



# NDAR Webinar | Introduction to NDAR

June 2010

Questions? [NDARhelp@mail.nih.gov](mailto:NDARhelp@mail.nih.gov)



# Agenda

- What is NDAR?
- Who is NDAR?
- How does NDAR provide value to the research community?
- How is NDAR designed and implemented?
- NDAR Query Tool Demonstration
- How do I get involved with NDAR?
- Questions and Answers

# What is NDAR?

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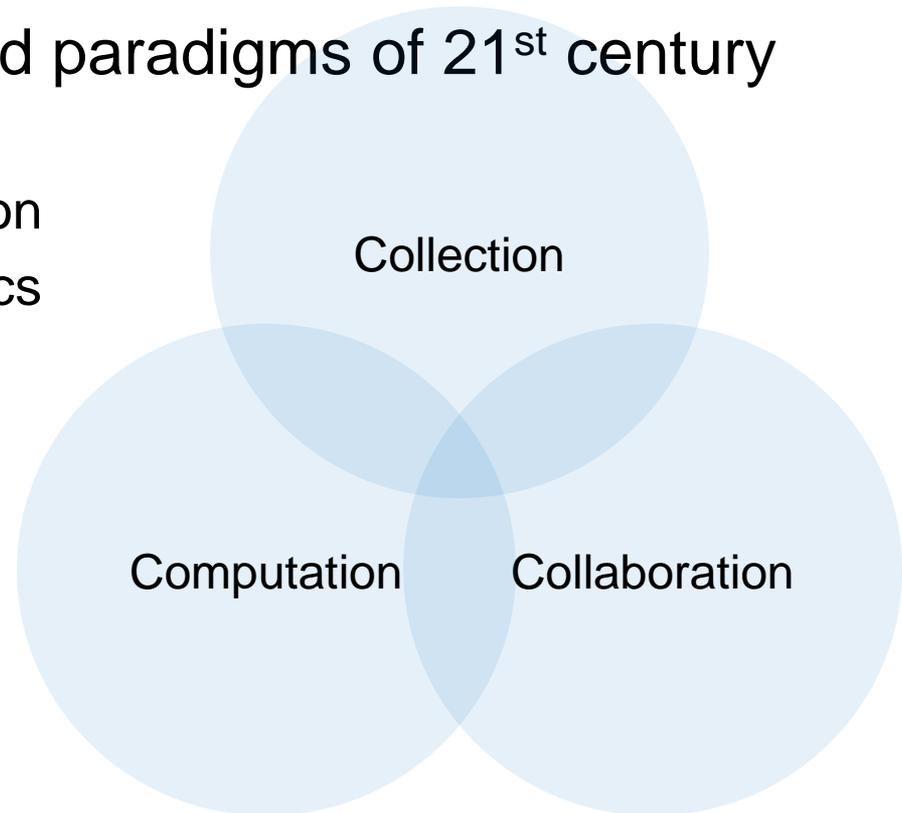
- The NDAR research portal is a secure bioinformatics platform for scientific collaboration and data sharing for Autism Spectrum Disorder (ASD) investigators

*"Open access to data from many people and many studies is paramount in ASD research because of the tremendous range of symptom type and severity among those affected."*

—Thomas R. Insel, M.D.,  
Director, National Institute of Mental Health (NIMH)

# What is NDAR?

- NDAR promotes new ways of doing ASD research
- Supports three interrelated paradigms of 21<sup>st</sup> century scientific research
  - High Volume Data Collection
  - Computation and Informatics
  - Collaborating Laboratories



# What is NDAR?

- The NDAR research portal is a secure bioinformatics platform for scientific collaboration and data sharing for Autism Spectrum Disorder (ASD) investigators
  - Facilitates data sharing and scientific collaboration
  - Provides bioinformatics solutions to address community-wide needs
  - Enables the effective communication of detailed research data, tools, information, and results

# Who is NDAR?

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## ■ NIH Funding Organizations

- National Institute of Mental Health (NIMH)
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
- National Institute of Neurological Disorders and Stroke (NINDS)
- National Institute of Environmental Health Sciences (NIEHS)

## ■ NIH Contributing Organizations

- Center for Information Technology (CIT)

## ■ NIH Advisory Groups

- NDAR Governance Board
- NDAR Implementation Team (NIT)
- Autism Coordinating Committee (ACC)

