

# The Autism Speaks Autism Treatment Network Registry Data: Opportunities for Investigators

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**abstract** **OBJECTIVE:** Patient registries can effectively collect data over a long period of time to provide a better understanding of the typical presentation of specific conditions. The autism spectrum disorders (ASDs) have experienced a marked increase in reported prevalence over the past 20 years for reasons that are not completely clear. The Autism Treatment Network (ATN) Registry was established to facilitate investigations into a variety of questions critical to expanding our understanding of ASDs. Here we describe the establishment of the registry, its components, some of its findings to date, and opportunities for further use of this data.

**METHODS:** Participants are eligible for enrollment into the ATN registry if they are between the ages of 2.0 and 17.6 years at the time of enrollment and meet criteria for ASD as determined by clinical consensus on the basis of specific diagnostic measures (*Autism Diagnostic Observation Schedule/Autism Diagnostic Observation Schedule, Second Edition*; *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition/Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*). Baseline measures include demographics, autism assessment, cognitive assessment data, behavioral data, sleep habits, quality of life, sensory data, and treatments. Several of the measures are collected at annual follow-up visits.

**RESULTS:** More than 6800 children with ASD have been enrolled in the Autism Speaks ATN registry. Data from the registry have been reported at numerous scientific meetings and in several publications and have led to new recommendations for best practices in the management of ASD.

**CONCLUSIONS:** A patient registry for children and adolescents with ASD has had and will continue to have a significant impact on care for this population. Investigators are encouraged to query this database to further its impact by testing novel hypotheses and conducting preliminary proof-of-concept analyses.



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Dr Murray directs the Autism Treatment Network (ATN) for Autism Speaks, coordinated and drafted the initial manuscript, and critically reviewed and revised the manuscript; Ms Fedele oversees the registry for the ATN, contributed to the initial draft of the manuscript, and critically reviewed and revised the manuscript; Ms Shui works with the registry as part of the ATN Data Coordinating Center, pulled and organized data for the manuscript, contributed to the initial draft of the manuscript, and critically reviewed and revised the manuscript; Dr Coury, medical director of the ATN, contributed to the design of the ATN registry and data collection, contributed to the initial draft of the manuscript, and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

**DOI:** 10.1542/peds.2015-2851E

**To cite:** Murray DS, Fedele A, Shui A, et al. The Autism Speaks Autism Treatment Network Registry Data: Opportunities for Investigators. *Pediatrics*. 2016;137(S2):e20152851E

**TABLE 1** ATN Centers Located Across North America

Region	ATN Member Site
Eastern	Children's Hospital Philadelphia Lurie Center University of Pittsburgh Medical Center University of Rochester
Midwestern	Cincinnati Children's Hospital Medical Center Nationwide Children's Hospital University of Missouri at Columbia Knights of Columbus Development Center at SSMHealth Cardinal Glennon Children's Medical Center and St Louis University School of Medicine
Southern	Arkansas Children's Hospital/University of Arkansas Medical School Vanderbilt University Medical School
Western	Children's Hospital of Los Angeles Center for Autism and Neurodevelopmental Disorders at University of California-Irvine
Canada	Holland Bloorview Kids Rehabs, Surrey Place Centre, Hospital for Sick Children—Toronto University of Alberta and Glenrose Rehabilitation Hospital

The effective diagnosis and treatment of health conditions evolve from initial descriptions of the condition and efforts to ameliorate the condition's symptom manifestations. Gathering consistent data on aspects of the condition helps provide a better understanding of the condition and its variations. Similarly, through observation of responses to treatments, health care providers can learn more about the condition itself as well as make modifications to the treatment regimen. This iterative process moves forward continuously. The result is an increasingly detailed understanding of the condition itself, and more comprehensive and effective management of the condition.

Patient registries can effectively collect data over a long period of time to provide a better understanding of the typical presentation of specific conditions. By collecting a standard battery of assessments at baseline and at specific time points afterward, a registry can provide insight into the natural course of the condition. This process is especially helpful for relatively uncommon conditions for which the experience of a single practitioner or site may be limited by small numbers of affected patients. For example, registries have successfully promoted the delivery of

guideline-concordant primary care for diabetes and hypertension.<sup>1-3</sup> Less-common conditions such as leukemia and other childhood cancers have benefited from similar patient registries.

