

Attachment H.
Research Quantitative Data Collection Form

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According to the Paperwork Reduction Act of 1995, an agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0915-0335. The time required to complete this information collection is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.

1. CONDUCT RESEARCH ON AUTISM SPECTRUM DISORDER (ASD) INTERVENTIONS

In Table 1, please document your Network's/grant's progress in completing the originally proposed studies, developing and implementing additional studies, and obtaining leveraged funding. Only include activities that occurred during the following time periods:

AIR-P, AIR-B: September 1, 2015–August 31, 2020

DBPNet: September 1, 2016–August 31, 2021

HW-RN: July 1, 2016–June 30, 2021

Autism SIIP: September 1, 2017–August 31, 2022

Please note the following: Leveraged funding is defined as a situation in which Network/grant funds were used to write proposals for new funding, which builds on research projects that were recently completed or in progress at the time of proposal writing. This process is different from mixed funding, otherwise known as instances in which a study receives supplemental funds from another source (e.g., Autism Speaks).

Table 1. Summary of Number, Type, and Status of Studies and Their Financial Support

Activity	Total Number
Research Proposals Developed	
Number of research proposals developed or supported with Network/grant funding	
Number of research proposals developed or supported with leveraged funding	
Status of research protocols supported with FY 2017–FY [INSERT YEAR]	
Autism CARES funding ONLY (not leveraged funding)	
A: Number of studies approved but not yet started	
B: Number of studies in progress	
C: Number of studies completed	
Total number of studies supported with Network/grant funding (A + B + C)	
Status of research protocols supported with leveraged funding	
A: Number of studies funded but not yet started	
B: Number of studies in progress	
C: Number of studies completed	
Total leveraged studies funded (A + B + C)	
Sustainability of projects	
Number of studies with mix of Autism CARES funding and funding from another source*	
Dollar amount of outside funding obtained as a consequence of the Autism CARES funds (e.g., leveraged funding)	

*Note: This is for informational purposes and is not a program requirement. Please show N/A if not applicable.

In Table 2, we provide a list of the studies conducted using only Autism CARES funding and leveraged funding, based on information sent in progress reports [INSERT DATE RANGE]. Please

1. review and correct any information listed,

2. add the number of participants (families or children) recruited or anticipated to be recruited for each study (last column),
3. add any new studies to the blank rows at the bottom of the table, and
4. include all studies active during or since **[INSERT DATE]**.

Note: Please make sure the studies listed in Table 2 match the number of studies reported in Table 1.

Table 2. List of Studies and Their Goals and Status of Study Activity

Study Title	Primary or Secondary Study	Goal of Study	Year Initiated	Current Status	Number of Anticipated Final Products	Number of Participants Recruited*	List of Collaborators
Example: Markers of Iron Status and Metabolism in Children with ASDs	Primary	The objective of this cross-sectional study was to evaluate associations among iron intake, iron status, GI symptoms, and novel markers of iron status, iron absorption, and inflammation in children aged 2-11 years.	2018		4 expected by August 2019: 2 poster 1 guideline 1 tool	RECRUITED: 160 .: 158 participants	CHOP, UCLA, and UMass

* Note: If recruitment efforts are not completed, insert PLANNED number. Otherwise, input ACTUAL number.

Please review the information in Table 3 and enter the number of participants in each population group, if this is applicable to the study. Add a row for each study not listed.

Note: Check all that apply. Please make sure the list of studies matches those listed in Table 2. If the study is not finished recruiting, enter the anticipated number of enrolled participants in each population group.

Table 3. Inclusion of Underserved Populations⁰ in Research Studies

Study Title	Underserved Population				
	Hispanic	African American	Low-Income	Rural	Other Underserved Population Group
1.					
2.					

In Table 4, please detail your efforts to serve minority and underserved populations and to engage with families. Note: Before being sent to grantees, this table will be updated to reflect the latest DGIS measures.

⁰ Underserved ASD populations include low-income, racial/ethnic minorities, immigrants, females, geographically remote, and other groups that are not already well-represented in current research on children and adolescents with ASD.

Table 4. Reducing Barriers for Families and Underserved Populations

	Number of Studies
Minority and Underserved Populations	
Number of studies that are responsive to the cultural and linguistic needs of special populations	
Number of studies listed in above table having one or more underserved category as more than 30 percent of study participants	
Engage in Family-Centered Activities	
Number of studies with families as participants	
Number of studies with families as partners in all study processes (study design through study implementation, analysis, and reporting)	
Number of studies in which parents have been consulted at some point in the study (e.g., during study design, instrument design, or interpretation of the results)	
Number of parents involved in study processes	

Please review the information in Table 5 and add/remove appropriate checks to the table. Add a row for each study not listed.

Note: Check all that apply. Please make sure the list of studies matches the list in Table 2.