# Who is NDAR?

## ■ Federation Partners

- NIH NIMH Genetics Repository
- NIH NIMH Transcriptional Atlas of Human Brain Development
- NIH Pediatric MRI Data Repository
- Autism Genetic Resource Exchange (AGRE)
- Interactive Autism Network (IAN)

## ■ Autism Informatics Consortium

- Autism Genetic Resource Exchange (AGRE)
- Interactive Autism Network (IAN)
- Simons Foundation Autism Research Initiative (SFARI)

# Who is NDAR?

- **Michael F. Huerta, Ph.D., NDAR Director**
  - Associate director of the NIMH for scientific technology research and leads neuroscience and neurotechnology programs and initiatives at the NIH
  - Directs the NIH's National Database for Autism Research, the Human Connectome Project, and the Office of Cross-Cutting Science
  - Co-chairs the coordinating committee of the NIH Blueprint for Neuroscience Research, and is involved in many NIH efforts related to informatics and data sharing

# Who is NDAR?

- Mike Huerta, PhD – Director
- Anne Sperling, PhD – Policy Analyst
- Dan Hall – Manager
- Matt McAuliffe, PhD – Technical Manager, Imaging Lead
- B. Lynn Young, PhD – Genomics Lead
- Gretchen Navidi – Principal Analyst, Clinical Assessments
- Kristin Mead – ARRA Outreach Coordinator
- Eric Stanton – ARRA Web Programming

# How does NDAR provide value to the research community?

# How does NDAR provide value?

- The NDAR research portal offers a single point of access to ASD-relevant research data
- Researchers can query simultaneously:
  - Data stored in the NDAR Central Repository
  - Federated (external) data sources
- Results can include:
  - Phenotypic data – clinical assessments and demographics
  - Imaging data – MRI, fMRI, spectroscopy and volumetric data
  - Genomic data – microarray, expression, SNP, etc.
  - Additional data types such as EEG, MEG, outcomes, etc.
    - Links to supporting documentation
    - Links to publications

# How does NDAR provide value?

- Allows qualified researchers to download datasets
  - Secondary analysis
  - Meta-analysis
- Provides a workspace to plan a research study:  
“NDAR Study”
  - Create a Study
  - Query shared data
  - Select data associated with specific individuals
  - Save specific individuals to the Study
  - Save queries to the Study
  - Give colleagues access to the Study
  - Formulate a hypothesis

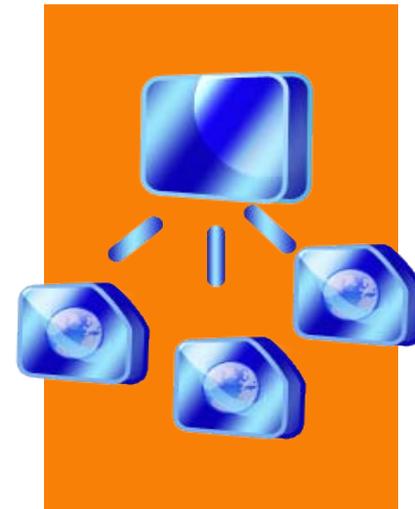
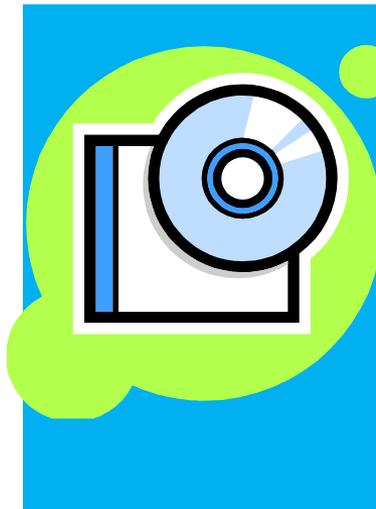
# How does NDAR provide value?

