**Attachment H.**

**Research Quantitative Data Collection Form**

## Research Quantitative Data Collection Form

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 | In recruitment | 4 expected by August 2019:2 poster presentations1 guideline1 tool | RECRUITED: 160ACTUAL: 158 participants  | CHOP, UCLA, and UMass  |
|  |  |  | Choose an item. | Choose an item. |  |  |  |
|  |  |  | Choose an item. | Choose an item. |  |  |  |
|  |  |  | Choose an item. | Choose an item. |  |  |  |

\* 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 Populations[[1]](#footnote-2) 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.*

***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** |
| 1. | **Example:** Diet and Nutrition in Children with Autism Spectrum Disorders: An Autism Treatment Network Collaborative | Diet/Nutrition | Choose an item. | Choose an item. | Choose an item. |  |
| 2. |  | Choose an item. | Choose an item. | Choose an item. | Choose an item. |  |
| 3. |  | Choose an item. | Choose an item. | Choose an item. | Choose an item. |  |

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**  |
| 1. Number of manuscripts in preparation
 |  |
| 1. Number of manuscripts submitted
 |  |
| 1. Number of manuscripts accepted/In press
 |  |
| 1. 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. Choose an item.
 |
| **Manuscripts in Press:** | **Publication Type** |
| 1. | 1. Choose an item.
 |
| **Manuscripts Submitted:** | **Publication Type**  |
| 1. | 1. Choose an item.
 |
| **Manuscripts in Preparation:** | **Publication Type** |
| 1. | 1. Choose an item.
 |

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  |  |  |  |  |  |  |

### 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[[2]](#footnote-3) |  |
| 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)  |  |
| 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 | Choose an item. | June 2012 | 8,780 |
| 1. |  |  | Choose an item. |  |  |
| 2. |  |  | Choose an item. |  |  |
| 3. |  |  | Choose an item. |  |  |

\* 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. | Choose an item. | 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 the identification, evaluation, and management of insomnia in c and adolescents with autism spectrum disorders. *Pediatrics, 130*(Supplement 2), S106–S124. |
| 2. |  |  | Choose an item. |  |
| 3. |  |  | Choose an item. |  |

### 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) | Families | * 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 | Healthcare providers | * Dissemination
 |
| 1. |  | Choose an item. |  |
| 2. |  | Choose an item. |  |

### 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 |  |  |  |  |  |  |  |  |  |  |
| 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 |  |

1. 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. [↑](#footnote-ref-2)
2. Note: Validation may range from an informal validation by the internal team to a more rigorous validation utilizing psychometric studies. [↑](#footnote-ref-3)