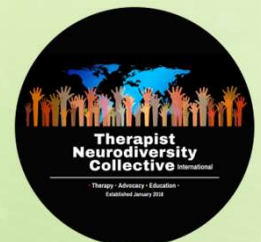


Webinar #3P:

How can you contribute to comparative effectiveness research?

Project Comparative Autism Research Effectiveness
(CARE)

This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (Contract # EACB-25633).

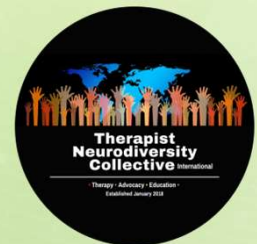


Webinar #1P:

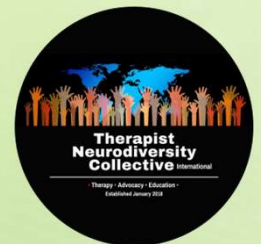
What is research? How can you get involved?

Project Comparative Autism Research Effectiveness (CARE)

This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (Contract # EACB-25633).



Who are we?



Project CARE Project Lead and Co-Project Leads



Alejandro Brice, University of South Florida, Project Lead,
aebrice@usf.edu

PL Alejandro Brice is a Full Professor with over 35 years of clinical and research experience. Dr. Brice immigrated with his family from Cuba to the U.S. in 1960. In 2010, Alejandro sustained a subarachnoid hemorrhage (SAH- considered to be an acquired neurodivergence). As a result, he has been both a patient and person-centered outcome researcher. As a speech-language pathologist, he has worked extensively with culturally and linguistically diverse (CLD) populations with communication disorders and developmental disabilities. He was the PI for *PCORI BRIDGE Grant (EAIN-7111)*.

Project CARE Project Lead and Co-Project Leads

D'Jaris Coles-White, Western Michigan University,
Co-Project Lead, djaris.coles-white@wmich.edu



Co-PL D'Jaris Coles-White began her research investigating language in children from CLD backgrounds. Dr. Coles-White was involved in developing the *Diagnostic Evaluation of Language Variation (DELV)* (Seymour et al., 2018), designed to differentiate language differences from disorders from non-mainstream dialects. D'Jaris received a *Mentored Patient-Oriented Research Career Development Award* from NIH/NIDCD in 2001 aimed at pinpointing clinical markers for language difference from language disorder in diverse populations. Since 2005, and after the diagnosis of autism for two of her sons, Dr. Coles-White's clinical and research efforts have focused on social communication in the autistic population.

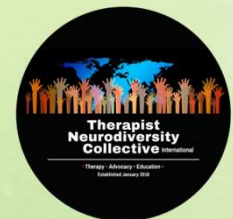
Project CARE Project Lead and Co-Project Leads



Julie Roberts, Therapist Neurodiversity Collective,
Co-Project Lead, julie.roberts@therapistndc.org

Co-PL Julie Roberts, M.S., CCC-SLP, is a speech-language pathologist clinician with experience in various healthcare settings with pediatric and adult populations. Julie is a late diagnosed autistic. Ms. Roberts is currently CEO of *The Therapist Neurodiversity Collective (TNDC), an international neurodiversity-affirming therapy, education and advocacy organization.* TNDC supports individuals, clinicians, and parents who are autistic and neurodivergent. Ms. Roberts has held key healthcare leadership positions, including National Field Director of Corporate Compliance and also Multi-state Clinical Director for the nation's largest provider of rehabilitation post-acute care.

What is our purpose?



The purpose of Project CARE is:

- To host a conference and connect stakeholders interested in autism research.
 - Who are some of the key stakeholders?
 - Autistics, caregivers/family members, researchers, and clinicians (neurodivergent and neurotypical).

The purpose of Project CARE is:

- To expose more stakeholders to the Neurodivergent Paradigm.
 - Why?
 - To inform consumers, researchers and healthcare/clinicians of alternatives to the current best practice models.
 - e.g., a neurodiversity-neurodivergent intervention affirming models/frameworks.