The autism spectrum disorders (ASDs) have experienced a marked increase in reported prevalence over the past 20 years for reasons that are not completely clear. What is clear is that a condition with an estimated prevalence of ~4 in 10 000 in the 1980s to early 1990s<sup>4</sup> has surged to a reported prevalence of 1 in 68<sup>5</sup> in a short period of time. The rapid growth has given urgency to increasing our limited understanding of the disorder to provide the best evidence-based care to this population. The Autism Treatment Network (ATN) Registry was established to serve this purpose.

### DESCRIPTION OF THE REGISTRY

The Autism Speaks ATN was established in 2005 through a partnership between the Northwest Autism Foundation and the MassGeneral Hospital for Children's Learning and Developmental Disabilities Evaluation and Rehabilitation Services (LADDERS) program, now known as the Lurie Center for Autism.<sup>6</sup> The sites

focused on developing a consensus-based model of care that provided multidisciplinary care, including medical evaluations to individuals on the autism spectrum; created a patient registry; and improved the quality of life for the individuals and their families. Clinicians at these programs were focused on medical aspects of autism that they felt were not receiving adequate attention and study and addressed these topics in their research. The ATN has previously been described in more detail.<sup>6</sup>

### PARTICIPANTS

The ATN registry is composed of retrospective and prospective data on patients with ASD collected from the 14 ATN sites across the United States and Canada (Table 1). Patients undergo clinical assessments and receive standard care as determined by the patient's physician. These clinical data are regarded as routine standard of care of ASD, such as laboratory results, medication usage, and health and behavior assessments, and are submitted to the ATN registry databases. Assessments and schedule of data collection are shown in Table 2.

Enrollment in the ATN registry occurs when a participant meets eligibility criteria and consents to participate. Participants are eligible for enrollment into the ATN registry if they are between the ages of 2.0 and 17.6 years at the time of enrollment and meet criteria for ASD as determined by clinical consensus on the basis of specific diagnostic measures (*Autism Diagnostic Observation Schedule [ADOS]/the second edition of ADOS [ADOS-2]; Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition/ Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*). It is expected that the majority of children will meet criteria for autism/ASD on the ADOS/ADOS-2. In limited

**TABLE 2** ATN Assessment Battery and Schedule

ATN Instruments	Screening (–12 Months Through Date of Consent)	Visit 01: Baseline (0–9 Months After Date of Consent)	Visit 02: First Annual (9–15 Months Post Clinician’s Baseline)		Visit 03: Second Annual (21–27 Months Post Clinician’s Baseline)		Visit 04: Third Annual (33–39 Months Post Clinician’s Baseline)		Interim Visit	Termination From Study
			In Clinic	Via Mail	In Clinic	Via Mail	In Clinic	Via Mail		
ADOS-2	X <sup>a</sup>									
DSM-IV Symptom Checklist	X <sup>a</sup>									
Enrollment	X									
Lead autism specialist		X							X <sup>b</sup>	
Baseline										
Interim										
Follow-up			X		X					
Parent		X								
Baseline										
Visit		X			X				X <sup>b</sup>	
Mail follow-up				X			X			
Child Behavior Checklist		X								
Vineland Adaptive Behavior Scale		X <sup>a</sup>					X <sup>c</sup>			
PedsQL		X		X			X			
Aberrant Behavior Checklist		X		X			X			
Cognitive assessment		X <sup>a,c</sup>		X			X <sup>c</sup>			
Communication measure		X <sup>a,c</sup>		X			X <sup>c</sup>			
Satisfaction questionnaire		X		X			X			
Termination										X

ADOS-2, *Autism Diagnostic Observation Schedule, Second Edition*, DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. X= assessment administered at visit.

<sup>a</sup> Assessments completed at –12 months through +9 months of consent date will be accepted in the ATN registry.

<sup>b</sup> Interim visit data should be collected at a maximum of once every 3 months (no more than quarterly).

