

Supporting Statement A for

Autism Spectrum Disorder Research Portfolio Analysis
(Office of Autism Research Coordination at the
National Institute of Mental Health)

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- Attachment 1: Privacy Impact Assessment (PIA) – NIMH Network System
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- Attachment 3: Listing of Representative Funders who were Consulted
- Attachment 4: Data Collection Guidance
- Attachment 5: Data Collection Instrument (spreadsheet)

A.1 Circumstances Making the Collection of Information Necessary

The NIMH Office of Autism Research Coordination (OARC), on behalf of the Interagency Autism Coordinating Committee (IACC), plans to conduct several comprehensive portfolio analyses of major autism spectrum disorder (ASD) research funders.

The IACC is a Federal advisory committee convened by the Department of Health and Human Services (HHS) and 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 under the Combating Autism Reauthorization Act (CARA) of 2011 (Public Law 112-32). 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*.

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 Research* correlate to 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 for 2008, 2009, and 2010) have been limited to U.S. Federal agencies and fewer than 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 would be valuable to conduct additional portfolio analyses to include international funders of ASD research. Collectively, this information will enable the IACC to provide advice to the Secretary of HHS from a more comprehensive knowledge base.

Based on the *2010 Portfolio Analysis* data collection process, it is estimated that in the future at least ten Federal and twelve 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 (ICs) allocate and manage project funding independent of one another, and are 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 17 respondents based on the number from the 2010 analysis. Thus, OARC anticipates a total of 26 Federal respondents and 12 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.

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 will include 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 2008, 2009, and 2010 *IACC ASD Portfolio Analysis Reports*.

The intent of these analyses is to assist the IACC in fulfilling the requirements of the CAA 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 Research. 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 will be 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 along with instructions to fill in several data columns for each project. The type of information collected will include project title, principle investigator, research institution, state or country, annual funding, award period, project description, weblink (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.

Collection of data from funders is essential to the IACC being able 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 (Attachment 1). Once analyzed, the data will be summarized in the *IACC ASD Research Portfolio Analysis Reports* and made publicly accessible via an online *Web Tool* on the IACC website. The *Web Tool* is hosted by the NIMH server. There is currently a Privacy Impact Assessment (Attachment 2) in place that covers all NIMH hosted Web applications.

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

The proposed data collection is 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 will be made publicly accessible, 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 proposed international data collection will represent the only source of this type of information.

A.5 Impact on Small Businesses or Other Small Entities

While small entities will be invited to participate in this data collection, it will not create an unreasonable burden on those organizations. 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 will 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 in order 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 Comments in Response to the Federal Register Notice and Efforts to Consult Outside Agency

As required by 5 CFR 1320, a 60-day notice of this proposed data collection was published in the Federal Register, Volume 78, Number 101, Page 31568-31569 on May 24, 2013, and allowed 60 days for public comment. One public comment was received; in this comment, a request was made for access to any data that is collected on autism projects that are funded. This comment was considered, but it did not result in alteration to the data collection or data management process because steps are already in place to make the data publicly accessible via an online *Web Tool* on the IACC website as described in Section A.3. No comments that specifically addressed cost and hour burden were received.

OARC receives input from the IACC regarding the need for data collection, and the frequency of data collection, and other issues related to the data collection. Annually, OARC consults with representative funders during the data collection process (see Attachment 3 for a list of funders who were contacted during the collection of data included in the *2010 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 most recent iteration 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 now

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 in this data collection 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 network (see Attachment 1 for PIA), and only accessed by OARC staff. The data will be analyzed and the analyses will be 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 be made accessible to the public in a secure database called the *IACC ASD Research Portfolio Analysis Web Tool* (see Attachment 2 for PIA). In the *Web Tool*, 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 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 4 provides a full description of requested information and guidance to funders on data submission and how to use the spreadsheet data entry instrument (Attachment 5).

