CPAR

Community Partnerships in Autism Research

Participatory Research Training

University of Vermont

UVM AUTISM COLLABORATIVE

1. Why CPAR?
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3. Research partner roles
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Module 1 Introduction

Duration 0:40

TRANSCRIPT

TRANSCRIPT: Module 1 Introduction

“Hi, my name is Liliane Savard. In this module you will hear why Community Partnerships in Autism Research, or CPAR, might be good for you!

- You will hear from research partners themselves.
- You will be introduced to the history of autism research.
- You’ll learn about ableism and how it may affect research.
- Finally, you may discover some unexpected benefits of doing this type of research!

We have also added optional videos and reading if you want more details or resources.

Get started and click on each lesson below to learn more.”

Module 1

Why CPAR?

Lesson 1: Hear from research partners

Lesson 2: History of autism research

Lesson 3: Introduction to ableism

Lesson 4: Benefits of involving community partners

Something to think about

Lesson 1: Hear from research partners

Research is a formal way to look for answers to our questions so we can be confident in the findings.

One way to be more confident in research findings is to involve people with lived experience.

Community Partnerships in Autism Research

CPAR stands for **C**ommunity **P**artnerships in **A**utism **R**esearch.

In CPAR, we call autistic people and other team members **research partners**.

Research partners include autistic and non-autistic people:

- People on the autism spectrum
- Researchers
- Family members and supporters
- Professionals like doctors, therapists, and teachers
- Other community members or groups

People often have more than one role or identity.

Let’s hear from research partners about why CPAR is important.

Hear from research partners

Non-autistic researcher, professor, and senior academic leader

- Language and the way we communicate is important.
- Research partners change how we think about autism research.
- Join us to address questions important to autistic research partners.

Duration 1:29

TRANSCRIPT

TRANSCRIPT: Non-autistic researcher, professor and senior academic leader

“Hello, I've been asked to talk a little bit about my experience working on the CPAR project and that really focuses on allowing the individuals that you're doing research for to really be a part of the design of the research, the implementation, the write up of that research.

I found in our project with our autistic partners it's been an extraordinary experience for me as a seasoned researcher and someone who prided herself as being a patient and family-centered care practitioner.

I've learned so much from my autistic partners and how I should be thinking about research questions and what I'm interested in may not necessarily be what's important to them or what is of interest to them.

I've also learned from my autistic partners that the language that I use and how I communicate my message really makes a difference and so I've really changed how I teach my course in autism and how I write my syllabus and how I think about differences and strengths.

So, I continue to enjoy my experience working with autistic partners on research and I know I have a lot more to learn from them and I hope you will join me in similar research so that we're asking the right questions and answering the questions that our autistic partners really want to answer.

Thank you!”

Non-autistic parent

Duration: 1:02
TRANSCRIPT

Improve research design so autistic people with more support needs are not excluded from research.

TRANSCRIPT: Non-autistic parent

“I am the parent of two boys with autism or two autistic boys.

One of the things that's been good or that I think is helpful and necessary is, you know, there have been some studies that my boys have, we've tried to participate in and have been unable to participate in due to the severity of their autism, of their symptoms.

We would have had to look at, you know, could there be modifications, how could we modify this, so it wouldn't be as intimidating. And, and, we probably would have needed to build in more time.

Individuals who are as significantly affected by autism as my sons, tend to get excluded from a lot of studies because they're just, they're not as easy to study. And that, that, with a little bit of collaboration and preparation, can be overcome.”

Autistic partner

Duration: 1:19
TRANSCRIPT

- Create research that meets people needs.
- Promote respect and accessibility.

TRANSCRIPT: Autistic partner

“For me, being involved in this, you know, important research, is actually understanding the individual needs of the person that's priority number one.

In my, you know, my work, because their access needs, is their… It's essential to their daily lives. And with that in mind, is how they interact with others, and also is how they communicate with others too, as well, but also it's how they learn.

And for me, as an individual of color that has autism, uh, I see this in a very, you know, perspective view of why I join. I join because it's an opportunity to rewrite the mistakes that have been plaguing us for forever, no if, ands, or buts. But I want to make sure that the information we give you, the resource we give you, the technology, the advancement, etc., that we give you, that it works for you and you alone, nobody else.

That individual kindness, compassion and you know, respectful of one another. And that's how we'll, you know, thrive together and we'll survive together.

Thank you.”

Non-autistic researcher

Duration: 0:31
TRANSCRIPT

Have a real-life positive impact on the community.

TRANSCRIPT: Non-autistic researcher

“Hi, my name is Dr. Liliane Savard. My favorite type of research is research that's done with research partners because then I know that it has a chance of having an impact. It's not just an idea that comes from my, um, brain as a researcher but it's really pursuing a question, um an issue that is important, um, to my community.”

Autistic partner

Duration: 0:19
TRANSCRIPT

- Learn research skills.
- Know what's important to our community.

Autistic partner

“Hi, my name is Nicole. It is important to do research because you learn research skills and how to complete a research project. Including self-advocates is important because we know what is important to our community”

Autistic partner

- Opportunity for autistic and non-autistic people to talk together.
- Research impacts what is available for support
- Involve autistic people in decision-making about research.