- Provides a focal point for the community to harmonize ASD data definition
  - Data structures
  - Data elements
- Facilitates communication to parents and advocates on behalf of the research community
  - Clinical Trials information (ClinicalTrials.gov)
  - Publications (PubMed)
  - Current research funded (IMPACII public data)

# How is NDAR designed and implemented?

# NDAR Implementation

- NDAR core capabilities link data in a meaningful way
- **Global Unique Identifier (GUID)** – universal subject ID
- **Data Dictionary** – flexible framework for harmonizing data across studies and institutions
- **Federation** – linkage to other relevant data repositories



# NDAR Global Unique Identifier (GUID)

- Universal subject ID unique to each participant
- Allows researchers to share data specific to a study participant without exposing personally identifiable information (PII)
- Links multiple types of data collected from a single participant across multiple projects, regardless of where and when that data was collected



# NDAR Global Unique Identifier (GUID)

- GUID system first conceptualized by Simons SFARI
- Implemented as an NDAR Web service
- Personally identifiable information remains at the research site
- Double-encryption scheme protects participant confidentiality
- Approved by NIH Office of General Counsel



# NDAR Global Unique Identifier (GUID)

- Derived from four elements found on a typical birth certificate
  - Full legal name of participant at birth (as it appears on the birth certificate)
  - Participant date of birth
  - Gender
  - Town or municipality of birth (as it appears on the birth certificate)
- Participants provide this information when they consent to share data in NDAR



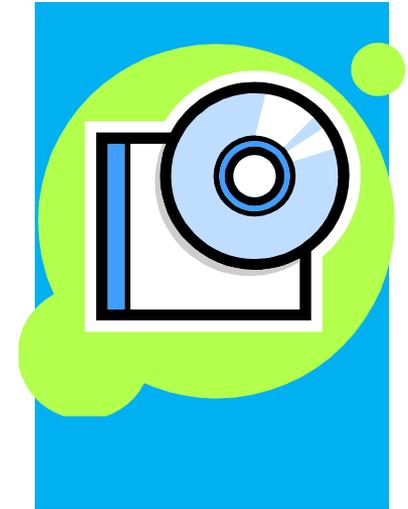
# NDAR Global Unique Identifier (GUID)

- Approach for sharing retrospective data from previous research studies
  - Re-consent participants for data-sharing with NDAR
  - Collect the four required elements for a GUID
- Pseudo-GUIDs
  - Randomly generated identifier
  - Doesn't link participant across other datasets
- Can be promoted to a GUID



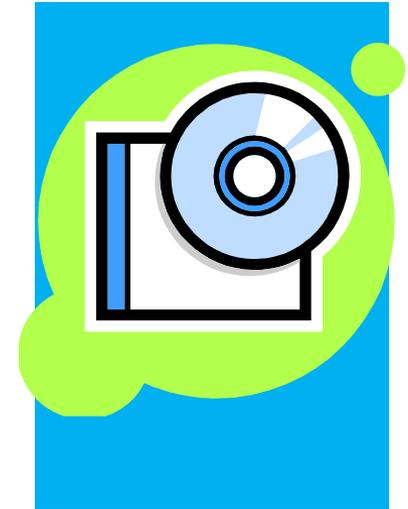
# NDAR Data Dictionary

- Flexible and extensible framework for data definition
- Accommodates any data type and data structure
- Alias feature provides linkage between a project's and NDAR data structures
- Extended by the ASD research community
- Curated by NDAR
- Will support ontology integration



# NDAR Data Dictionary

- Brings the scientific community together to establish common data elements
  - NDAR account holders can add keywords and aliases
  - Add comments to a data element and establish a dialog
- Promotes detailed data definition and specificity
- A research community platform for defining and standardizing the complex language that characterizes ASD research



Data Dictionary | NDAR Portal - Windows Internet Explorer

File Edit View Favorites Tools Help

https://ndarportal.nih.gov/ndarportal/listDataStructures/listPublished.html

Data Dictionary | NDAR Portal

Welcome, **kmead** | Logout

Home Collection Study **Data Dictionary** Query Download Manager Permission Groups Shared Documents Accounts My Profile