Response burden estimates are shown in Table A.12-1. Based on previous experience, 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 3 for a list of funders who were contacted during the collection of data included in the *2010 ASD Research Portfolio Analysis*). The annual burden for each type of respondent was estimated by multiplying the estimated response time per project (15 minutes) by the estimated number of projects to be reported by that respondent (funder), by the number of respondents, by the frequency of response.

The number of projects in the table below was estimated differently for the U.S. and International funders based on the data available:

- 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 *2010 ASD Research Portfolio Analysis Report*, since the same funders will be included in OARC’s proposed expanded analyses.

- International Funders. Because there are no previous portfolio analyses from which to draw information, the number of projects for the “Government” and “Private” categories was estimated using existing data collected for the *IACC/OARC ASD Research Publications Analysis*, a report published in 2012. This report examined ASD-related research publications from 2010, and as part of this analysis, a list of government and private international funders of ASD research was generated based on the funding acknowledgements sections of those papers. For the current purposes, those funders who received five or more acknowledgements in 2010 were selected as representative ASD research funders. Based on the assumption that a typical grant produces an average of one publication per year, these funding acknowledgements were used to estimate the number of ASD-related projects supported by each funder in 2010. This was used as the best estimate for the number of projects that each funder might contribute to future portfolio analyses.

Table A.12-1 Estimates of Annual Burden Hours

Type of Respondents (Funders)	Number of Respondents	Number of Response per Respondent	Average Time per Response (in hours)	Total Burden Hours
U.S. Federal	26	36	15/60	234
U.S. Private	12	54	15/60	162
International Government	4	14	15/60	14
International Private	4	9	15/60	9
Total	46			419

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.

Table A.12-2: Annualized Cost to Respondents						
Type of Respondents (Funders)	Number of Respondents	Frequency of Response¹	Average Number of Projects per respondent	Average Time per Response (in hours)	Hourly Wage Rate	Total Respondent Cost
U.S. Federal	26	1	36	15/60	\$38	\$8892
U.S. Private	12	1	54	15/60	\$38	\$6156
International Government	4	1	14	15/60	\$38	\$532
International Private	4	1	9	15/60	\$38	\$342
Total	46					\$15,922

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 are based on the assumption 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 members 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 *Web Tool* (online database). The annual cost listed below, broken down by task, is based on previous portfolio analyses conducted by OARC:

Table A.14-1: Annualized Cost to Federal Government	
Task	Estimated Annual Cost
Project Management	\$21,000
Web Design (<i>Web tool</i> and putting the publication online)	\$7,600
Data Collection (collection, verification, coding, and analysis)	\$32,000
Reports (writing, editing, and publication cost)	\$24,550
Total	\$85,150

Thus, the grand total annualized cost to the Federal government to conduct an annual data collection for a portfolio analysis of U.S.-funded autism research as well as one data collection every three years for a portfolio analysis of non-U.S. funded autism research is \$85,150.

No other operational expenses will be incurred by this collection of information.

A.15 Explanation for Program Changes or Adjustments

This is a new collection of 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 Research* is also assessed to ensure that the codes have been applied consistently between funders. The *IACC Strategic Plan* is organized into seven consumer-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 and how the funding amount measures up to the recommended amount of funding in that area. 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	Estimated Time Schedule after OMB approval
Begin data collection from ASD funders	2-4 weeks
Finish data collection from ASD Funders	1-3 months
Data analysis by OARC	3-4 months
Writing the Portfolio Analysis Report	5-6 months
Publication	7 months after OMB approval
Data available online via <i>Web Tool</i>	7 months after OMB approval

Analysis Plan

The final published analysis will include a table that lists all of the funders of ASD research 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 Research*. 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 database (*Web Tool*) online.

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

NIMH intends to display the OMB control number and expiration date in the upper right hand corner of the data collection tool. No waiver is being sought to display the expiration date for OMB approval.

A.18 Exceptions to Certification for Paperwork Reduction Act Submissions

NIMH is in full compliance with the provisions contained within the Certification for Paperwork Reduction Act Submissions. No exceptions to the Certification for Paperwork Reduction Act Submissions are requested.