Duration: 1:34
TRANSCRIPT

Autistic partner’

“I think community partner research in autism is important um because it gives an opportunity to really have dialogue between um researchers who um often aren't people who've had the experience of um living with autism or even necessarily had a lot of experience with autistic people in person um, to have input and hear both our needs and what we're like as people and to see both our strengths and our challenges and um how to make research that's really effective um.

Also for us to bring our own ideas into that as community partners. Autistic people haven't been as much a part of the decision making and of how research has been done and thereby what's available to us in the community and um I really look forward to seeing the community partnerships that are possible to change that. So that's, I think, why we need community partnerships um and why I think it's a great thing for our community.”

Lesson 2: History of autism research

- Until recently, research was done without asking autistic people what they want.
- Parents often spoke for autistic children and adults through surveys or interviews.
- The research was often not on topics that autistic people say are important to them (for example: improving their quality of life).[2]

Optional resources

Understanding the autistic experience

- A lot of research has included autistic people as subjects but not as research partners.
- Non-autistic researchers may have difficulty understanding the experience and behaviors of autistic people.[3]
- Autistic people should always advise research done about them.

Optional resources

Example: Stimming

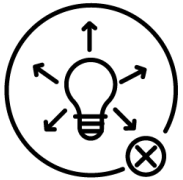
- Some intervention research focuses on stopping autistic people from making repetitive or stereotypic movements called “stimming.”[4]
- Research done with autistic research partners shows that stimming helps some autistic people manage their stress.[4]
- If autistic people had been consulted, they might have explained that stimming is not a problem for them.[4]

Optional resources

Consequences of research without inclusion

Autistic research partners can help avoid biases and invalid assumptions in research.

Not including autistic people as research partners can have important consequences:

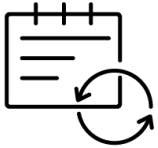


Biases and incorrect assumptions in the research process affect how data reflects the real world (validity).

Invalid data leads to invalid research conclusions.

These invalid research conclusions sometimes lead to harmful practices.

Some of these harmful practices are still in use today.[4,5]



Optional resources

Example

Duration: 4:00
TRANSCRIPT

Comment from an autistic participant: *". . . it is sad how many autistics still believe they are the issue like this survey continues to act like."*

Research on autistic meltdowns and shutdowns

- The researchers created a form for autistic people to tell their doctor about their meltdowns and shutdowns.
- Autistic people said the form was not helpful as it felt like there was a problem with the way they respond to stress.
- We could have avoided this if we had included autistic people on our team from the start.
- We now include autistic people on our team from the beginning of a project.

TRANSCRIPT: Example of consequences of research without inclusion
Research on autistic meltdowns and shutdowns

"Hi! My name is Laura Lewis and I am a nurse and a researcher at the University of Vermont. I wanted to share an example of one way that working with community partners has made my research more meaningful, respectful, and accessible.

A couple of years ago, I led a research team in a study about what it is like to have a meltdown or a shutdown for autistic adults. When we were done with this study, our team decided to use our findings to create a communication tool that health care providers could use to talk to their patients about meltdowns and shutdowns. We called this tool the Meltdown & Shutdown Scale for Autistic Adults, or the MSSAA. We came up with a form that patients could fill out, answering questions about what their experiences were like with meltdowns and shutdowns. We thought health care providers could use this form to help Autistic patients with any safety risks that they may have when they are having a meltdown or a shutdown.

As a first step to see if this communication tool would be helpful, we surveyed Autistic adults to see what they thought of the MSSAA. We wanted to know if they thought it was easy to use, if it made sense, and if it captured information they thought was important to share with their health care team. We planned to survey about 300 people. But instead we had to stop our survey after just 54 responses, because we already knew the answer: this communication tool was NOT supported by the Autistic community.

TRANSCRIPT: Example of consequences of research without inclusion
Research on autistic meltdowns and shutdowns (continued)

As our team tried to understand where we went wrong, we asked a few members of the community to join our research team. These were Autistic adults who had lived experience with meltdowns and shutdowns. They were also well connected in the autism community and could speak to a broader picture of how others might feel about our communication tool. In just a few meetings, these community partners identified major flaws with the tool, flaws that helped us understand the feedback we heard from the community.

For example, these community partners pointed out that the very idea of this tool made it seem like there was a problem with the way that Autistic people responded to stress. It made it seem like the core problem in meltdowns and shutdowns was with the Autistic person – not with the environment that caused them stress to begin with. Our Autistic partners helped us understand how this is offensive to Autistic people, and can actually cause harm in a health care setting.

Our community partners also helped us understand that answering questions on a form might not be an accessible way for all people to communicate with their providers. They helped us understand the importance of offering options for writing in open-ended responses, drawing, and having a conversation with providers, for example.

TRANSCRIPT: Example of consequences of research without inclusion
Research on autistic meltdowns and shutdowns (continued)

Finally, and perhaps most importantly, our community partners helped us understand that safety needs to come first. For many Autistic people, the main reason they do not talk to their health care providers about meltdowns and shutdowns is because they do not have a relationship with their provider where they feel safe having these conversations.

