

Supporting Statement A for

Autism Spectrum Disorder (ASD) Research Portfolio Analysis, NIMH

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Check off which applies:

- New
- Revision
- Reinstatement with Change
- Reinstatement without Change
- X Extension
- Emergency
- Existing w/o OMB approval

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Attachments

1. NIMH Privacy Impact Assessment (PIA)
2. List of ASD Research Funders
3. ASD Research Funding Data Collection Guidance
4. ASD Research Data Collection Spreadsheet

A. Justification

The National Institute of Mental Health (NIMH) Office of Autism Research Coordination (OARC), on behalf of the Interagency Autism Coordinating Committee (IACC), plans to continue conducting comprehensive portfolio analyses of major autism spectrum disorder (ASD) research funders. The purpose of the annual ASD research portfolio analysis is to collect research funding data from U.S. and international ASD research funders, to assist the IACC in fulfilling the requirements of the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019, and to inform stakeholders of the funding landscape and current directions for ASD research. These analyses will continue to examine the extent to which current funding and research topics align with the *IACC Strategic Plan for ASD*. The findings will also help to guide future funding priorities by outlining current gaps and opportunities in ASD research as well as serving to highlight annual activities and research progress.

A.1 Circumstances Making the Collection of Information Necessary

The [IACC](#) is a Federal advisory committee convened by the Department of Health and Human Services (HHS) consisting of Federal and public members (governed by the provisions of the Federal Advisory Committee Act, as amended [5 U.S.C. Appendix 2]) that coordinates all efforts within HHS concerning ASD. The IACC was established under the Combating Autism Act (CAA) of 2006 ([Public Law 109-416](#)) and reauthorized most recently under the CARES Act of 2019 ([Public Law 116-60](#)). As mandated by the CAA, one of the statutory responsibilities of the IACC is to monitor Federal activities with respect to ASD. The Committee is also charged with advising the Secretary of HHS regarding appropriate changes to ASD activities, as well as developing and annually updating a strategic plan for ASD research and related activities.

A.2 Purpose and Use of the Information Collection

The purpose of the ASD portfolio analysis is to collect data on nationally- and internationally-funded ASD research. The ASD research funding data includes Federal agencies and private organizations and will be analyzed by OARC staff in separate *Portfolio Analysis Reports* for each year. OARC has conducted previous U.S. data collections to be used as the basis of the *2010-2016 IACC ASD Portfolio Analysis Reports*, which are made publicly available on the IACC website at <https://iacc.hhs.gov/publications/portfolio-analysis/2016/>. The intent of these analyses is to assist the IACC in fulfilling the requirements of the CARES Act and to better inform the IACC and interested stakeholders about the funding landscape and current directions for ASD research. Specifically, these analyses examine the extent to which current funding and research topics align with the *IACC Strategic Plan for ASD*. This will help guide future funding priorities by outlining current gaps and opportunities in ASD research as well as serving to highlight current activities and research progress. In addition, this information is used to help the IACC in their annual update of the *Strategic Plan*. Funding organizations will be asked to provide specific data on individual research projects that they support. Each funder will receive a spreadsheet (see Attachment 4 - *ASD Research Data Collection Spreadsheet*) along with instructions to fill in several data columns for each project (see Attachment 3 - *ASD Research Funding Data Collection Guidance*). The type of information collected will include project title, principal investigator, research institution, state or country, annual funding, award period, project description, web link (if available), project number (if applicable), and project status (new or ongoing). In addition, funders will be asked to categorize (or approve OARC categorization for) each project according to the *IACC Strategic Plan* Question and Objective with which it best aligns. Once the data are received by OARC, the office will ensure

that all data entries are complete by following up with funders to collect missing information as needed. OARC will review all coding to ensure data consistency across all funders.

OARC provides management and support to the IACC to assist them in carrying out these responsibilities. To help the IACC fulfill its requirement to monitor Federal activities, OARC produces an annual [ASD Research Portfolio Analysis Report](#) based on data provided by Federal funders about ASD research projects that they support. In addition, based on the committee's interest in gaining a fuller understanding of the research landscape, the IACC also has requested that the report annually include funding data from private organizations. Each funder provides a list of funded projects in a particular year, along with project descriptions and dollar amounts. These collected data are then analyzed to provide information on the level to which various objectives in the [IACC Strategic Plan for Autism Spectrum Disorder](#) correlate with Federally- and privately-funded research projects. The IACC uses the results of the analyses when developing and updating subsequent iterations of the *Strategic Plan*, which in turn informs government policymakers, advocacy organizations, and the public about the critical areas of need for autism research.

