NCHATS Data and Analytics: Workstream Overview and Research Data Governance Primer

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National Center for Health and Justice Integration for Suicide Prevention

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Disclosures

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National Center for Health and Justice Integration for Suicide Prevention (NCHATS)

- A national NIMH-funded research center meant to build information bridges between health care organizations and criminal legal systems to identify individuals at risk for suicide and connect them to care, evaluating both the clinical and cost-effectiveness of suicide prevention practices in this context.
- Includes more than 100 working partners, 30 investigators, and 15 institutions
- Main projects
  - Project 1: Syncing Screening and Services for Suicide Prevention Across Health and Jail Systems
  - Project 2: Real-Time Managed Care Updates of Subscriber Justice-System Involvement for Suicide Prevention
  - Project 3: Suicide Risk Identification in Jails Using Data Linkage and Automation
  - Project 4: Improving Mental Health Treatment for Individuals in Crisis Interacting with the Criminal Justice System

http://nchats.org
### NCHATS Methods Core Workstreams

- **Data and Analytics Workstream**
  - **Engagement & Implementation Science Workstream**
  - **Health & Justice Workstream**
  - **Interventions, Safety & Ethics Workstream**
  - **Health Equity Workstream**

- **Provide support for Center Signature, Exploratory, and Pilot Feasibility projects and other Center functions**
  - Methodological expertise and operational support
  - Think Tank facilitation
  - Consultation, mentorship, and training

- **NCHATS Data and Analytics Workstream**
  - Study Design
  - Health Economics
  - Biomedical Informatics
Study Design

- RCT methods
- Pragmatic trial designs (e.g., cluster-randomized trials, stepped wedge, SMART designs)
- Quasi-experimental designs
- Experimental therapeutics
- Power analyses
- Multilevel modeling
- Qualitative design and analysis
- Services and policy research
Health Economics

- Intervention Costs
  - Cost as an implementation outcome
- Economic evaluation
  - Cost-benefit
  - Cost-effectiveness
  - Cost-utility (QALY = 1 - DALY)
- Perspectives
- Equity: who pays & who benefits
- Valuing intangibles - willingness to pay
- Cost as a regression variable
Interdisciplinary field that studies and pursues the effective uses of biomedical data, information, and knowledge for scientific inquiry, problem solving and decision making, motivated by efforts to improve human health.
A Brief Introduction to Data Governance

➢ What is data governance?
➢ Why is data governance important?
➢ How to implement data governance?
➢ What are some exemplars?
What is Data Governance?

➡ Policies
➡ Procedures
➡ Standards

Secure
Accurate
Available
4 Pillars of Data Governance

Data Governance

Data Quality
Data Stewardship
Data Protection & Compliance
Data Management

People, Process, & Technology
4 Pillars of Data Governance

**Data Quality:** the accuracy, completeness, consistency, and timeliness of data

**Data Stewardship:** the accountability for and responsibility of managing and maintaining data assets

**Data Protection and Compliance:** security controls, encryption, access management, and data classification policies to protect data assets and ensure compliance with relevant regulations

**Data Management:** data integration, data architecture, data modeling, data storage, data retention, and data lifecycle management
Research Data Governance

The Legal and Ethical Stewardship of Protected Health Information

Human Subjects Protection

GDPR

HIPAA

Data Use Agreements

NIH Data Management and Sharing

IRB
Research Data Governance

❖ Ensure data security
❖ Provide accurate and reliable data
❖ Uphold ethical standards
❖ Enhance collaboration and support open science
❖ Maximize the credibility of research findings
❖ Enable advanced analytics
❖ Promote technological efficiencies
❖ Maintain regulatory compliance
❖ Facilitate reproducibility
Implementing Data Governance

A step-by-step guide to setting up a data governance program - by IBM

Data Governance - Strategy & Planning

➢ Engage Stakeholders
➢ Establish a Framework
  ○ Scope
  ○ Goals
  ○ Objectives
  ○ KPIs
  ○ Implementation Strategy

Data Governance is a Shared Responsibility
Data Governance - Design & Build

➢ Policies and Standards
➢ Data Management Processes and Procedures
➢ Technology Solutions
➢ Metrics and Reporting
Data Governance - Deliver & Measure

➢ Implement according to plan
➢ Monitor KPIs
Data Governance - Refine & Expand

➢ Review performance
➢ Adapt to “realities”
➢ Refine the strategy
➢ Expand the scope
Implementing Data Governance

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Exemplar 1: Health Data Sharing in Rhode Island

**URSA Process and Governance**

<table>
<thead>
<tr>
<th>Define Research Question &amp; Population/Cohort</th>
<th>Understand Data Source &amp; Create Data Specification</th>
<th>Determine How to Obtain &amp; Store Data</th>
<th>Perform Data Processing &amp; Analysis/Visualization</th>
<th>Report &amp; Disseminate Findings</th>
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</thead>
<tbody>
<tr>
<td>Design research study (goal and aims)</td>
<td>Examine content and format of data (structured or unstructured, standardized, data quality issues, etc.)</td>
<td>Submit IRB Protocol for approval or exemption (as needed)</td>
<td>Perform initial data analysis (IDA) and exploratory data analysis (EDA)</td>
<td>Obtain data provider approval to export or disseminate results in products (publications, presentations, etc.) (as needed)</td>
</tr>
<tr>
<td>Conduct literature review</td>
<td>Determine codes and logic for cohort</td>
<td>Complete Data Use Agreement(s) (as needed)</td>
<td>Pre-process and transform data for subsequent analyses</td>
<td>Publish and present research</td>
</tr>
<tr>
<td>Specify eligibility criteria for population/cohort</td>
<td>Specify data elements</td>
<td>Identify computing environment for storage and analysis based on data risk level and requirements</td>
<td>Perform modeling, analysis, and data quality assessment</td>
<td>Share dataset (if permissible) and code</td>
</tr>
<tr>
<td>Identify data source(s)</td>
<td>Assess feasibility of study</td>
<td>Determine process to extract and de-identify data (as needed)</td>
<td>Post-process results</td>
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<tr>
<td>Determine what type of dataset is needed (e.g., de-identified or limited)</td>
<td>Complete Data Request Form(s) (as needed)</td>
<td>Establish data transfer process (as needed)</td>
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</tr>
</tbody>
</table>

For more information, visit: [https://advancectr.brown.edu/ursa-initiative](https://advancectr.brown.edu/ursa-initiative)
Exemplar 2: All of Us Researcher Workbench
Exemplar 3: N3C Data Enclave

References

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For NCHATS Projects, sign up for office hours with the Data and Analytics Workstream at:

https://nchats.org/cores/methods-core/#data-analytics