

SPARK Recruitment Process Document

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Overview: SPARK

What is SPARK?

SPARK, which stands for Simons Foundation Powering Autism Research for Knowledge, is a landmark autism research project with the mission of speeding up research and advancing our understanding of autism to help improve lives. Funded by the [Simons Foundation Autism Research Initiative](#) (SFARI), SPARK's goal is to recruit at least 50,000 individuals in the U.S. that have a professional diagnosis of autism, and their family members, into an online research cohort. SPARK is the result of a collaboration between SFARI and more than 31 university-affiliated clinics and community partners.

For more information on SPARK, please visit the [SPARK website](#) and the SFARI website for the [SPARK cohort](#). For questions about requests for resources and new recruitment studies, please visit the [SFARI Base page](#).

What resources are available for my research project?

Qualified, approved researchers can request access to phenotypic and genetic data, as well as recruit from our registry of SPARK families for their own studies through Research Match via the web portal [SFARI Base](#).

Please note that phenotypic and genetic data for an individual participant may not be released at the same time. SPARK will announce new releases of data via SFARI.org newsletters and SPARK Research newsletters.

A full list of the phenotypic measures given to SPARK participants is [available here](#). Since SPARK is an online study, participants choose which measures to complete and at what time. Therefore, any given participant may have different phenotypic data available.

For information on requesting data and biospecimens, please visit the [SFARI Base page](#).

This document provides additional information on recruiting SPARK families for your new research project. You may contact collections@sfari.org with any specific questions regarding your potential project.

How do I get permission to recruit SPARK families to participate in my research project?

If you want to recruit SPARK families as research participants, you will need to follow the recruitment study process as detailed below. Please note that you will need to place a separate request and receive SFARI approval for access to phenotypic or genetic data. If you would like to access recruited participants' coded SPARK data by linking the data you collect in your new study, you will need to include authorization language, such as bidirectional data-sharing language, in your consent form(s). Please work with the SPARK recruitment liaison to ensure that you will be able to access the data.

Overview: Recruiting SPARK Participants (Research Match)

Investigators that are interested in conducting research studies with SPARK families can initiate a new recruitment study request through [SFARI Base](#). See [here](#) for additional details about submitting a new recruitment study request.

As an investigator, you will be required to create a log-in name and password, affiliate with an institution, sign the joinder agreement to the Researcher Distribution Agreement (RDA), and complete a new recruitment study request application. For new recruitment studies involving SPARK participants, application deadlines are at the end of each quarter (March 31, June 30, September 30, December 31) and cannot be extended for individual circumstances.

It is strongly suggested that researchers limit to one application per review cycle. If you choose to submit multiple applications in a cycle, a SFARI team member may request that you choose one application to be reviewed and to defer other applications to the next quarter.

After you have submitted your application:

1. A SFARI support team member will contact you to confirm the details of your request, including the eligibility criteria and number of participants. If needed, the support team member will also put you in touch with the SPARK recruitment liaison to begin planning your study materials.
2. The SPARK Participant Access Committee (PAC) meets on a quarterly basis to consider applications submitted during the previous quarter (e.g., the committee meets in April to consider applications submitted during Q1: January 1 - March 31). You will be notified when your request is approved. A SFARI support team member will notify you if additional details are required or if your request needs to be revised and resubmitted. If your request is not approved, someone from SFARI will contact you with an explanation.

Note: If you have questions about the review and approval process, please contact collections@sfari.org.

3. Upon approval of your request, your project's information will be sent to the SPARK recruitment liaison. You will be contacted to schedule an introductory call with the Research Match team. You may also need to provide other documentation (e.g., recruitment materials). **Please note, it is not mandatory to draft recruitment materials prior to the call. If you decide to draft recruitment materials prior to the call, it is strongly encouraged that you send your recruitment materials to a SPARK recruitment liaison for review before submitting them to your IRB.**
4. In order to launch your new recruitment project, you will work directly

with the SPARK recruitment liaison, Research Match team, and our information technology team (Tempus Dynamics) regarding the timeline and other recruitment project details. Specific study workflows vary depending on the study protocol (see below for details on types of studies). Please note that authorization to contact SPARK participants is limited to only the approved study and, as such, SPARK participants may not be asked to consent to join a lab's local research registry or to agree to be contacted about future research not approved by SPARK.