<sup>c</sup> Assessments completed from a trusted source outside the ATN site will be accepted in the ATN registry.

circumstances, a center may enroll a child who met criteria on the *Diagnostic and Statistical Manual of Mental Disorders* but not ADOS when there is a strong clinical consensus among the ATN team that the child meets criteria for ASD. To enroll in the registry, the child should have a plan for ongoing care at the ATN center to facilitate longitudinal data collection. The parent or guardian must be fluent in English or Spanish, and English or Spanish should be spoken in the home with the child at least 75% of the time. Exclusion criteria include medical conditions (eg, blindness or deafness) precluding valid testing.

## METHODS

The center submits the inclusion/exclusion form to the ATN via the Internet System for Assessing Autistic Children (ISAAC) electronic data-capture system. During this process, the system provides a unique ATN participant identification number. This number is used throughout participation to identify all assessments for this individual. Centers also generate a Global Unique Identifier by using a computer program approved by the National Institutes of Health. This Global Unique Identifier reviews personal information and assigns a unique identification code that cannot be traced back to the personal information. Use of this number ensures that subjects, particularly those participating in genetic databases, are not duplicated in analyses. Subjects who consent and enroll in the ATN registry have de-identified baseline and follow-up information collected and processed. All data collected are managed and audited by the MassGeneral Biostatistics team, which serves as the ATN’s Data Coordinating Center.

Baseline measures including demographics, autism assessment,

cognitive assessment data, behavioral data, sleep habits, quality of life, sensory data, and medications were described. Frequencies for categorical variables were tabulated, and descriptive statistics (number of observations, means and SDs) were generated for continuous variables. Counts were provided for the number of children with longitudinal data available for each measure.

## RESULTS

The majority of the children in the registry are male (83.8%), white (79.9%), and non-Hispanic (89.8%); have an ASD diagnosis of autism (73.0%); have a primary caregiver educational level of at least some college (78.6%); and have a mean age at enrollment of 6 years ( $6.4 \pm 3.6$  years). Descriptive statistics are also provided for the calibrated ADOS severity, IQ, the Children's Sleep Habits Questionnaire, the Pediatric Quality of Life Inventory (PedsQL), Vineland Adaptive Behavior, the Short Sensory Profile, the Child Behavior Checklist, and medications and parent-form questions (available at [asatn.org](http://asatn.org); Supplemental Table 4).

A growing subset of children in the registry have longitudinal data (annual medical follow-up visits in years 1, 2, and 3). Medication use had the most longitudinal data available. Information on medication use, including attention-deficit/hyperactivity disorder medications,  $\alpha$ -agonists, anticonvulsants, selective serotonin reuptake inhibitors, atypical antipsychotics, and melatonin, is available for 4114 children at baseline and at first follow-up; for 2471 children at baseline and the first and second follow-ups; and for 1439 children at baseline and the first, second, and third follow-ups. Similar counts are provided for the Aberrant Behavior Checklist irritability subscale: 1013 at baseline and the first

follow-up; 368 at baseline and the first and second follow-ups; and 104 at baseline and the first, second, and third follow-ups. For the PedsQL total scale, 2511 children had data at baseline and the first follow-ups; 1184 had data at baseline and the first and second follow-ups; and 570 had data at baseline and the first, second, and third follow-ups. There are similar counts for the Clinical Global Impression rating scale for severity of autism and level of autism, the Vineland Adaptive Behavior composite standard scores, and several cognitive assessments and parent-form questions. These measures and counts at each visit are summarized in Table 3. Since 2009, the data in the registry have been analyzed and used to publish 34 journal articles. Topics of these analyses have included the prevalence of gastrointestinal and sleep conditions,<sup>7-9</sup> attention-deficit/hyperactivity disorder symptoms,<sup>10</sup> quality of life,<sup>10-12</sup> use of psychotropic medications,<sup>13</sup> and complementary and alternative therapies,<sup>14</sup> to name a few.

## DISCUSSION

The goal of the registry is to provide data to identify medical conditions and comorbidities and to track medical, behavioral, and quality-of-life outcomes in children and adolescents with ASD to improve care, help identify best practices, and build a platform for research. The registry encompasses phenotypic data on medical, developmental, and behavioral concerns as well as family history.