Rather than focusing our research on what structured questions to ask patients on a form, we need to start with research that can improve providers' understanding of autism. We need to work on making health care offices a safe place for Autistic people to share their needs and trust that they will be heard. Until we work on that, any communication tool that we come up with is unlikely to meaningfully help Autistic people.

If we had included community partners on our team at the start, we could have saved a lot of time, effort, and cost – and frankly, we could have conducted better research. Working with community partners on this study and others has transformed the way I collect data and interpret findings. I now work with community partners from the very start of each study I conduct. We work together to develop research questions that are important to improving the lives of Autistic people. These partners also help make sure the ways we conduct our studies are inclusive and accessible. As a researcher, I cannot overstate the value that community partners have added to my work."

Lesson 3: Introduction to ableism

Ableism is:

- Thinking disabled people cannot do things or need to be “fixed.”
- Thinking disabled people are less than others.
- Treating people badly because of their disability.
- Excluding people because of their disability.

Optional resources

Knowing about ableism is important

- Ableism introduces biases into autism research.
- It's often hard to see ableism because we learn it from our daily lives.
- Internalized ableism:
  - Is when people with or without disabilities are not aware that they have ableist beliefs.
- Systemic ableism:
  - Is everywhere in society. It's part of all systems and institutions.
  - Makes us think there is a right way to be or do things.

Optional resources

Video Example: Uncovering ableist biases

Simulated interaction

An autistic research partner schedules his focus group. He has more than one identity.

Duration 2:11
TRANSCRIPT

TRANSCRIPT: Ableist bias (a simulation)

Ableist bias. This is a simulated interaction.

Liliane (non-autistic researcher): “Hey hi Michael I'm so happy you're interested in joining uh this research project. So the autistic participants will meet on Wednesday um around 3 o'clock. Will that work for you?

Michael (autistic research partner): “Yeah I I think I can come Wednesday at 3:00 um. Uh is there any other groups that are happening? You said the autistic participants.”

Liliane: “Yes, well in this project we have autistic people but we also have um a group of researchers and a group of um healthcare providers and a group of parents”

Michael: “Okay that that that's interesting so now if I'm a autistic person and also a uh researcher and a parent how does that work?”

Liliane: “Oh I didn't think about that. I guess I guess you could choose which group you want to be part of. Thank you for making me think about it!”

TRANSCRIPT: Ableist bias (continued)

Narrator: “When setting up focus groups we did not realize that people might have multiple identities.”

Liliane: “So you which group would you like to join?

Michael: Well, I I let let's say how about the the the parent and researcher, I'm sorry the autistic people and researchers groups”

Liliane: “Yes okay so I'll sign you up for uh those two groups.

Michael: “But yeah, that, that's helpful. Yeah, I'm, I just wanted to make sure that that we thought of all our bases.

Liliane: “Yeah, that's you know, how we're really doing things better when we have all our brains together. Thank you for your input on that, Michael.”

Michael: “You're welcome.”

Example: Uncovering ableist biases

In a focus group with autistic people, we used this prompt:

“What would make you feel comfortable in a group that also includes researchers and parents?”

Some autistic partners noted that the question made it seem like autistic people could not be researchers or parents.

Autistic people have many life roles:

- Autistic parents
- Autistic researchers
- Autistic healthcare providers
- And more…

We used to think of partners as parents, autistic people, or researchers.

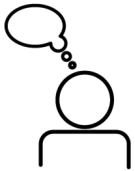
Now we think of autistic people in all of those groups.

Lesson 4: Benefits of involving community partners

Community partners…

- Bring knowledge from living their daily lives.
- Know what problems are most important to them.
- Improve research design so it is valid and accessible.
- Raise awareness of ableist biases in research.
- Help research focus on what has real life impact.

Something to think about



Real-life impact: Important research starts with a topic that is a priority for the community.

What autism topics are you interested in researching?

- ◯ Physical Health
- ◯ Mental Health
- ◯ Employment
- ◯ Education
- ◯ Communication
- ◯ Relationships
- ◯ Gender & Sexual Health
- ◯ Therapeutic Interventions
- ◯ Autism in Society
- ◯ Autism Across the Lifespan
- ◯ Quality of Life
- ◯ Features of Autism
- ◯ Other

Module 2: Introduction

Duration: 0:21
TRANSCRIPT

TRANSCRIPT: Module 2 Introduction

“My name is Nicole.

In this module you will learn what CPAR is.

You will also learn who pays for this type of research.

Finally, you will learn the difference between being on an advisory board and a research team.”

Module 2

What is CPAR?

Lesson 1: Defining CPAR

Lesson 2: Who supports this type of research

Lesson 3: Different levels of engagement

Something to think about

Lesson 1: Defining CPAR

Community Partnerships in Autism Research

Photo by fauxels

- CPAR is research done **with** people who have **real-life experience.**
- Research partners are **valued** and **equal** members of the research team.
- Research discussions are **accessible** and decision-making is done **collaboratively**.

CPAR is a type of participatory research. It means that the research is done with people who have lived experience.

