



OBJECTIVES:

- There is a critical need to accelerate the participation of autistic people and autism families in research.
- In order to facilitate recruitment into research studies, ASF created a searchable database of research studies across the US.
- Researchers submit their study and are asked to explain study goals, participation requirements, and how it will help people.
- Families and autistic individuals can search based on research topic interest, age or geographic location.
- We asked users and researchers their opinions on ease of reading of the studies as well as overall experience.
- A different group of individuals participated in a focus group to provide specific suggestions of how to improve and expand the tool.

METHODS:

- Survey and focus group participants were recruited from a social media campaign. The focus group included self-advocates, parents and other caregivers.
- We asked researchers and survey participants about their overall experience and readability.
- The readability of the written descriptions was independently assessed using readability metrics: Flesch-Kincaid Grade level and Flesch Readability Ease.

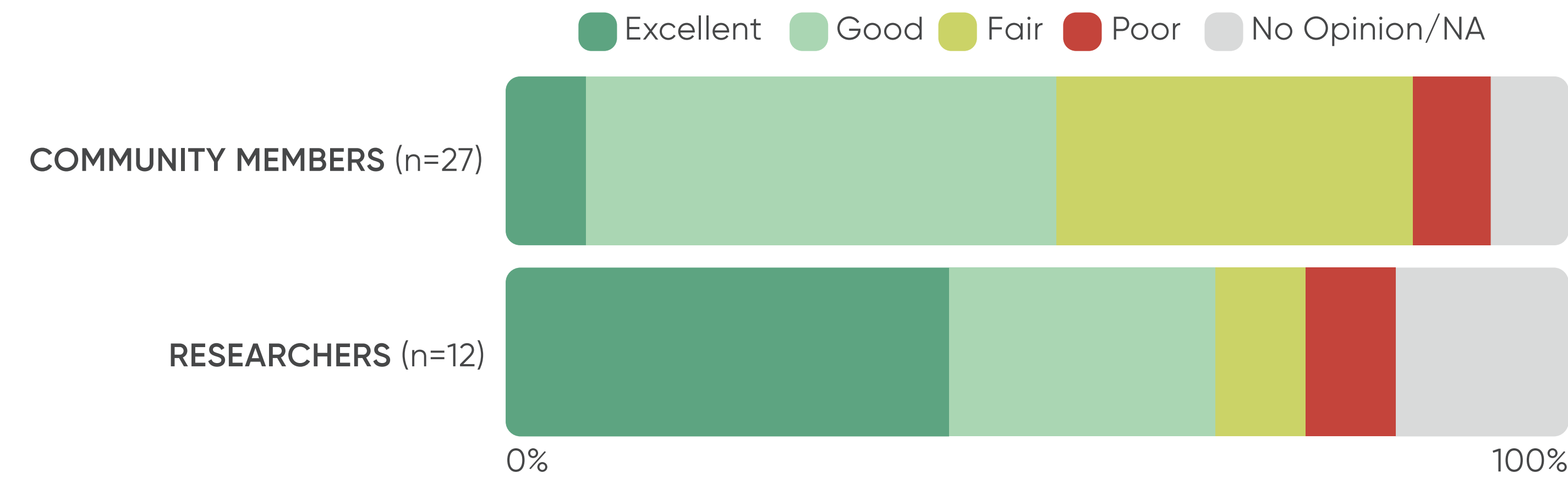
RESULTS:

- Most people had excellent or good experience, although community members felt less enthusiastic.
- Researchers were confident that their listings were clear, informative and compelling, but community members did not always agree.
- Mean readability scores were:
 - 30 for FRE and
 - 14.1 for FKGL

This indicates that on average, the explanations of the study are being shared at a more advanced reading level than what is recommended.
- Community members were less likely to click on the title of study that was not clear, suggesting lay titles are important.