Previous analyses (conducted on data from 2010-2016) have been limited to U.S. Federal agencies and nine U.S. private organizations. For future analyses, the IACC would like to include data from a larger number of U.S. private funders in order to obtain a broader understanding of the ASD funding landscape in this country. Furthermore, because biomedical research is an international enterprise, it is valuable to conduct additional portfolio analyses including international funders of ASD research. OARC completed its first International Portfolio Analysis in 2019, in collaboration with organizations in the United Kingdom, Australia, and Canada. In the future, OARC plans to conduct this international analysis triennially. Collectively, this information

will continue to enable the IACC to provide advice to the Secretary of HHS from a more comprehensive knowledge base.

Based on previous portfolio analysis data collection, it is estimated that in the future at least 11 Federal and nine private funders will be included in every U.S. portfolio analysis and approximately the same number for every international portfolio analysis. In general, each funder equates to one respondent. The only deviation from this concerns the National Institutes of Health (NIH), which is the largest funder in the U.S. analysis. NIH Institutes or Centers allocate and manage project funding independent of one another, and therefore their data are collected separately for the purposes of the portfolio analysis. OARC predicts that future NIH data collections will be comprised of approximately 14 respondents based on the number from the 2016 analysis. Thus, OARC anticipates a total of 25 Federal respondents and nine private respondents in each U.S. portfolio analysis. Each respondent will be asked to fill out the data request once per portfolio analysis, which equates to once per year for U.S. funders and approximately once every 3 years for non-U.S. funders. Collection of data from funders is essential for the IACC to carry out its ASD research monitoring activities. Requesting information directly from the funders is the most accurate and efficient way of compiling these records for the Committee to use in their decision-making processes. Without these data, the IACC's ability to advise the Secretary of HHS is significantly diminished.

A.3 Use of Information Technology and Burden Reduction

All data will be collected via electronic submission, thereby reducing both hours of effort and financial costs. Specifically, each funder will receive an email along with a spreadsheet for data collection. The information collected in the spreadsheet will be stored on the National Institutes of Mental Health (NIMH) network, which is covered by a Privacy Impact Assessment for

all NIMH hosted Web applications (see Attachment 1). Once analyzed, the data will be summarized in the *IACC ASD Research Portfolio Analysis Reports* and made publicly accessible via the online **Autism Research Database (ARD)** on the IACC website at <https://iacc.hhs.gov/funding/data/>.

A.4 Efforts to Identify Duplication and Use of Similar Information

This data collection continues to be unique in that it is the only place where information from numerous funders of ASD research is compiled into a single report or database for comprehensive analysis. There is no similar information available for use. While some funders post limited information about their funded projects online, the data gathered through this process is more extensive than what is available through any other single database or website. For example, the information collected through this activity aligns research projects with objectives of the *IACC Strategic Plan*, and this information is not available elsewhere. Also, many funders do not include the funding amount for a grant or the duration of the project activity. Both of these data are requested from funders and included in this analysis for all projects. The funding amount is particularly crucial information, as it is one of several measures used to assess research progress by the IACC.

No other agencies, organizations, or entities are carrying out data collection for autism research projects with the same expansive scale or scope as OARC. Furthermore, because these data and reports are made publicly accessible on the IACC website, the portfolio analysis may be used to help reduce duplication in the ASD field by providing a tool to make scientists and funders aware of similar research efforts. Additionally, no known portfolio analysis has been conducted on worldwide ASD research funding, so the international data collection represents the only source of this type of information.

A.5 Impact on Small Businesses or Other Small Entities

Small entities are invited to continue participating in this data collection without creating additional unreasonable burden. The feedback from private organizations about the most recent data collection was positive, particularly since OARC offers to assist organizations with coding projects to reduce the effort required from them to submit the data. Every effort has been made to keep the information requested from all funders to the minimum amount required for the intended use. Although the type of information collected for smaller and larger entities will be the same, the smaller entities generally have fewer projects for which to provide data and thus their burden of time and effort will be significantly less than that for larger organizations with extensive investments in autism research projects.

A.6 Consequences of Collecting the Information Less Frequently

By law, the IACC is responsible for updating the *IACC Strategic Plan for ASD Research* on an annual basis. In order to do this, they require up-to-date information concerning U.S. ASD research funding to identify where the areas of progress, gaps, and opportunities lie. To this end, the portfolio analysis of U.S. ASD research funders is conducted annually. Conducting the portfolio analysis less frequently would limit the availability of timely funding data and therefore inhibit the IACC's ability to update the *IACC Strategic Plan*.

A.7 Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

No special circumstances are anticipated. This project fully complies with the guidelines of 5 CFR 1320.5.

