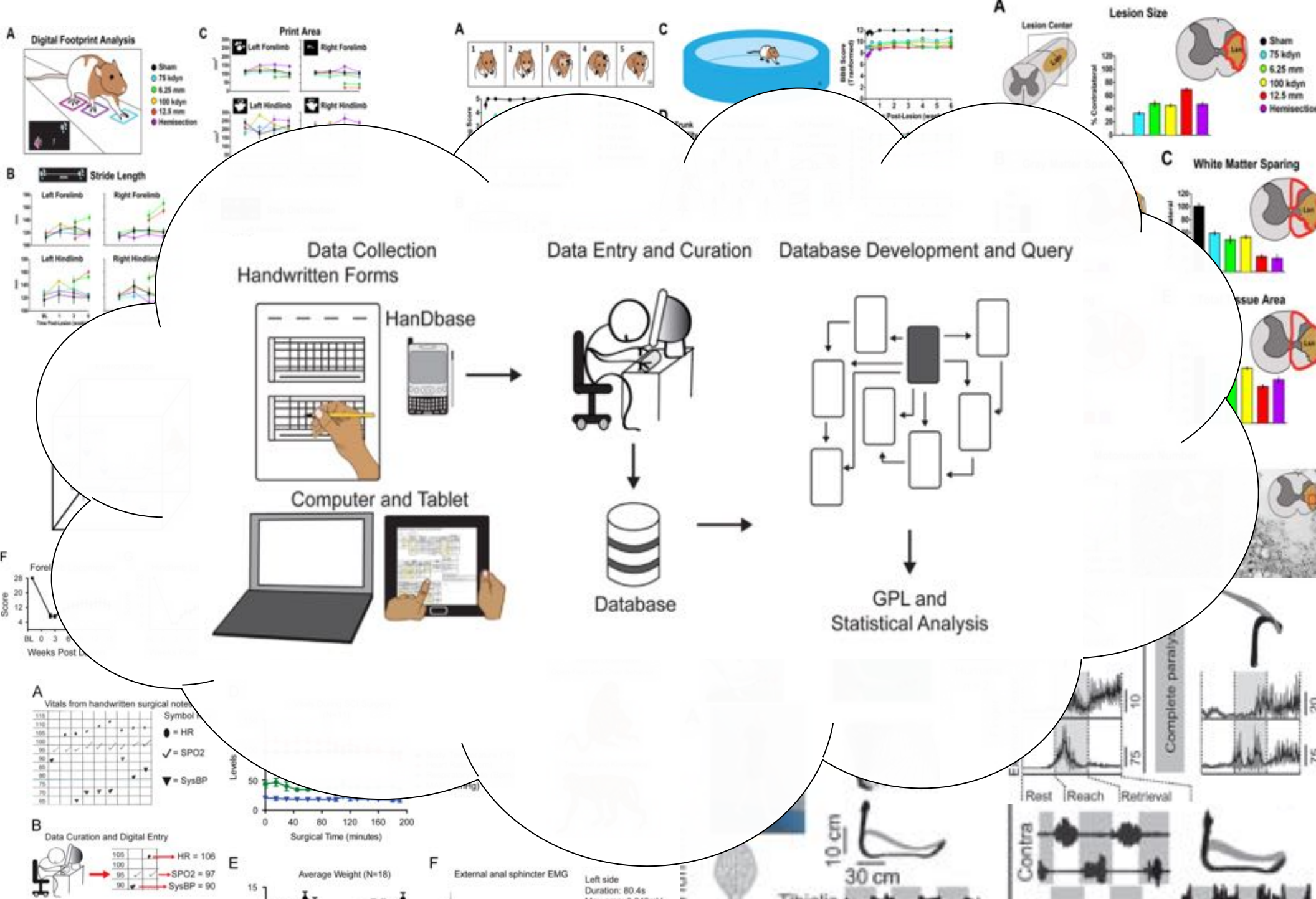


Figure Sources: Rosenzweig et al., 2010; 2019 *Nat Neurosci*; Ferguson et al., 2013 *PLoS One*; Nielson et al., 2014, *J Neurotrauma*; Nielson et al., 2015, *Brain Res.*; Friedli et al., 2015 *Science TM*; Rosenzweig et al., 2019 *Nat Medicine*

CNS Injury as a 'big data' problem?



- volume
- velocity
- variety

Ferguson et al., Nat Neuro
2014; Huie et al., 2019,
Curr Opin. Neurology

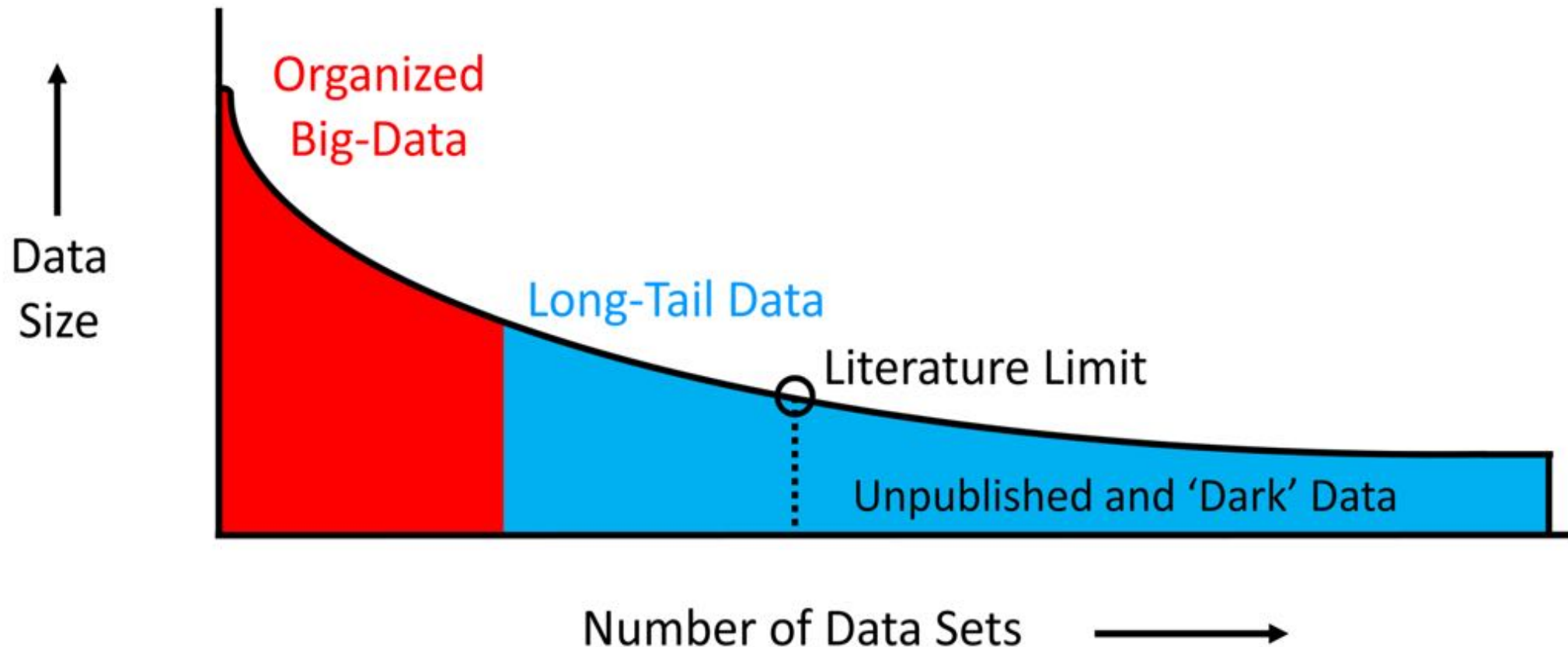
CNS Injury as a 'big data' problem?



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- velocity
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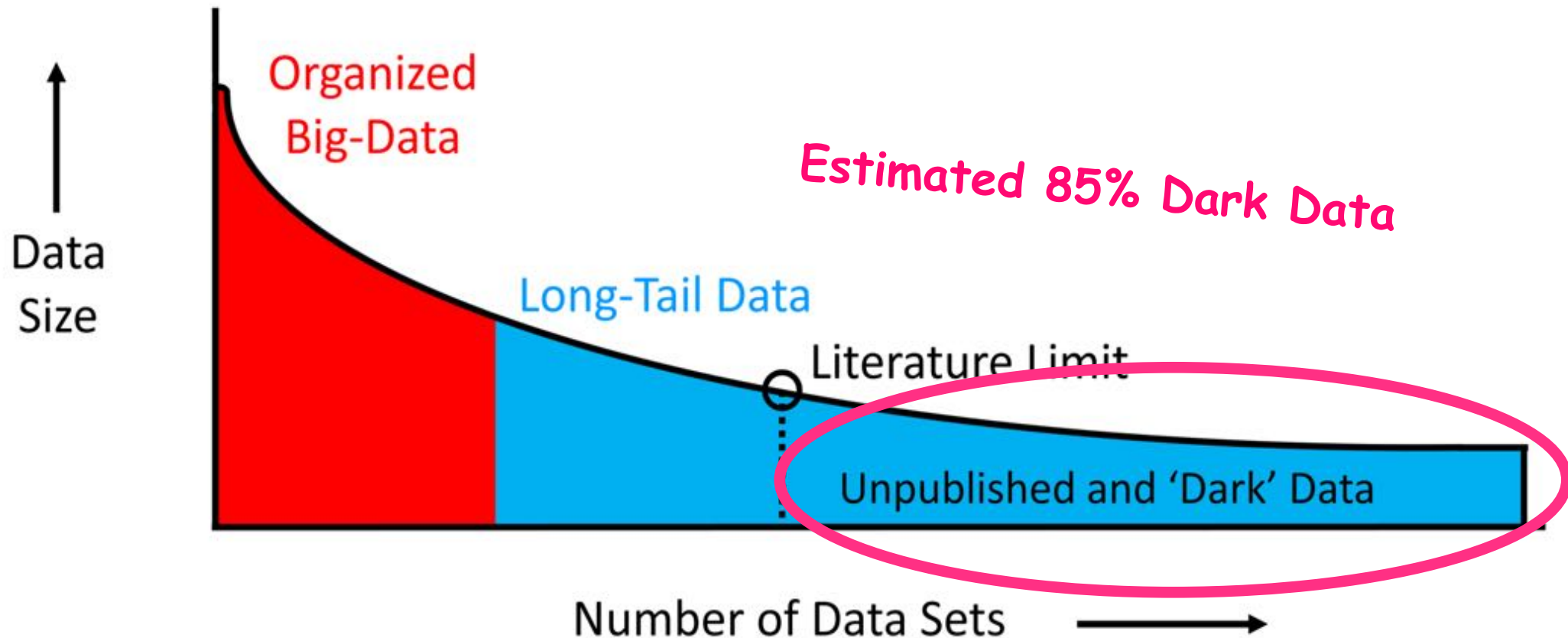
Ferguson et al., Nat Neuro
2014; Huie et al., 2019,
Curr Opin. Neurology

