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Resources for Data Management

Lisa R. Yanek, MPH, CPH

February 21, 2019

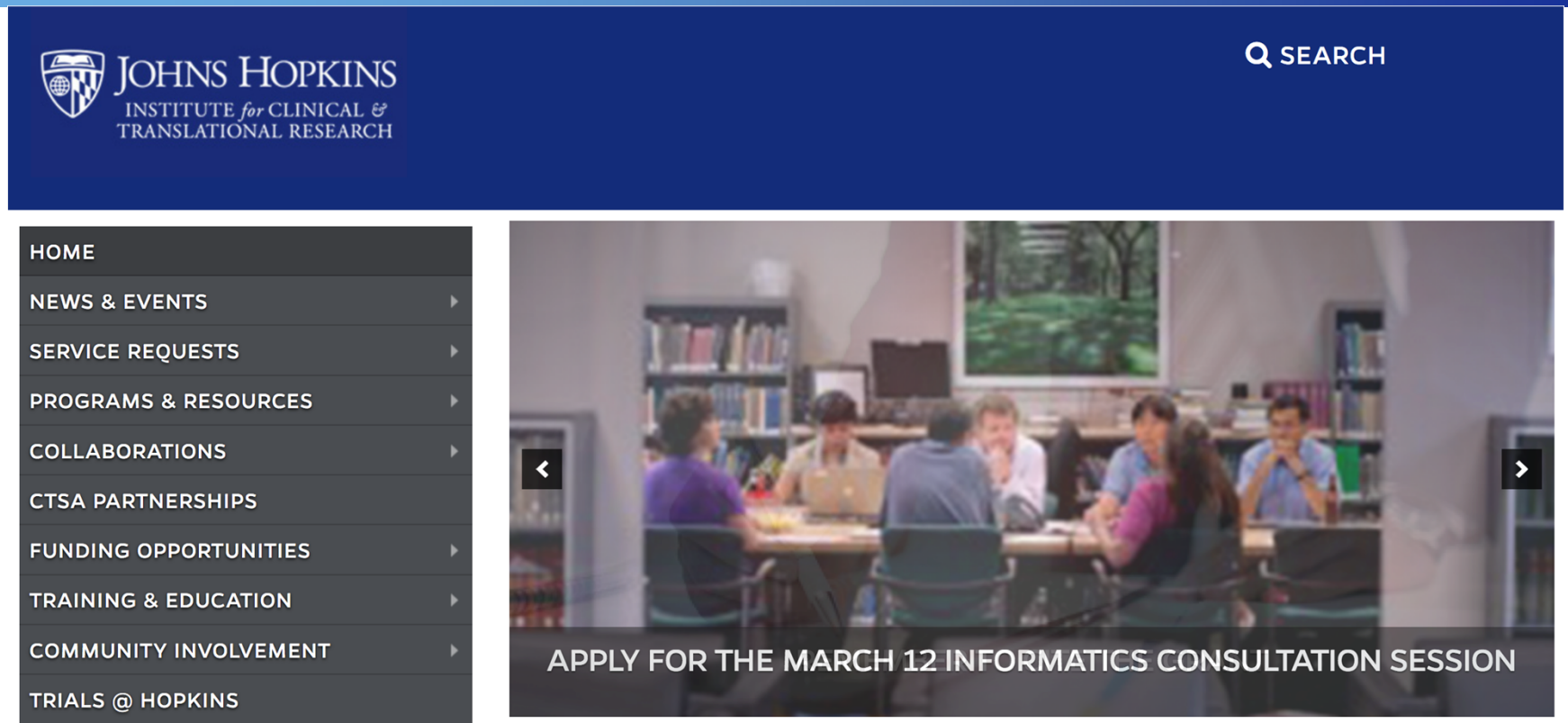
Data Management

What is data management?

The practice of constructing and maintaining a system for the lifecycle of information

- Collection
- Storage
- Protection
- Sharing
- Archiving

ICTR Resources: ictr.johnshopkins.edu



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ICTR Resources: Data Management / Quantitative Methodologies

Biostatistics Program

Supports JU faculty by offering a maximum of 5 hours of free consultation per clinical and translational project.