The purpose of Project CARE is:

- To facilitate the building of teams to conduct comparative effectiveness research (CER) in autism.
 - How?
 - Establish research collaborations with stakeholders listening to autistics to better investigate/examine interventions, policies, service delivery, etc.
 - **Generate new guides and guidelines around neurodiversity-neurodivergent model of evidence-based research and practice (a first in US).**

At the end of this webinar, you will be able to:

1. Talk about roles you can play in research.
2. List at least two questions you can ask about comparative effectiveness research (CER)?

The Scientific Method

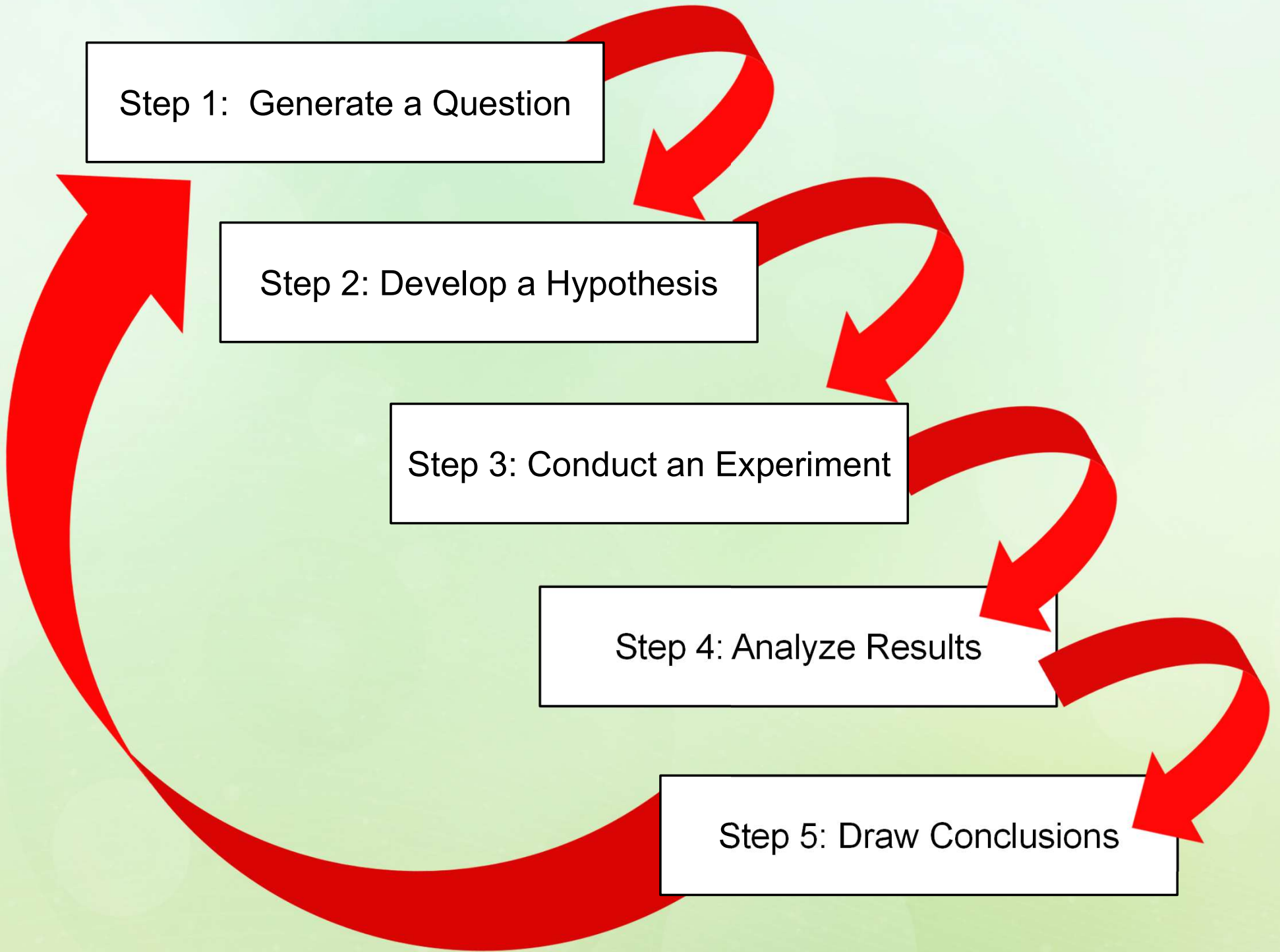
Step 1: Generate a Question

Step 2: Develop a Hypothesis

Step 3: Conduct an Experiment

Step 4: Analyze Results

Step 5: Draw Conclusions



Step 1: Generate a Question

- Researchers need to:
 - Write a very specific research question.

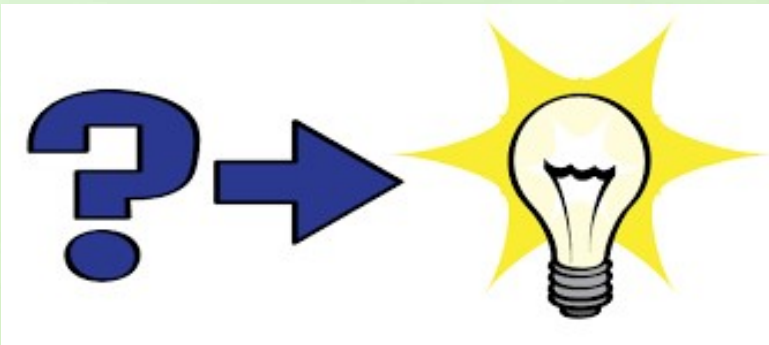
What can autistics and caregivers do?

- Provide input on which topics or questions are most important to YOU!



Step 2: Develop a hypothesis

- Researchers need to:
 - Choose exactly how to do the research



What can autistics and caregivers do?

- Help create materials that explain personal research in an understandable way.
- Provide input on which outcome measures might be most meaningful.

Step 3: Conduct an experiment

- Researchers need to:
 - Choose exactly how to do the research



What can autistics and caregivers do?

- Help ensure that the recruitment materials and consent process are clear and understandable.
- Help recruit participants by distributing information or posters.

Step 4: Analyze Results

- Researchers need to:
 - Analyze the data



What can autistics and caregivers do?

- Provide a different perspective on the data or results found.

Step 5: Draw conclusion

- Researchers need to:
 - Write up the results of the study and publish it.



What can autistics and caregivers do?

- Suggest places to disseminate (e.g., publish, presentation) the study that will be important to autistics.
- Provide feedback on any drafts that are intended for person-partners or other lay audiences.
- Have a great discussion about what should come next.

Questions you can ask a researcher

1. Help me understand your research.
2. How could your research change things (e.g., how might it help someone autistic like me)?



Questions you can ask a researcher

3. What can I do to help you?
4. Please show me what you are asking me to do.
5. I have an idea. Can I share it with you?



Everybody can help!

Researchers and Clinicians

- Have a lot of special knowledge and skills
- Are trained to do research
- Want to work with you
- Want to listen to your ideas
- May be very busy!

