

OPINION, Q&A

A new hub for participatory research: Q&A with Zachary Williams

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When **Zachary Williams** joined the Autistic Researchers Committee of the International Society for Autism Research (INSAR), he knew one of the group's priorities would be to promote **participatory research** — an approach in which scientists work with autistic people and other members of the autism community to design, conduct and interpret the results of their experiments.

But that priority really started to take shape when the committee itself solicited input. “One of the questions we got was, ‘I love this idea of participatory research, but how do I go about finding people to be my community partners?’” says Williams, a medical and doctoral student at Vanderbilt University in Nashville, Tennessee.

That question led Williams and his fellow committee members to develop a new resource. The **INSAR Community Collaborator Request** (ICCR), launched in January, is an online message board where autism researchers can post about their projects and the kind of participation they're seeking. Members of the autism community can respond to the posts to move the partnership forward.

Williams spoke with *Spectrum* about how to use the ICCR and what researchers need to get started.

***Spectrum:* When should a researcher use the ICCR?**

Zachary Williams: This can be at really any stage of a research project — from just generating ideas about what to research to the actual dissemination of results, and everything in between. The real goal is to lower the barriers to participatory research for autism researchers and autistic people and other stakeholders alike.

Getting to collaborate with autistic people can give [researchers] many useful insights into the research process and how their work could be interpreted by the people it stands to benefit.

S: What kind of collaborations do you see coming from this?

ZW: The ideal, really, is to have autistic people and researchers as equal partners, forming these long-term relationships where they go on to do many, many research projects together. **Research partnerships** like those between **Laurent Mottron** and **Michelle Dawson**, or **Christina Nicolaidis** and **Dora Raymaker**, etc. — these folks are the paragons of what this could look like.

But I'd also be very happy if there were more one-off consulting opportunities for [autistic] people as well. Let's say the researcher needs just to run things by an autistic point of view and understand what the optics of the research project are — I think that's a very acceptable use of this as well.

Once the researcher and the community partner are in contact with one another, then it's up to them as to the terms of the relationship or what they want to do with it. We're trying to just take that first step of allowing people to be connected.

S: So, if someone wants to get started on this, what is the first step?

ZW: The process is that a researcher goes ahead and posts an opportunity, and then that is answered by the community members.

What you'll need to do is make a post in INSAR's **Career Center**. You go to the Career Center, click on "new post," flag it as an 'INSAR Community Collaborator Request,' and then fill out the information that's needed within that post, which includes things such as what kind of collaborator you're looking for, what the team is and what the research project itself is. You should be as descriptive as possible about what you're asking for.

For researchers who are interested in potentially making a post, looking at the existing posts that are currently on the ICCR might be a good way to model their own advertisements and the things that they're looking for in a collaborator.

The community members don't have to have an account. However, the researcher must have a currently active INSAR membership. If you go to our website, there are **detailed instructions**.

S: What are your future plans for the ICCR?

ZW: There are going to be little tweaks and things as we figure out what works and what doesn't. But the biggest step right now is just to get people to use it. There are a lot of opportunities and possibilities, but I don't know who is going to be the group of people that subscribes to these

[posts], who is going to be the group of researchers who makes these, or what this will turn into. And a lot of that really just depends on community usage.

S: Are you getting good feedback so far?

ZW: Yeah! The funniest thing was that two or three people who didn't know that I made this sent it to me, like, "Zack, look at this; it seems like it's right up your alley." And — yes, it is!

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