There are other names for participatory research:

- **CBPR**: **C**ommunity-**B**ased **P**articipatory **R**esearch
- **PAR**: **P**articipatory **A**ction **R**esearch
- **CPAR**: **C**ritical **P**articipatory **A**ction **R**esearch
- **PCOR**: **P**atient-**C**entered **O**utcomes **R**esearch
- And more…

Optional resources

A type of research often done with PCOR is **Comparative Effectiveness Research** (CER).

CER:

- Compares two or more interventions.

- Helps people make health decisions.

Lesson 2: Who supports this type of research?

PCORI stands for **P**atient-**C**entered **O**utcomes **R**esearch **I**nstitute.

PCORI is the leading funder of research done with the community.

- It was authorized by Congress in 2010.
- So far, it has provided more than 3 billion dollars for research.

Optional resources

The research that PCORI funds is:

- Patient-Centered Outcomes Research (PCOR) and

- Comparative Effectiveness Research (CER)

Optional resources

PCORI also funds:

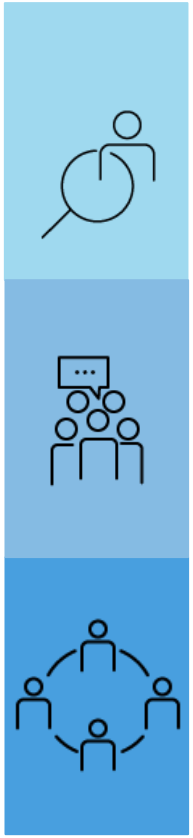
- Engagement: connecting researchers with community partners

- Dissemination: sharing information about applying research findings in the real world

A brief list of other funders is included in the optional resources for this module.

Optional resources

Lesson 3: Levels of research engagement



There are 3 levels of research engagement:

Input

Consultation

Collaboration

Optional resources

Input

Community members are research subjects. The research is ABOUT them. This is not considered CPAR.

Data is gathered through focus groups or a survey of the community. Providing study data requires limited time and resource commitments.

Input is how community partners may first hear about CPAR opportunities.

Example

For this project, some people provided feedback through surveys like this one or through focus groups.

Building Safe Space

Many in the Autism Community don't trust doctors and researchers.

Autistic people and non-autistic parents often have different opinions.
Some things are hard to talk about.

Think about a group that includes autistic and non-autistic people like doctors, parents, researchers, and community members:

What makes it SAFE for everyone to be heard in this kind of group?

Expand

What makes it EASY to feel safe?

Expand

What makes it HARD to feel safe?

Expand

Consultation

Community members provide ideas and feedback for researchers. They usually don’t participate in making research decisions.

Community partners are advisory board members or outside consultants. It requires additional time commitment.

Consulting and advisory boards can be an introduction to doing CPAR.

Example

Our Center for Disability and Community Inclusion has an advisory council.

Collaboration

Community members are equal research partners and team members. They are involved in decisions about the research. The research is done WITH them.

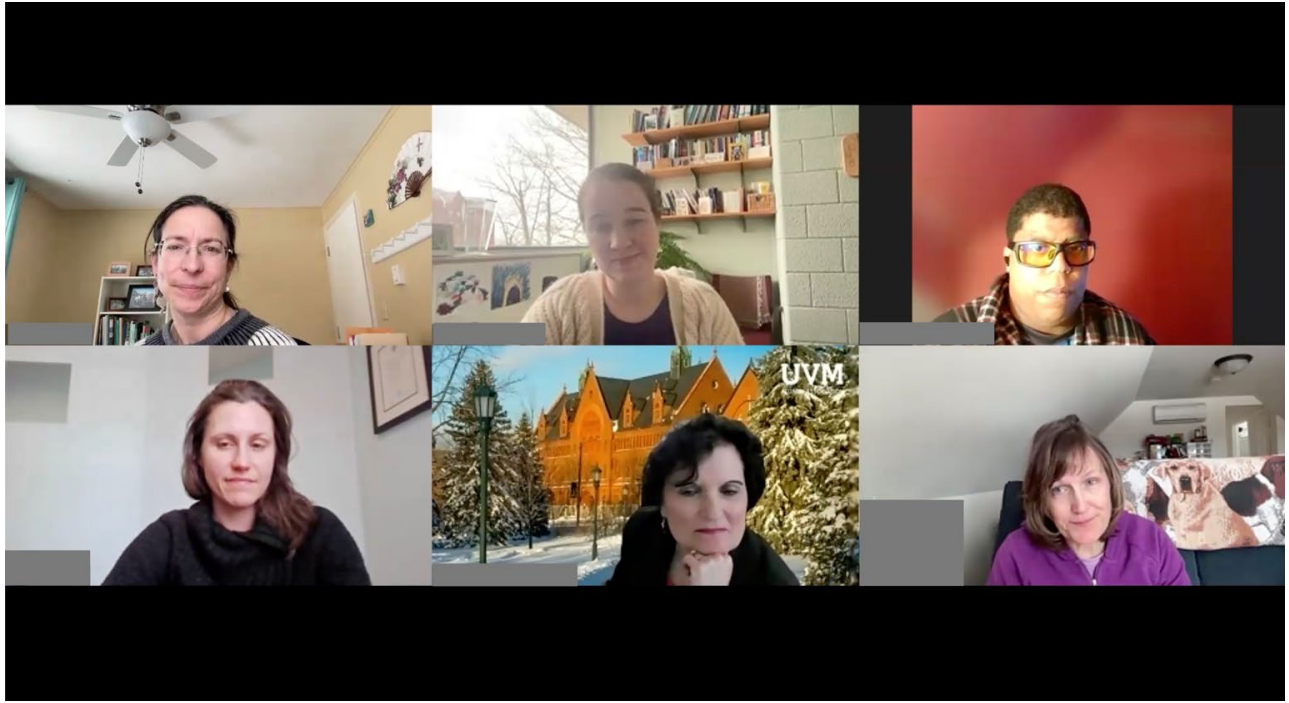
Trusting relationships and accessible practices make the collaboration work.