The enrollment of well-characterized subjects into the registry has provided clarity to several controversial issues surrounding the physical aspects of autism. For example, there have been conflicting reports regarding the prevalence of gastrointestinal conditions in individuals with autism, running

the gamut from no increase to a marked increase. The ATN registry, through its data collection, has been able to describe a high rate of gastrointestinal concerns in the enrolled subjects and first reported on this in 2010.<sup>15</sup> Studies by other investigators since then have confirmed an increase in gastrointestinal symptoms, including a recent study of infant symptom data collected prospectively before the children received an autism diagnosis.<sup>16</sup> The confirmation of an increased rate of gastrointestinal problems, especially constipation, led to network clinicians developing a best-practice pathway for the management of constipation in ASD.<sup>17</sup> These studies have also attempted to better identify clinical phenotypes. Data collected through the ATN registry have allowed for the examination of relationships between reported medical conditions and behaviors.<sup>18,19</sup> Findings from these studies have also led to quality-improvement work to increase awareness of medical providers to evaluate comorbid medical conditions when behavioral concerns are raised.

Analyses of other medical conditions accompanying ASD such as epilepsy and sleep disorders have been conducted with the registry data and used to guide the development of clinical interventions. Registry data identifying sleep problems, especially insomnia, led to work on effective treatments for these problems.<sup>20,21</sup> More important, registries may answer questions that a clinical trial could never address. Well-controlled clinical trials can address very specific treatment strategies. Patient registries can provide data regarding several treatment measures or modalities and outcome variables, providing data to conduct retrospective comparative effectiveness analyses.

Although cross-sectional data are valuable, there is a critical need to

**TABLE 3** Longitudinal Data

Registry Item	Baseline	With Baseline and First Follow-up Data, <i>n</i>	With Baseline and First and Second Follow-up Data, <i>n</i>	With Baseline and First, Second, and Third Follow-up Data, <i>n</i>	With Baseline and Second Follow-up Data, <i>n</i>	With Baseline and Third Follow-up Data, <i>n</i>
ABC Irritability Subscale	14.3 ± 9.9 ( <i>n</i> = 2705)	1013	368	104	623	264
PedsQL Total Scale	65.1 ± 15.9 ( <i>n</i> = 5970)	2511	1184	570	1736	1049
CGS Severity of Autism	4.1 ± 1.1 ( <i>n</i> = 2275)	486	138	—	251	—
CGI Level of Autism <sup>a</sup>	3.3 ± 0.9 ( <i>n</i> = 661)	196	49	—	196	76
Cognitive assessments <sup>b</sup>	75.7 ± 23.4 ( <i>n</i> = 5214)	—	—	—	—	75
Vineland Adaptive Behavior composite standard score	71.4 ± 12.4 ( <i>n</i> = 5801)	—	—	—	—	211
Communication <sup>c</sup>	72.4 ± 23.0 ( <i>n</i> = 557)	—	—	—	—	—
Medications <sup>d</sup>		4114	2471	1439	2970	1973
ADHD medications	746 (10.8)	—	—	—	—	—
α-Agonists	447 (6.5)	—	—	—	—	—
Anticonvulsants	141 (2.1)	—	—	—	—	—
SSRIs	400 (5.8)	—	—	—	—	—
Atypical antipsychotics	398 (5.8)	—	—	—	—	—
Melatonin	684 (9.9)	—	—	—	—	—
Sleep problems <sup>e</sup>	2150 (42.5)	2049	914	386	1378	736
Neurologic problems <sup>e</sup>	723 (14.4)	2039	909	384	1368	739
Gastrointestinal problems <sup>e</sup>	1958 (38.7)	2053	917	387	1377	739
Eating problems <sup>e</sup>	3822 (60.4)	2053	1204	550	1796	1074
Anxiety problems <sup>e</sup>	3724 (59.1)	2599	1195	544	1785	1075
Sensory problems <sup>e</sup>	4843 (76.6)	2617	1196	549	1784	1075
Social interactions <sup>e</sup>	5156 (81.7)	2609	1197	548	1787	1073
Aggression <sup>e</sup>	3049 (48.3)	2610	1201	553	1789	1079
Self-injurious <sup>e</sup>	2044 (32.4)	2617	1200	553	1787	1083
Repetitive thoughts and behavior <sup>e</sup>	4235 (67.1)	2616	1204	554	1794	1082
Lost or losing skills <sup>e</sup>	1725 (27.4)	2613	1205	554	1795	1082
Hyperactivity <sup>e</sup>	4347 (68.8)	2616	1203	555	1792	1078
Attention span <sup>e</sup>	5180 (82.1)	2611	1199	551	1788	1078
Mood swings <sup>e</sup>	3525 (55.9)	2602	1199	550	1788	1081
Any behavioral or educational services <sup>e</sup>	4842 (83.4)	2479	1155	539	1705	1021
Any CAM interventions <sup>e</sup>	1452 (23.0)	2618	1212	562	1800	1089