List of Data Structures

Published | [Awaiting Publication](#) | [Draft](#) | [Mine](#) | [All](#)

| Title                                                             | Version | Data | Status    | Owner            | Last Updated | Date Created |
|-------------------------------------------------------------------|---------|------|-----------|------------------|--------------|--------------|
| <a href="#">Aberrant Behavior Checklist - Community</a>           | 1       | C    | Published | Navidi, Gretchen | 24-Dec-2009  | 22-Dec-2009  |
| <a href="#">Affections</a>                                        | 1       | G    | Published | Stanton, Eric    | 07-May-2010  | 07-May-2010  |
| <a href="#">Autism Diagnostic Interview - R (ADI-R) - (2003)</a>  | 1       | C    | Published | Navidi, Gretchen | 22-Dec-2009  | 22-Dec-2009  |
| <a href="#">Autism Diagnostic Observation Schedule - Module 1</a> | 1       | C    | Published | Navidi, Gretchen | 22-Dec-2009  | 22-Dec-2009  |
| <a href="#">Autism Diagnostic Observation Schedule - Module 2</a> | 1       | C    | Published | Navidi, Gretchen | 22-Dec-2009  | 22-Dec-2009  |
| <a href="#">Autism Diagnostic Observation Schedule - Module 3</a> | 1       | C    | Published | Navidi, Gretchen | 22-Dec-2009  | 22-Dec-2009  |
| <a href="#">Autism Diagnostic Observation Schedule - Module 4</a> | 1       | C    | Published | Navidi, Gretchen | 22-Dec-2009  | 22-Dec-2009  |
| <a href="#">Biological Sample Protocols</a>                       | 1       | G    | Published | Stanton, Eric    | 07-May-2010  | 07-May-2010  |
| <a href="#">Biological Sample Treatment Information</a>           | 1       | G    | Published | Stanton, Eric    | 07-May-2010  | 07-May-2010  |
| <a href="#">Biological Samples</a>                                | 1       | G    | Published | Stanton, Eric    | 07-May-2010  | 07-May-2010  |

**Actions**

- [Create Data Structure](#)
- [Create Data Element](#)
- [Manage Data Structures](#)
- [Manage Data Elements](#)

**Navigation**

- [NDAR Home](#)
- [Create New Collection](#)
- [Create New Study](#)
- [Submit Data](#)

Data Dictionary | NDAR Portal

Local intranet 100%

Data Dictionary | NDAR Portal - Windows Internet Explorer

File Edit View Favorites Tools Help

https://ndarportal.nih.gov/ndarportal/viewDataStructure/viewDataStructure.html?dataStructureId=4

Data Dictionary | NDAR Portal

### Data Structure Details

**Title** Aberrant Behavior Checklist - Community  
**Short Name** abc\_community  
**Description** Aberrant Behavior Checklist - Community  
**Data Type** Clinical Assessments

**Date Created** 22-Dec-2009  
**Last Updated** 24-Dec-2009  
**Owner** Navidi, Gretchen  
**Status** Published  
**Version** 1  
**Number of Data Elements** 99  
**Publication Date** 04-Jan-2010

### Data Structure Publication

This Data Structure is Published

### Data Elements Associated with this Data Structure

| Pos | Data Element Name                           | Type    | Length | Required?   | Modified Date | Modified By         |
|-----|---------------------------------------------|---------|--------|-------------|---------------|---------------------|
| 1   | <a href="#">subjectkey [edit]</a>           | GUID    | 20     | Required    | 22-Dec-2009   | Administrator, NDAR |
| 2   | <a href="#">src_subject_id [edit]</a>       | String  | 20     | Recommended | 03-Feb-2010   | Hall, Dan           |
| 3   | <a href="#">interview_date [edit]</a>       | DATE    |        | Required    | 09-Mar-2010   | Navidi, Gretchen    |
| 4   | <a href="#">interview_age [edit]</a>        | Integer |        | Required    | 15-Apr-2010   | Hall, Dan           |
| 5   | <a href="#">comments_misc [edit]</a>        | String  | 255    | Optional    | 22-Dec-2009   | Administrator, NDAR |
| 6   | <a href="#">inter_relationparent [edit]</a> | String  | 50     | Recommended | 22-Dec-2009   | Administrator, NDAR |

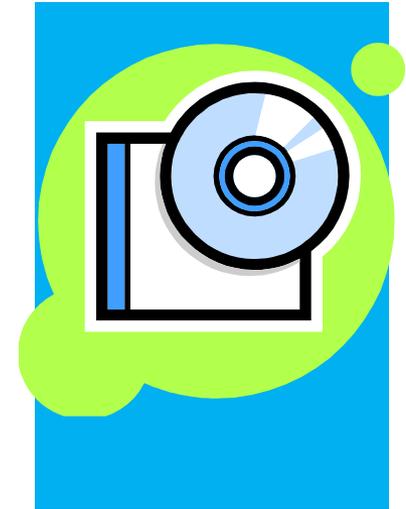
Data Dictionary | NDAR Portal

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- #### Navigation
- [NDAR Home](#)
  - [Create New Collection](#)
  - [Create New Study](#)
  - [Submit Data](#)