Read more

Center for Clinical Trials Study Design Consulting Service

Offers investigators an opportunity to discuss and formulate their research question about the design, conduct or analysis of data from clinical trials.

Read more

Computational Biology Consulting Core

Provides analyses of sequencing data for a variety of genomics and other sequencing based experiments.

Read more

Computational Genomics Consulting and Education

Established to integrate the work of basic scientists, statisticians and computer scientists.

Read more

Computational Medicine Program

Serves investigators interested in mathematical modeling of complex biological systems in health and disease.

Read more

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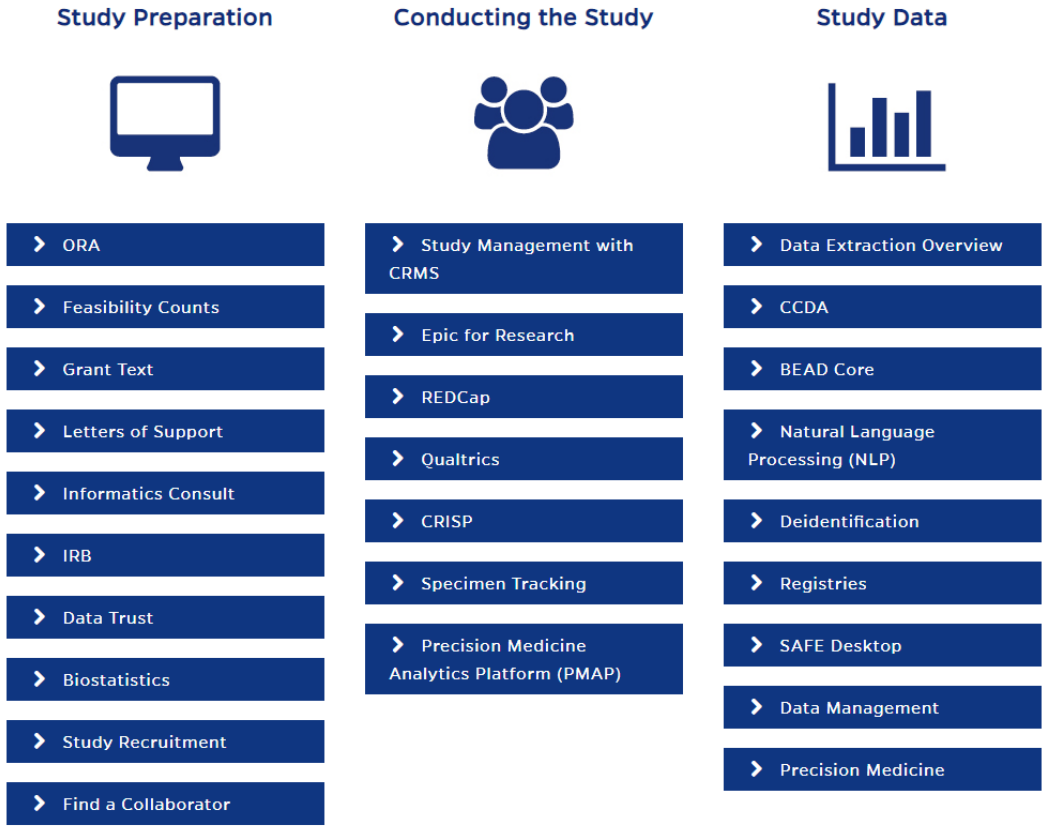
ICTR Resources for Data Management

- https://ictr.johnshopkins.edu/programs_resources/programs-resources/i2c/



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JHU Data Services

http://dms.data.jhu.edu

Consulting

- Data management planning
- Data access and discovery
- ArcGIS
- Geospatial data visualization

Training

- Data management & sharing
- De-identifying PII/PHI data
- ArcGIS and web mapping
- R
- Network analysis
- Open science and tools

Archiving

- Locating the best data sharing options
- JHU Data Archive (**archive.data.jhu.edu**)
- Research data preservation

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MAR 12 Tue

Best Practices for Research Data Management and Sharing @ Brody Learning Commons 4040, Homewood Campus
Mar 12 @ 12:00 pm – 1:00 pm

