

SFARI Base SPARK

Researcher Welcome Packet

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SPARK Participation Criteria

The **Simons Foundation Powering Autism Research for Knowledge (SPARK)** aims to recruit, engage and retain a community of individuals with autism and their family members. SPARK families enroll online at www.SPARKforAutism.org, agree to share their data and to be contacted for future research opportunities and, should they choose, provide saliva samples for genetic analyses.

The phenotypic data currently available include basic family and medical history information and standardized measures; all are detailed in the table below. Clinical lab results also are available on a subset of individuals who underwent clinical confirmation and have had their genetic results returned to them.

Inclusion Criteria

Diagnostic information

- All individuals with a professional diagnosis of autism spectrum disorder (ASD) can participate.
- ASD includes DSM-V Autism Spectrum Disorder, and DSM-IV Asperger Disorder, Autistic Disorder, Rett Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

NOTE:

The ASD diagnosis in SPARK is proxy/self-reported. Multiple studies have confirmed the validity of parent-reported ASD diagnosis in children/dependents enrolled in online autism cohorts. The validity of self-reported ASD diagnosis in independent adults is less well established. For participants enrolled under 18 by their caregivers, the Social Communication Questionnaire (SCQ) - Lifetime, an autism screening measure, is collected for those between ages 2-17.9 years. Previous studies have found that an SCQ score ≥ 11 optimizes the sensitivity and specificity of identifying ASD, and has therefore been adopted as the cutoff in many large autism research studies. No SCQ data are available for self-enrolled participants joining SPARK over the age of 18. (See references for more information.)

Age

- Individuals of all ages are welcome to participate in SPARK. Infant siblings enrolled under 15 months of age are considered at risk of ASD and will be followed over time. Periodically, parents will be asked to provide additional information about the child's development.

Family members

- Parents and full or half- biological siblings can participate in SPARK. Only one unaffected biological sibling is eligible to participate unless the family has more than one child with ASD (in this situation, all unaffected biological siblings may enroll.) Adoptive parents who are legal guardians of children or adults with ASD are also able to register and answer surveys for their adoptive children - but information is not collected on the adoptive parents.

Exclusion Criteria

Residence

- Only residents of the United States can participate in SPARK at this time.

Language

- Participants must be able to read and understand English or Spanish.
 - o At this time, only select surveys are available to Spanish speaking participants. This battery will continue to be enhanced in the future.

Family members

- Only biological family members participate in SPARK biospecimen collection.

SPARK Measure Table

Instrument Name and Publisher	Measure Format	Measure Description	Administrations available by role
ADOS ADOS (original version), modules 1-4 ADOS-2, modules T-4 WPS	Medical record abstraction by SPARK Clinical site Network staff members	ASD diagnostic test	Available on select ASD participants from select clinical sites
Area Deprivation Index Kind AJH, Buckingham W. University of Wisconsin School of Medicine and Public Health, 2019	Systematically generated based on parent/guardian/self-report of physical address	Rank of socioeconomic disadvantage by neighborhood Both version 2015 and 2020 are included in the data file	All SPARK participants
Adult Self-Report ASEBA 2003	Online, self-report	Adaptive functioning, emotional and psychiatric traits, and substance use	Independent ASD adults 18-59 years Non-ASD adults, 18-59 years
Background History Questionnaire-Adult SPARK	Online, self-report	Demographics, treatment, and social history	Independent ASD Adults
Background History Questionnaire-Child/Dependent SPARK	Online, parent/guardian report	Demographics, treatment, developmental milestones and social history	ASD children Dependent ASD Adults
Background History Questionnaire-Sibling SPARK	Online, parent/guardian report	Demographics, treatment, developmental milestones and social history	Non-ASD siblings <18 years

Basic Medical Screening Questionnaire SPARK	Online, self or parent/guardian report	Medical history, including comorbidity variables	All ASD individuals Non-ASD Parents Non-ASD Siblings
Child Behavior Checklist for ages 1.5 to 5 years (CBCL/1-5) ASEBA 2000	Online, parent/guardian report	Problem behavior, psychiatric traits	ASD children, 1.5-5 years
Child Behavior Checklist for ages 6 to 18 years (CBCL/6-18) ASEBA 2001	Online, parent/guardian report	Problem behavior, psychiatric traits	ASD children, 6-18 years
Developmental Coordination Disorder Questionnaire (DCDQ) B.N. Wilson	Online, parent/guardian report	Motor Delays	ASD children, 5-15 years
Intellectual Quotient data (IQ)	Medical record upload by Clinical site Network staff members	IQ scores and classifications from a variety of IQ tests and batteries. Please review the data dictionary for a full list of possible test types	Available on select ASD participants from select clinical sites
Approximated-cognitive impairment SPARK	Machine learning and manual algorithms	Machine learning and manual algorithms predicting intellectual disability	ASD children and dependent adults
Repetitive Behavior Scale- Revised (RBS-R) Bodfish 2000	Online, parent/guardian report	Repetitive behaviors	ASD children, 3 years and older Dependent ASD adults
Social Communication Questionnaire (SCQ) – Lifetime WPS 2003	Online, parent/guardian report	Screeners of ASD markers	ASD children, 2-17 years 11 months Non-ASD siblings, 2-17 years 11 months

Social Responsiveness Scale - 2; Adult Self-Report (SRS-2) WPS 2012	Online, self-report	Screening for ASD; quantifies ASD traits	Independent ASD adults, 19 years and older Non-ASD adults, 19 years and older
Social Responsiveness Scale - 2; School Age (SRS-2) WPS 2012	Online, parent/guardian report	Screening for ASD; quantifies ASD traits	ASD children, 4-18 years 11 months Non-ASD siblings, 4-18 years 11 months
Social Responsiveness Scale - 2; Adult Other-Report (SRS-2) WPS 2012	Online, parent/guardian report	Screening for ASD; quantifies ASD traits	Dependent ASD adults, 19 years and older
Vineland Adaptive Behavior Scales-3rd Edition (Vineland-3) Pearson Assessments 2016	Online, parent/guardian report	Adaptive behaviors	ASD children Dependent ASD adults

- *Participants also complete longitudinal updates on family members' ASD diagnoses and cognitive functioning, which are incorporated into the dataset.*
- *For detailed information on measures including variables and answer choices, please refer to the SPARK Data Dictionary and SPARK Release Notes, which are available on SFARI Base and included in the SPARK dataset zip drive.*

Genomic Data

Genetic data are available for over 150,000 SPARK participants. The SPARK integrated whole exome sequencing cohort (SPARK iWES v3) contains over 140,000 individuals (>55,000 with ASD) across nine sequencing batches (WES1 through WES9) and the SPARK integrated whole genome sequencing cohort (SPARK iWGS v1.1) contains over 12,000 individuals (>3,500 with ASD) across five batches (WGS1 through WGS5). Over 2,500 individuals have both whole exome and whole genome sequencing data. Please visit SFARI Base (base.sfari.org) to request access to genomic data.

Sequencing reads (CRAM format files) are available for all individuals in each dataset. Most individuals also have SNP genotyping data, either via Illumina Global Screening Arrays (GSA) or through genotyping-by-sequencing (GxS). SNV/INDEL variant calls are provided using DeepVariant and GATK (for WES data, additionally weCall). Individual gVCFs, as well as jointly-called pVCFs are provided for each variant caller, with GLnexus used to perform joint calling.

Research Match

Research Match is a service that enables approved researchers to recontact participants from SFARI autism cohorts, including SPARK, for recruitment into new research studies. Researchers may be approved to recruit participants for in-clinic or remote studies, or to utilize the Research Match platform to build their online surveys. As of June 2026, over 163,000 families participating in SPARK have been invited to join a study through Research Match, and 76,500 families have responded to Research Match invitations. In addition, over 160 [papers and preprints](#) have been published based on these studies.

Please note that applications to access the SPARK Research Match service must be submitted on SFARI Base. Applications are reviewed and approved on a quarterly basis by a Participant Access Committee, with application submission deadlines on March 31, June 30, September 30, and December 31 of each year. Click [here](#) for more information on using Research Match services.

How to Access SFARI Base and Request SFARI Resources

1. Log into SFARI Base [here](#). If you do not have a SFARI Base account, you may create one. As part of account creation, you will need to affiliate with an institution. If your institution is not registered on SFARI Base, you will be prompted to provide institution details as part of registration. This includes the name and email address for a Signing Official who has authority to represent your institution in a legal agreement, similar to a material transfer agreement.
2. Review your institution's executed Researcher Distribution Agreement (RDA) and agree to the joinder to the RDA. The RDA specifies the legal issues pertaining to research data and specimens, and requires approval from the PI's institution. Each PI and collaborator must agree to the joinder agreement to the RDA for their respective institution.

For institutions that do not yet have an executed RDA, it will be sent to the institutional officer for review and signature upon approval of a request in SFARI Base.

3. Create a SFARI Base project, which includes the title, abstract, and an IRB approval or exemption document (if required).
 - a. Most datasets do not require IRB approval or exemption documentation, in line with the Common Rule. For some SFARI resources, a letter from an institutional review board (IRB) may be required. For any projects containing these resources, the project must be governed by a protocol approved or exempted by an IRB. A protocol specifies the regulatory issues pertaining to the research and may include co-investigators at multiple institutions. You will need to obtain a PDF copy of the letter from your IRB approving or exempting your protocol.
4. Create a SFARI Base request, which includes specifying the type of resource you would like to request access to (phenotype, genetic, or imaging data; biospecimens; and/or Research Match application). The submitted request will be reviewed by the SFARI science team or appropriate committee.

References

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If you have additional questions, email sdbr@simonsfoundation.org.