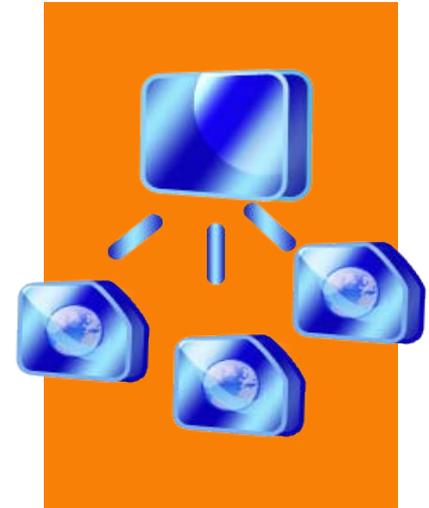
# NDAR Data Dictionary

- Works with the NDAR Validation Tool
- Data submitted to NDAR are validated against the Data Dictionary
  - Validation against each data element
  - Errors are reported for rapid resolution
- As data structures are refined:
  - Data Dictionary is updated
  - Validation Tool is updated
- Updated codebooks are posted to the NDAR Web site
  - Clinical Assessments, Imaging and Genomics data
  - XLS files



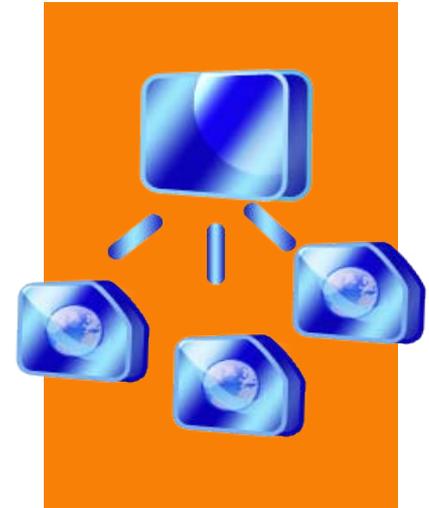
# NDAR Federation

- Links the NDAR Central Repository with external data sources
- Provides single query access to all data
- Data elements are aliased through the NDAR Data Dictionary
- Data can be validated with NDAR Validation Tool prior to submission to a federated repository
  - NIMH Genetics Repository
- Supports the data access policies of the federated resource



# NDAR Federation

- Federation underway with ASD-relevant repositories
  - Autism Genetic Resource Exchange (AGRE)
  - Interactive Autism Network (IAN)
  - NIMH Genetics Repository
  - NIMH Transcriptional Atlas of Human Brain Development
  - Pediatric MRI Data Repository
- Rich phenotypic, genetic and imaging data from Pediatric MRI Data Repository available Summer 2010



# How is NDAR implemented?

## ■ NDAR Policies

- Approved by NIH Office of General Counsel
- Use of NDAR is restricted to qualified researchers affiliated with NIH-recognized institutions