TOWARD 'DATAFICATION' OF BIOMEDICAL RESEARCH



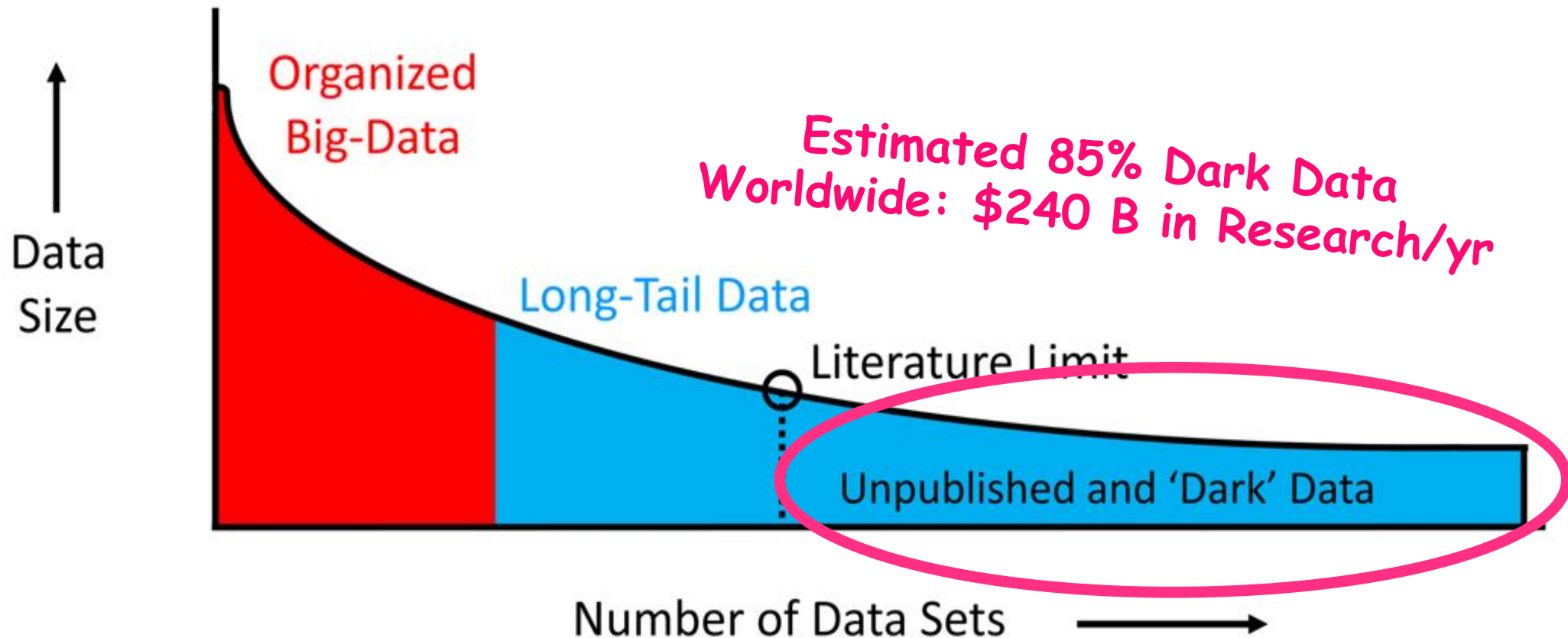
Ferguson et al., 2014, *Nature Neuroscience*
Huie et al., 2019, *Current Opinion in Neurology*
Hawkins et al., 2019, *Journal of Neurotrauma*

TOWARD 'DATAFICATION' OF BIOMEDICAL RESEARCH



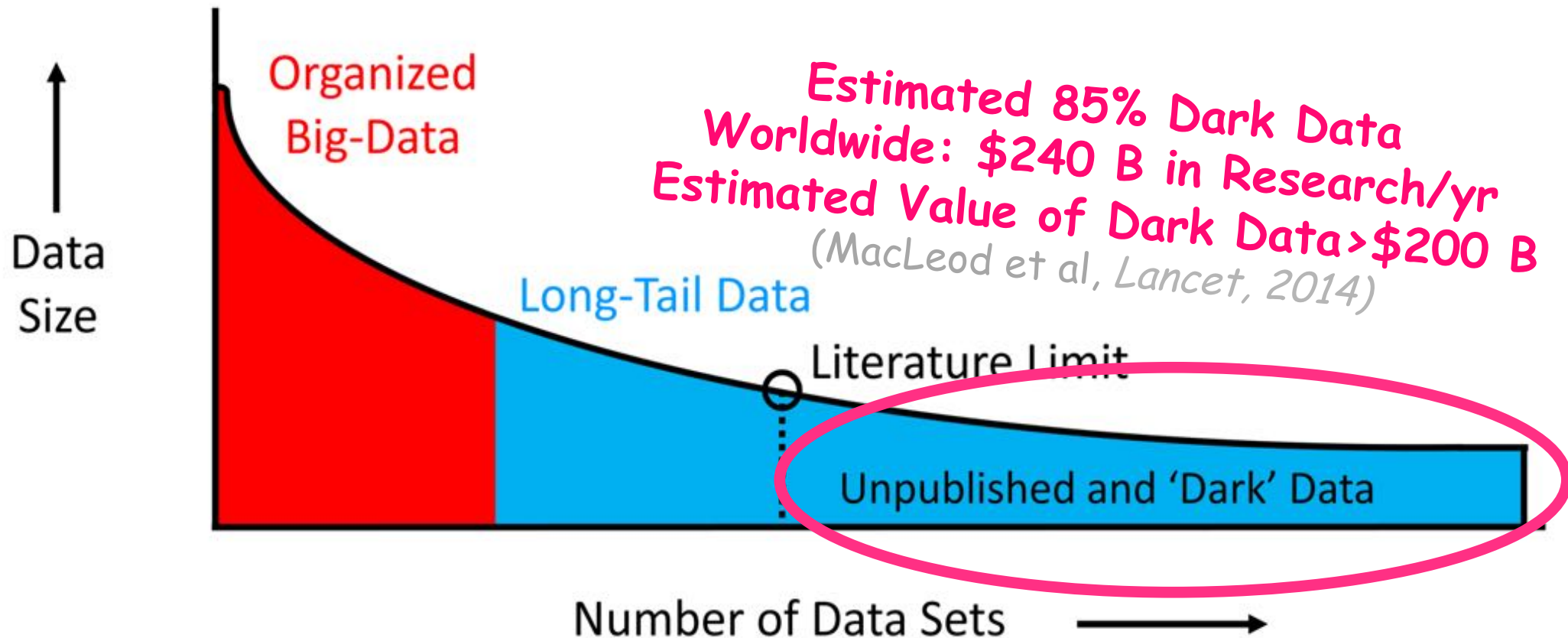
Ferguson et al., 2014, *Nature Neuroscience*
Huie et al., 2019, *Current Opinion in Neurology*
Hawkins et al., 2019, *Journal of Neurotrauma*

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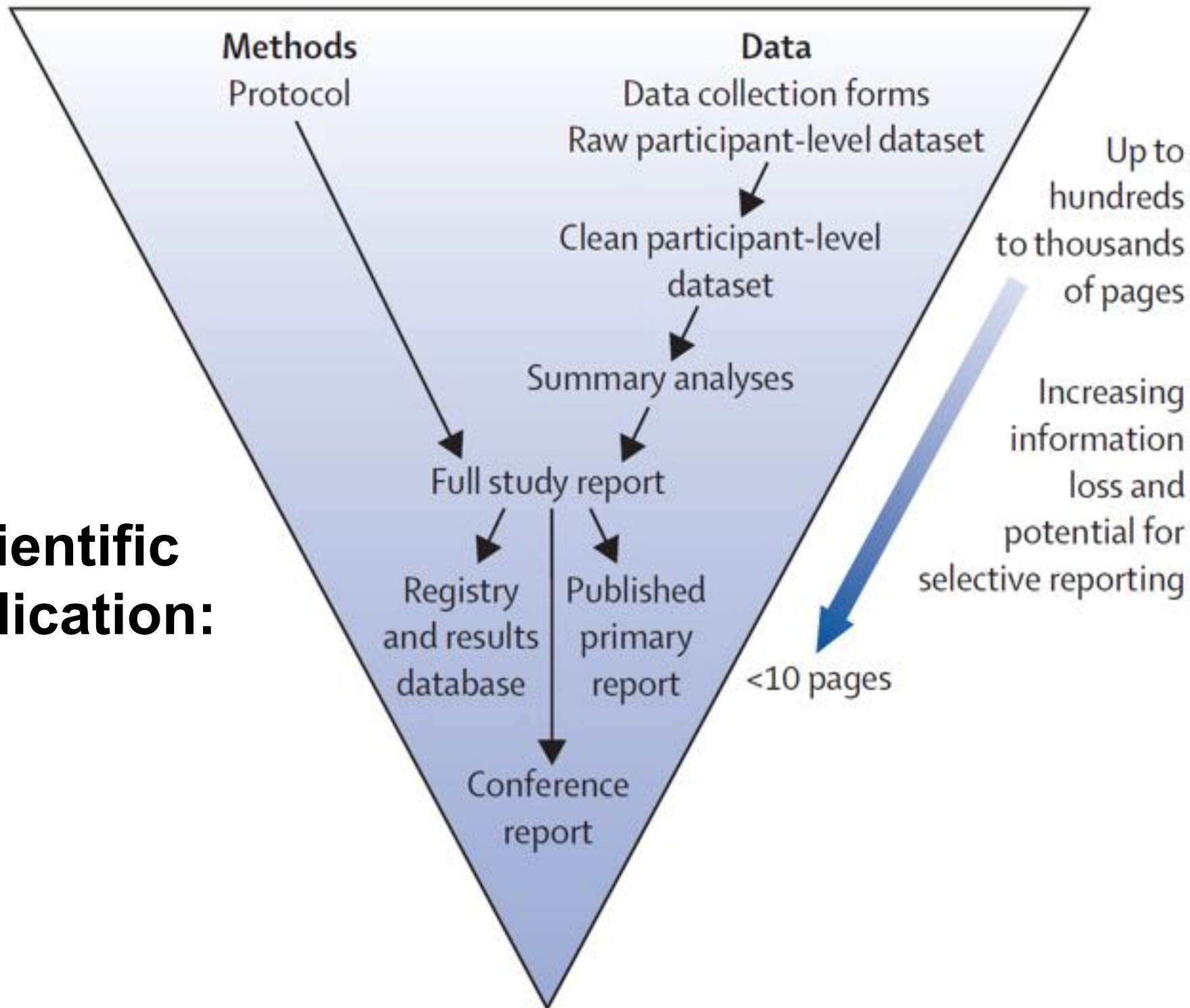