MAR 15 Fri

De-identifying Human Subjects Data for Sharing @ Brody Learning Commons 4040, Homewood Campus
Mar 15 @ 12:00 pm – 1:30 pm

MAR 25 Mon

Bringing Your Data Alive Through Story Telling @ Lab#1, 2024 E Monument St Building, Medical Campus
Mar 25 @ 9:00 am – 11:00 am

APR 3 Wed

Best Practices for Research Data Management and Sharing @ Lab#1, 2024 E Monument St Building, Medical Campus
Apr 3 @ 11:30 am – 12:30 pm

Introduction to R for Absolute Beginners @ Lab#1, 2024 E Monument St Building, Medical Campus
Apr 3 @ 12:30 pm – 3:30 pm

APR 9 Tue

Introduction to R for Absolute Beginners @ Brody Learning Commons 5015/5017, Homewood Campus
Apr 9 @ 12:00 pm – 3:00 pm

APR 25 Thu

De-identifying Human Subjects Data for Sharing @ Lab#1, 2024 E Monument St Building, Medical Campus
Apr 25 @ 3:30 pm – 5:00 pm

JHU Data Management Services

http://dms.data.jhu.edu

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Welch Medical Library

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Services & Resources

Consultations on data related issues …

- Planning for data management/sharing
- Tools for data collection/management/visualization
- Data deposit assistance
- JHM policies on data security and governance
- Funder/publisher mandates

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Welch Medical Library

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Services & Resources

Help with finding, requesting and responsibly using data

- Publicly available data
  - de-identified aggregate data
- Restricted data
  - data with PHI or PII
- Data available by subscription
  - proprietary data
- Ethics/Compliance
  - IRB approval, Data Use Agreement, data citation

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Services & Resources

You are invited!

Finding Health Statistics and Datasets: Overview & search tips

Monday, March 25, 2019 10-11:30 AM
Bloomberg School of Public Health, W2015

Instructor: Young-Joo Lee (Data Informationist)

More info & registration → welch.jhmi.edu

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Welch Medical Library

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BEAD Core

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BEAD Core Team

- Jacky Jennings, PhD, MPH – Director
- Jay Vaidya, MPH, PhD, MBBS – Assoc Dir, GIM
- Kevin Psoter, PhD, MPA – Assoc Dir, Pediatrics
- Jamie Perin, PhD – Lead Faculty Biostatistician, International Health/BSPH
- Megan Tschudy, MD – Lead Faculty, Pediatrics
- Laura Pritchett, PhD – Lead, Pediatrics
- Lisa Yanek, MPH – Lead/Sr. Analyst, GIM
- Veena Billioux, PhD – Lead, Pediatrics
- Sean Tackett, MD – Lead Faculty/GIM
- Jasmyne Jardot, Project Coordinator
- Di Chen, MS – Sr. Programmer/Analyst
- Linxuan Wu, MS – Sr. Programmer/Analyst
- Jessica Wagner, MS – Sr. Programmer/Analyst
- Ximin Li, MS – Sr. Programmer/Analyst
- Lavisha McClarin, MS – Data manager
- Steven Huettner – Sr. Project Coordinator
- Brian Stackhouse – Consultant Workshops
- Sarah Polk, MD – Lead Faculty for eval projects
- Sara Johnson, PhD – Faculty Lecturer, Pediatrics
- John McGready, PhD – Faculty Lecturer, Biostatistics/BSPH
- Kai Kammers, MSc, PhD – Faculty Lecturer, Oncology
- Kristin Voegeltine, PhD – Faculty Lecturer, Pediatrics
- Christina Schumacher, PhD – Faculty Lecturer, Pediatrics
- Julia Kim, MD – Faculty Lecturer, Pediatrics
- Erica Sibinga, MD – Faculty Lecturer, Pediatrics
- Janet Holbrook, PhD – Faculty Lecturer, Epidemiology

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BEAD

Biostatistics, Epidemiology And Data Management

Mission

To provide research support services that promote, strengthen and expand the research of the JHU faculty so that we remain one of the top interdisciplinary research institutions, focused on improving the health and well-being of individuals, families and their communities.