Collaboration is what makes CPAR a form of participatory research. CPAR is research designed collaboratively from the start.

Example

Our team came up with the idea for this project.

We met regularly to make important decisions together.



Let’s talk about tokenism

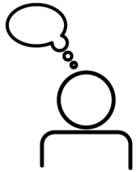
We say people are treated as a “token” when:

- Someone is invited to join a group but there is no effort to really understand and value their input.

Welcoming different perspectives is hard and takes practice.

You will learn more about creating a safe space when you complete the Working Together training.

Something to think about



For what level of engagement are you ready?

- ◯ **Input**: I am happy to listen to/share lived experience but I have limited time or resources for participatory research.
- ◯ **Consultation**: I am interested in a regular relationship to consult on research.
- ◯ **Collaboration**: I am ready to make decisions with trusted researchers and community members to design and conduct new research projects.

Module 3: Introduction

Duration: 0:23
TRANSCRIPT

TRANSCRIPT: Module 3 Introduction

“My name is Zeph,

In this module you will hear about the roles of different people on a research team.

We will look at who can be on a research team, their roles, and how you can get involved.

We have also added optional videos and reading if you want more details or resources.

To get started click on each lesson below.”

Module 3

Research partner roles

Lesson 1: Who is on a CPAR research team?

Lesson 2: Roles in the research world

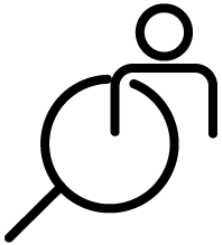
Lesson 3: What research partners can do

Something to think about

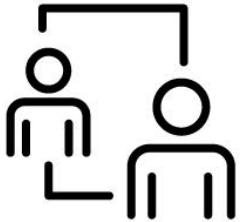
Lesson 1: Who is on a CPAR research team?

- People with autism
- Family members and supporters
- Professionals and researchers
- Advocates and community members
- Consultants and organizations

What is the difference between research participants & partners?



Research Participant
Someone who is participating in a research project as a subject of the research.



Research Partner
Someone who is expert in their lived experience and may be involved in any or all research steps.

Lesson 2: Roles on the research team

In general, the role of **researcher** is to bring:

- Scientific knowledge from studies that have already been done on a topic;
- Expertise in research method and process;
- Knowing how to write grants and research articles.

Photo by fauxels

While the role of **research partner** from the community is to…

- Bring knowledge from living their daily lives.
- Improve research design so it is valid, accessible and cost efficient.
- Raise awareness of ableist biases in research and other ethical issues.
- Help research focus on what has real life impact.

There are many roles on a research team, including:

- **Principal Investigator (PI)/Co-Principal investigator (Co-PI):** in charge of the research.

- **Project Coordinator:** manages research activities.

- **Research Assistant:** helps the project director carry out the research activities.

- **Project Team Member:** shares lived experience or expertise in research to make research decisions.

- **Consultant:** someone outside the research team who provides expert advice based on their lived experience or their job.

Research partners from the community may have any of these roles.

Community partners may work with different people at colleges and universities:

- **Faculty Members:** professors who teach courses and/or do research.
- **Undergraduate Students:** students who are working towards their bachelor degree.
- **Graduate Students:** students working towards a master's or doctorate degree.
- **Post-Doctoral Fellows**: recently graduated researchers who continue to learn under a mentor.

Contributions

Contributions are recognized when sharing research results.

- **Authors:** people who came up with the idea, collected and analyzed data, or prepared results for sharing.
- **Research Credits:** given to people who shared lived experience, advised on research, or reviewed results for sharing.

Lesson 3: What research partners can do

There are 7 steps to the research process.

1 **Choose a research question**

Discuss what research questions should be studied. Review the research to see what has already been studied.

2 **Plan how to do the research**

Design the study and what it will be like for participants.

3 **Find a way to pay for the study**

Write grants or do fundraising to pay for team member salaries, participant reimbursement, equipment, etc.

4

Find people to participate in the study

Recruit participants who meet the requirements of the study.

5

Do the study & collect the data

Collect data from surveys, interviews, focus groups, and other means. For some studies, this might take only a few days; for other studies, this may take months or even years.

6

Analyze the data & write the results

Look at all the data together and figure out what it means. Write the results for sharing with others.

7

Understand & share results

The results can then be shared in an academic journal, at a conference, through social media, etc.