PLOS Medicine | www.plosmedicine.org

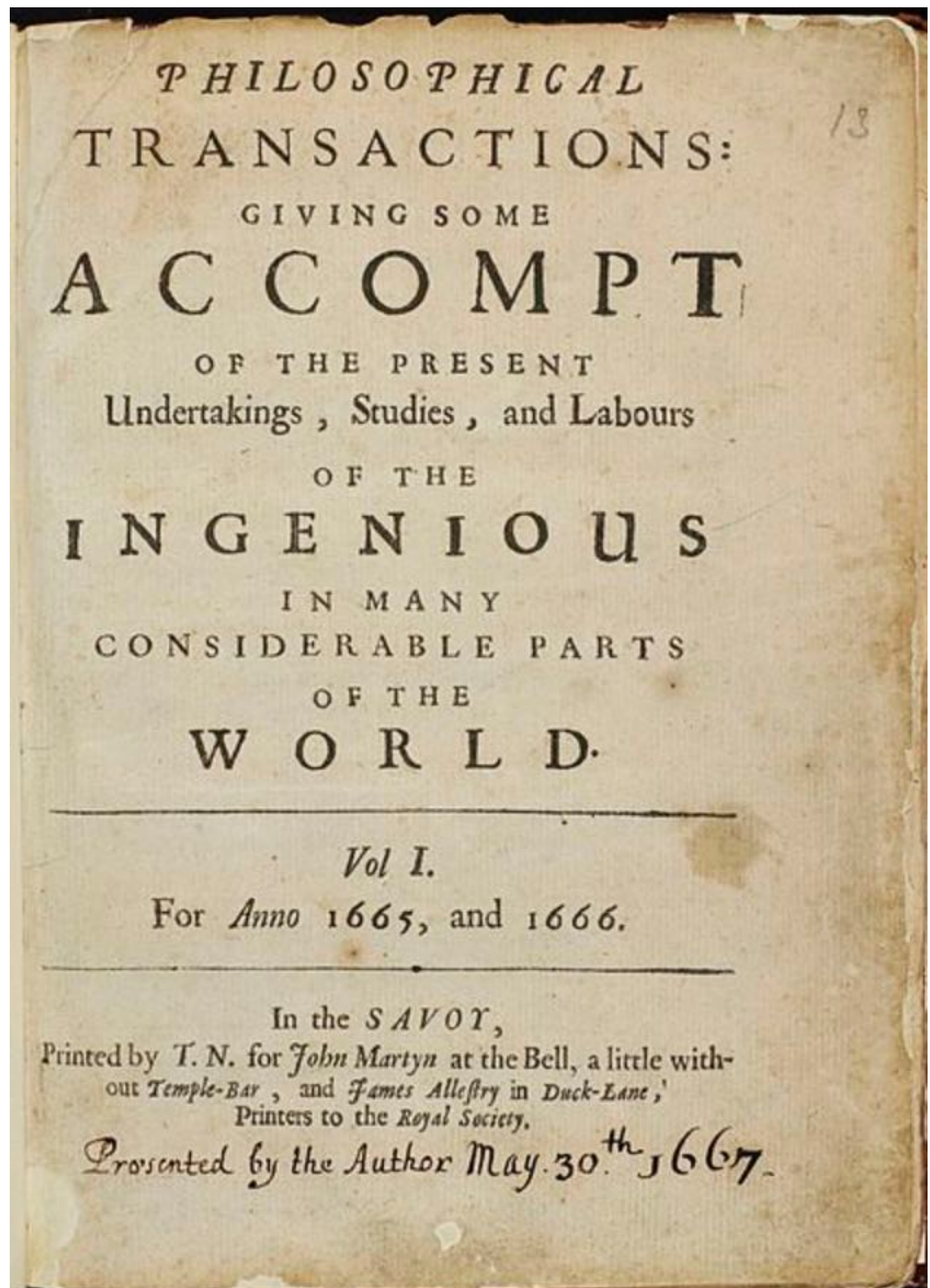
Why Most Published Research Findings Are False

John P. A. Ioannidis

Scientific Publication:



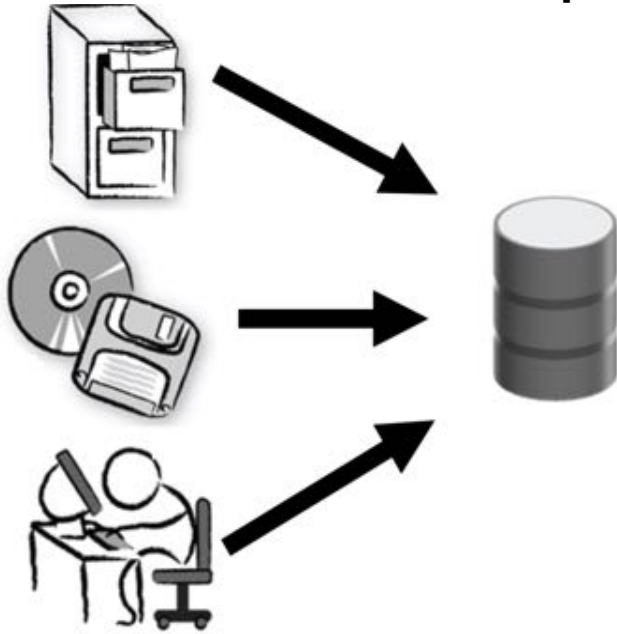
**Scientific
Publication:**
A 17th century data-
sharing technology



21st Century Solution?

Raw Data Sources

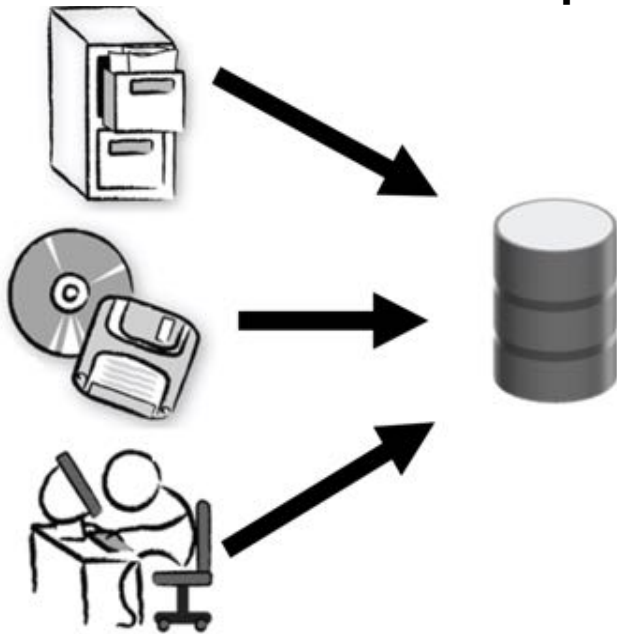
Multispecies Data Repository



Raw Data
Sources

Multispecies
Data Repository

*~60 million data-points from ~4000
basic science and **human** medical
records; 13 centers*

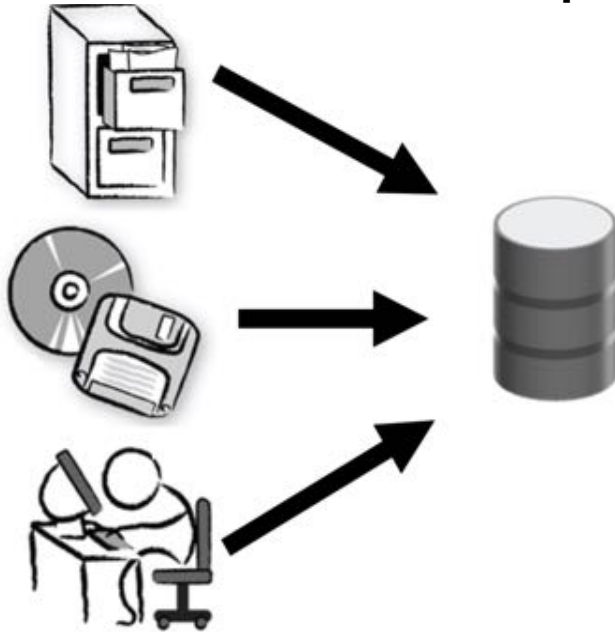


‘VISION-SCI’ Repository

Raw Data
Sources

Multispecies
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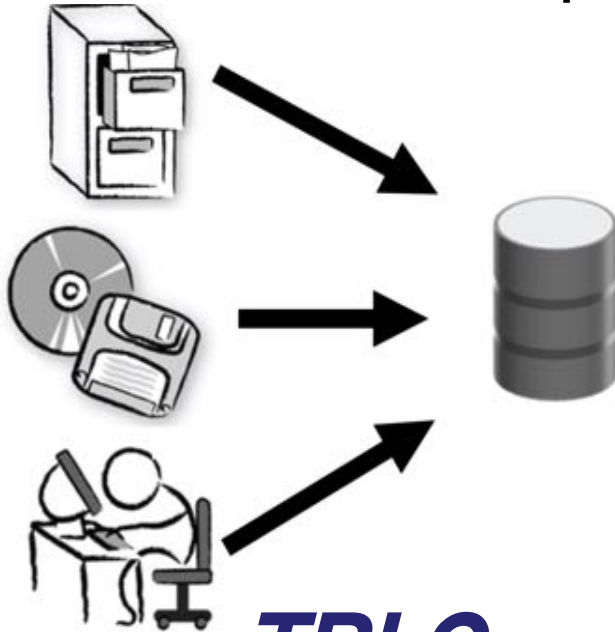
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'VISION-SCI' Repository