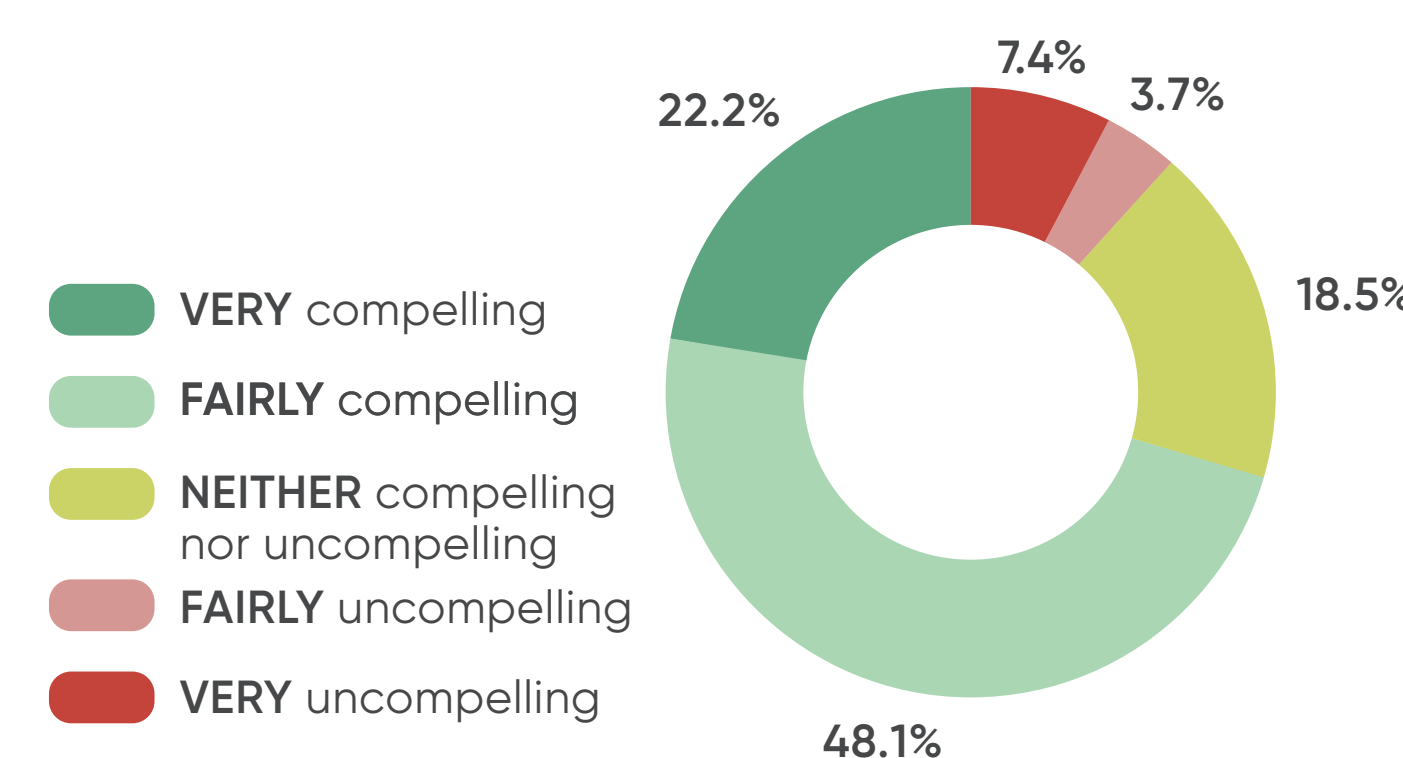
SURVEY & FOCUS GROUP FINDINGS:

