

A guide for autistic people to create effective partnerships with researchers in a scientific study

Partnering with researchers as an autistic person can add your unique voice and life experience to studies that may not have considered this perspective before. It can be a big commitment, but a valuable one.

CHOOSING TO INITIATE PARTNERSHIPS

- What motivates you to partner with researchers?
- How much time can you spend?
- What lived experience do you bring to a partnership?
- What parts of the research process do you want to partner in?

USING A PROJECT ROADMAP

- Have the researchers provided a detailed project map?
- Do you feel comfortable asking questions?
- Do you have any special talents or interests (technical writing, data analysis, or graphic design)?

MEETING WITH RESEARCHERS

- Can you meet in person, or is online better? (Consider transportation, equipment, dietary concerns, etc.)
- What time of day and day of the week work best for you?
- How often will you be meeting? How much notice do you need?

ENVIRONMENTAL CONSIDERATIONS

- What are your sensory preferences, and what do you need to avoid?
- Do you need to have something to help you focus or feel calm?
- How long can you comfortably participate in a meeting?
- Do you feel comfortable speaking up for what you need, or do you need assistance in this?

NAVIGATING THE RESEARCH PROCESS

- What questions do you have before beginning?
- Is there a good communication method in place so you can ask questions?
- What's the best way for you to ask questions?
- Would you like a tutorial or short course on research methodology?

COMPENSATION FOR PARTICIPATION

- Would you like to be compensated for your time?
- Is money best, or would tangible gifts like meals or event tickets be better?
- Would you like to co-author the study, or present the research at conferences?

KEEPING IN TOUCH

- Do you want to keep in touch with researchers?
- How often would you like updates and contact?
- Did you have a chance to give genuine feedback?
- Do you feel your participation had meaning?

