



Data Management Policies and Issues with Life Science Data

February 21, 2012

Case in Point



What is Data?



Bio-Data Management



Issues and Challenges





“You can’t have
everything. Where
would you put it all?”

— Steven Wright



Privacy Concerns



Lack of Knowledge



Lack of Time





Cost Outweigh Benefits

102

Date: _____

_____ \$ Too Much

Dollars

Institutional Barriers

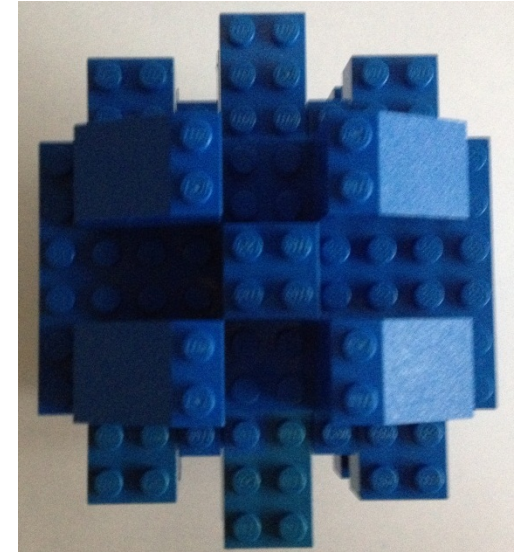


Culture of Sharing?



Best Practices for Management

- Data need to be retained
- Data need to be digital
- Data need to be discoverable
- Data should be free and open





DATA SHARING & MANAGEMENT POLICIES

National Institutes of Health



- In effect October 2003
- Required for projects \$500k and higher
- Participants rights must be protected (HIPAA)
- Data should be free of identifiers

NCBI Databases

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[See 1619 articles about BRCA1 gene function](#)

See also: [BRCA1 breast cancer 1, early onset](#) in the Gene database

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☐ [Vitamin D receptor gene polymorphisms and male breast cancer risk in Turkish population.](#)

1. Kizildag S, Gulsu E, Bagci O, Yuksel E, Canda T.
J BUON. 2011 Oct-Dec;16(4):640-5.

PMID: 22331715 [PubMed - in process]

[Related citations](#)

☐ [The potential of exploiting DNA-repair defects for optimizing lung cancer treatment.](#)

2. Postel-Vinay S, Vanhecke E, Olaussen KA, Lord CJ, Ashworth A, Soria JC.
Nat Rev Clin Oncol. 2012 Feb 14. doi: 10.1038/nrclinonc.2012.3. [Epub ahead of print]

PMID: 22330686 [PubMed - as supplied by publisher]

[Related citations](#)

Titles with your search terms

BRCA1 and BRCA2: breast/ovarian cancer suscep [Carcinogenesis. 2010]

Neighbor of Brca1 gene (Nbr1) func [Proc Natl Acad Sci U S A. 2010]

Two novel variants in the 3'UTR of the E [Breast Cancer Res Treat. 2011]

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Am J Psychiatry. Author manuscript; available in PMC 2010 February 1.
Published in final edited form as:
[Am J Psychiatry. 2009 February; 166\(2\): 182-188.](#)
Published online 2008 October 15. doi: [10.1176/appi.ajp.2008.08050645](#)

PMCID: PMC2635420
NIHMSID: NIHMS81977

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Older adults' attitudes toward noncompetent subjects participating in Alzheimers research

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Jason.karlawish@uphs.uepnn.edu

- ▶ The publisher's final edited version of this article is available at [Am J Psychiatry](#)
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Formats: [Abstract](#) | [Full Text](#) | [PDF \(324K\)](#)

PubMed articles by these authors

- ▶ Karlawish, J.
- ▶ Rubright, J.
- ▶ Casarett, D.
- ▶ Sankar, P.

PubMed related articles

- ▶ Toward revising the ethical boundaries of research with noncompetent subjects. [Am J Psychiatry. 2009]
- ▶ Impaired decision-making ability in subjects with Alzheimer's disease and willingness to participate [Am J Psychiatry. 2002]
- ▶ Alzheimer disease ethics--informed consent and related issues in clinical trials: results of a survey [Int Psychogeriatr. 2003]
- ▶ **Review** Research with Alzheimer's disease subjects: informed consent and proxy decision [J Am Geriatr Soc. 1992]
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Older adults' attitudes toward noncompetent subjects

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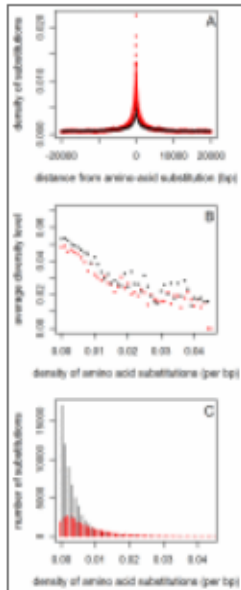


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1.