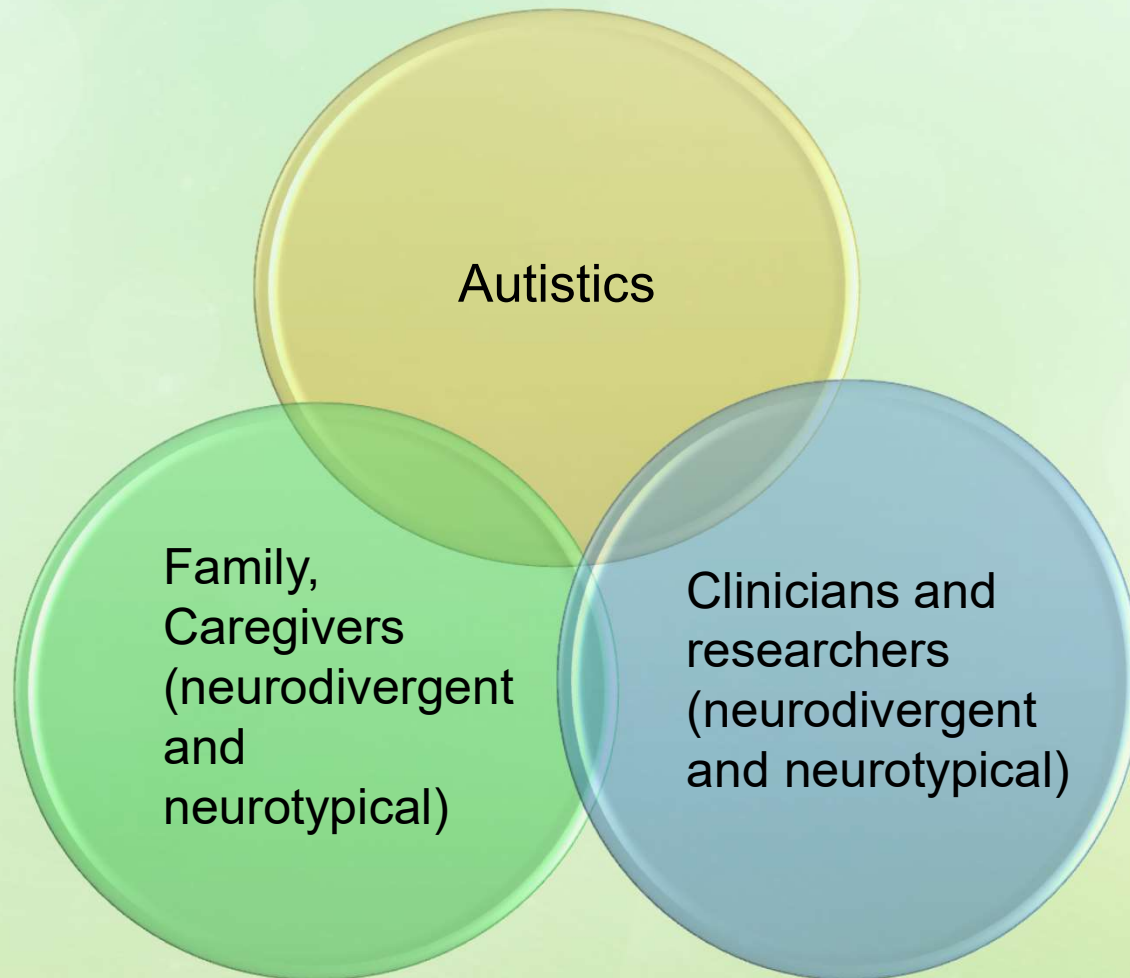
Autistics and family members

- Are affected by research – whether it is known or not
- Can give their opinions and views
- Can help researchers
 - Get people to participate
 - Make information understandable

Research helps to:

- Understand autistics needs and supports better.
- Come up with new therapies and services.
- Know which therapies and services are best for autistics with or without co-occurring conditions (e.g., language disorder, anxiety).
- Change policies and practices.

Mark your calendars for the CARE conference October 20 & 21, 2023



Have you participated in a PCORI event or initiative?

Are you interested in learning more about patient-centered outcomes research and how to inform your community about making better health decisions?

Are you interested in partnering with PCORI to disseminate and implement PCORI research findings?

Become a PCORI Ambassador

<https://www.pcori.org/engagement/engage-us/become-pcori-ambassador>

