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 . 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 |  |
| 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 . 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 | In recruitment | 3 expected by August 2014  2 poster presentations  1 guideline  1 tool | RECRUITED: 160  ACTUAL: 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. 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 . 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 . 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** |
| 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 progress in developing publications and scientific conference presentations as of August 31, 2017.

Table . 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 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 . 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 . Publication Types

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

1. 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 . 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 . 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 August 31, 2017

1. 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 . 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 . 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. | 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 children and adolescents with autism spectrum disorders. *Pediatrics, 130*(Supplement 2), S106–S124. |
| 2. |  |  | Choose an item. |  |
| 3. |  |  | Choose an item. |  |

1. 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 . 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 . Collaboration

|  |  |  |  |
| --- | --- | --- | --- |
| **Project Title** | | **Primary Target Audience** | **Nature of Collaboration** |
| E1 | **Example**: Family Advisory Committee (FAC) | Choose an item. | 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 | Choose an item. | Dissemination |
| 1. |  | Choose an item. |  |
| 2. |  | Choose an item. |  |

1. 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 . 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 |  |

1. 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 . 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.