We are a recognized iLAB Core of the Johns Hopkins School of Medicine.

BEADCore@jhmi.edu
http://beadcore.jhu.edu

Research Support Services

- Epidemiologic study design and approach
- Quantitative and qualitative analyses
- Grant submissions, scientific manuscripts, reports
- Data collection instruments
- Sample, power and effect size calculations
- Research training and education workshops

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CORE VALUES

1. **RESPECT** for intellectual curiosity and all forms of knowledge and inquiry
2. **INTEGRITY** in our work ethic and, services provision and in our professional performance
3. **CREATIVITY and FLEXIBILITY** in our approach and dedication to innovative solutions, practices and services
4. **APPROACHABILITY** of our team, accessibility and engagement with the clients we serve
5. **COMMUNICATION** with consistency, clarity and professionalism
6. **TEAM SCIENCE** with experts from multiple disciplines and training backgrounds

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Benefits of the BEAD Model

- Conceptualization of faculty research as a developmental process
- Model of support that is service-based, responsive and efficient
- Strong focus on epidemiology and a mentored support structure
- Built on teamwork and collaboration
- Extensive grantsmanship experience (NIH, Foundation grants, PCORI)
- Breadth of content, methods, statistical expertise

Example FY18 Pediatric Annual Deliverables

- **58 Pediatric Faculty from 18 Divisions supported.**
  - 70% of clients served were ≤ Assistant Professors
- Services provided
  - 50 One hour consultancies
  - **168 services** including basic and complex biostatistical analyses, power calculations, study design consults, statistical plans, **data management, database development/maintenance**, GIS, manuscript preparation, and survey review.
  - **16 Grant submissions**
  - **14 Scholarly publications**
  - 2 research training and education workshops- 80% of respondents said they are "very likely" to attend a future BEAD workshop

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How does the BEAD Core work?

- iLab request
- Initial one hour consultation for a needs assessment
  - Scope of work and quote for services
  - Work commences guided by BEAD Core lead faculty and you
  - Work completed and final invoice → Scholarly products!
- Payment/Rates – Internal and external clients
  - Free vouchers for Bayview/Pediatric/Medicine faculty
    - 20 hours per investigator
    - 20 hours per trainee with primary faculty mentor
- Transition to direct-fee-for-service for value and sustainability
- Rates in line with other institutional support services

- **BEADCore@jhmi.edu**
- **http://beadcore.jhu.edu**

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REDCap
Research Electronic Data Capture

Welcome to JHU - REDCap!

Redcap.jhu.edu

Questions? We can help.
Andre Hackman (SPH) ahackman@jhu.edu
Scott Carey (ICTR) scarey@jhmi.edu

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REDCap

- REDCap is a mature, secure web application for building and managing online surveys and databases. Using REDCap's stream-lined process for rapidly developing projects, you may create and design projects using the online method from your web browser using the Online Designer and/or the offline method by constructing a 'data dictionary' template file in Microsoft Excel, which can be later uploaded into REDCap. Both surveys and databases (or a mixture of the two) can be built using these methods.
- REDCap provides automated export procedures for seamless data downloads to Excel and common statistical packages (SPSS, SAS, Stata, R), as well as a built-in project calendar, a scheduling module, ad hoc reporting tools, and advanced features, such as branching logic, file uploading, and calculated fields.

REDCap

REDCap Tiered Access Model

-- Effective January 1, 2017 --

[Rev 1. - 20161214a]

Feature	Bronze	Silver	Gold
	Per PI	Per Project	Per Project
Cost	FREE	$50/Month	$100/Month
Availability	SOM / SON / SPH	All JH Entitees	All JH Entitees
Data Points	20,000	500,000	1,000,000
Storage Limit	30MB	1GB	2GB
Activity Auditing	✓	✓	✓
Unlimited User Accounts	✓	✓	✓
Reporting	✓	✓	✓
Data Export	✓	✓	✓
CSV Data Import	✓	✓	✓