5. Projects are approved to recruit for one year. Recruiting participants from SPARK past one year requires a renewal application and is contingent on approval from the SPARK PAC. The renewal application requires researchers to provide a summary of recruitment efforts over the past year and scientific justification for continued recruitment from the SPARK cohort. Projects may submit up to two renewals for consideration.

Overview: Types of Research Match Studies

All Research Match studies begin with an invitation email ([Appendix B](#)) which tells eligible participants about your research study and encourages them to take the next step to learn more. From here, interested participants are directed down a workflow that may vary based on your specific study type and protocol. Please see some examples below.

In-clinic/hand-off studies

If you need to invite participants to visit your clinic or conduct an in-person research protocol, your study will typically use the following workflow. This workflow is also used for hand-off studies, including online tasks SPARK is unable to build, focus groups, and phone interviews. We typically determine whether your study should be a hand-off study or an online survey study during the introductory call.

Workflow:

1. After responding to the interest email, participants are directed to an online screen ([Appendix A](#)), where they can read more about your study and answer additional eligibility questions, if applicable.
2. If interested and eligible, participants electronically sign an authorization form ([Appendix A](#)) granting permission for SPARK to send their contact information to your lab. You will be able to access the information of participants who granted this authorization through a secure web portal. In addition to the contact information, a Temporary Recruitment ID will be provided for each participant.
3. Contact families to obtain their consent to participate in your study. Follow your institutional review board (IRB)-approved study protocol for consent and other study procedures.

4. In the same secure online portal through which you obtained the contact information, enter the consent and participation status for each participant (e.g., declined consent, consented, lost to follow-up/never responded) and other information (e.g., dates and methods of contact). The SPARK recruitment liaison will work with you to define which fields need entry for your particular study.
5. The secure online portal will make available to you the SPARK Publishable ID (SP_ID) *only for participants who consented into your study*. The SP_ID will allow you to identify the family in the SFARI Base data set and link to the participant's phenotypic and genetic data.

Online survey studies

If your study consists of an online survey, SPARK typically recommends allowing us to build the survey into our own workflow system. This streamlines the participant experience, increases response rates, and facilitates data sharing. The SPARK recruitment liaison can discuss your specific study details with you, and our Research Match team will work closely with you to build and test your survey, including conversion to an online format and database variable names. For online studies that include components other than a survey (e.g., custom tasks requiring additional programming, animation, or unique interactive tasks), SPARK recommends using the hand-off workflow described above.

Workflow:

1. After responding to the interest email, participants are directed straight to your study consent form.
2. If they consent, they proceed straight to your first survey and continue until they have completed the entire protocol.
3. The Research Match online system may be able to distribute electronic incentives when the participant submits the last survey in the workflow. Discuss this with the SPARK recruitment liaison to see if this is a good fit for your study.
4. At the conclusion of the study, you will receive a final data set with your study data, indexed by SP_ID, so that you can link to the coded SPARK data on SFARI Base.

Frequently Asked Questions

1. **How do I submit a request to recruit SPARK families as participants in my research project?**

Create your request and submit your project documentation for access to SPARK resources on [SFARI Base](#).

See [here](#) for additional details about submitting a new recruitment study request. If you have any problems submitting the application or if you have additional questions about a specific field in the application, please contact collections@sfari.org.

2. **How long will it take to approve my new recruitment study request?**

The request will be considered by SFARI and/or the SPARK Participant Access Committee, and we will communicate with you regarding its status (approve, deny, or additional questions). The SPARK Recruitment Access Committee meets once per quarter (e.g., in April for applications received during Q1: January 1 - March 31), but we may do an initial review of your application and ask you some questions in advance of that meeting. It is not usually possible to expedite a new recruitment study request, so please consider the quarterly meeting timeline when planning your project. If you want to check on the status of your application, please contact collections@sfari.org.