A.8.1 Comments in Response to the Federal Register Notice

As required by 5 CFR 1320, a 60-day notice of this proposed data collection was published in the Federal Register on October 3, 2019, Vol 84 FR 52888 and allowed 60 days for public comment. No public comments were received.

A.8.2 Efforts to Consult Outside Agency

OARC receives input from the IACC regarding the need for data collection, the frequency of data collection, and other issues related to the data collection. OARC annually consults with representative funders during the data collection process (see Attachment 2 for a list of funders who were contacted during the collection of data included in the *2016 ASD Research Portfolio Analysis*). The funders provide informal feedback regarding the information gathering process, including examples where additional instructions could be useful to help them complete their task. OARC is responsive to these suggestions in subsequent data collections in an effort to streamline the process and reduce burden on the participants. Many of the U.S. Federal agencies and private organizations that fund research also are represented on the IACC, thus providing another route by which funders provide input into the portfolio analysis process. OARC also made some changes to the recent iterations of the portfolio analysis data call in response to specific remarks from funders; some funders indicated that coding their projects with respect to the *IACC Strategic Plan* was difficult and time consuming. OARC offers to preliminarily code projects for the funders to verify, which helps reduce the funders' burden.

A.9 Explanation of Any Payment of Gift to Respondents

No payment or gift will be given to respondents.

A.10 Assurance of Confidentiality Provided to Respondents

This data collection is carried out on behalf of the IACC, a federal advisory committee whose process and products are to be transparent to the public in accordance with the Federal

Advisory Committee Act. Participation is entirely voluntary, and public disclosure of any information that the funder provides is explained to participants at the outset of the process. The data call invitation states that data submitted in response to the data call will become a part of the public record and will be released to the public as a part of specified IACC research monitoring and reporting activities. Following collection, the original data will be stored on a secure NIMH network and only accessed by OARC staff. The data is analyzed, and the analyses are made available to the public in a written report posted on the IACC website. The verified data, related summaries, and analyses conducted using the data will continue to be made accessible to the public in a secure database called the *IACC/OARC Autism Research Database*. In the *Autism Research Database*, the funding amounts for individual projects will be attributed to specific funders but not to individuals within the funding agency/organization that reported the data.

A.11 Justification for Sensitive Questions

No questions of a sensitive nature will be asked. Questions are of a general nature and disclosure would not create harm to individuals. All respondents have the right not to answer particular data categories or stop their participation at any time without consequence.

A.12.1 Estimates of Hour Burden Including Annualized Hourly Costs

U.S. Federal and private funders and international government and private funders will be asked to provide information about the ASD-related research grants, contracts and other types of relevant projects awarded within a one-year period. The information requested includes project title, principle investigator, institution, and annual funding amount. Attachment 3 (the *ASD Research Funding Data Collection Guidance* document) provides a full description of requested information and guidance to funders on data submission and how to use the spreadsheet data entry instrument.

Response burden estimates are shown in Table A.12-1. Based on collections conducted since 2010, OARC estimates that the data collection tool takes approximately 15 minutes per project to complete. This figure was derived from conversations between OARC staff and funders who participated in previous portfolio analyses (see Attachment 2 for a list of funders who were contacted during the collection of data included in the 2016 ASD Research Portfolio Analysis). The number of projects in the table below was estimated based on the data available as of the last data collection conducted in 2016.

Table A.12-1 Estimated Annualized Burden Hours

Type of Respondents	Number of Respondents	Number of Projects per Respondent	Average Time per Response (in hours)	Total Burden Hours
U.S. Federal	25	88	15/60	550
U.S. Private	9	63	15/60	142
Individuals/households - International Government	1	61	15/60	15
Individuals/households - International Private	2	13	15/60	7
TOTAL	37	2854		714

A.12-2 Annualized Cost to Respondent

The response burden estimates in Table A.12-1 were used to calculate the annualized costs to the respondents, which are shown in Table A.12-2 below.

Table A.12-2 Annualized Cost to Respondents

Type of Respondents	Total Burden Hours	Hourly Wage Rate *	Total Respondent Cost
U.S. Federal	550	\$36.62	\$20,141

U.S. Private	142	\$36.62	\$5,200
Individuals/households - International Government	15	\$36.62	\$549
Individuals/households - International Private	7	\$36.62	\$256
TOTAL	714		\$26,147

*The United States Department of Labor Bureau of Labor Statistics (May 2018) National Occupational Employment and Wages by Major Occupational Group is being referenced (*Life, Physical and Social Science Occupations*) - see <http://www.bls.gov/oes/current/oes190000.htm>.

A.13 Estimate of Other Total Annual Cost Burden to Respondents or Record Keepers

There are no capital, start-up, or operation/maintenance costs associated with this data request for any respondents. In addition, there are no services that will need to be purchased in order to carry out this request.