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REDCap

- FOR CURRENT USERS ONLY
- There are several scheduled REDCap Bronze Walk-In Clinics scheduled for the next few weeks at both the Downtown and Bayview campuses. Sessions are limited to 8 participants, so register soon! There is a link on the left side of your REDCap project.
- Currently open sessions:
  DOWNTOWN: Tuesday - 02/26/19 @ 10am (2024 Bldg, Room 1-500A)
  BAYVIEW: Wednesday - 03/13/19 @ 10am (301 Building, Room 2208)
  DOWNTOWN: Tuesday - 03/19/19 @ 10am (2024 Bldg, Room 1-500A)
- Redcap.jhu.edu

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Qualtrics

- Qualtrics is the world's leading enterprise survey company, used by 1,300 colleges and universities worldwide, including every major university in the United States. Qualtrics makes it easy to create and distribute engaging surveys.
- Qualtrics is **free for use** by all **School of Medicine** faculty, students and staff for research, evaluations, event registration and more. Surveys can be created and distributed by anyone with a current university login. In order to protect sensitive data, **please use Qualtrics instead of Survey Monkey for your surveys**.

- https://ictrweb.johnshopkins.edu/ictr/connection/som_qualtrics.cfm

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Open Specimen

- OpenSpecimen is a bio-bank management tool used to collect, manage, process, annotate and distribute bio-specimens and associated data to selected users. At Johns Hopkins, OpenSpecimen is currently being used in Gastroenterology, Cardiology and Oncology.

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OpenSpecimen

OpenSpecimen offers a comprehensive feature set, including:

- Biospecimen collection, inventory, and tracking
- Ability to track specimen events (thaws, spins, etc.)
- Customizable support for storage containers (i.e. freezers, shelves, racks, boxes, position)
- User-definable forms for patient, collection event, and specimen annotations
- Flexible specimen ordering and distribution workflows
- Graphical custom report builder
- Integrated bulk loading capabilities for existing data
- Support for multiple biorepositories and locations

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Open Specimen

CONTACT

- **PAMELA MURRAY**
  Systems Development Manager
  410-234-9845 | pmurray@jhmi.edu

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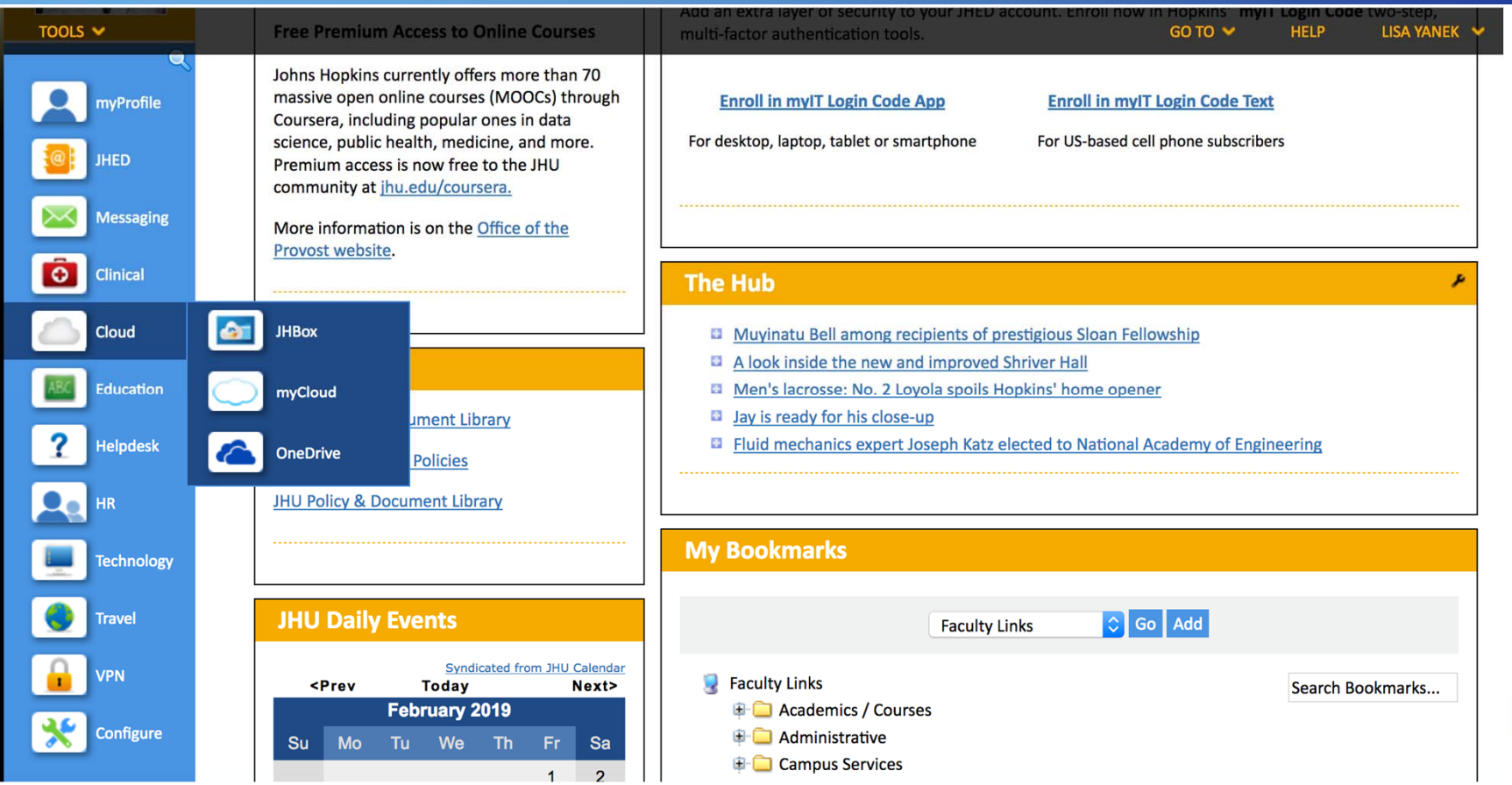
Resources from the JH Portal