Table 5. Topic of Research Studies

Study Title	Topic of Study				
	Topic 1	Topic 2 (optional)	Topic 3 (optional)	Topic 4 (optional)	Other Topic
Example: Diet and Nutrition in Children with Autism Spectrum Disorders: An Autism Treatment Network Collaborative					

In Table 6, please document your Network's/grant's progress in developing publications and scientific conference presentations as of **[INSERT DATE]**.

Table 6. Publication Activities

	Total Number
Publications	
A. Number of manuscripts in preparation	
B. Number of manuscripts submitted	
C. Number of manuscripts accepted/In press	
D. Number of manuscripts published	
Total publications (A + B + C + D)	
Scientific Conference Presentations	
Number of scientific conference presentations made (Note: include each presentation made, even if it was the same presentation given several times; exclude grand rounds presentations)	
Number of presentations planned (i.e., abstracts accepted for a future presentation) within the next 12 months	

In Table 7, we provide a list of the papers published, in preparation, submitted, or accepted, as of **[INSERT DATE]**. Please update the citations and list any new papers.

In the column “Publication Type,” please specify an “Other” subject, if one cannot be selected from the drop-down menu.

Note: Please make sure this list matches the numbers reported in Table 6.

Table 7. Manuscripts

Published Manuscripts:		Publication Type
1.	1.	<input type="text"/>
Manuscripts in Press:		Publication Type
1.	1.	<input type="text"/>
Manuscripts Submitted:		Publication Type
1.	1.	<input type="text"/>
Manuscripts in Preparation:		Publication Type
1.	1.	<input type="text"/>

In Table 8, please document the subject of each of the publications listed above.

NOTE: Please count each manuscript only once, even if it covers multiple topics.

Table 8. Publication Types

	Subject of Publication					
	Total Number	Intervention New	Improving Care Practices	Measures/ Tools	Guidelines	Other
Number of manuscripts published, prepared, submitted, or accepted						

2. DEVELOP AND VALIDATE TOOLS FOR ASD SCREENING/INTERVENTION

In Table 9, please list the number of tools and/or any outcome measures used for programs or interventions that were developed or finalized as of **[INSERT DATE]**.

Table 9. Measures and Tools

	Total Measures and Tools
Measures	
Total number of measures developed or validated ⁰	
Number of measures piloted in care or community settings (if applicable)	
Number of measures developed or validated for underserved communities (defined as any of the groups listed in Table 3)	
Number of measures endorsed by other organizations/associations beyond the Network/grant (e.g., American Academy of Pediatrics)	
Tools	
Total number of tools developed or validated	
Number of tools piloted in care or community settings (if applicable)	
Number of tools developed or validated for underserved communities (defined as any of the groups listed in Table 3)	
Number of tools endorsed by other organizations/associations beyond the Network/grant (e.g., American Academy of Pediatrics)	

⁰ Note: Validation may range from an informal validation by the internal team to a more rigorous validation utilizing psychometric studies.

Total Measures and Tools

Number of tools finalized (made available to public or published)

In Table 10, please update and provide a list of tools and outcome measures developed, validated, piloted, or released between **[INSERT DATE RANGE]**. Please

1. review and correct any information listed,
2. update the last column on dissemination plans or progress for these tools,
3. add any new tools to the blank rows at the bottom of the table, and
4. include only those tools for which activity occurred between **[INSERT DATE RANGE]**.

Note: Please make sure this list matches the numbers reported in Table 10.

Table 10. Description of Tools

Toolkit Name	Description	Current Status (e.g., under development, in pilot testing, finalized)	Release Date	Number of Cumulative Downloads**
Example: Applied Behavioral Analysis	An informational guide to Applied Behavioral Analysis (ABA) designed to provide parents with a better understanding of ABA and resources for seeking ABA services	<input type="text"/>	e 2012	8,780
1.		<input type="text"/>		
2.		<input type="text"/>		
3.		<input type="text"/>		

* These are available for download online at <http://www.autismspeaks.org/family-services/tool-kits>.

** As of **[INSERT DATE]**.

3. DEVELOP GUIDELINES FOR ASD INTERVENTIONS

In Table 11, please list the number of guidelines that were developed or finalized between **[INSERT DATE RANGE]**.

Table 11. Guidelines

	Total Guidelines
Total number of guidelines developed, drafted, or updated	
Number of guidelines finalized	
a. Number of guidelines released to providers and the public (for instance, posted on the website)	
b. Number of guidelines published in journals and peer-reviewed publications	
c. Both	
Number of guidelines piloted in care or community settings (if applicable)	
Number of guidelines adopted/endorsed by other organizations/associations beyond the Network/grant (if applicable)	

In Table 12, we provide a list of the guidelines developed, piloted, or released between **[INSERT DATE RANGE]**. Please

1. review and correct any information listed,

2. update the last column on dissemination plans or progress for these tools,
3. add any new guidelines to the blank rows at the bottom of the table, and
4. include only those guidelines for which activity occurred during or since [INSERT DATE].