Research partners can work at any step of the research process!

- Some people like to come up with the initial research question.
- Others like to advise on research that is already designed to make it better.
- Some people like analyzing data to come up with research results.
- Others prefer to share results of research with their community.

Training or skills needed

- Community members are experts in their lived experience.

- There is generally no training or other skills needed for community members to be research partners.

- Research ethics training may be required:
  - When research partners have contact with research subjects.
  - When research partners work with data that identifies research subjects.

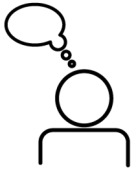
Helpful training

Training that can be helpful:

- Learning about the research process (like in this training).
- You will learn more about creating a safe space in the “Working Together” training.
- Self-advocacy training can also help build confidence.

Optional resources

Something to think about



What part(s) of research are you most interested in doing?

Check all that apply.

- ○ Choose a research question
- ○ Plan how to do the research
- ○ Find a way to pay for the study
- ○ Find people to participate in the study
- ○ Do the study & collect the data
- ○ Analyze the data & write the results
- ○ Understand & share results

Module 4: Introduction

Duration: 0:20
TRANSCRIPT

TRANSCRIPT: Module 4 Introduction

“My name is Nicole.

In this module you will learn how to get started with doing research with community partners.

You will also learn how to come up with a research question.

Finally, you will learn about research methods and how to include different people to work together.”

Module 4

How to do CPAR

Lesson 1: Getting started

Lesson 2: Research questions

Lesson 3: Research standards

Lesson 4: Safe research space

Something to think about

Lesson 1: Getting started

It's never too late to get started with CPAR!

- Developing relationships and trust takes time.
- There are lots of ways for community partners and researchers to work together.
- The important part is to take the first step.

Getting started for researchers

Researchers can reach out to community members:

- Invite past research participants to talk about your research.
- Reach out to people within your institution.
- Work with your accessibility office to share information about your work.
- Let the public know how to contact you to learn more about your research.

Photo by Jopwell

Non-autistic researcher's perspective

Duration: 1:49

TRANSCRIPT

Summary:

- Many community partners want to help.
- Reach out to people you already know with lived experience.
- Get feedback on your current work no matter where you are in the process.

TRANSCRIPT: Non-autistic researcher's perspective on getting started with CPAR

"Hi, my name is Liliane. One challenge with doing participatory autism research is just to get started.

Often time research teams have funding for a research project that's already going on and they may not have planned uh time and resources to hire a community partner on their team. And so it becomes this series of pushing it to later to start doing it.

A lot of community partners don't ask to be paid. Obviously, if you can have some uh funding internally from your um institution, that is great but don't take that as an excuse if you don't have the funding.

TRANSCRIPT: Non-autistic researcher's perspective on getting started with CPAR (continued)

If you have a project going on already, reach out to people, maybe previous research participants and tell them you want to talk about this project that you're leading and get their input on it.

Um as you improve what you're doing, you're going to have new ideas um as you listen to your research partners. Then you're going to be in a great position to write this really nice new grant that does have input from your community partners from the beginning and you'll have thought about what you need in order to engage in that new project in terms of time, resources um, and salaries.

So, I'm so excited you're interested in doing participatory research with community partners and know that there are many people in the community who are just waiting for you to reach out to them."

Getting started for community members

Photo by fauxels

Community members can reach out to researchers:

- Look for researchers who are working on topics of interest to you.
- Participate in a research study and develop a relationship with a researcher.
- If you have an idea that you want to develop, you can look for collaborators.

There is now grant funding available for studies initiated by community members! See the optional resources to learn more.

Optional resources

Autistic research partner’s experience

Duration: 2:33

TRANSCRIPT

Summary:

- Zeph talks about how they got involved with the UVM Autism Collaborative.
- They also talk about how they met a researcher and worked with them.
- They did qualitative analysis and other research tasks.

TRANSCRIPT: Autistic researcher's perspective on getting started with CPAR

"So my name is Zeph and I'm an adult diagnosed autistic. Um, the way that I got involved with the UVM Autism Collaborative is that I answered an ad for one of the researchers to do one of their research projects. And it was this really cool project where they put this neural network of electrodes over your head and had you watch cartoons and answer questions about language. And throughout the course of the several meetings that Emily and I had to do this research project, we kind of developed a rapport.

And then it was a couple months later that I got an email from her and she's like hey I know you're, you like research and we have this collaborative where autistic people are involved in research and would you have an interest in being a part of it. And I think I like, wrote out my application to be a part of it before I even joined a meeting. And my first meeting they voted on my um, on my participation in it.

TRANSCRIPT: Autistic researcher's perspective on getting started with CPAR (continued)

At one of the autism collaborative meetings we all go around and and we all introduce ourselves and talk about what our interests are. And I'm really interested in adult-diagnosed autistic issues so when Laura mentioned that those topics were of interest to her, I like I just reached out to her and I'm like hey I'm really interested in the topics that that you're working on let me know if I can help out with anything.