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SAFE Desktop

- SAFE, the Secure Analytic Framework Environment, is a virtual desktop that provides Johns Hopkins Medicine investigators (whether engaged in research or other data-intensive activities) with a secure environment to analyze and share sensitive data (e.g. PHI, PII) with colleagues.

- There is no cost for the “basic” SAFE, which includes use of the virtual desktop, 100 GB of storage space, and the licensing for SAS and Stata. Investigators can request additional software or increase the storage space on the file share for a fee.

SAFE Desktop

https://johnshopkins.service-now.com/serviceportal?id=sc_cat_item&sys_id=61fa28a26ffb220088e1f13f5d3ee45e

SAFE Virtual Desktop Requests

Request a new SAFE desktop or request access to an existing SAFE project

Please complete the form below to request a new SAFE Virtual Desktop or new secure file folder or to request access to an existing secure file folder.

The SAFE is available to all staff with a JHED ID and is appropriate for use by staff who require analytic applications (Stata, R Studio, SAS). More information about the SAFE can be found on the SAFE ICTR web site.

Please note that when a new SAFE desktop is added for you, you will no longer have a Hopkins MyCloud desktop; however, the SAFE desktop offers all of the features of the MyCloud desktop plus a secure file folder and access to the analytic applications listed above.

Requests will be completed within the next half business day; however, some requests may take longer based on complexity.

Add to Cart

Add to Drafts

Order Now

Required information

Enter a name for your secure file folder:

Will you be the point of contact for this

Who should have access? (Type full nam

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JH Box

- **What is JHBox?**
- Johns Hopkins Box (JHBox) is a cloud-based file sharing and file storage service which enables people to collaborate and share information and can be accessed through any device: desktop, laptop, phone, or tablet.
- JHBox makes it easy to upload content, organize files, share links to files, and manage file and folder permissions. With JHBox you can collaborate with colleagues both inside and outside the Institution anytime, anywhere, from any device. In addition, accounts offer an ample 50GB of document storage space.
- **How do I access JHBox?**
- You can access your JHBox account by logging into the myJohnsHopkins portal and selecting the JHBox quick link under Cloud Apps.
- **How much space do I have in JHBox?**
- Users are provided with 50GB online storage.

