

## **Guidance for Submitting and Coding 20XX Autism Research Funding Data**

The Interagency Autism Coordinating Committee (IACC), in order to perform the monitoring of autism spectrum disorder (ASD) activities mandated by the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act and to inform their strategic planning activities, is asking agencies and organizations that make significant contributions to ASD research to report how their 20XX investments in ASD research correspond to the questions and research objectives of the [2016-2017 IACC Strategic Plan](#). This will greatly help the IACC to understand the current funding landscape and identify areas of progress, opportunity, and need. To view the analysis that was conducted using the 2016 ASD research project data, please see the [2016 Autism Spectrum Disorder Research Portfolio Analysis Report](#).

### **Overview:**

The [2016-2017 IACC Strategic Plan](#) is organized around seven critical questions faced by people and families living with ASD:

- Question 1 (Diagnosis and Screening) – How Can I Recognize the Signs of ASD, and Why is Early Detection So Important?
- Question 2 (Biology) – What Is the Biology Underlying ASD?
- Question 3 (Risk Factors) – What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted?
- Question 4 (Treatments and Interventions) – Which Treatments and Interventions Will Help?
- Question 5 (Services) – What Kinds of Services and Supports are Needed to Maximize Quality of Life for People on the Autism Spectrum?
- Question 6 (Lifespan Issues) – How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood?
- Question 7 (Infrastructure and Surveillance) – How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community?

The “20XX ASD Research Spreadsheet” accompanying this guidance contains a listing of projects provided by your organization to the IACC for fiscal year 20XX, as well as space for you to include projects that were newly funded in 20XX. On behalf of the IACC, the Office of Autism Research Coordination (OARC) is requesting information on your organization’s 20XX projects. This would include all ongoing and newly funded projects from 20XX (either fiscal year or calendar year, whichever measure is used by your organization). Please refer to the instructions below to fill out the 20XX ASD Research spreadsheet. In deciding which projects to include in the spreadsheet, please list all projects that are responsive to objectives in the [2016-2017 IACC Strategic Plan](#). In cases where potentially relevant projects that were new in 20XX could be identified through websites or online databases, OARC pre-populated the spreadsheet with these projects and provided draft coding for agency review. Projects may be added or deleted, and revised coding may be suggested as needed. If you have any questions about whether a particular project should be included, please feel free to contact OARC for assistance.

## Instructions:

### 1) Verify information for ongoing projects

All of the information for autism research projects that was provided by your organization for 20XX is already in the spreadsheet. Please review this information for accuracy and fill in additional information where required in the following columns:

- **Project Status in 20XX:** If a project had any funding or any project activity at any time in 20XX, then please use the drop-down box to list the project as “Ongoing.” If there was no funding or project activity in 20XX, then please use the drop-down box to list the project as “Terminated.”
- **Multi-Site (Yes/No):** This is a new item added to our analyses to keep track of projects that have more than one location where research activities are taking place. A project is considered to be multi-site if a funded project supports research activities at multiple locations or the project is one of several projects that make up a research network. Please pick “yes” or “no” from the drop down menu for each project.
- **20XX Funding:** Please fill in the 20XX funding amount; if the project remained active in 20XX but did not receive funding please add \$0 to the space.
- **New or Revised Weblink/New or revised Project description:** Please fill out only if any information has changed from 20XX.
- **20XX SP Question/20XX SP Objective:** Please verify the coding of each project according to the *2016-2017 IACC Strategic Plan*. The coding from 20XX is listed (in the “Previous SP Question Code” and “Previous SP Objective Code” columns).
  - If you agree with the Question and objective codes suggested by OARC, no further action is required. If you do not agree with the pre-coding, you may suggest an alternative Objective Code in the “20XX Objective Code (by Agency/Org)” column. For your convenience, a Coding Reference Sheet is in the first tab of the spreadsheet and lists all of the Strategic Plan objectives.
  - **NOTE:** There is a new cross-cutting objective (CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population). Projects from any SP Question category can be coded to this Objective.
  - If you would like to change the Question Code for a project, please use the drop down boxes under the “20XX SP Question Code (By Agency/Org)” columns to select first the Question and then the Objective that you think best describes the project according to the *IACC Strategic Plan*. Please include a note in the “Comments” column to explain the reason(s) for the change in Question coding.