[Figure 2. The reduction in diversity around **amino acid** substitutions, controlling for clustering.. From: Pervasive Adaptive Protein Evolution Apparent in Diversity Patterns around **Amino Acid** Substitutions in *Drosophila simulans*.](#)

A. The density of **amino acid** (red) and synonymous (black) substitutions as a function of distance from an **amino acid** substitution. The synonymous density was multiplied by 0.4 (the ratio of the average **amino acid** to the average synonymous densities) in order to make the comparison of densities more transparent. B. A comparison between the average diversity levels around **amino acid** (red) and synonymous substitutions (black) as a function of the density of **amino acid** substitutions in their vicinity. Diversity levels and density of **amino acid** substitutions were measured in a window size of 1kb centered at the substitution under consideration. C. The numbers of **amino acid** (red) and synonymous substitutions (black) used to estimate the average diversity levels at each density.

Shmuel Sattath, et al. PLoS Genet. PLoS Genet;7(2):e1001302.

[Citation](#) [Full text](#)

2.



[Fig. 2. Comparison of the **amino acid** pairs located in the N-terminal cleavage sites \(Pn1-Pn1'\) and the C-terminal cleavage sites \(Pc1-Pc1'\) in the tumor antigen and viral antigen epitopes. From:](#)

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ClinicalTrials.gov is a registry and [results database](#) of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals. [Read more...](#)

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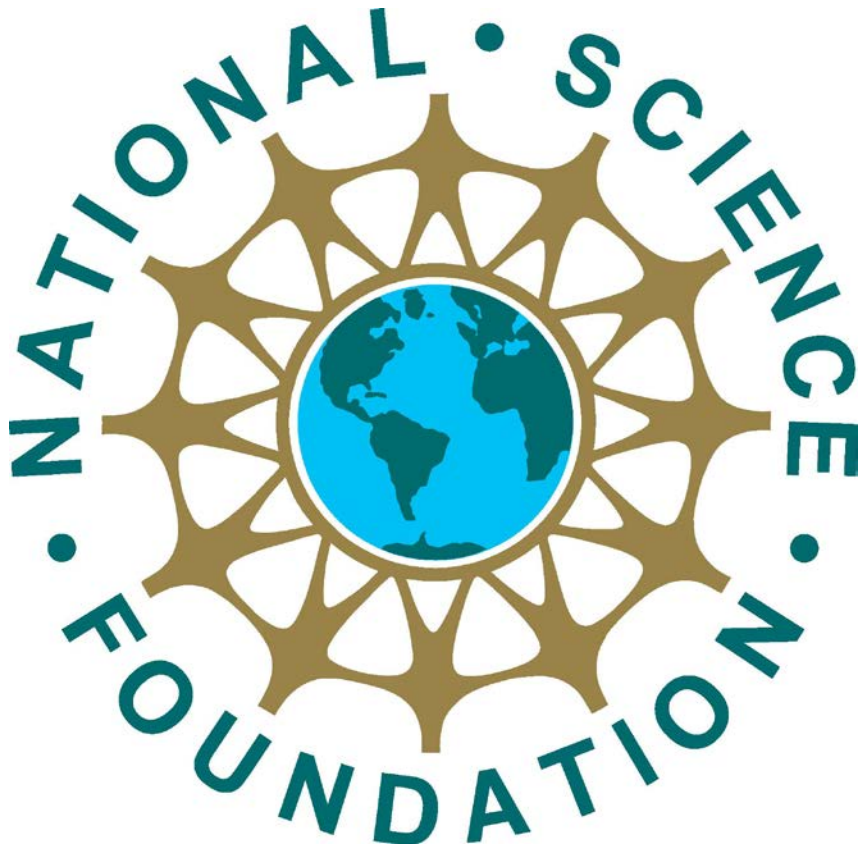
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Rank	Status	Study
1	Terminated Has Results	A Positron-Emission-Tomography (PET) Study to Measure the Blockade of Dopamine Receptors (D2) in Specific Areas of the Brain in Relation to the Plasma Concentrations of Paliperidone Extended Release (ER) and Oral Risperidone in Schizophrenia Patients and Healthy Controls Condition: Schizophrenia Interventions: Drug: Paliperidone ER; Drug: Oral risperidone; Other: PET Scan
2	Completed Has Results	Evaluation of Effectiveness and Safety of Paliperidone Extended Release in Patients With Schizoaffective Disorder. Conditions: Schizoaffective Disorder; Psychotic Disorder Interventions: Drug: Paliperidone ER; Drug: Placebo
3	Completed Has Results	Evaluation of Effectiveness and Safety of Flexible-dose Paliperidone Extended Release in Patients With Schizoaffective Disorder. Conditions: Schizoaffective Disorder; Psychotic Disorder Interventions: Drug: Placebo; Drug: Paliperidone ER
4	Completed Has Results	Effectiveness and Safety of 3 Fixed Doses (25 mg eq., 100 mg eq., and 150 mg eq.) of Paliperidone Palmitate in Patients With Schizophrenia Condition: Schizophrenia Interventions: Drug: Paliperidone palmitate 25 mg eq.; Drug: Paliperidone palmitate 150 mg eq.; Drug: Placebo; Drug: Paliperidone palmitate 100 mg eq.
5	Completed	A Double-blind, Placebo-controlled Study of the Safety and Efficacy of Paliperidone Extended Release (ER) in the Treatment of Schizophrenia in