Note: Please make sure this list matches the numbers reported in Table 11.

Table 12. Descriptions of Guidelines

Guideline or Algorithm Name	Description	Current Status	Anticipated Final Products (if applicable)
1. Example: Managing Sleep Behavior	This report describes the development of a practice pathway for the identification, evaluation, and management of insomnia in children and adolescents who have ASD. The Sleep Committee of the Autism Treatment Network (ATN) developed a practice pathway, based on expert consensus, to capture best practices for an overarching approach to insomnia by a general pediatrician, primary care provider, or autism medical specialist, including identification, evaluation, and management. A field test at four ATN sites was used to evaluate the pathway. In addition, a systematic literature review and grading of evidence provided data regarding treatments of insomnia in children who have neurodevelopmental disabilities.		Malow, B. A., Byars, K., Johnson, K., Weiss, S., Bernal, P., Goldman, S. E., . . . Glaze, D. G. (Sleep Committee of the Autism Treatment Network). Practice pathway for identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorders. <i>Pediatrics</i> , 130(Supplement 2), S106-S124.
2.			
3.			

4. DISSEMINATE INFORMATION

In Table 13, summarize your Network's/grant's activities directed to disseminating information between [INSERT DATE RANGE].

Note: These activities should be related to the CARES funding or to the funded research.

Table 13. Dissemination Activities

	Total Number
Materials Developed and Disseminated	
Number of print or electronic materials (e.g., briefs, articles, newsletters, or informational materials) developed as of [INSERT DATE], excluding study publications and conference presentations	
Cumulative number of "hits" on Network/grant websites	
Health or School Professional Training Sessions (e.g., grand rounds, medical teleconferences, and others)	
Number of grand rounds, training sessions, and medical teleconferences geared toward health or school professionals	
Number of health or school professionals reached	
Parent Training Sessions (e.g., toward parents, parent volunteers, and family advocates)	
Number of parent training sessions	
Number of parents trained	
Community Outreach Sessions Conducted (e.g., presentations, lectures, or seminars for the public)	

Number of community outreach sessions
 Number of individuals reached through community outreach sessions

In Table 14, list all major collaborations with other Autism CARES grantees between [INSERT DATE RANGE] and describe the activity.

Table 14. Collaboration

Project Title	Primary Target Audience	Nature of Collaboration
E1 Example: Family Advisory Committee (FAC)	<input type="text"/>	<ul style="list-style-type: none"> Research translation and dissemination Parents are engaged at site and Network level in planning events, identifying topics, toolkit development and review, and content development for website and newsletter
E2 Example: Spread strategies of three streams through Collaborating Research Entities (CREs) and surrounding communities by identifying primary care physician champions at each CRE	<input type="text"/>	<ul style="list-style-type: none"> Dissemination
1.	<input type="text"/>	
2.	<input type="text"/>	

5. DEVELOP NEW INVESTIGATORS

In Table 15, please document your Network's/grant's progress in developing and mentoring new investigators between [INSERT DATE RANGE].

Table 15. Researchers Trained

Activity	Total Number	Gender		Race			Ethnicity		Educational Level		
		Male	Female	Non-White	White	Hispanic	Non-Hispanic	High School Graduate; Some College	College Graduate; Bachelor's Degree	Advanced Degree; Master's and/or Doctorate	
Number of new investigators mentored or developed in the ASD/DD field (please include efforts to support small research projects from junior investigators, webinars targeting new investigators, new investigators serving as co-authors, and graduate students and/or postdoctoral fellows on projects)											
Number of new investigators mentored during a study											
Number of early investigators running AIR-P studies											

Activity	Total Number	Gender		Race		Ethnicity		Educational Level		
		Male	Female	Non-White	White	Hispanic	Non-Hispanic	High School Graduate; Some College	College Graduate; Bachelor's Degree	Advanced Degree; Master's and/or Doctorate
Number of webinars targeting new investigators										
Number of graduate students or postdoctoral fellows on studies/projects										
Number of graduate students or postdoctoral fellows as co-authors on projects										

6. PROMOTE IMPLEMENTATION OF PRACTICES/IMPROVE CARE

In Table 16, please list your efforts to transfer findings on the following, as applicable to your Network/grant: interventions, guidelines, tools, and systems management approaches to practice settings and communities that promote implementation of practices.

Table 16. Activities Designed To Promote Implementation of Practices

Activity	Number of Activities
Activities designed to promote implementation of practices	
Number of care plans developed and implemented by providers? (if applicable)	
Number of tools and/or algorithms implemented in specific community settings such as health, schools, etc. (if applicable)	
Number of locations where successful implementation occurred (if applicable)	
Implementation of validated outcome measure at Network/grant sites	