

GUIDE FOR DOWNLOADING PHENOTYPIC DATA

1. Access the AGRE website by going to www.agre.org using a web browser.
2. Click on the link for “Phenotype Data.”
3. You will be directed to the AGRE data center and prompted to enter your username and password. After these have been entered, click on the submit button.
4. Once in the AGRE Data Center, you will be presented with the following options:
 - a. **PHENOTYPIC DATA DOWNLOAD AND ANALYSES**
 - b. **DESCRIPTION OF ASSESSMENTS**
 - c. **FAMILY PEDIGREE STRUCTURES**
 - d. **GENOTYPIC DATA DOWNLOAD, INFORMATION AND ANALYSES**
 - e. **CANDIDATE GENES, LOCI AND SPECIAL ANALYSES**
 - f. **AGRE RESEARCHER NEWS, REPORTS, DATA ANALYSES**
 - g. **AGRE DATA KEYS**
5. To access ISAAC, either:
 - a. Click on the “P” , or
 - b. Click on the “Go” link next to **PHENOTYPIC DATA DOWNLOAD, AND ANALYSES**
You will be redirected to the “**PHENOTYPIC DATA DOWNLOAD AND INFORMATION.**” page.
 - c. Scroll down and click on the ISAAC icon. A new web browser window will be launched, which serves as the ISAAC portal and Maximize window.
6. Click on “View Download List” and this will display a listing of all data available for download from ISAAC.

Download Data or Code Books - Microsoft Internet Explorer

powered by **ISAAC**

AGRE

Autism Genetic Resource Exchange

log off

Download/View Data

Select the questions you want to include:

- Include Interview Data (Regular form questions)
- Include Automated Scoring Values*

Enter the max. number of columns to include in each file:

Click the **View Download List** button.

View Download List

After making changes to the settings above, click the View Download List button to regenerate the list of downloadable tables.

You may download your data from one or all projects for which you are registered, for any of the forms/tools in ISAAC. Simply click on the **View Download List** button to see which tables you can download and how many records each table holds. If you make a change to the download settings on the left, click the **View Download List** button again to regenerate the list.

The data will be pulled from ISAAC, compressed using the zip format, and downloaded to wherever you select on your local or network drive. **The data will be in a tab delimited, ASCII format.** It is suffixed with .xls, to be easily opened in a spreadsheet, but it can also be used directly by many statistical packages.

The first row contains the field names for that column, and corresponds to the field

7. On the right hand side of the webpage, a list of the phenotype exams will be displayed. You may alter the default setting for the number of columns included in a single table at this time. The default setting will divide a large exam table, such as the ADIR, into two smaller tables so that programs such as Microsoft Excel which have limitations on the number of columns allowed may open the tables.

In order to have all the data exported into a single file, change the maximum number of columns to include in each file from 250 to 999. In order to download the data for a particular exam, click on the “Download This Data” link. Another small browser window will be launched to initialize the data set. Once the dataset has been compiled, the window will display a hyperlink describing the specific data set. Click on the hyperlink (i.e. the name of exam), and you will be prompted to “Open” or “Save” the data set to a local place on your computer.

Download/View Data

Select the questions you want to include:

- Include Interview Data (Regular form questions)
- Include Automated Scoring Values*

Enter the max. number of columns to include in each file:

Click the **View Download List** button.

View Download List

ADOS Module 1: Pre-Verbal/Single Words
Project: AGRE Records: 250
[Download This Data](#)
[View this Form's Codebook](#)

ADOS Module 2: Phrase Speech
Project: AGRE Records: 131
[Download This Data](#)
[View this Form's Codebook](#)

ADOS Module 3: Fluent Speech Child/Adolescent
Project: AGRE Records: 202
[Download This Data](#)

8. Open the file, which is in tab delimited text format (but appended with .XLS to make the file opened by Microsoft Excel). Each record in the Excel spreadsheet represents data for one subject, and each column is an item on a questionnaire or other exam. Each record is indexed by the Individual Code of the subject, which consists of the AU family ID and the pedigree ID.

Please wait...

Building list of columns to download...

File 1

Accessing data tables...

Aggregating and formatting data...

Creating XLS file...

File 2

Accessing data tables...

Aggregating and formatting data...

Creating XLS file...

Archiving the data in a zip file...

File creation completed.

[AGRE Medical History: Affected Child Data](#)

[Close Window](#)

9. In case the number of maximum columns was not adjusted a second spreadsheet for a given exam indicates that there were too many columns (data points) per subject. In this case, the second Excel spreadsheet (ex. ADIR2.xls) will not contain the Individual Code of the patient but will contain a linking number called PatientRecordID which links it to the first table. This allows one to put the tables side by side.
10. Exam and item descriptions are provided in the codebooks for each individual exam. You can click on “View This Form’s Codebook” from the main ISAAC page. A new web browser window will be launched with ISAAC at the top, and it will show the Variable Name (e.g. the name at the top of the column for that form’s data), the Question Text (e.g. the question asked or the exam done), the Response Type (ex. Text, Dropdown, Numeric Range), and the Selection List (e.g. value definitions).

Form Name: ADOS Module 4: Fluent Speech Adolescent/Adult Code Book **Version:** ADOS-G Mod4 (2000 or earlier)

Form Text: This semi-structured assessment consists of various activities that allow you to observe social and communication behaviors related to the diagnosis of pervasive developmental disorders.

Publisher Note: Complete definitions and descriptions of items and codes available through original administration materials available from the publisher: Western Psychological Services, 12031 Wilshire Boulevard, Los Angeles, CA 90025, USA, (www.wpspublish.com).

Section Type: Regular Form

Section Number: 1
Section Name: A. Language and Communication

Question Label: 1 **Variable Name:** A1

Question Text: Overall Level of Non-echoed Language

Response Type: Select (DropDown)

Selection List:

Select Value	Stored Value	Answer Text
0	0	Refer to original materials
1	1	Refer to original materials
2	2	Refer to original materials
3	3	Refer to original materials
- Blank on Form	-1	Indicates that no response was entered on the collection form/instrument for this question.

11. While many of the column headings will be self-explanatory, some data sets will require a detailed understanding of the instruments. A starter with hyperlinks for further information is available on the AGRE website by entering the AGRE Data Center and clicking on the “Go” link next to “**DESCRIPTION OF ASSESSMENTS**”.