Data are presented as means ± SDs or *n* (%) unless otherwise indicated. ABC, Aberrant Behavior Checklist; ADHD, attention-deficit/hyperactivity disorder; CAM, ; CGI, Clinical Global Impression rating scale; CGS, ; SSRI, serotonin reuptake inhibitor.

<sup>a</sup> CGI starts at first follow-up because it is a measure of improvement: baseline = first follow-up, first follow-up = second follow-up, second follow-up = third follow-up.

<sup>b</sup> IQ uses scores from Stanford-Binet (Full Scale and Abbreviated), Mullen (ELC-Early Learning Composite Standard Score), WASI, Wechsler Abbreviated Scale of Intelligence (Full-2), DAS-II, Differential Ability Scales -Second Edition (SA-School Age, and EY-Early Years, Lower and Upper), WISC-IV, Wechsler Intelligence Scale for Children - Fourth Edition (Full Scale), WPPSI-III, Wechsler Preschool and Primary Scale of Intelligence - Third Edition (Full Scale), and Bayley (Cognitive composite) by availability in this order.

<sup>c</sup> Communication uses scores from PLS-IV, Preschool Language Scale- Fourth Edition (TLS -Total Language Score Standard Score), OWLS, Oral and Written Language Scales (Oral Composite Standard Score), CELF-P2, Clinical Evaluation of Language Fundamentals -Preschool Second Edition (Core Language Standard Score), and CELF-IV, Clinical Evaluation of Language Fundamentals - Fourth Edition (Core Language Standard Score) by availability in this order.

<sup>d</sup> Counts for available longitudinal data are for each medication class.

<sup>e</sup> From the parent form.

track children over time to better examine the trajectory of medical comorbidities in ASD and their impact on neurodevelopmental outcomes. A subset of children in the current registry have longitudinal data (medical follow-up visits in years 1, 2, and 3), but attrition limits the data available for analysis. For example, the available sample size decreased by >50% for each subsequent follow-up visit on the

PedsQL and the parent-form sleep problem question from baseline to the third follow-up visit. The ATN has recently made a focused effort to reduce attrition and increase the longitudinal data in the registry to provide researchers with more opportunities to examine medical and clinical changes in children with ASD over time. In addition, the National Institute of Mental Health has funded 2 pilot studies to also

collect biospecimens (whole blood, cell lines, and urine) on a subset of the registry. Supplementing the registry data by collecting additional therapy information and outcome measures would allow more comparative effectiveness research to be conducted with these data.

More than 6800 children with ASD have been enrolled in the Autism Speaks ATN registry, and the ATN

continues to enroll and collect longitudinal data on measures such as autism assessment, cognitive assessment data, behavioral data, quality of life, and therapies received. The ATN registry is available for secondary data analyses. Interested researchers may submit their request for data, with a signed Researcher Distribution Agreement, to <http://asatn.org/request/data>. A query

tool has been developed to assist interested researchers. This query tool allows investigators to evaluate the existing data set and is available at <http://asatn.org/asatn-query>. Investigators are encouraged to use the query tool to probe hypotheses or identify existing data on subjects with select characteristics. The ATN registry has already had an impact on patient care and conduct of pilot studies and has the potential to

continue to do so for some time.

#### ABBREVIATIONS

ADOS: Autism Diagnostic Observation Schedule  
ASD: autism spectrum disorder  
ATN: Autism Treatment Network  
PedsQL: Pediatric Quality of Life Inventory

Accepted for publication Nov 9, 2015

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** The authors have indicated they are supported by employment or grant funding by Autism Speaks to oversee the activities of the Autism Treatment Network.

**FUNDING:** The Autism Speaks Autism Treatment Network registry is funded by Autism Speaks.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

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*Pediatrics* 2016;137;S72

DOI: 10.1542/peds.2015-2851E

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