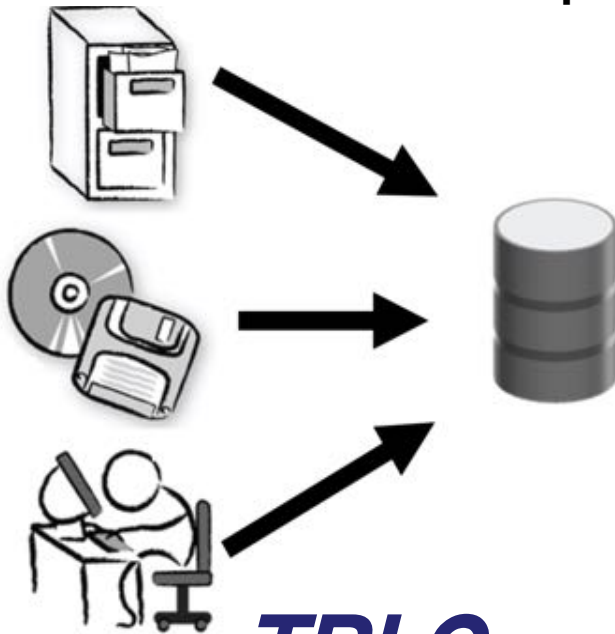


***TBI Open Data
Commons***
[*http://odc-tbi.org*](http://odc-tbi.org)

Raw Data
Sources

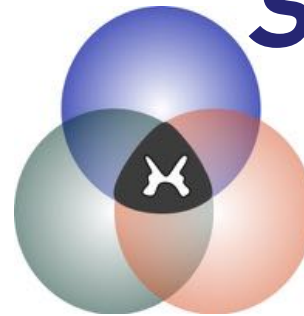
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***SCI Open Data
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Initiative***



***TBI Open Data
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[***http://odc-tbi.org***](http://odc-tbi.org)

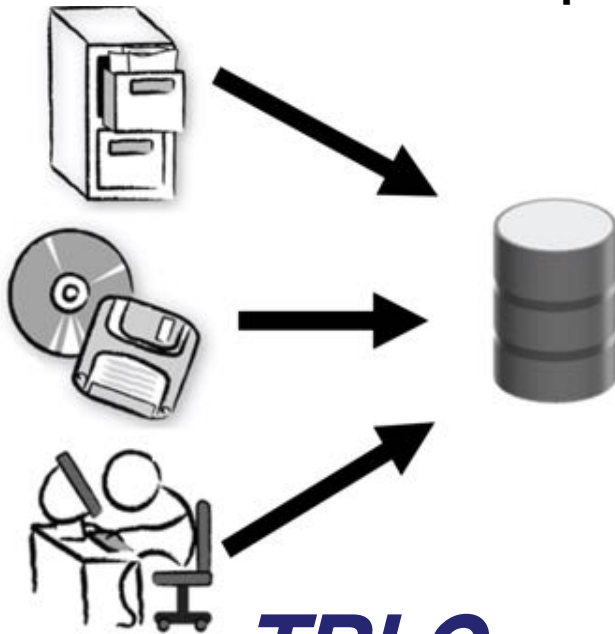


**VA Gordon
Mansfield SCI
Consortium**

Raw Data
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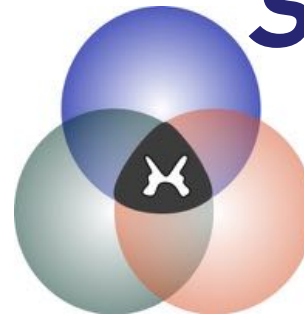
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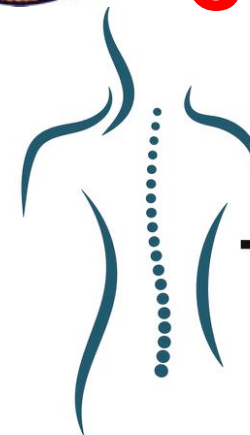
**VA Gordon
Mansfield SCI
Consortium**



TRACK-TBI

*Transforming Research and Clinical Knowledge
in Traumatic Brain Injury*

International Traumatic Brain Injury Research Initiative



TRACK-SCI

TRANSFORMING RESEARCH AND CLINICAL
KNOWLEDGE IN SPINAL CORD INJURY

FAIR Data Stewardship

- **Findable:** (meta)data is uniquely and persistently identifiable. Should have basic machine readable descriptive metadata.
- **Accessible:** data is reachable and accessible by humans and machines using standard formats and protocols.
- **Interoperable:** (meta)data is machine readable and annotated with resolvable vocabularies/ontologies.
- **Reusable:** (meta)data is sufficiently well-described to allow (semi)automated integration with other compatible data sources.



Wilkinson et al, 'The FAIR Guiding Principles scientific data management and stewardship,' Nature Scientific Data, 2016



Developing a **FAIR** Share Community

Sharing Data that is

Findable

Accessible

Interoperable

Reusable

October 4-5, 2016
6001 Executive Blvd.
North Bethesda, MD

Developing a FAIR Share Community

Sharing Data that is

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FAIR-SCI Ahead

SCI Preclinical Community
Readiness and Next Steps

Washington DC,
November 10, 2017

Developing a FAIR Share Community

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October 4-5, 2016
6001 Executive Blvd.
North Bethesda, MD

FAIR-SCI Ahead

SCI Preclinical Community
Readiness and Next Steps

Washington DC,
November 10, 2017

STREET-FAIR

SCI Team Research, Enabling Expansion
and Translation of FAIR data sharing

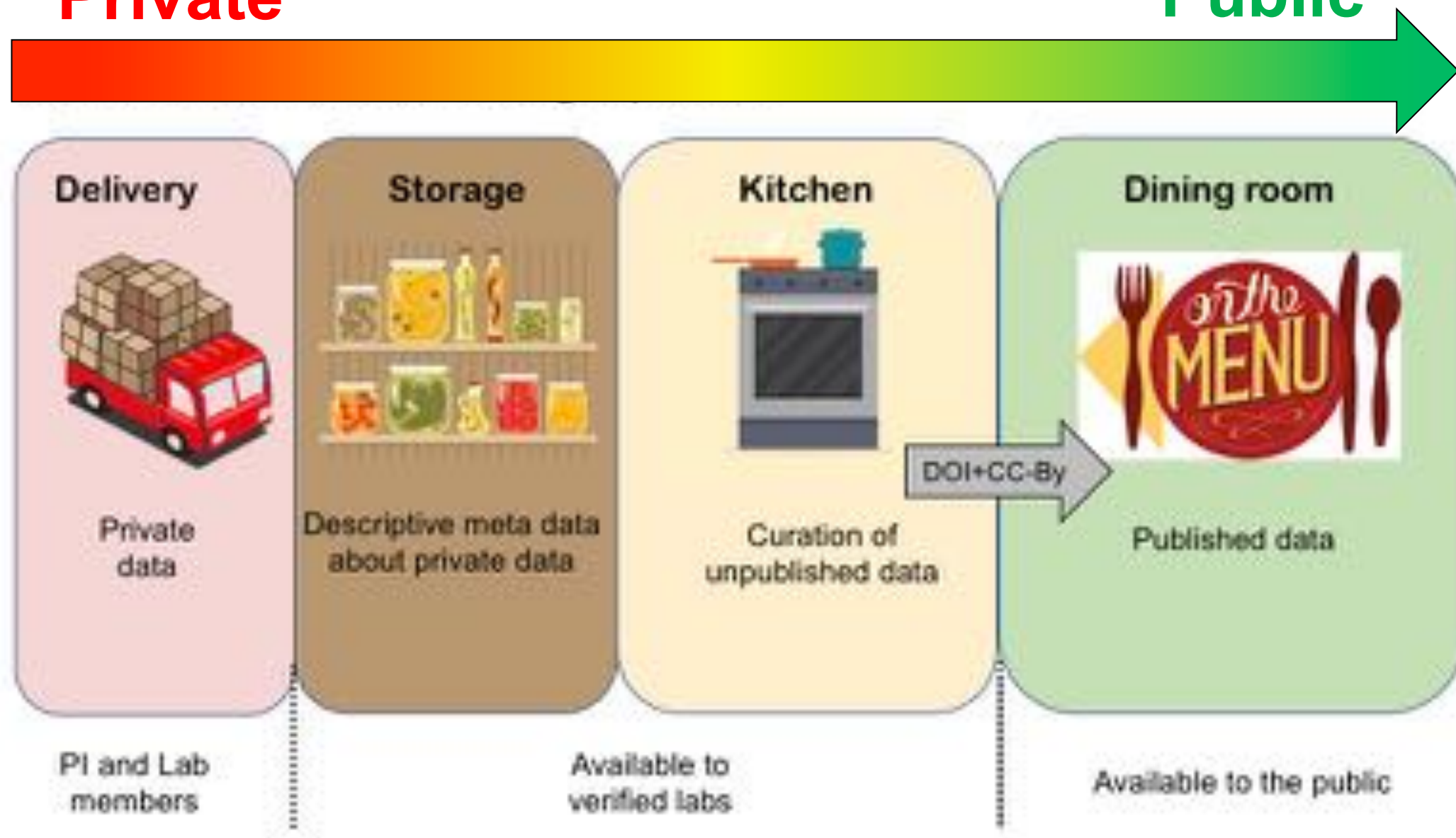
November 4, 2018
San Diego, CA



[HTTP://ODC-SCI.ORG](http://ODC-SCI.ORG)

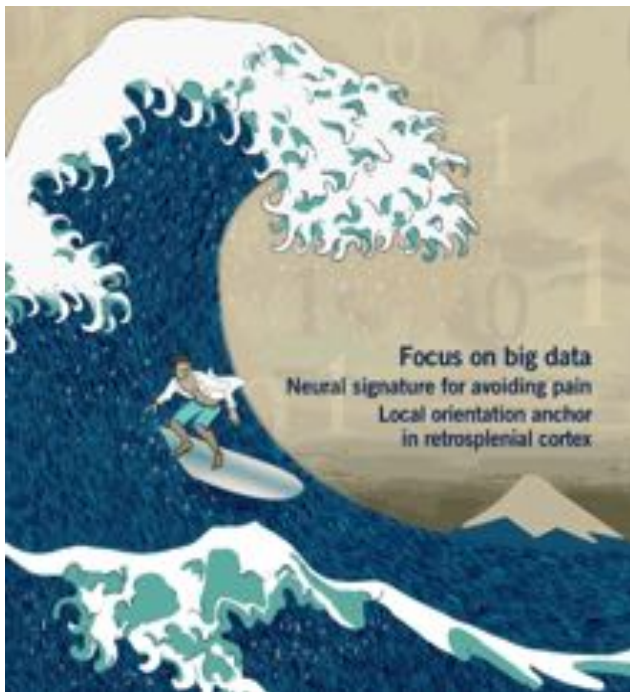
Private

Public



Fouad et al., submitted

So you now have big data...
THEN WHAT??



