

**AUTISM INTERVENTION RESEARCH
NETWORKS
DATA COLLECTION FORM**

Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act Autism Intervention Research Networks

Data Collection Form

AIR-P, AIRB, HCT-RN: September 1, 2014–August 31, 2017
 DBPNet: September 1, 2013–August 31, 2016; September 1, 2016–August 31, 2017
 HW-RN: July 1, 2013–June 30, 2016; July 1, 2016–August 31, 2017

1. Conduct Research on ASD Interventions

In table 1, please document your Network’s progress in completing the originally proposed studies, developing and implementing additional studies, as well as in obtaining leveraged funding. Only include activities in the following time period:

AIR-P, AIRB, HCT-RN: September 1, 2014–August 31, 2017
 DBPNet: September 1, 2013–August 31, 2016; September 1, 2016–August 31, 2017
 HW-RN: July 1, 2013–June 30, 2016; July 1, 2016–August 31, 2017

Please note the following:

Leveraged funding is defined as a situation where network 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 is different from mixed funding—instances where 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 funding	
Number of research proposals developed or supported with leveraged funding	
Status of Research Protocols supported with FY 2014–FY 2017 (DBPNet FY 2013–FY 2017); HW-RN FY 2013–FY 2017) CARES funding ONLY (not leveraged funding)	
A: Number of studies approved by the Network but not yet started	
B: Number of studies in progress	
C: Number of studies completed	
Total number of studies supported with Network 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	

Activity	Total Number
C: Number of studies completed	
Total leveraged studies funded (A + B + C)	
Sustainability of Projects	
Number of studies with mix of CARES funding and funding from another source*	
Dollar amount of outside funding obtained as a consequence of the 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 CARES funding and leveraged funding, based on information sent in progress reports (September 2014–August 2017 [FY 2013–FY 2017 for DBPNet and HW-RN]). 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.
4. Include all studies active during or since September 1, 2014 [September 1, 2013 for DBPNet and July 1, 2013 for HW-RN].

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

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

Study Title	Goal of Study	Year Initiated	Current Status	Number of Anticipated Final Products	Number of Participants Recruited*	List of Collaborators
0. Example: Markers of Iron Status and Metabolism in Children with ASDs	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.	2010		3 expected by August 2014 1 guideline 1 tool	RECRUITED: 158 participants	CHOP, UCLA, and UMass
1.						
2.						
3.						

* 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. 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 Populations 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: Prior to sending to grantees, this table will be updated to reflect the latest DGIS measures.*

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 where parents have been consulted at some point in the study (e.g., during study design, instrument design, or the 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 those listed 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 progress in developing publications and scientific conference presentations as of August 31, 2017.

Table 5. 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 August 31, 2017. 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 6. 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 7. Publication Types

Subject of Publication

	Total Number	Intervention Research	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 August 31, 2017.

Table 8. Measures and Tools

	Total Measures and Tools
Measures	
Total number of measures developed or validated	
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 (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 (e.g., American Academy of Pediatrics)	
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 September 1, 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN]. 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.
4. Include only those tools for which activity occurred between September 1 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN].

Note: Please make sure this list matches the numbers reported in table 9.

Table 9. Description of Tools

	Toolkit Name	Description	Current Status (e.g., under development, in pilot testing, finalized)	Release Date	Number of Cumulative Downloads* *
0.	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		e 2012	8,780
1.					
2.					
3.					

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

** As of August 31, 2017

3. Develop Guidelines for ASD Interventions

In table 11, please list the number of guidelines that were developed or finalized during this 3-year period.

Table 10. 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 Web site)	
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 (if applicable)	

In table 12, we provide a list of the guidelines developed, piloted, or released between September 1, 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN]. 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.
4. Include only those guidelines for which activity occurred during or since September 1, 2014 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN].

Note: Please make sure this list matches the numbers reported in the above table.

Table 11. 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 autism spectrum disorders (ASDs). 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). (2012). A 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 activities directed to disseminating information between September 1, 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN].

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

Table 12. 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 August 31, 2017, excluding study publications and conference presentations		
Cumulative number of “hits” on Network Web sites		
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 CARES grantees between September 1, 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN] and describe the activity.

Table 13. Collaboration

	Project Title	Primary Target Audience	Nature of Collaboration
E1	Example: Family Advisory Committee (FAC)		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 Web site and newsletter.
E2	Example: Spread strategies of three streams through CREs and surrounding communities by identifying PCP champions at each CRE		Dissemination
1.			
2.			

5. Develop New Investigators

In table 15, please document your Network’s progress in developing and mentoring new investigators between September 1, 2014, and August 31, 2017 [Start date would be September 1, 2013, for DBPNet and July 1, 2013, for HW-RN].

Table 14. Researchers Trained

Activity	Total Number
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 studies AIR-P studies	
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 manuscripts	

6. Promote Implementation of Practices/ Improve Care

In table 16, please list your efforts to transfer network findings on the following, as applicable to your network: interventions, guidelines, tools and systems management approaches into practice settings and communities to promote implementation of practices.

Table 15. 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 sites	

Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0915-XXXX. Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10C-03I, Rockville, Maryland, 20857.