## ■ To submit research data

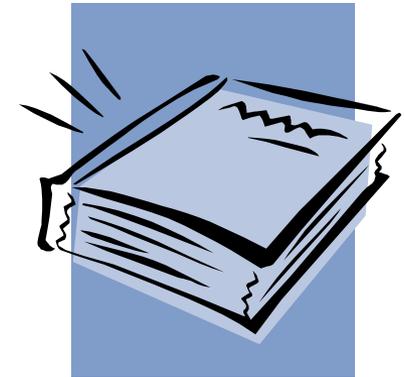
- Data Submission Agreement

## ■ To access research data

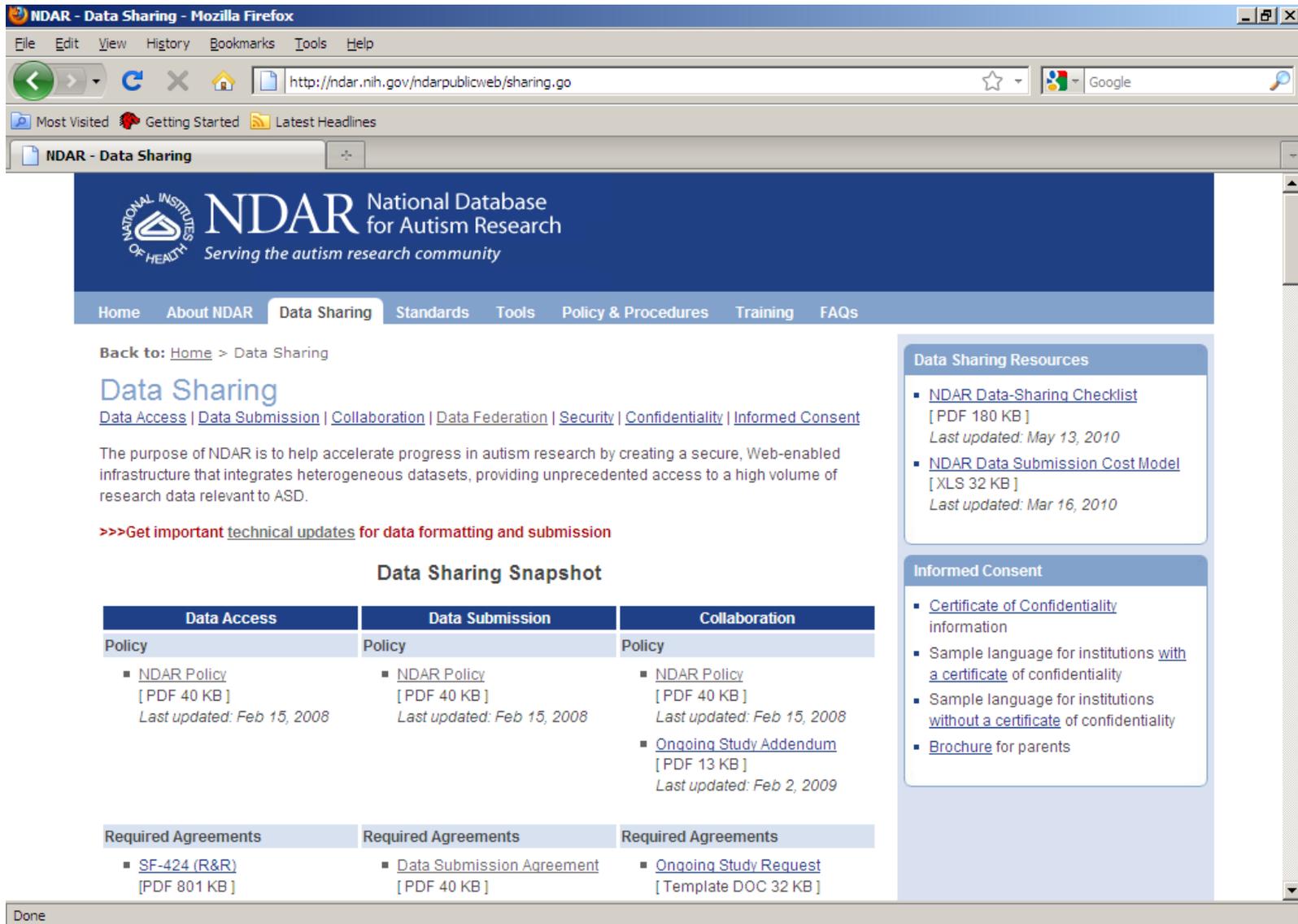
- Simplified SF-424R&R
- Data Use Certification

## ■ To generate GUIDs

- Software Transfer Agreement



# How do I get involved with NDAR?



**NDAR - Data Sharing - Mozilla Firefox**  
 File Edit View History Bookmarks Tools Help  
 http://ndar.nih.gov/ndarpublicweb/sharing.go  
 Most Visited Getting Started Latest Headlines  
**NDAR - Data Sharing**


**NDAR** National Database for Autism Research  
 Serving the autism research community

[Home](#) [About NDAR](#) **[Data Sharing](#)** [Standards](#) [Tools](#) [Policy & Procedures](#) [Training](#) [FAQs](#)

Back to: [Home](#) > Data Sharing

## Data Sharing

[Data Access](#) | [Data Submission](#) | [Collaboration](#) | [Data Federation](#) | [Security](#) | [Confidentiality](#) | [Informed Consent](#)

The purpose of NDAR is to help accelerate progress in autism research by creating a secure, Web-enabled infrastructure that integrates heterogeneous datasets, providing unprecedented access to a high volume of research data relevant to ASD.