Overall Experience Using the Participate in Research Directory

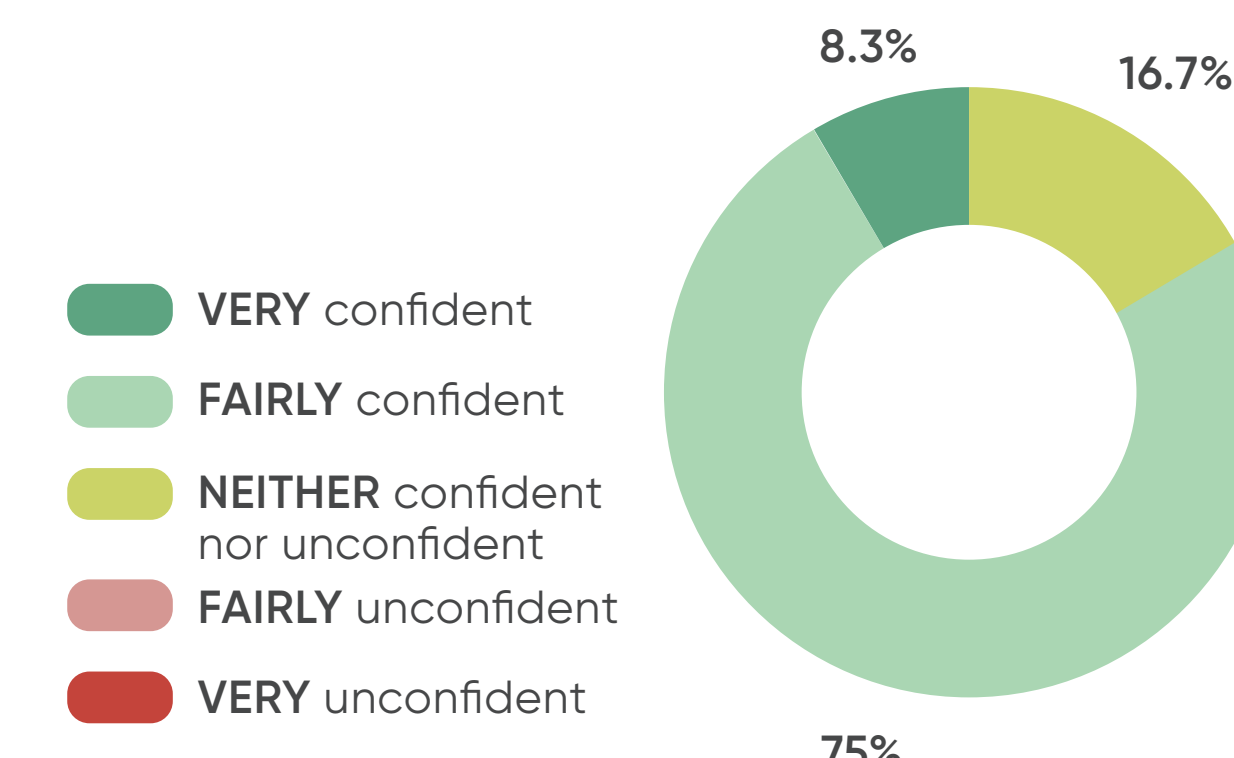


User Opinion of Study Listings