Note: SPARK clinical sites may be eligible for fast-track application status if the project will only recruit from the site's own affiliated participants. Email collections@sfari.org for questions specific to SPARK clinical sites.

3. **What should I do if I need to edit my request?**

Contact collections@sfari.org. Please also contact collections@sfari.org if your approved research protocol has changed significantly from what you originally submitted (e.g., addition or removal of a task, change in type of incentive or feedback).

4. **How long does it usually take to launch a new recruitment project after approval?**

Time to launch varies widely and depends on some project-specific details such as the complexity of your protocol, your IRB approval timeline, and other factors such as the need to stagger project launches to ensure optimal recruitment for all principal investigators (PIs). Typical time from the post-approval introductory call to launch is between two to four months, but actual timeline may be shorter or longer.

5. **When can I expect to receive the families' contact information (for in-clinic or hand-off studies)?**

The contact information will become available to you in real time as participants authorize, following the launch of your new recruitment

project. You will be able to pull this information from the secure portal as often as you wish while your study is active. Once your project closes, you will no longer have access to this information.

- 6. What options do I have for new recruitment study workflows?** You should discuss the specifics of your project with the SPARK recruitment liaison, but SPARK has the ability to support many different kinds of research. Briefly, your options could include:
- a) SPARK can contact participants and ask them to complete an authorization to share their contact information with you. Then, your lab staff can contact the participants to discuss the study and get their consent directly. This is often the option preferred by in-clinic projects.
 - b) SPARK may be able to host both the authorization and your study consent form online and share with you the information of participants who provide consent.
 - c) SPARK may be able to host the authorization, your consent form, and online questionnaires. Some questionnaires may already be available, while others may be difficult or impossible for us to build online. Speak with the SPARK recruitment liaison for details.
- 7. Who should I contact if I have additional questions?**
For all additional questions, please contact collections@sfari.org. This includes any issues with website navigation, difficulties uploading forms, questions about the fields in the new recruitment study application, and questions about the status of your application.
- 8. How do I find the SPARK phenotype and genetic data for the families that agree to participate in my study?**
A SPARK participant must consent for you to link their SPARK data and new recruitment project data before we can provide you with this information. *If you wish to link data from your project and the SPARK study, you must include the bidirectional data-sharing language (see highlighted example below, under item #10) in your consent form in order to receive the identified data. This language must be approved by both the SPARK recruitment liaison and your institutional IRB.* Failure to follow this step in its entirety may result in you being unable to obtain the SPARK data.

The secure portal provided as part of your new recruitment project (the same one where you obtain the participant contact information) will track consent status (if your consent form is hosted by SPARK) or allow you to enter consent status for each participant. Once you indicate that a family has consented to participate in your study, and therefore agreed to the bidirectional data-sharing language, we will show you the SP_ID linked to the temporary Recruitment ID. You will be able to use the SP_IDs to obtain the SPARK data on SFARI Base. If you have an online survey study, the SP_IDs are distributed as part of your final dataset. The SPARK recruitment liaison can explain this process in more detail.

9. How do I know what information should be included in my new recruitment project email and authorization form? What about my consent forms?

Template email and authorization form scripts are provided at the end of this document for your convenience (Appendices A and B). You will work with the SPARK recruitment liaison to optimize these materials after your project is approved.

For your consent form, you must be sure to include two aspects of data transfer (bidirectional data-sharing language):

- a) Consent for you (Researcher) to receive *linked, identified* phenotype and genetic data from the SPARK database using the participant's SP_ID.
- b) Consent to transfer participants' data from your study into the SPARK database.

You must receive approval from the SPARK recruitment liaison before submitting these consent changes to your IRB. Failure to follow this step may result in you being unable to obtain the linked SPARK data. Note that in most cases, a PI must submit one additional IRB amendment as part of the pre-project launch process. This submission should include your final, approved consent forms, authorization form with bidirectional data sharing language, and recruitment emails (invitation and reminder emails), as well as any other documents required to build your workflow as discussed with your SPARK recruitment liaison.

10. What is the bidirectional data sharing language that must be included in my consent form?

This language allows you to receive *linked, identified* data from SPARK on the participants in your study. These data are shared using a linked ID number (SP_ID) that is not provided until participants consent to be in your study and sign their agreement to bidirectional sharing of their data. This language also provides consent for you to share your study's data back with SPARK, for inclusion in the SPARK database, in order to continue to enhance the SPARK resource. Suggested language is provided below. *Please allow your SPARK recruitment liaison to review your consent forms during the pre-project launch phase before resubmission to your IRB. Failure to do so, or failure to include the language in your consent form at all, may result in delays to and/or cancellation of your project, or make it impossible for SPARK to share identified data with you.*

(If study contains non-SPARK participants, start with: For those individuals who participated in the SPARK study,) we are asking your consent for the SPARK study, hosted by the Simons Foundation, to share with {University} the clinical, demographic, and genetic data collected during your participation in SPARK. This information will be shared using

your linked research ID number and using a secure transfer system. We are also asking for your consent to share the data we collect during the study here at {University} with SPARK in order to add to the information that was collected during your participation in SPARK. Please note that because you are a participant in both studies, SPARK and this study will be able to share and link your identifying information, as well as any future data you may contribute to either project.

The Simons Foundation funds innovative research and provides coded data access (data with your identifying information removed) to qualified researchers. Researchers can file an application with the Simons Foundation to obtain access to your study data for research purposes. Experts at the Simons Foundation who protect health and science information will look at every request carefully to minimize risks to your privacy.

Please ensure that you have accounted for all roles (e.g., parents, siblings, individuals with ASD) for which you want to obtain data. Data-sharing consent must be obtained for each individual, and all independent adults must consent for themselves.

11. What is the process for data sharing with SPARK?

Once a participant has completed your study consent form (agreed to bidirectional data sharing) and you have the SP_ID for a participant, you will be able to link to the data in the SPARK database.

You will also be required to share data from your study back with SPARK, to enhance the SPARK database. This will include participation data as well as study-specific data. SPARK will work with you on the terms of this data sharing, but in general, the expectation is that data will be made available for SPARK to distribute to researchers publicly upon publication or within one year of the end of data collection, whichever comes first. These terms are also outlined in the [Researcher Distribution Agreement \(RDA\)](#), which your institution signed, and the Joinder to the RDA that you acknowledged when you first created an account on SFARI Base.

We will also ask for your help creating a lay-friendly summary of your research to share with SPARK participants when recruitment for your project is completed.

12. Is there a fee for SPARK recruitment services?

At this time, SPARK does not charge a fee. However, this policy may change in the future, in which case documentation will be provided. Research teams are responsible for any licensing and copyright fees for use of standardized measures in their studies. Any requests for custom tasks may incur additional charge. Please contact collections@sfari.org to determine your specific study requirements and potential costs.

Checklist for New Recruitment Projects

For initial application review:

Application items in SFARI Base:

- ☐ Completed application
- ☐ IRB project approval
- ☐ IRB approved consent form
- ☐ IRB approved surveys, interview questions, and/or related project materials

Please email collections@sfari.org if you have questions related to the SFARI application and approval process.

For approved projects:

The following items should be forwarded to the SPARK recruitment liaison after project approval:

- ☐ Any updated IRB materials (including final surveys), or templates from Appendix A and B, if not already sent in the application.