**>>>Get important [technical updates](#) for data formatting and submission**

### Data Sharing Snapshot

| Data Access                                                                                                                                                          | Data Submission                                                                                                                                                      | Collaboration                                                                                                                                                                                                                                                                             |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Policy</b><br><ul style="list-style-type: none"> <li> <a href="#">NDAR Policy</a><br/>           [ PDF 40 KB ]<br/> <i>Last updated: Feb 15, 2008</i> </li> </ul> | <b>Policy</b><br><ul style="list-style-type: none"> <li> <a href="#">NDAR Policy</a><br/>           [ PDF 40 KB ]<br/> <i>Last updated: Feb 15, 2008</i> </li> </ul> | <b>Policy</b><br><ul style="list-style-type: none"> <li> <a href="#">NDAR Policy</a><br/>           [ PDF 40 KB ]<br/> <i>Last updated: Feb 15, 2008</i> </li> <li> <a href="#">Ongoing Study Addendum</a><br/>           [ PDF 13 KB ]<br/> <i>Last updated: Feb 2, 2009</i> </li> </ul> |
| <b>Required Agreements</b><br><ul style="list-style-type: none"> <li> <a href="#">SF-424 (R&amp;R)</a><br/>           [PDF 801 KB ]         </li> </ul>              | <b>Required Agreements</b><br><ul style="list-style-type: none"> <li> <a href="#">Data Submission Agreement</a><br/>           [ PDF 40 KB ]         </li> </ul>     | <b>Required Agreements</b><br><ul style="list-style-type: none"> <li> <a href="#">Ongoing Study Request</a><br/>           [ Template DOC 32 KB ]         </li> </ul>                                                                                                                     |

#### Data Sharing Resources

- [NDAR Data-Sharing Checklist](#)  
 [ PDF 180 KB ]  
*Last updated: May 13, 2010*
- [NDAR Data Submission Cost Model](#)  
 [ XLS 32 KB ]  
*Last updated: Mar 16, 2010*

#### Informed Consent

- [Certificate of Confidentiality](#) information
- Sample language for institutions [with a certificate](#) of confidentiality
- Sample language for institutions [without a certificate](#) of confidentiality
- [Brochure](#) for parents

Done

# Data Access

1. Read the NDAR Policy  
<http://ndar.nih.gov/ndarpublicweb/policies.go#policy>
2. Complete the Data Access Permission Request  
<http://ndar.nih.gov/ndarpublicweb/policies.go#sop4>
3. Request an NDAR Account  
<http://ndarportal.nih.gov>

# Data Submission Planning Tools

- Data-Sharing Checklist

[http://ndar.nih.gov/ndarpublicweb/Documents/NDAR\\_Data-Sharing\\_Checklist\\_10152009.pdf](http://ndar.nih.gov/ndarpublicweb/Documents/NDAR_Data-Sharing_Checklist_10152009.pdf)

- Data Submission Cost and Level of Effort Model

[http://ndar.nih.gov/ndarpublicweb/Documents/NDAR\\_Data\\_Submission\\_Costs.xls](http://ndar.nih.gov/ndarpublicweb/Documents/NDAR_Data_Submission_Costs.xls)

- Data Structures

<http://ndar.nih.gov/ndarpublicweb/DataStructures.go>

# NDAR Technical Assistance

- E-mail: [ndarhelp@mail.nih.gov](mailto:ndarhelp@mail.nih.gov)
- Web site: <http://ndar.nih.gov>
  - Standard Operating Procedures (Policy & Procedures page)
  - Webinars (Training page)
  - Online Tutorials (Training page, Spring 2010)
- Listservs: <http://ndar.nih.gov/ndarpublicweb/Listserv.go>
  - **NDAR General:** System enhancements, Web updates, training schedules, meetings and special events
  - **NDAR Data:** Timely technical updates, system releases, new data structures, data management-related tools and trainings
- Demonstration Environment: <http://ndardemo.nih.gov>
  - Request an Account
  - Practice setting up data structures and submitting data