National Science Foundation



- DMP required for all proposals submitted on or after January 18, 2011
- No more than two pages
- Directorate –level guidance



NSF DMP BIO Directives



1. Products of Research

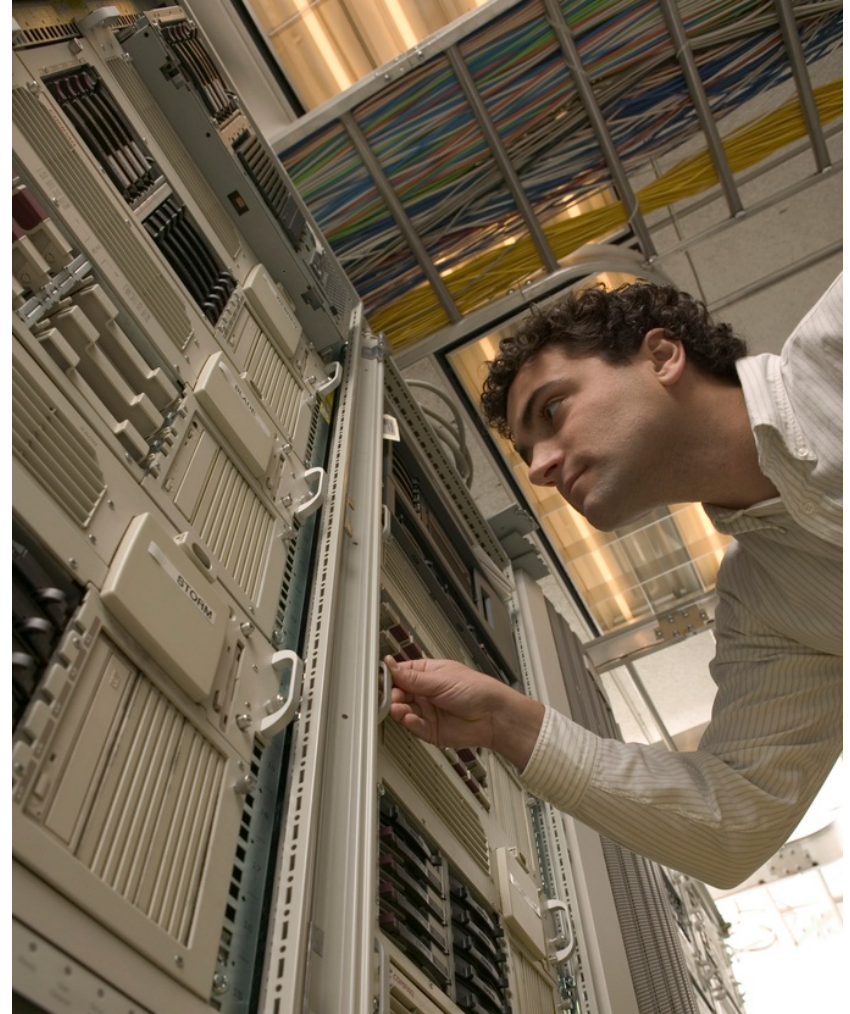
- Type of data
- Retention
- Quality control



Image: <http://www.hsc.wvu.edu/wvcohorts/database.html>

2. Data Storage & Preservation

- Physical
- Cyber resources



3. Data Formats & Metadata

```
<?xml version="1.0" encoding="UTF-8"?>
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http://www.w3.org/TR/xlink http://www.loc.gov/standards/mets/xlink.xsd
http://www.loc.gov/METS/ http://www.loc.gov/standards/mets/mets.xsd
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  </mets:dmdSec>
  <mets:fileSec>
    <mets:fileGrp>
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        <mets:FLocat LOCTYPE="URL"
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      </mets:file>
    </mets:fileGrp>
  </mets:fileSec>
  <mets:structMap>
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      <mets:fptr FILEID="file01"/>
    </mets:div>
  </mets:structMap>
</mets:mets>
```

4. Data Dissemination & Sharing



5. Roles and Responsibilities



The Data Interview



Further Information

- NIH Data Sharing Policy:
http://grants.nih.gov/grants/policy/data_sharing/
- NIH Public Access Policy
<http://publicaccess.nih.gov/>
- NSF Data Sharing and Management
<http://www.nsf.gov/bfa/dias/policy/dmpfaqs.jsp>
- E-Science Portal for New England Librarians
<http://esciencelibrary.umassmed.edu/>



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Editorial



Editorial: Welcome to the Journal of eScience Librarianship

Elaine R. Martin

doi:10.7191/jeslib.2012.1009

Letter to the Editor

<http://escholarship.umassmed.edu/jeslib/>

Questions?

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NN/LM SCR

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