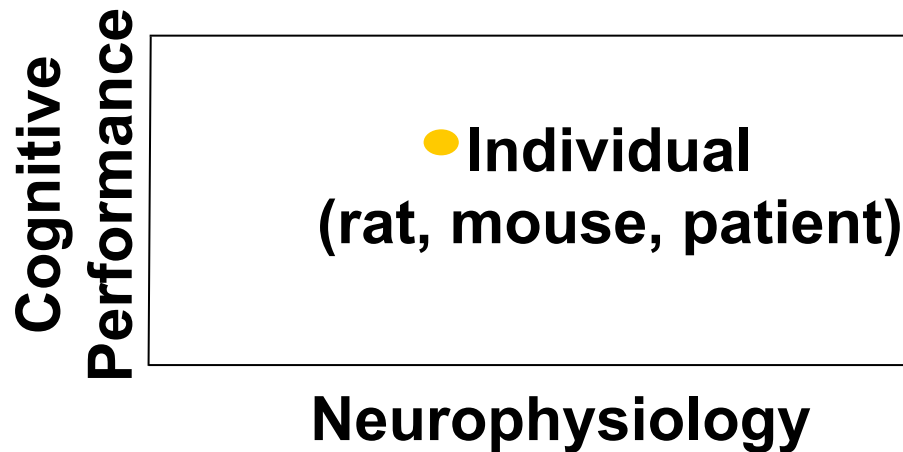
???

???

A set of six red question marks arranged in two rows of three, representing uncertainty or a lack of direction.