And from there we just created a really cool working relationship. We generally will have um, meetings on a weekly basis where we do co-work with other autistic partners. Um and then there's some stuff that's assigned in between the meetings for us to read up on. But we've done qualitative analysis as a part of the group work but a lot of um. One of the projects we're at the phase where we're working on a lot of the language regarding the IRB and the disclosures and the recruitment materials and how to best convey the information that we need to convey but how do we also collect the information we need about, while being respectful of equity issues.

It's been fun. I've learned a lot."

Making connections

Parent and self-advocacy organizations can help with:

- Connecting researchers to community partners.
- Sharing what they know about research needed by the community.

Other resources include:

- University Centers of Excellence in Developmental Disability (UCEDD)
- State Departments (Health, Education, Disability Services, etc.)
- Local hospitals or health centers

Optional resources

Lesson 2: Research questions

- Research starts with research questions that are important for the community.
- Then we search to see if an answer already exists.
- Finally, we decide if and what research is needed.

Optional resources

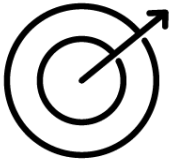
What’s in a research question?

We use the abbreviation **PICOT** to help us understand what’s in a research question.

Person

Intervention

Comparison



Outcome

Time

A problem important to the community

The stories and experiences of community partners have many elements of a research question.

Example:
An autistic young adult on a research team says:

> “I go to the doctor as little as possible because they do not know how to speak with me. Doctors need more trainings about autism.”

Using PICOT to create a research question

P For autistic **young adults**

I Would providing **autism training** to doctors

C **Compared** to doctors who don't have training

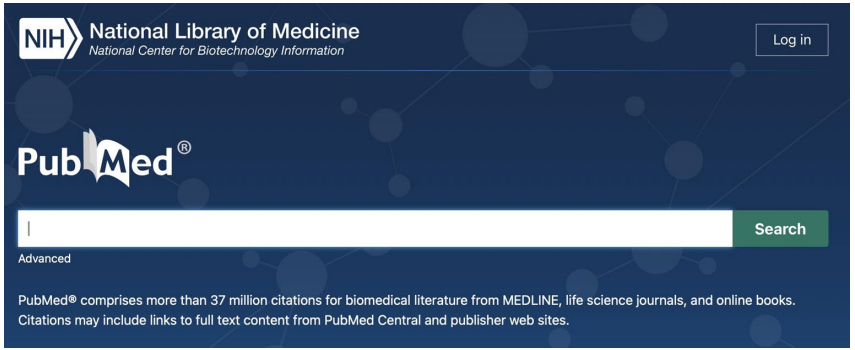
O Improve **satisfaction**

T At the **first visit** to a new doctor?

Does an answer exist?

PubMed and Google Scholar are helpful tools to find existing research.

Use 2 or 3 keywords from the research question to search for information.



Example:

- Doctor training
- Autistic adults
- Satisfaction

Optional resources

Is new research needed?

Discuss the existing research as a team.

- Summaries in plain language can help everybody participate.

Change the research question as needed.

Decide if or what new research should be done.

Optional resources

Lesson 3: Research standards

A research team needs to balance multiple priorities.

- Research needs to be ethical and safe to protect research participants.
- Methods must be used that allow results to be trustworthy.
- The research study must meet the requirements of the funding agency.

Research ethics

Photo by Pavel Danilyuk

Each research organization works with an **Institutional Review Board** (IRB).

The IRB is a group of people that includes researchers and people from the public. They review research proposals to make sure they respect the Belmont Principles.

Belmont Principles

The **Belmont Principles** are rules that need to be followed for doing ethical research. They include:

Respect for the person: The research subjects can choose if they want to participate and stop anytime. There are clear steps to make sure confidentiality is respected.

Beneficence: The benefit from the research is more important than the harm it may cause. Methods are used to minimize potential sources of bias.

Justice: The research is fair and equitable. It includes diverse participants to share the benefits and also the risks from the research.

Optional resources

Research methods

Zeigler Forum - Photo by Joshua Defibaugh

Research methods are ways to collect and analyze data.

Choosing the right research method helps us have confidence in study results.

Optional resources

Qualitative methods

UVM Photo by Ryan Wiklund

Qualitative methods are ways to learn about ideas and experiences.

They include tools like:

- Interviews
- Focus groups
- Observations of behaviors
- Observations of objects, texts, art, etc.

Optional resources

Quantitative methods

Quantitative methods focus on measuring quantities. The data is analyzed to find patterns or averages.

Quantitative methods use tools like:

- Surveys
- Questionnaires
- Tests and measures

Mixed method studies combine both qualitative and quantitative methods.

Optional resources

Funding agencies

- **Funding agencies** have requirements that need to be respected.
  - Timelines
  - Budget
  - Research priorities

- These requirements may affect what study is accepted for funding.

- When a study is accepted for funding, it may be hard to make changes.

- Timelines and budgets should be planned with flexibility in mind.

Optional resources

Lesson 4: Safe research space

Here are some basic guiding principles for building a safe research space:

- Make sure everyone knows what to expect.
- Use group norms and facilitation.
- Respect people and their need for confidentiality.

Building trust requires a safe research space and being brave to learn together.