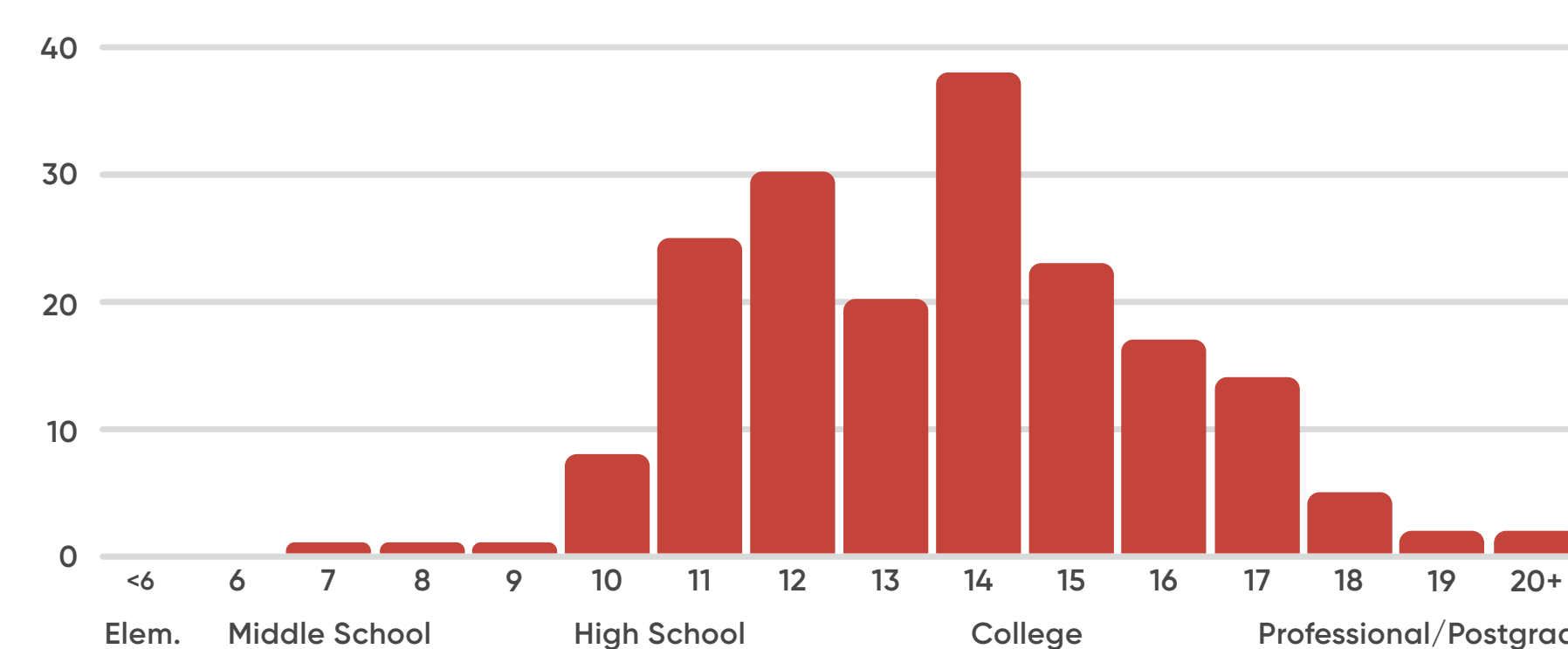
COMMUNITY MEMBERS were asked: "How clear, informative, and compelling did you find the study listings?"