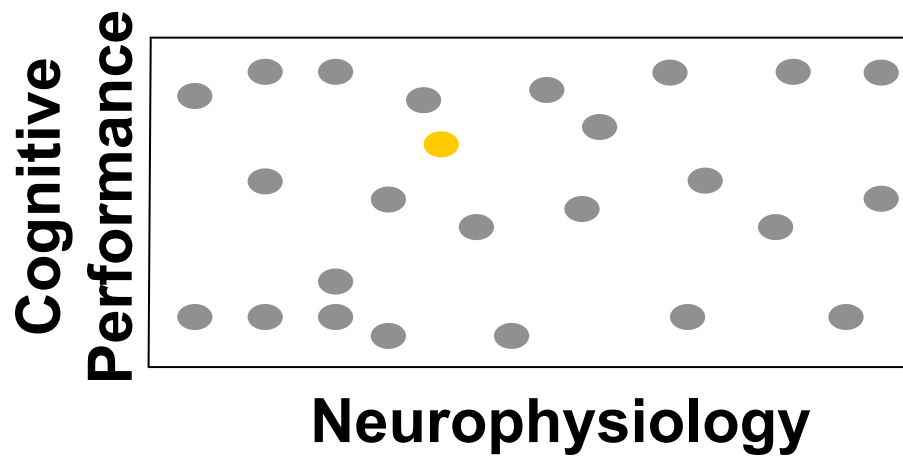
Syndromic Data Integration

Functional Changes

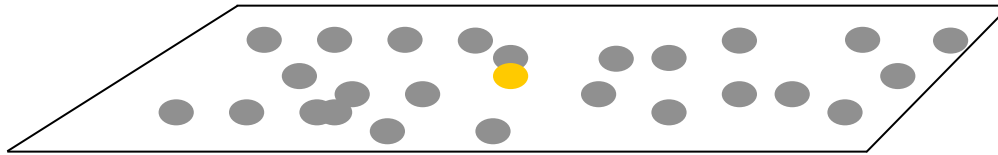


Syndromic Data Integration

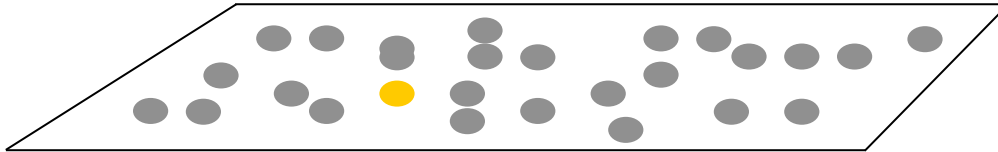
Functional Changes



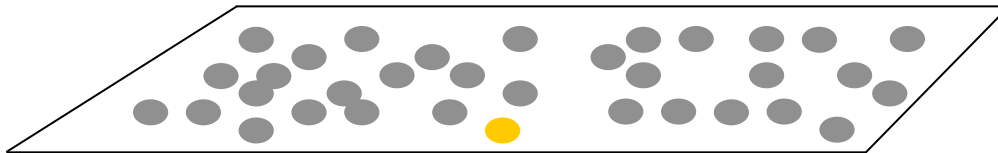
Syndromic Data Integration



**Functional
Changes**

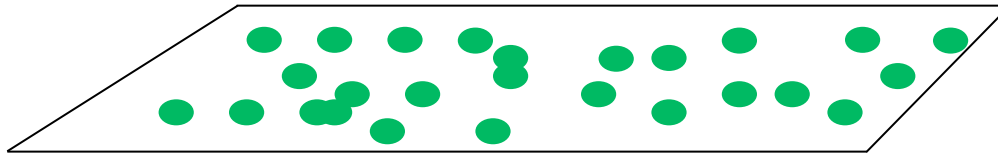


Biomarkers

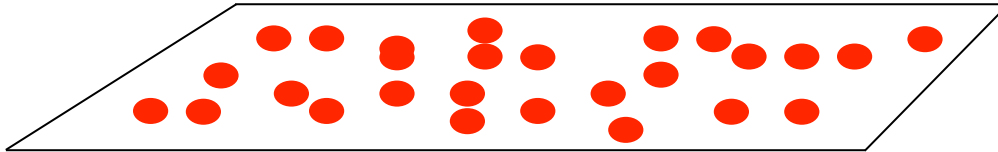


**Tissue
Changes**

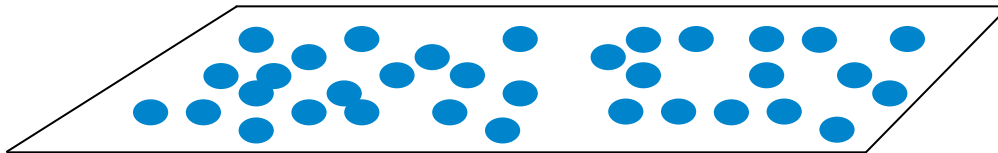
Syndromic Data Integration



**Functional
Changes**

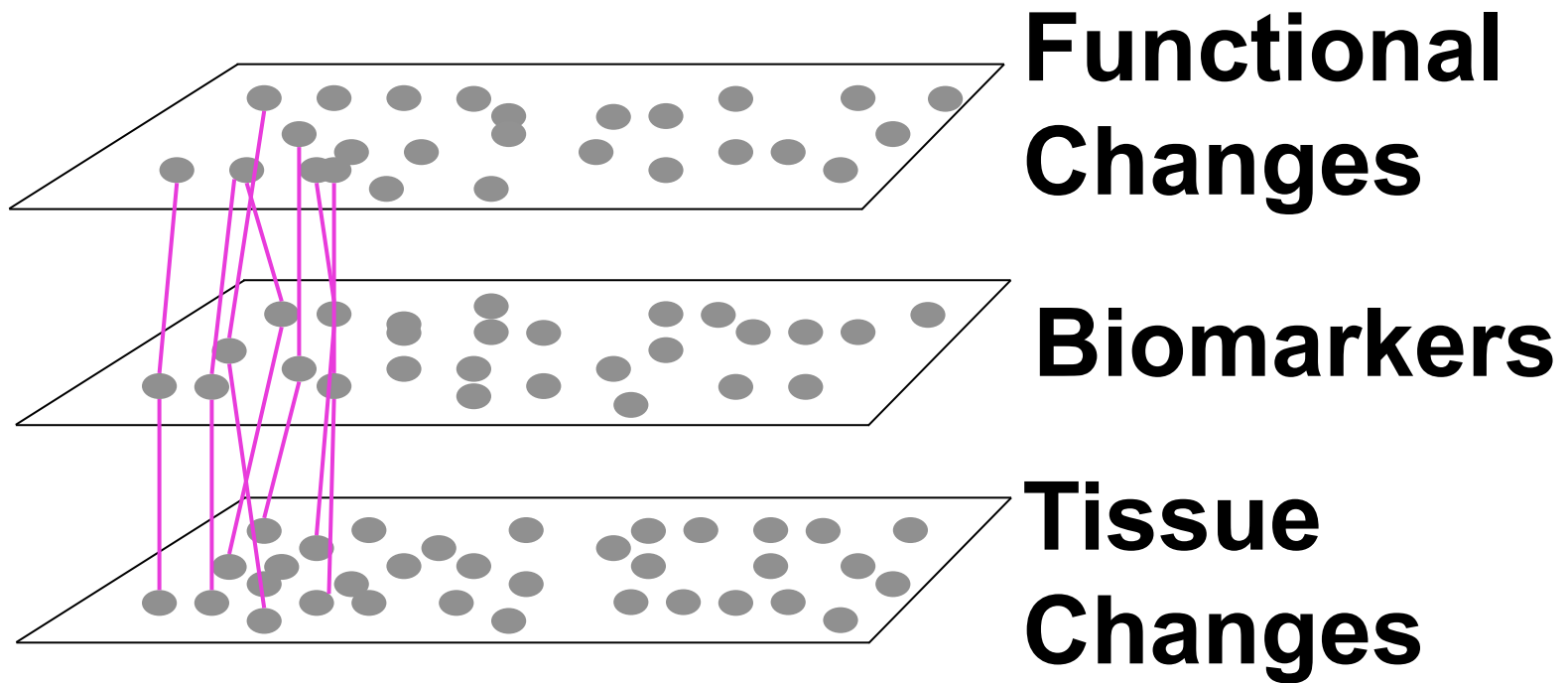


Biomarkers

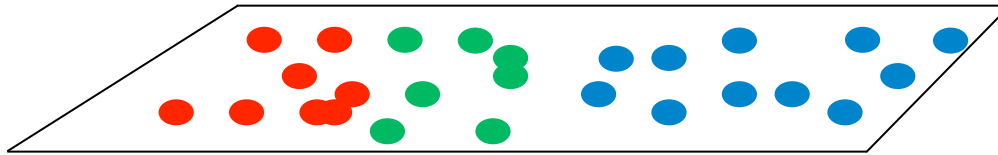


**Tissue
Changes**

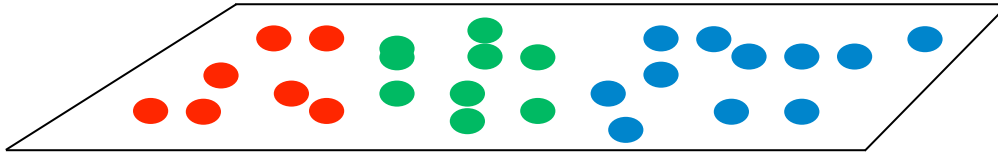
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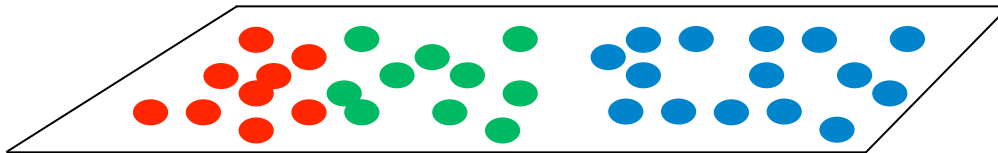
Syndromic Data Integration



**Functional
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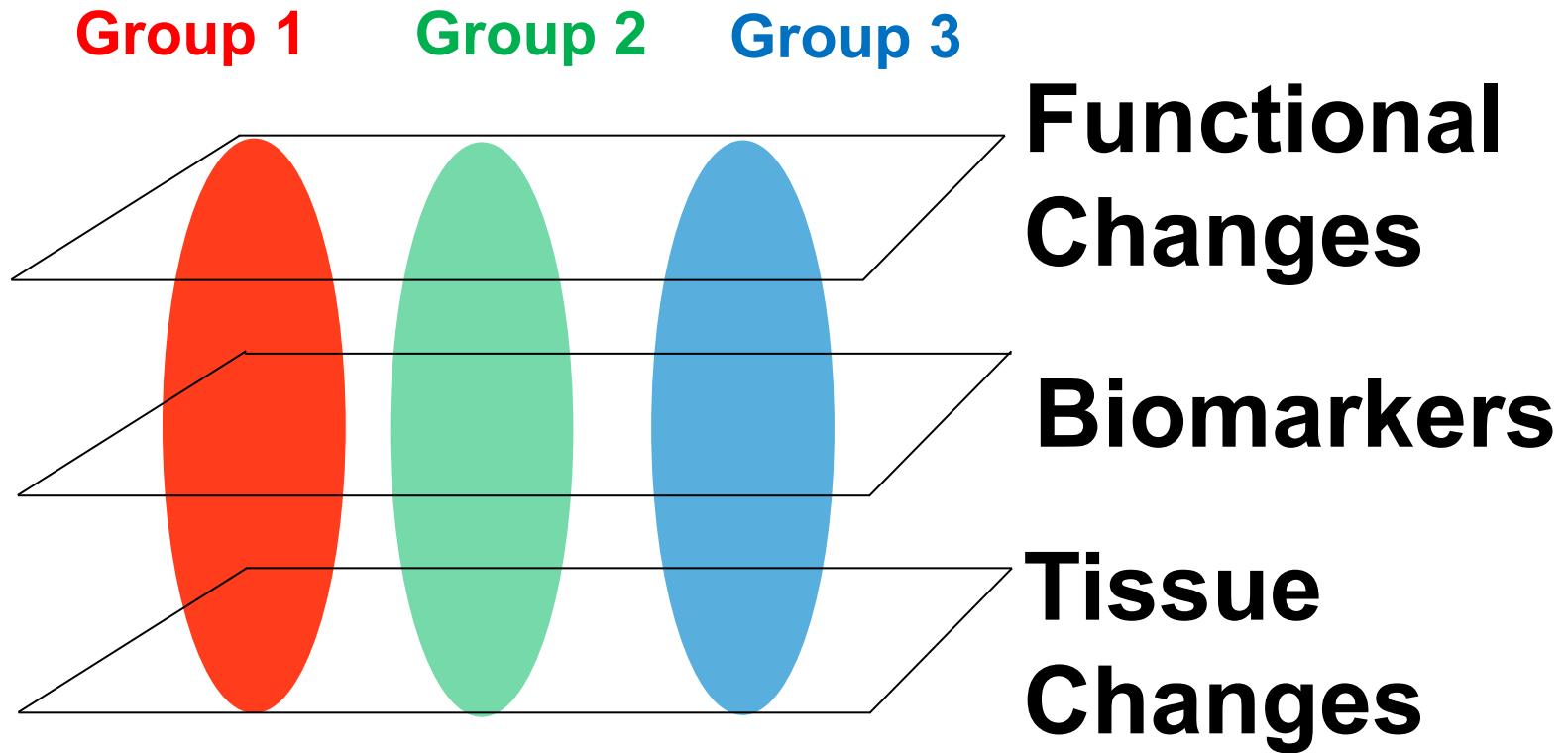


Biomarkers

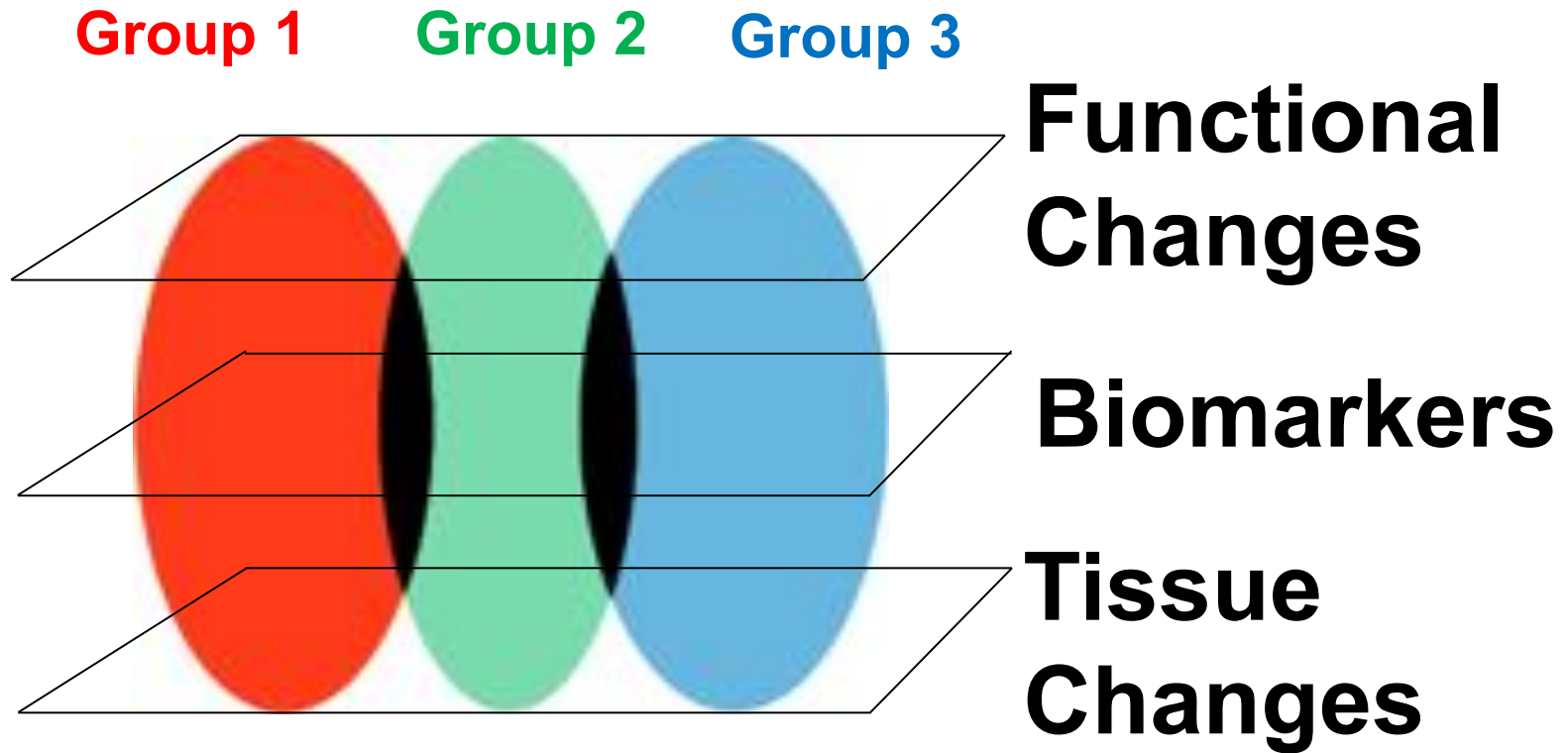


**Tissue
Changes**

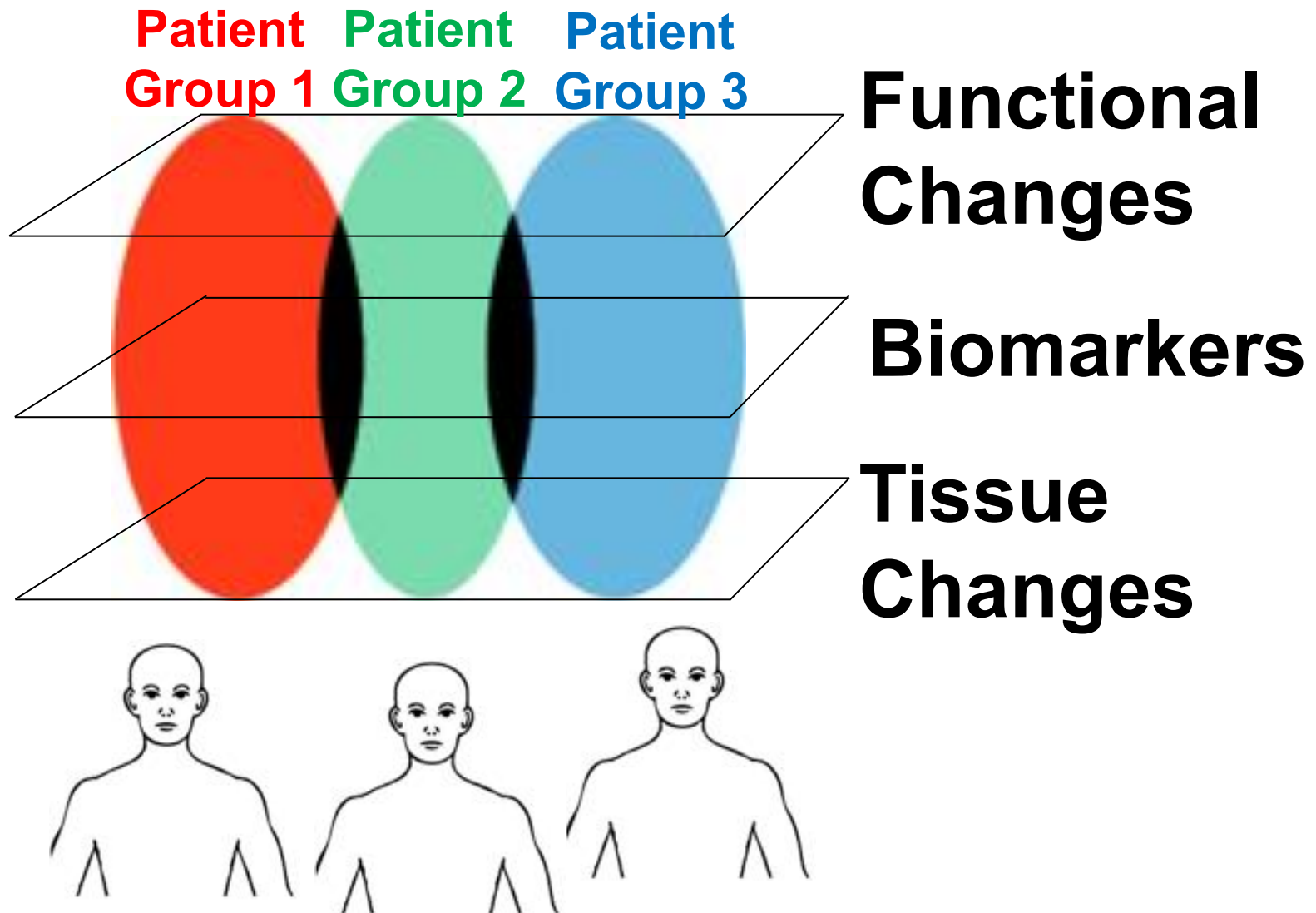
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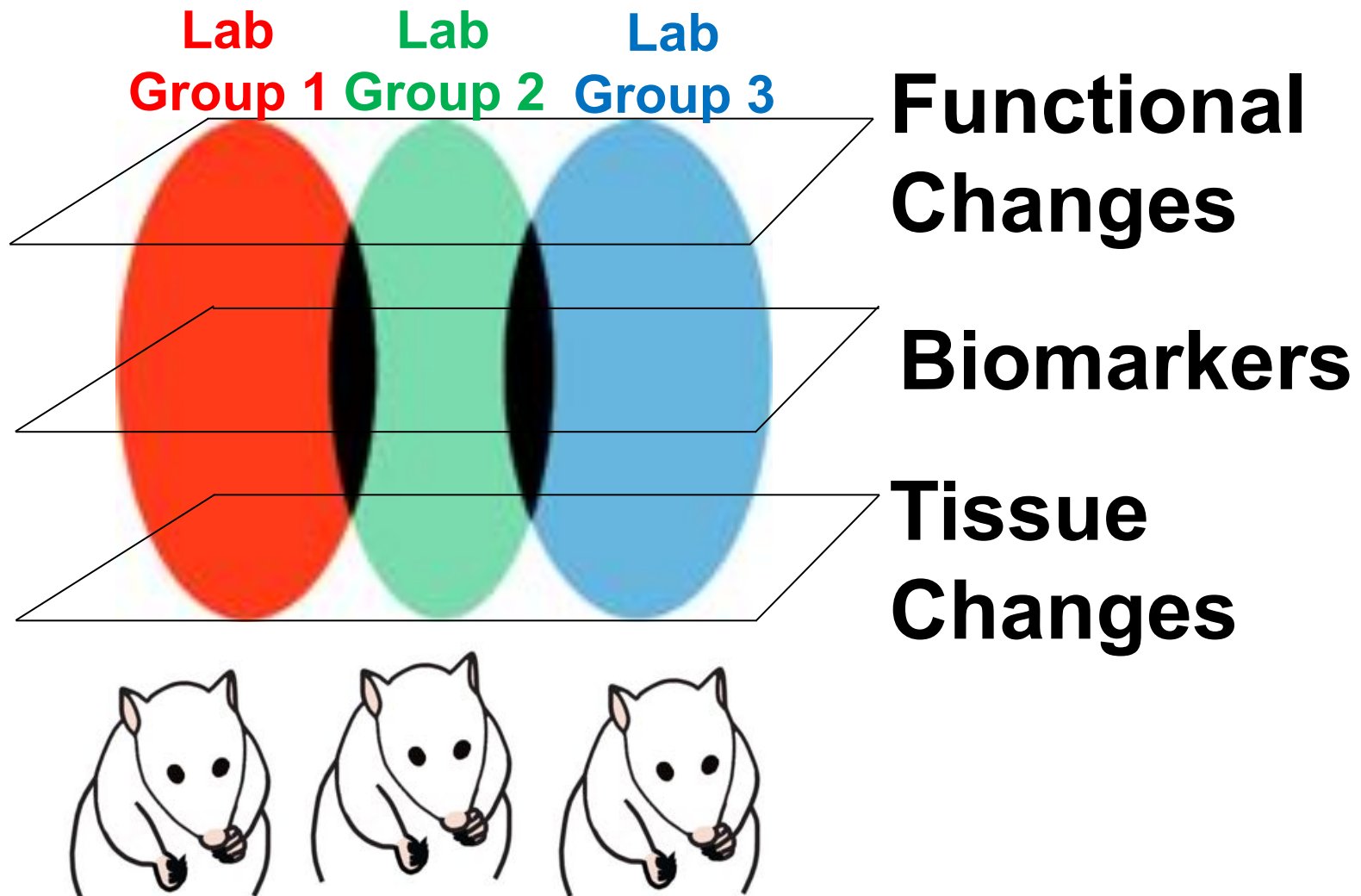
Syndromic Data Integration



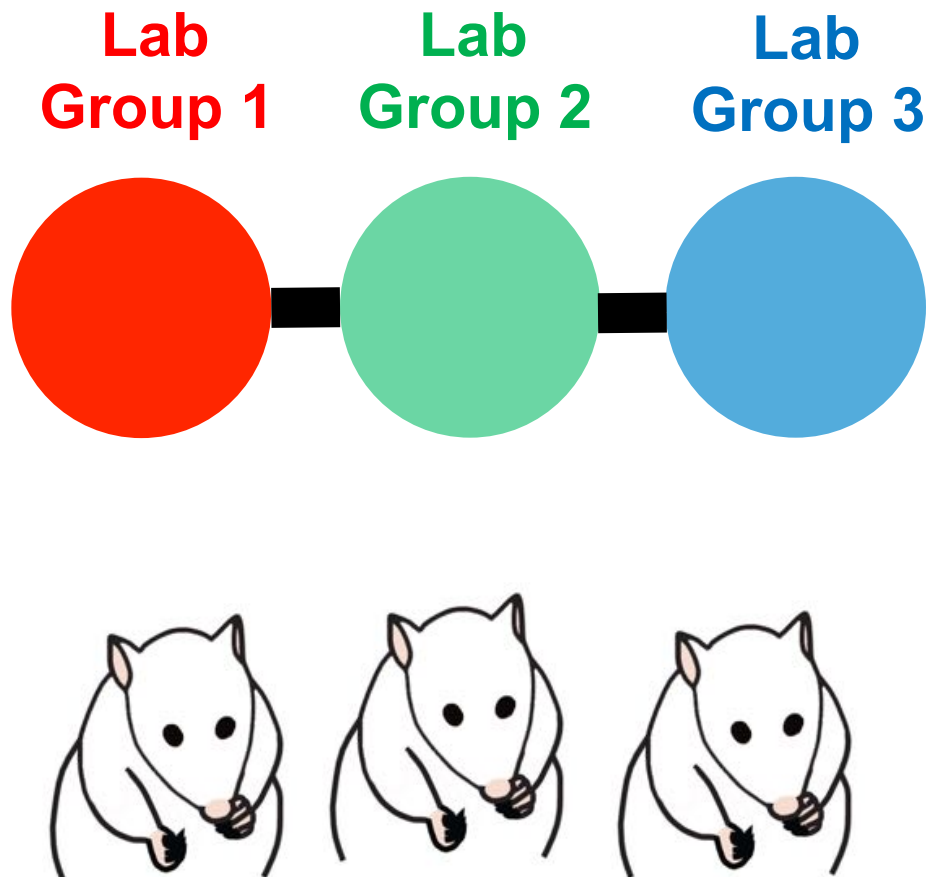
Precision Medicine



Precision Reproducibility?



Precision Reproducibility?





