ATN Registry Description
The Registry is designed as a multi-center observational study that collects both retrospective and prospective data on patients with ASD. Patients undergo clinical assessments and receive standard of care as determined by the patient’s physician. Clinical data that are regarded as routine standard of care of ASD, such as laboratory results, medication usage, health, and behavior assessments are included in the ATN Registry. Parental survey data on patient’s medication usage, health and behavioral interventions, and other information are also included in the ATN Registry.

ATN Registry Data
Subjects enrolled into the ATN Registry have baseline information collected from parents and clinicians, including: medical history, physical exam, neurological exam, diagnosis and problems, medical and behavioral treatment, behavioral, cognitive, communication measures, and sleep health assessment. A subset of participants will have biomaterials (blood or urine samples) available as well as follow-up data either through repeat visits in the registry or through the Call-Back Study described below.

For a full list of assessments included in the ATN Registry, please click here:

Researchers may have access to ATN Registry data (pending approval) through an online Request for Data (RFD) submission. There is no data hold-back period for Registry data.

A Request for Data (RFD) is the mechanism by which an individual may submit a formal request to obtain raw data from the ATN Registry or to obtain assistance with analyses of data from the ATN Registry. Once the online RFD form and all supporting documents are complete, the submission is electronically routed to the MGH Clinical Coordinating Center (CCC) and Autism Speaks for review and approval. Upon approval, the MGH Data Coordinating Center (DCC) — the MGH Biostatistics Center — will conduct necessary follow-up and provide the appropriate output and analyses.

IMPORTANT: In order to avoid delays for other investigators who may be interested in similar data, you will have 30 calendar days from the date you receive your data to respond to clarifications for data analysis requests from the DCC and 3 months to demonstrate that you are actively working on the results of analyses. The Clinical Coordinating Center team will prompt you at that time to determine the status of your RFD activity. If it is determined to be INACTIVE, we will consider your RFD closed.

If interested in preparing a RFD, please click here: http://asatn.org/request/data

ATN Research Studies:

1. “Registry Call Back Assessment Study (RCBA)”
The RCBA includes longitudinal follow-up data on a subset of Registry subjects. These data include: physical exam, diagnoses and problems, medical and behavioral treatment, and behavioral, cognitive, and communication measures.

DATA HOLD-BACK PERIOD:
There is a standard 12-month data hold-back period for any individuals not directly involved in this RCBA study. The study ended on 1/18/2018.

Access to RCBA data, during the hold-back period, is limited to current ATN members who have been directly involved in the study design and data collection and/or IRB efforts.

For individuals not directly involved in the RCBA study, the data will become available on 1/18/2019.

2. “Family Navigation Study (FN)”
The FN study includes preliminary data on a self-selected convenience sample of families. These data include: demographics, type, date, length, and mode of service provided, structural, organizational, and transactional characteristics of families, parent knowledge, skill, and confidence for self-management of their child, and the extent to which families experience additional demands, responsibilities, and difficulties resulting from caring for a child with emotional or behavioral disorders.

DATA HOLD-BACK PERIOD:
There is a standard 12-month data hold-back period for any individuals not directly involved in this FN study. The study ended on 12/7/2017.

Access to FN data is limited to current ATN members who have been directly involved in the study design and data collection and/or IRB efforts.

For individuals not directly involved in this FN study, the data will become available on 12/7/2018.

The DSM-5 study is comprised of data collected to examine the potential consequences of the change in diagnostic criteria for Autism Spectrum disorders (ASD) from DSM-IV-TR to DSM-5. Data were collected using a prospective approach with a large sample of children and adolescents seen for diagnostic evaluations.

This data is currently available.

May I request access to RCBA or FN data?
You may request access to RCBA or FN data if you answer YES to all of the following questions:

Q1. Are you located at a currently funded ATN center (listed here, alphabetically)?
   • Children’s Hospital of Los Angeles
   • Children’s Hospital of Philadelphia
   • Cincinnati Children’s Hospital
   • Lurie Center for Autism / Massachusetts General Hospital for Children
   • Nationwide Children’s Hospital / The Ohio State University
   • Toronto (Holland Bloorview Rehab, Surrey Place Centre, and the Hospital for Sick Children)
   • University of Alberta and Glenrose Rehabilitation Hospital
   • University of Arkansas for Medical Sciences
   • University of California – Irvine
   • University of Missouri – Columbia
   • University of Pittsburgh
   • University of Rochester
Vanderbilt University Medical Center

Q2. Have you been directly involved in study design and data collection related to the RCBA or FN study?

If you answered YES to both questions, you have access to RCBA, FN, or DSM-5 data. We encourage you to submit a formal Request for Data (RFD), found here: http://asatn.org/request/data

If you answered NO to either question, RCBA, FN, or DSM-5 data is not currently available to you. We encourage you to seek collaboration with an ATN member(s) located at a currently funded ATN center.