After your final study materials are approved and submitted to your institutional IRB:

- ☐ Final IRB project approval
- ☐ Final IRB-approved consent form
- ☐ Final IRB-approved authorizations, scripts, and emails
- ☐ (If applicable) Final IRB-approved surveys

Typically, communication regarding recruitment materials begins after SFARI approval. However, in certain circumstances, it may be necessary to initiate communication earlier. Please discuss this with the SPARK recruitment liaison via collections@sfari.org.

Please be aware:

- x As a result of a successful authorization, you will receive only a limited amount of information on participants, via the secure portal hosted. This includes names, contact information, and a Temporary ID. You must contact and get consent from participants in order to receive additional information and the SP_ID.
- x Data transferred as a result of an authorization CANNOT be used for research unless/until the individual(s) in question have consented for a project. The data transferred during authorization expire and must be destroyed by the researcher after one year if the research participant does not join the study.
- x Data transferred as a result of an authorization CANNOT be used for any study other than the approved study. SPARK participants **may not** give consent to be contacted by your lab about additional research opportunities unless this has also been approved by the SPARK PAC.

- x For every individual, including other family members, for whom you want SPARK data, you must have consent, authorization, or some other IRB-approved process in place. Make sure to have a strategy to obtain all identified SPARK data that you need for your analysis. Discuss this with the SPARK recruitment liaison if you have questions about the process.

Appendix A – Authorization Template

Recruitment Project Authorization Online Screens for SPARK

In this template, items that will always appear no matter what study is recruiting appear in black. Researchers provide text for the green items to fit their criteria.

Additional Study Information [Screen 1]

Here, the outside study is explained in more detail. This may include the goals of the study, eligibility criteria, what participation involves, how much time it will take to participate, and any incentives provided. The explanation must contain language reassuring the participant that they do not have to answer any specific questions and can withdraw from the study at any time. It must also include the following: Participating (or choosing not to participate) in this study will not change your participation in the SPARK study. You may also choose to withdraw your participation at any time.

Eligibility Question(s):

For most studies, families will be eligible based on their SPARK status or information we already possess and have screened for (such as child's age). If there are any additional eligibility criteria, we will screen for them here.

Please keep questions simple (e.g., yes/no answers) and list the pass/fail criteria.

Participation/Authorization Section:

Please note that SPARK is serving as a resource linking SPARK families and researchers who are conducting research families may wish to join. This study is not part of the main SPARK study. You do not have to participate in this new study. Not participating will not affect the care you receive from any health provider nor your standing as a participant in SPARK. Please note: This study is being performed by [NAME OF INSTITUTION]. SPARK is not conducting nor endorsing this research project.

[IF STUDY INCLUDED ELIGIBILITY CRITERIA, THIS SECTION WILL APPEAR AS A SEPARATE PAGE; COPY STUDY DESCRIPTION FROM PAGE 1 HERE]

1. [FULL NAME], would you be interested in participating in the [STUDY TITLE] study?

Yes

No

2. [Shows only if answer to #1 is YES] We request that you grant SPARK and the [NAME OF INSTITUTION] research team permission to share information as described below.

Read the authorization, and then click “yes” or “no”, as you choose.

I HEREBY AUTHORIZE

1) The **[NAME OF INSTITUTION]** research team to release information about my involvement in the **[STUDY TITLE]** study to SPARK so the SPARK team will know how many families were interested in, started, and actually completed the study.

and

2) SPARK to release the information listed below for [designated family members such as PARENT, PROBAND, SIB1] to the **[NAME OF INSTITUTION]** research team so they can **contact me** about study participation and **link information** they collect through the study with information already collected through my family’s participation in SPARK. (This makes research more efficient because the team won’t need to ask you to do the same tests, interviews, or surveys again. Instead, they can spend time with you and your family addressing new research questions but still access relevant information from these earlier studies to help them in their analysis.)