Jessica Nielson, PhD

Now: Assistant Professor University of Minnesota

Dept. Psychiatry and Institute of Health Informatics (IHI)



ARTICLE

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OPEN

Topological data analysis for discovery in preclinical spinal cord injury and traumatic brain injury

Jessica L. Nielson¹, Jesse Paquette², Aiwen W. Liu¹, Cristian F. Guandique¹, C. Amy Tovar³, Tomoo Inoue⁴, Karen-Amanda Irvine⁵, John C. Gensel⁶, Jennifer Klope⁷, Tanya C. Petrossian⁸, Pek Y. Lum⁹, Gunnar E. Carlsson^{7,10}, Geoffrey T. Manley¹, Wise Young¹¹, Michael S. Beattie¹, Jacqueline C. Bresnahan¹ & Adam R. Ferguson^{1,12}

Long-tail data archive: Multicenter animal spinal cord injury study (MASCIS) 1994-1996

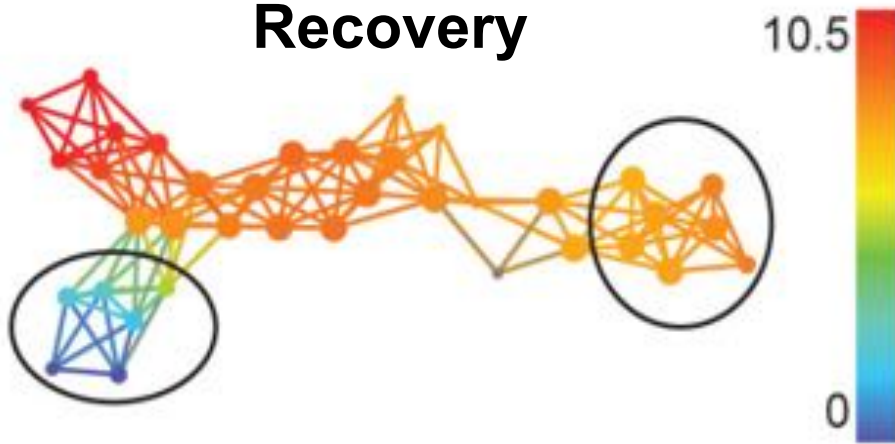


Data integration
team



Multicenter Animal SCI Study (MASCIS 1994-96)

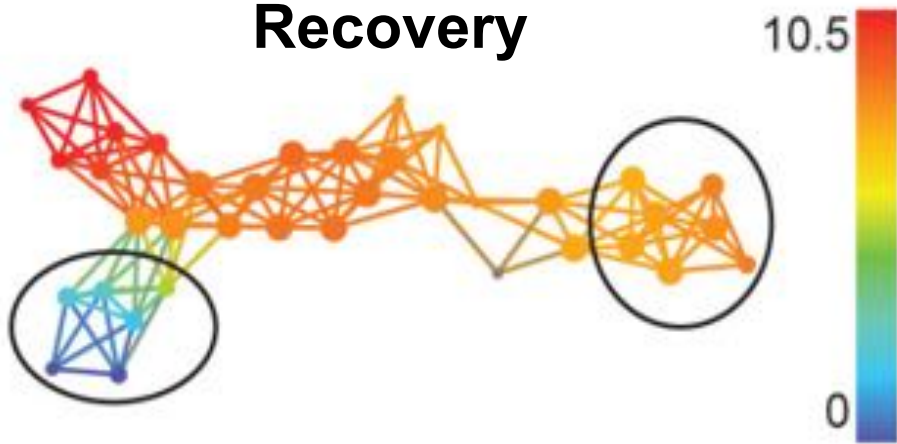
**Locomotor
Recovery**



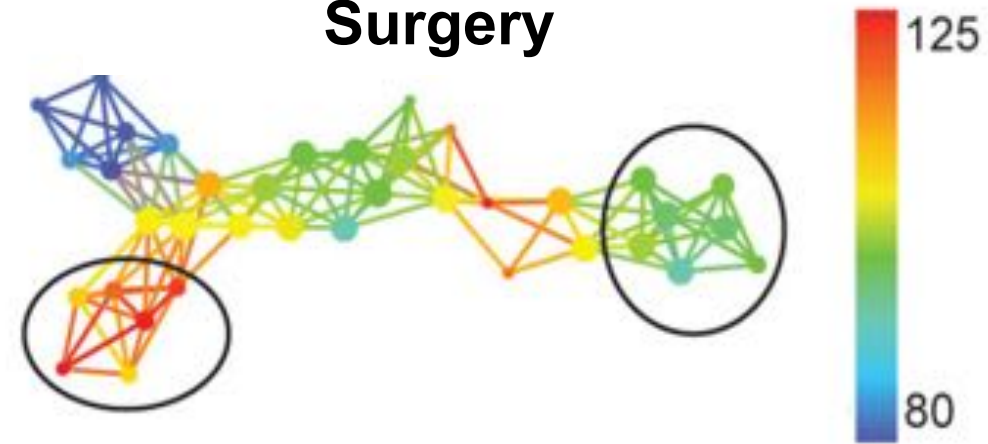
Nielson et al., 2015
*Nature
Communications*

Multicenter Animal SCI Study (MASCIS 1994-96)

**Locomotor
Recovery**



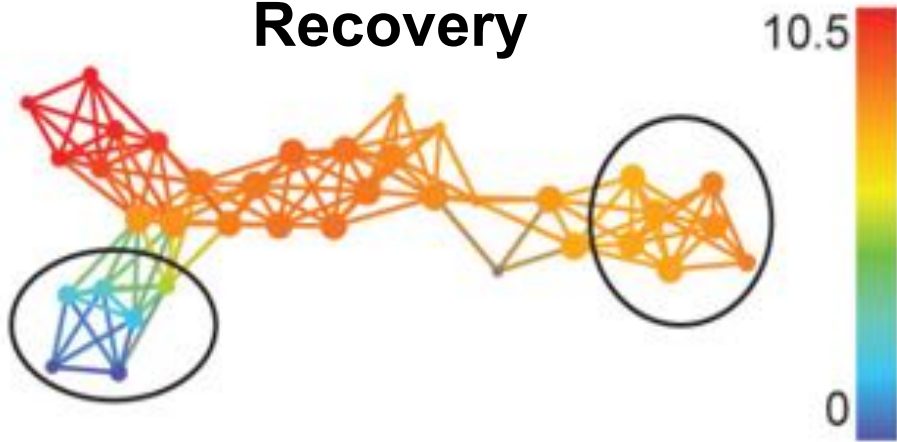
**Blood Pressure During
Surgery**



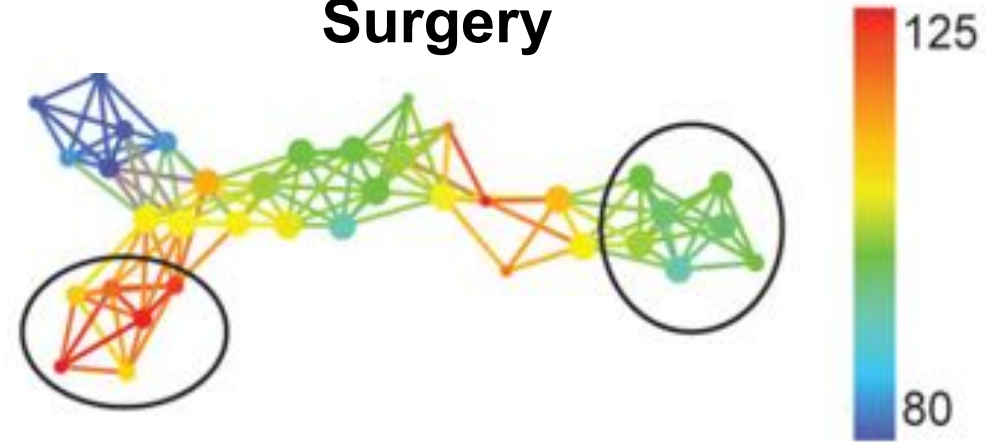
Nielson et al., 2015
*Nature
Communications*

Multicenter Animal SCI Study (MASCIS 1994-96)

Locomotor
Recovery

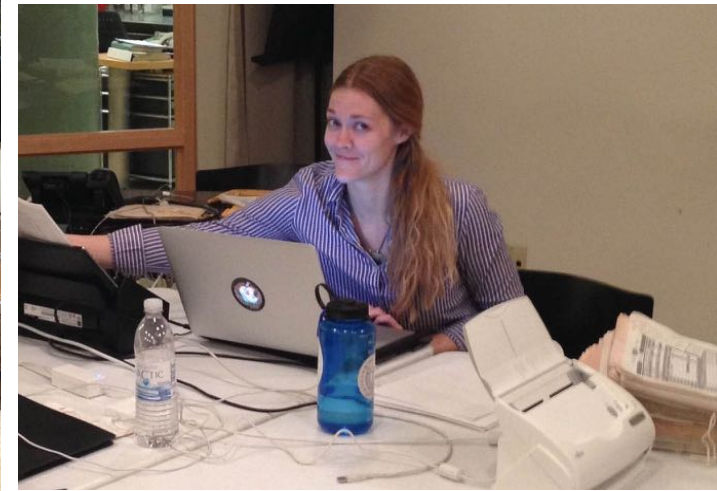


Blood Pressure During
Surgery



Nielson et al., 2015
*Nature
Communications*

Jessica Nielson, PhD



Dark data see the light

Ellen P. Neff

Lab**Animal**

46 Volume 47, No. 2 | FEBRUARY 2018

TECHNOLOGY FEATURE

Dark data see the light

Ellen P. Neff

Lab**Animal**

46 Volume 47, No. 2 | FEBRUARY 2018

NEWS FEATURE

Predictable response:

Finding optimal drugs and doses using artificial intelligence

By Shraddha Chakradhar

NATURE MEDICINE VOLUME 23 | NUMBER 11 | NOVEMBER 2017

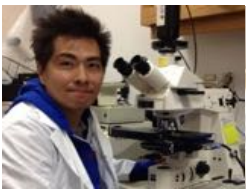
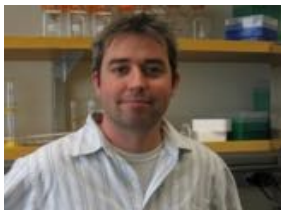
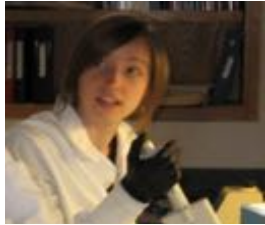
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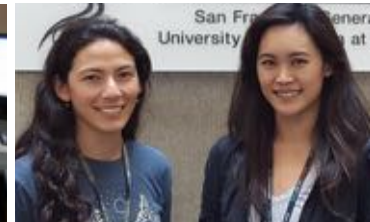
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Texas A&M University

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 Michelle A. Hook, PhD

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 I01RX002787; **US Department of Defense:**
 SC150198, SC150177

**Craig H. Neilsen |Wings for Life|International
 Spinal Research Trust**

Questions?