

Advertisement – consultation group

Would you like to advise researchers on how to investigate mental health experiences of autistic people?

Rachel O'Connor (trainee clinical psychologist) is conducting research on the mental health experiences of autistic adults at University College Dublin in collaboration with AsIAM. They would like to understand:

- What factors impact the mental health of autistic adults?
- What are autistic adults' experiences of getting support for mental health difficulties in Ireland?

The researchers would like to create a **panel of experts by experience** to advise them throughout this research project. This means, they are recruiting autistic adults to join a **consultation group**. If you are interested in giving your opinion on how autism research is conducted, read more below and please get in touch!

What would I have to do?

Members of the consultation group will advise on the following aspects of the study:

- Project development (what the study investigates)
- Participant recruitment (how we find people to take part)
- Methods of data collection (how we ask autistic people questions)
- Interpretation of findings (how we understand our results)
- Dissemination of findings (how we share our results with others)

The consultation group will meet with members of the research team (**Rachel and Gaibhin**) via Zoom to discuss the research project together. They will be given the list of questions for discussion in advance so they know what to expect. We would simply like to hear the opinions, ideas and advice of the consultation group to make sure the research is helpful to the autistic community.

We understand that some people may not feel comfortable speaking with a group via Zoom. In this case, group members are welcome to join the Zoom with their camera and microphone switched off and simply type their input in the chat box. Alternatively, members could provide an email response to the questions, or they could meet individually with a member of the research team.

We estimate that members would need to give approximately 5 hours of their time to the project over the next 12 months, though there will be opportunity to spend more time on certain aspects, if you wish.

Members of the consultation group may also participate in the research study itself, though this is completely optional and voluntary.

Why have a consultation group?

The purpose of the consultation group is to ensure that the project is conducted in a way that is in line with autistic people's priorities and best interests. In addition, the consultation group will help us to ensure that the research findings

are communicated in an impactful way, which will improve the lives of autistic people.

What do I get in return?

We hope that the consultation group members will gain a lot from the experience. For example, you will:

- Experience how research is conducted and have your say on an important project on mental health.
- Have the opportunity to contribute to research articles, conference presentations and other research outputs (depending on how much you would like to contribute, you would be listed as a co-author).
- You will be gifted a €50 OneForAll voucher when the project is complete as a thank-you for your valuable input.

What should I do if I am interested?

If you are interested, please send an email to Rachel (rachel.o-connor@ucdconnect.ie) simply stating that you are interested in joining the research consultation group. Rachel will then respond to you asking for some information about yourself. This will be things like your gender, age, ethnicity, any LGBTQ status any other diagnoses and reason for your interest¹. You will also have the opportunity to ask any questions you may have at this stage.

What will happen then?

We are hoping to establish a group of 6 autistic people. It is possible that we will receive more applications than this. If we do, we will choose members in a way that will represent diversity in terms of gender, age, LGBTQ status, other diagnoses. Aside from these criteria, we will operate on a 'first come first serve' basis. You will receive an email from Rachel letting you know whether we are inviting you to become a member of the consultation group.

Even if you are not invited to be part of the consultation group, you can still take part in the research if you would like. Keep an eye on the AsIAM website and social media over the coming months.

If I am invited to join the consultation group, what happens next?

If you are invited to join the consultation group and you accept this invitation – thank you! We are happy to have you on board! You will then be given a list of consultation activities along with approximate dates for these. Final dates will be provided at least 3 weeks in advance of any activity. The majority of consultation activities will take place over the next 12 months (November 2020 – November 2021), with the possibility of additional *optional* activities thereafter.

We ask that you please commit to advising us on two occasions:

1. November/ December 2020: advising the researchers on project development, participant recruitment, data collection and dissemination activities.

¹ This data will only be used for the purposes of identifying a diverse consultation group. Your data will be stored securely and anonymously for the duration of the project.

2. Summer 2021: assisting in the interpretation of data from interviews with autistic people.

As outlined previously, you will do this by joining a Zoom group discussion session that will be facilitated by Rachel and Gáibhin. Or, if you don't feel comfortable participating via Zoom, an alternative arrangement that is acceptable to you will be arranged.

Other consultation activities and meetings will be optional for you to participate in if you wish. We will let members of the consultation group know about these as they arise.

What if I change my mind?

We understand that sometimes other responsibilities come up, or people simply change their minds. That is fine! If you no longer want to be part of the consultation group, just let us know if you can, by emailing Rachel (rachel.o-connor@ucdconnect.ie). You don't need to provide a reason – there will be no questions asked! We would welcome you back in the future if you so choose.

Can I have a support person with me?

All members of the consultation group are welcome to have a support person with them when they are advising us. This might be a friend, family member or a carer. You might like to have them there to help you communicate, to help you stay relaxed or simply for some moral support. You don't need to tell us why you have a support person, simply bring someone along or ask someone for support whenever you need it. However, remember that your opinions are important to us and these may be different to your support person's opinions.