Challenges for community partners

Photo by Marcus Aurelius

- Some community members have had negative experiences with research in the past.
- They are sometimes concerned that their input will not be valued and their time will be lost.
- Community members may need time to trust researchers and feel heard and valued.
- They want to be treated with patience and respect.

Challenges for researchers

- Researchers want to do a good job at including community members and making sure they feel heard and valued.
- They are working hard to overcome their own internalized ableism. They may be afraid to make mistakes.
- They may struggle to explain that research standards get in the way of what community members want to do.

Tips for clear expectations

Photo by RF._.studio

- Agree on the research team's goals.
- Understand each person's individual goals.
- Understand where the funding for a team or project comes from.
- Clarify the research process and each person's role.
  - How people meet and share information
  - Timeline for tasks and flexibility
  - How decisions are made
- Understand how power is shared within your team.

Group norms and facilitation

You can help create a safe research space when you:

- Share information and materials in a way that's accessible for everybody.
- Take time to understand each other.
- Give team members time to process and respond.
- Welcome different perspectives.
- Share the concerns you have.
- Ask people to explain something you don't understand.

You will learn more about creating a safe space in the "Working Together" training.

Confidentiality

Confidentiality for **study participants** is part of the standard of research.

Confidentiality for **research partners** is different:

- Research partners are not study participants.
- It is important to be clear about the level of confidentiality to expect from research team members.
- People may share personal stories and details about their life.

Sharing people's information or ideas should only be done with their permission.

Important considerations

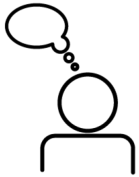
Mandated reporters:

- Remember that team members may be mandated reporters. They must report if someone is unsafe at home or at risk of being hurt.
  - This is important to state up front.
  - It may affect what people choose to share.

Self-advocacy:

- Sometimes, parents and their child or adult relative are on the same team. Each person should have space to communicate for themselves.

Something to think about



What skills and expertise are you excited to bring to autism research? Check all that apply.

- ◯ Lived Experience
- ◯ Creativity & Problem Solving
- ◯ Organizational Skills
- ◯ Plain Language & Accessibility
- ◯ Writing or Editing Skills
- ◯ Summarizing Complex Information
- ◯ Social Media or Public Speaking Skills
- ◯ Math, Statistics, or Computer Science
- ◯ Making people feel safe to share their experience
- ◯ Other:

You can now download your certificate of completion.

Return now to the PDF download page and click “finish” to download your certificate.

Continue to the next training program:

Working Together

Resources

Glossary

How we talk about autism

1. Dwyer P. Stigma, Incommensurability, or Both? Pathology-First, Person-First, and Identity-First Language and the Challenges of Discourse in Divided Autism Communities. J Dev Behav Pediatr. 2022 Feb-Mar 01;43(2):111-113. doi: 10.1097/DBP.0000000000001054. PMID: 34984993. https://journals.lww.com/jrnldbp/fulltext/2022/03000/stigma,_incommensurability,_or_both_.7.aspx

Module 1

History of autism research

2. Office of National Autism Coordination, National Institute of Mental Health, National Institutes of Health (on behalf of the Interagency Autism Coordinating Committee). *2019-2020 IACC Autism Research Portfolio Analysis Report*. March 2024. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/portfolio-analysis/2020/
3. Milton DE. On the ontological status of autism: the 'double empathy problem.' *Disability & Society*. 2012; 27(6): 883-887.

Autistic perspective on stimming

4. Kapp SK, Steward R, Crane L, et al. 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*. 2019; 23(7): 1782-1792. doi:10.1177/1362361319829628.

Harm and autism research

5. Dawson M, Fletcher-Watson S. When autism researchers disregard harms: A commentary. *Autism*. 2022; 26(2): 564-566. doi:10.1177/13623613211031403.

6. Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? Cogent Psychology, 6(1), 1641258.

Ableism

- Ableism across a lifetime video
- Ableism and Violence: A Plain Language Guide

Module 2

Participatory Research

- Webinar on Conducting Quality Participatory Autism Research
- Participatory Research Methods

Patient-Centered Outcomes Research Institute (PCORI)

- About PCORI
- PCORI's National Priorities for Health

Other funding sources

- Grants.gov
- Patient Centered Outcomes Research Institute (PCORI)
- National Institute of Health (NIH)
- Department of Defense (DOD)
- Private foundations and non-for-profit funders (community or researcher initiated study)

Module 3

Roles on research teams

- PCORI: Roles of Patient and Stakeholder Partners in Patient-Centered Research
- Indeed.com: Key roles and responsibilities of research teams
- Society of Clinical Research Associates (SOCRA): Team science principles

Module 4

Autism and self-advocacy organizations

- Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
- Autistic Self-Advocacy Network (ASAN)
- Association of University Centers on Disability (AUCD)

Research methods

- PCORI: Research Fundamentals

Finding research articles

- PubMed PICO tool
- How to find research articles in PubMed
- PubMed
- Google Scholar

Accessible ethics training

- https://re4all.org/

Inclusive Team practices

- PCORI: Building Effective Multi-Stakeholder Research Teams
- PCORI: Leading and Contributing to Team Decisions
- PCORI: Valuing All Voices Checklist

Disclaimer

The project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award EACB 24096.

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