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One Drive

- **What is OneDrive?**
- OneDrive is the personal cloud storage component of the Office 365 product suite that allows users to store and share documents and files from any device with an internet connection. In addition to unlimited storage space per user, OneDrive also allows you to share documents with colleagues easily – even those who may not be affiliated with Johns Hopkins or have JHED accounts.
- OneDrive meets all HIPAA and FERPA compliance standards for secure file sharing and storage.
- **How do I access OneDrive?**
- You can access your OneDrive account by logging into the myJohnsHopkins portal and selecting the OneDrive quick link under Cloud Apps.
- **How much space do I have in OneDrive?**
- Users are provided with 5TB online storage.

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JHBox vs OneDrive

- See https://it.johnshopkins.edu/services/collaboration_tools/BoxOneDriveCompare

Data Sharing

- Data Trust
- https://intranet.insidehopkinsmedicine.org/data_trust/index.html

- Institutional Review Board
- https://www.hopkinsmedicine.org/institutional_review_board/index.html

- Data Use Agreements
- Please contact the Office of Research Administration (ORA) or JHURA jhura@jhu.edu
- https://www.hopkinsmedicine.org/research/resources/offices-policies/ora/

Data Trust

- http://intranet.insidehopkinsmedicine.org/data_trust/index.html
- The goals of the Data Trust are to:
- Ensure security and privacy of our patients' data.
- Consolidate teams to address organizational priorities and reduce redundancy.
- Increase the value of data through better integration and analytics.
- Investigators may be referred for a Data Trust review if their study meets certain review triggers, such as the sending of identifiable patient data outside of Johns Hopkins or storing large amounts of patient data outside of pre-approved secured servers. Dr. Christopher Chute and Dr. Stuart Ray co-chair the Data Trust Research Sub council which develops policy for research informatics, and analytics and reviews large research data requests and those requests involving third parties. http://intranet.insidehopkinsmedicine.org/data_trust/data-trust-organization/research-data-subcouncil.html

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ICTR Data Managers Interest Group

- Meetings
- Listserv
- Working Group
- Advisory Board

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Data Managers Interest Group listserv

- Individuals may join the Data Managers Interest Group listserv here.
- https://lists.johnshopkins.edu/sympa/subscribe/datamgrs

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Data Managers Interest Group Meetings

- Data security
- Deidentification of data
- Best practices
- EPIC data
- i2b2
- REDCap
- SAFE desktop
- Big data
- CMS data
- Ethics
- Imaging informatics
- GIS
- Welch services
- Genomic data

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Data Management Planning Session Highlights

What is a data management plan?

It is a formal document that outlines how data are to be handled both during a research project and after it is completed.

Should answer the following questions:

Who will be accessing the data?
What data are you requesting?
What is going to be shared?
Where is the data being stored?
When is data being shared?
How is the data being requested?
How is the data being shared?
How is it being de-identified?
Bonus: Why do you need this data to complete your project?

Other things to consider:

Ensure that all documentation matches. i.e. make sure that your HIPAA waiver, data management plan, and protocol are all talking about the same data elements.

Double check all timelines so that you can received your data when you need it. Make provisions for various IRB and ancillary reviews.

De-identification of Data Session Highlights

Identified Data Set vs Limited Data Set vs De-identified Data Set

De-identification is the process used to prevent a person's identity from being connected with information. Common uses of **de-identification** include human subject research for the sake of privacy for research participants.

A **Limited Data** set can have the following information: Dates, City, State, Zip code, and age. This information is still PHI

There are many ways to help smudge the data to make identification harder. Some examples are:

Shift all dates

Shift geolocations

Apply study IDs and keep a separate crosswalk

Important take away: Is it possible to have data that is both de-identified and usable? i.e. can someone confirm your results from a de-identified set?

http://johnshopkins.mediasite.com/Mediasite/Play/dab067c0d3264a43b93d374b28079d741d

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De-identification of Media Session Highlights

Many software applications available for de-identification of quantitative data and media (images, audio, qualitative data), but come with caveats:

Open-source with no or minimal support

Requires expertise

Expensive

De-identification of medical records with unstructured free text for research is challenging: one solution is custom natural language processing and text mining to remove PHI prior to release for research