Last Name, First Name, and Middle Initial

SPARK ID Number

Mailing Address

Email address and preference regarding which address researchers should email

Phone number and preference regarding which number researchers should call

Gender

Date of birth

ASD Diagnosis (or child’s ASD diagnosis)

Additional information depending on study protocol (e.g., verbal ability)

This authorization will expire one year from today’s date. I understand that I may revoke this authorization in writing (submitted to the SPARK team) except to the extent that action has already been taken. I understand that this authorization is voluntary. I understand that my and my family’s participation in SPARK will not be affected if I do not grant authorization for sharing of information and if I do not join this particular study.

On behalf of [SELF, PROBAND, SIB, etc.], I grant authorization for the exchange of information described above:

- Yes
- No

Please note: checking yes above is the equivalent of providing your signature on this authorization form. You may print out or save a copy of this form for your records.

Appendix B – Email Templates

Recruitment Project Email Templates (page 16 & 17)

In these templates, items that will always appear no matter what study is recruiting appear in black. Researchers provide text for the green items to fit their criteria. Please consider using participant-friendly language and avoid complex, lengthy explanations in your invitation email.

To edit the emails, double click the template and it will open in a new Microsoft Word document.

Invitation email template for SPARK Recruitment Studies

Subject: [Customized to fit project]. Examples include: “Invitation: Research Study about [study topic]” or “New research opportunity from SPARK” or “New study recruiting SPARK participants” ending with (RM0###PI Last Name)

SPARK



Research Match

New Research Study Opportunity

Study Name: Customized to fit the project

Dear NAME,

You are invited to participate in a new research study at [INSTITUTION NAME] led by [RESEARCHERS NAMES].

Study Information



What is involved?

- Brief, plain language description of what the participant will be asked to do. (1-3 sentences)



Purpose of the research

- Briefly describe what your research is trying to find. (1-2 sentences)



You may be eligible if

- Your child/you have a diagnosis of ASD
- Your child/you are ages [age range]
- Any other important inclusion criteria here



What will I receive if I participate?

- Is there an incentive for participation?
- Are transportation and parking costs covered? (if there are in-person visits)
- Do participants receive a report/evaluation?

To learn more, click the link below:

LEARN MORE

If you are NOT interested in this study, let us know and we will not send you any additional emails about the study. Not interested? Click [here](#).

This section thanks the family for their time, attention, etc. (1 sentence)

Sincerely,

Researcher’s Name
Institution

Why am I receiving this email?

When you joined SPARK, we promised to contact you about new research projects. This is an invitation from a research team looking for SPARK families to participate in their study. Contact SPARK at SPARK@SPARKResearchMatch.org if you have any questions about this research invitation.



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info@SPARKforAutism.org

SPARK Simons Foundation PO Box 1806 New York, NY 10159

Reminder email template for SPARK Recruitment Studies

Subject: [Customized to fit project]. Examples include: “Reminder: Research Study about [study topic]” or “Reminder: New research opportunity from SPARK” or “Reminder: New study recruiting SPARK participants” ending with (RM0###PI Last Name)



Research Match

Research Study Opportunity Still Available

Study Name: Customized to fit the project

Dear NAME,

You are invited to participate in a new research study at [INSTITUTION NAME] led by [RESEARCHERS NAMES].

Study Information



What is involved?

- Brief, plain language description of what the participant will be asked to do. (1-3 sentences)



Purpose of the research

- Briefly describe what your research is trying to find. (1-2 sentences)



You may be eligible if

- Your child/you have a diagnosis of ASD
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What will I receive if I participate?

- Is there an incentive for participation?
- Are transportation and parking costs covered? (if there are in-person visits)
- Do participants receive a report/evaluation?

To learn more, click the link below:

LEARN MORE

If you are NOT interested in this study, let us know and we will not send you any additional emails about the study. Not interested? Click [here](#).

This section thanks the family for their time, attention, etc. (1 sentence)

Sincerely,

Researcher’s Name
Institution

Why am I receiving this email?

When you joined SPARK, we promised to contact you about new research projects. This is an invitation from a research team looking for SPARK families to participate in their study. Contact SPARK at SPARK@SPARKResearchMatch.org if you have any questions about this research invitation.



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