**Please Note:** If other aspects of a project have changed since 20XX (e.g., PI, Project Title, Institution), please do not alter the information in these cells; instead, provide revised data in the “Comments” column in the spreadsheet. Please ignore any cells that are blacked out; you do not need to put any information in that column.

## **2) Provide information on projects that are new in 20XX**

Also in the third tab, labeled “20XX ASD Projects,” is space to list all the **new** projects funded by your organization in 20XX. This new project data should be entered in rows below the ongoing project data. The beginning of this section for data entry can be found by looking for rows that have a **yellow highlighted cell** on the far left. These cells indicate that all new project information should be entered into the adjacent cells to the right. Please fill in the missing information in the green cells for each project. The **Project Status in 20XX** (“New”) has been filled in for you. If you know of any projects that are ongoing that were inadvertently left out of the 20XX Data Call, please provide them in these rows as well, and choose “Ongoing” from the drop-down options for Project Status. Please fill in all of the required columns to the best of your ability according to the instructions above, including:

- **Project Status in 20XX:** This has been auto-populated to “New”.
- **Start/End Date:** Please fill in the column for start date and the column for end date. If available, use specific dates and not just the year.
- **20XX Funding:** Please fill in the 20XX funding amount; if the project was active but did not receive funding fill in \$0.
- **Project Description and Weblink:** A short, accurate project description (a few sentences is enough) or a weblink to a site where a project description can be found is very useful for verifying coding of the projects, as well as helping readers understand the activities included in the projects. If no project description or weblink is available, please type “Project description/weblink unavailable.”

Columns where previous information does not exist for new projects, such as 20XX funding, previous project descriptions or last year’s codes, have been blacked out. You need not put any information into these cells for the new projects.

**For some organizations with publicly available databases, OARC has pre-populated the spreadsheet with new projects that began in 20XX that were identified from the database as potentially being related to ASD research. We have made every attempt to include as much available data as possible as well as provide suggested objective and question coding. Please review these projects and revise the list as needed, supplementing any missing and/or incorrect data as well as adding additional projects if necessary.**

### **Coding**

In previous years, OARC has requested that funders code each project according to the objectives in the *IACC Strategic Plan*. **To reduce the burden on agencies and organizations participating in the IACC portfolio analysis data collection, the Office of Autism Research Coordination (OARC) is again offering the option to have organizations send their new project listings to OARC to assign preliminary codes, and then for OARC to return the coding to the organization for verification. Hopefully this second option will reduce the effort required of organizations to determine which code best fits each project. If you would like to take advantage of this opportunity, please follow the procedure below:**

### **Instructions for obtaining pre-coding of new projects from OARC:**

If you would like OARC to assign preliminary codes for new 20XX projects, then simply leave the 20XX Strategic Plan (SP) Question and Objective Code columns blank and return the spreadsheet with a note

stating that you would like the office to assign codes. Once OARC has assigned preliminary codes, the office will return the spreadsheet to you for coding verification. Once you receive the list of projects with preliminary coding added, you may review the coding and determine whether you would like to keep the preliminary codes or suggest alternate codes.

**Instructions for organizations that wish to do the preliminary coding of their own projects:**

If, instead, your organization would prefer to assign the codes, then you may use the drop-down boxes in the 20XX SP Question and Objective Code (by Agency/Org) columns to assign first the Question and then the Objective that best describes each project according to the Strategic Plan (the assignments must be made in that order). A project may also fit within a question but not a specific objective, in which case you can select the appropriate Question followed by “Not specific to Question X objectives” in the Objective column.

***3) Provide information regarding other projects if applicable***

If you are aware of additional projects funded by your organization that may address a broader scientific scope (e.g., that may include autism but are not limited to autism, such as projects pertaining to multiple disabilities or disorders) but still have relevance to autism or the *IACC Strategic Plan for Autism Spectrum Disorder*, please provide the project information in the “Other Projects” tab. These projects will not be included in the autism research project listing for your agency or organization and their funding will not be included in your agency’s or organization’s total for autism spending, but summary information about these projects may be made available to the IACC for their information and to the public via the *IACC Portfolio Analysis Report*, with the goal of informing the community of additional projects that may have relevance to autism research.

Send your completed ASD Research Spreadsheet to [IACCPortfolioAnalysis@mail.nih.gov](mailto:IACCPortfolioAnalysis@mail.nih.gov). Any questions may also be directed to this e-mail address, and one of the OARC staff will follow up.