Clinical imaging de-identification tools useful for many images, e.g., mammograms, X-rays, MRIs

ImageDrive used in Radiology: features include processing images uniformly, economy of scale for large numbers of images

Best Practices for Data Management

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Best Practices for Data Management

Categories

- Data Management Planning
- Documentation
- Data Archiving
- Data Backup
- Data Security
- Data Sharing

Data Management Planning (1)

- Assign/Define Roles and Responsibilities
- Clear and Accurate File Naming
- Clear and Appropriate Field/Table Name
- Data Dictionary / Codebook
- Date / Time Formatting
- Define Data Model
- Define Derived Variables
- Determine Data Collection Model
- Estimated / Annotated Values

Data Management Planning (2)

- Grant Proposal Data Management Plans
- Identify Appropriate Data Collection / Storage Tools
- Identify Data Sensitivity
- Licensed Data Source Use
- Missing / Not Applicable / Unknown Value Coding
- Project Description / Overview
- Quality Assurance/Quality Control
- Version Control Plan

Data Sharing

- Archiving of Shared Data Packages
- Assignment of Honest Broker
- Compliance - Institutional
- Compliance – Publication
- Compliance - Funding Source
- Data Use Agreements
- De-Identification
- Genomic Data Sharing
- Metadata
- Sharing data with identifiers
- Transmission of Shared Data
- Uploading de-identified data to repository

Draft Data Dictionary Best Practices (1)

A data dictionary consists of definitions of every data item (variable) that is being collected for a study. It is an essential part of successful data management and should be updated whenever a variable is changed or added.

Recommendations:

- Collect data in the simplest format with unambiguous variables that will allow you to easily and accurately report your findings.
- If your data management system doesn't do it automatically, create and maintain a data dictionary that provides the following information for every variable used.
- Variable Name
  - —A unique, unambiguous name should be given. Anyone, now and in the future, should be able to understand what information is stored in that variable.
  - —Avoid abbreviations whenever possible. 'sodium_serum', not 'na_serum'
  - —Include units of measure in the variable name, if appropriate. 'height_cm' (In this case abbreviations are included since they are commonly used and widely understood in many disciplines.)

Draft Data Dictionary Best Practices (2)

- Variable Type: what type of data can be stored in each variable. The titles and definitions of variable types are usually very similar across data management systems. Commonly used types include:
  - —Date
  - —Integer
  - —Float – decimal
  - —String – alphanumeric
  - —Text
  - —Select one option
  - —Select all options that apply
  - —Calculated
- Label / Definition: the definition of the variable in text. This may include the 'Question' or text that appears on a Case Report Form with the variable. It clearly instructs users what information should be entered in that variable.

Draft Data Dictionary Best Practices (3)

- Data Length and Format: Record how long the variable is, for example, how many characters or numbers may be entered or how the data should be displayed and stored. Examples:
  - —Date - MM/DD/YYYY
  - —Decimal - 6 characters, ###.##
  - —String - 15 characters
  - —Option - select response from a dropdown menu

- Variable Codes: if responses are selected from a list of options, what code for each option should be stored in the database. Examples:

  Option = 'Yes' Code = 1

  Option = 'No' Code = 0

Draft Data Dictionary Best Practices (4)

- Validation Rules: the criteria a response must meet to be considered a valid response: >10, between date A and date B
- Branching Logic Rules: the conditions under which data should not be collected for this variable:
  - —Rule: If subject is male, the pregnancy test result field should be disabled.
  - —Include the code that will be entered in the field to indicate that the field was purposely not answered (as opposed to simply being left blank).
- Version: changes in variable attributes should documented over time and a version number/date changed should be recorded for each iteration
  - —This should be 'versioned' over time as changes are made. Use the document provided previously.

Resources for Data Management Summary

- ICTR website
- JHU Data Management Services
- Welch Medical Library
- BEAD Core
- REDCap
- Qualtrics
- Open Specimen
- SAFE
- JHBox
- OneDrive
- Data Trust
- ICTR Data Managers Interest Group
- *Best Practices for Data Management*

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Acknowledgments

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Thank you!

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Where Science and People Connect