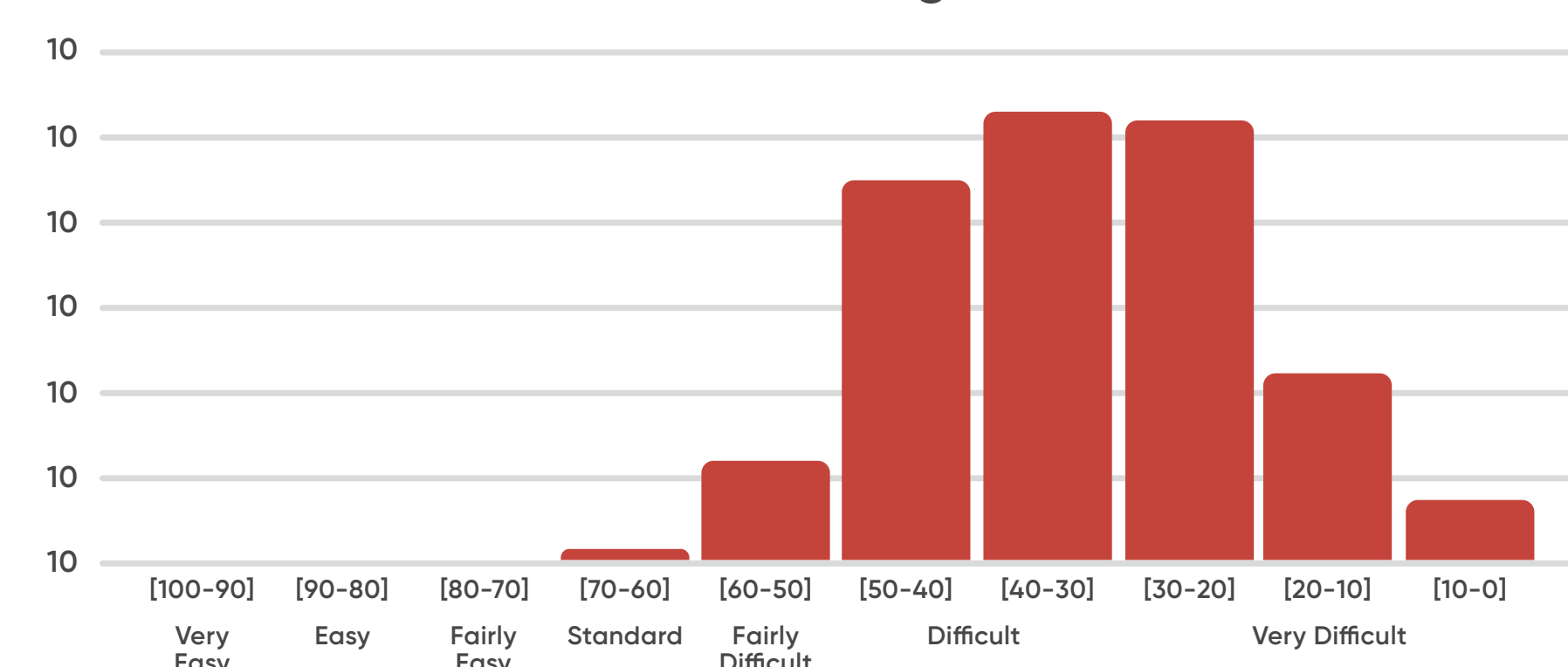
RESEARCHERS were asked: "How confident are you that your study listings are clear, informative, and compelling?"



Flesch-Kincaid Grade Level



Flesch Reading Ease



Focus Group Recommendations for Researchers

- Provide more visuals.
- Emphasize the main points, not details.
- Simplify descriptions, but be precise.
- Make summaries accessible.
- Keep participants informed during and after the study.
- Be responsive to questions.

IMPLICATIONS:

- The research directory format was updated in response to user feedback.
- Specifically, a visual highlighting the information that individuals wanted to know to read more was created (see below).
- People do want to participate in research, express a motivation to help learn about themselves and help other people and families.
- In order to better include families into research studies, summaries written by researchers must be friendly to a wider audience and the summaries should be simplified.
- Researchers should keep contacts up to date, respond to questions and keep study participants included in information after the study is over to improve the experiences of the participants.

STUDY SUMMARY VISUAL:

Experience of People Enrolled in Clinical Trials (EXPECT)

What's the study about?

Have you or your child ever participated in a clinical trial or research study? Why or why not? We want to learn why people choose to participate in autism research. We also want to know what kind of barriers keep people from participating in research. Are studies too far away or hard to get to? Are the reasons more personal? Do they vary by race, gender, age, or severity of disability? The Autism EXPECT study invites adults who have autism or have children with autism to complete a simple online survey about what affects their decision to participate in research.

Who can participate?

- Autistic adults (18+)
- Adults (18+) who have a child with autism
- With or without experience participating in research

What will participants be doing?

You will take an online survey about your personal experiences and/or opinions about research participation. There are about 30 questions, and it should take about 20 minutes to complete. As a thank you, you will be entered into a drawing to win an iPad.

Why is this important?

Effective study recruitment drives important autism research forward. If we can identify and address barriers to participation, we can make it more diverse and inclusive. This could ultimately lead to future discoveries that improve more people's lives.



Quick Facts

[WHO?] Dr. Alycia Halladay, Autism Science Foundation

[WHAT?] 10-15 minute survey about research participation

[WHERE?] Online at bit.ly/EXPECT

INTERESTED?

Participate [online ExpectStudy@gmail.com](mailto:ExpectStudy@gmail.com)

Ends January 1, 2023

Study Flyer:

