



Heini Natri <heini.natri@gmail.com>

RE: Some questions re: equity, inclusion, ethical engagement, and informed consent {44362606}

Amy Daniels <info@sparkforautism.org>

Mon, Jan 31, 2022 at 7:02 AM

Reply-To: info@sparkforautism.org

To: heini.natri@gmail.com

--reply above this line--

Good morning, Heini
Please find Dr. Chung's response below.

Best,
The SPARK Study Team

Dear Dr. Natri,

Thank you for reaching out to share your questions and concerns.

SPARK has engaged and integrated the autism community since its inception, starting with the initial planning and the pilot launch in late 2015. To ensure that we understand and represent the interests and concerns of families and autistic adults, we have a Scientific Advisory Board, a Community Advisory Council, and a Diversity, Equity, and Inclusion Advisory Board. These advisory councils include autistic adults, parents of autistic children, providers, and researchers who provide input into SPARK. The SPARK team is diverse in multiple dimensions including neurodiversity.

There are hundreds of researchers, including autistic researchers, using SPARK data through [SFARI Base](#), or recruiting SPARK participants through Research Match. All applications to use SPARK data are reviewed to ensure the use of data and biospecimens is in compliance with the Institutional Review Board (IRB)-approved consent language. SPARK Research Match studies go through multiple levels of review including review by the Participant Advisory Council. SPARK works closely with autistic adults, community members, and scientists to ensure that SPARK is respectful of SPARK research participants, has scientific merit, and advances a meaningful autism research agenda.

We are studying genetics to better understand the biology of the brain to support all people more effectively. This is similar to the strategy scientists have used to understand the biology of heart disease/heart attacks and led to the development of medicines that have helped millions of people live fuller and healthier lives.

SPARK recognizes that stigma and prejudice are concerns for autistic persons. We are not studying genetics because we are interested in getting rid of individuals with autism or in preventing autism. In fact, individuals with autism contribute to the richness and diversity of our world. The aim is to better understand brain biology which would allow us to support all people more effectively.

SPARK produces articles and webinars that address these issues. All of these materials are available on [the SPARK website](#).

SPARK has held Ask Me Anything sessions that are available to the community to keep communication channels open. You can access past sessions [HERE](#).

Sincerely,

Wendy Chung, MD PhD

SPARK Principal Investigator

From: **Amy Daniels**
1/27/2022 4:26:42 PM

Hi Dr. Heini,

Apologies for the delayed response.

I understand that you also reached out to the SPARK study PI, Dr. Wendy Chung, and she will get back to you shortly.

Best,
The SPARK Study Team

To the SPARK team,

I'm contacting you as a computational biologist, functional genomicist, and autistic person with a number of questions regarding the SPARK study. More specifically, I'm hoping for more information and your comments on community engagement, equity and inclusion, informed consent, and the ethical questions surrounding the use of GWAS variants and polygenic risk scores in pre-implantation genetic testing and embryo selection.

Some background to put these questions into a wider context:

- In the field of human genetics, there is an increasing focus and an ongoing conversation on eugenics. For example, ASHG and the NHGRI have acknowledged that eugenics is an existing threat, emphasizing the need to guard vulnerable groups and highlighting, e.g., the ethical concern surrounding new methods such as polygenic embryo selection.
- Recently, a large-scale autism GWAS named Spectrum 10K was paused in response to overwhelming negative feedback from the autistic community. The Health Research Authority (HRA) that previously granted the project an ethics approval has now requested that the Spectrum 10K principal investigators answer a number of questions regarding, for example, the complete mismatch between the official goals of the project and the recruitment materials, as well as the PIs connections to the ABA industry, Autism Speaks, and Cure Autism Now. The HRA letter to Spectrum 10K can be found here: <https://thelifeofathinker.files.wordpress.com/2021/11/letter-from-hra-to-spectrum-10k-26.11.21.pdf>
- These events and issues highlight the importance of equity and ethical engagement in human genetics research, particularly when researching vulnerable populations or traits/groups faced with stigma and prejudice.

Some specific questions are:

1) What proportion of the leadership and faculty members involved with SPARK are autistic? If there are no autistic people in leadership positions or this proportion is low, why?

2) What steps are SPARK taking to recruit autistic people to leadership roles? How about as researchers, trainees, staff members? How do the SPARK PIs support autistic undergraduate and graduate students? As the SPARK recruitment and marketing materials emphasize appreciating neurodiversity, I would hope that this appreciation shows in staff composition and in the institutions involved.

3) Have any of the PIs involved with SPARK previously published research or made statements in, e.g., books, articles, or interviews, about eradicating, curing, or preventing autism?

4) Do any of the SPARK PIs have connections to the ABA industry?

5) What proportion of the members of the community engagement panel are autistic?

6) What information does the engagement panel get about the use of GWAS variants and polygenic risk scores in pre-implantation genetic testing, embryo selection, and prevention? In response to this information, what feedback has the panel provided to the SPARK researchers, and how has SPARK responded to this feedback?

7) How does SPARK discuss topics such as prejudice, genomics research, polygenic embryo selection, and eugenics with the engagement panel? If eugenics has not been discussed, why not?

8) Why does the informed consent form not mention the possibility of group harm or the possibility that the GWAS and PRS information produced by the study could be used for pre-implantation genetic testing and embryo selection? This information would likely affect many potential subjects' willingness to participate in the study.

9) Why does SPARK partner with non-autistic-led organizations with a long history of causing harm to autistic people and centering neurotypical family members, e.g., Autism Speaks? In the HRA letter to Spectrum 10K, one of the questions was regarding the PI's previous connections to Autism Speaks and Cure Autism Now, suggesting that the HRA recognizes that these connections are problematic.

10) Why does SPARK not partner or engage with autistic-led organizations, such as ASAN?

11) How does SPARK guard against harm, such as increased stigma and prejudice, or the use of the PRSs produced by SPARK towards polygenic embryo selection? Why are these topics not discussed in

the recruitment materials?

12) Why do the SPARK recruitment materials and progress reports not discuss negative bias, stigma, prejudice, social exclusion, abuse, or coercion?

13) Why does SPARK not engage in open, transparent conversation with the wider autism community in, e.g., the possibility of harm and the connection between prejudice, genomics research, and eugenics?

14) Why do many of the SPARK materials continue to use othering, stigmatizing, and ableist language despite recommendations advising against such language? For example, see <https://www.liebertpub.com/doi/10.1089/aut.2020.0014>

15) A recent recruitment video published by SPARK and ASHG presents the autistic person as a child who has no understanding of the study, and as having no personal agenda or autonomy. The decisions are made by the researcher and the caregiver. Why was this choice to center caregivers instead of autistic people made? In addition to this setting, the language used in the video also suggests that autistic people were not included in the planning. For example, the video uses person-first language even though autistic people overwhelmingly prefer identity-first language. Where is the equity and inclusion in this video? Note that engaging with caregivers only and not with those directly affected by the research is not community engagement.

I'm looking forward to your response.

Sincerely,

Heini M Natri, PhD

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NOTE: When replying to this email please leave the subject-line intact.

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