A.14 Annualized Cost to the Federal Government

The estimates of the annualized cost to the Federal government assume that for U.S. funders, one portfolio analysis per year will be conducted, and for non-U.S. funders, an analysis will be conducted approximately once every three years.

The bulk of the annualized cost to the Federal government will be accrued through labor hours by OARC staff and costs associated with publishing the *Portfolio Analysis Report*, as indicated in Table A.14-1. The efforts of the staff member include developing the data collection materials, e-mailing information to respondents, corresponding with respondents to answer questions about the process, reviewing responses, coding projects, tabulation and analysis of data, writing the final report (and all drafts leading up to the final report), editing and proofreading drafts, arranging to print the final report, and entering the data into the **online Autism Research Database**. The annual cost listed below is based on previous portfolio analyses conducted by OARC.

Table A.14-1 Annualized Cost to the Federal Government

Staff	Grade/Step	Salary	% of Effort	Fringe (if applicable)	Total Cost to Gov't
Federal Oversight					
OARC Policy Analyst	GS-12/2	\$86,179	100%		\$86,179
Contractor Cost					
Travel					
Other Cost					
TOTAL					\$86,179

*The salary reported in table A.14-1 is cited from <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/19Tables/html/DCB.aspx>.

A.15 Explanation for Program Changes or Adjustments

The slight increase in burden hours relates to an increase in the number of U.S. respondents combined with an increase in the number of projects reported by international respondents:

- U.S. Funders.** The number of projects for the “Federal” and “Private” categories was estimated based on the number of projects reported by these funders in the 2016 ASD Research Portfolio Analysis Report, since the same funders will be included in OARC’s proposed expanded analyses.
- International Funders.** The first international portfolio analysis was performed using 2016 ASD research project information. Data was included from the United States, the United Kingdom, Canada, and Australia. Data collection methods varied among the countries. For the U.S., data had already been collected for 2016 using current data collection methods and did not require any new requests. For Canada, OARC used the same data collection method used with U.S. funders; one federal funder and two private funders were included in the international portfolio. The United Kingdom and Australia gathered funder data

from a database that already maintained all the ASD research project information needed, therefore, not burdening funders with additional requests. Based on the 2016 international portfolio analysis, only 3 additional funders were contacted to provide ASD research project information.

A.16 Plans for Tabulation and Publication and Project Time Schedule

Information collected from ASD research funders will provide the basis for future *Portfolio Analysis Reports* which OARC produces on behalf of the IACC. Data received from the funders are checked for completeness by OARC staff. The coding of projects according to the *IACC Strategic Plan for ASD* is also assessed to ensure that the codes have been applied consistently between funders. The *IACC Strategic Plan* is organized into seven community-focused research questions. Within each question is a set of specific research objectives, along with a recommended funding amount for each objective. Once all data are assembled, the total funding amounts for each objective in the *IACC Strategic Plan* are summed and the data are analyzed in terms of the total projects and funding that correspond with each objective. In the final report, descriptive comparisons to previous years of funding or coverage of objectives are made when applicable. In an additional layer of analysis, each autism research project is also assigned to a research subcategory that provides a more detailed breakdown of the types and subject matter of the funded research.

The ASD portfolio analysis will be an ongoing, annual (for U.S funders) and triennial (for international funders) data collection process. The plan is to begin data collection after OMB approval is received. The project schedule for completing data collection, processing, and data analysis is presented in Table A.16-1.

Table A.16-1 Project Time Schedule

Activity	Time Schedule
Begin data collection from ASD funders	2 - 4 weeks after OMB approval
Finish data collection from ASD Funders	1 - 3 months after OMB approval
Data analysis by OARC	3 - 4 months after OMB approval
Writing the Portfolio Analysis Report	5 - 6 months after OMB approval
Publication	7 months after OMB approval
Data available online via Autism Research Database	7 months after OMB approval

Analysis Plan

The final published analysis will include a table that lists all ASD research funders that are included in the analysis as well as the total dollar amount of the funding that each contributed. The full data set will be analyzed using simple descriptive statistics (charts, tables, etc.) to identify trends in ASD funding and how funding aligns with the *IACC Strategic Plan for ASD*. No statistical tests will be performed on the data. The analyses will be published as *ASD Research Portfolio Analysis Reports* and included in a publicly accessible companion online database (**the Autism Research Database**).

A.17 Reason(s) Display of OMB Expiration Date is Inappropriate

The OMB control number 0925-0682 will be displayed appropriately (current expiration date: 12/31/2019).

A.18 Exceptions to Certification for Paperwork Reduction Act Submissions

None.