

# Autism Insight Group – Application Form

## The Autism Insight group is...

a group of people with experience of autism, who are interested in influencing research.

If you have experience of autism, your insights can help improve the research process. Join the Insight group to help ensure that

- **What matters most to you** is what gets researched
- **Taking part in research** is a positive experience for autistic people
- **Assessments** used in research studies are appropriate for autistic people

## Will the role be suitable for you?

The role may be ideal for you if you are

- an autistic adult
- a parent or relative of an autistic person
- a carer of an autistic person

And you are interested in and committed to research which aims to build longer, happier, healthier lives for all autistic people. (Please note, you may fall into more than one of the above categories).

We do require Insight Group members to be able to respond to emails – this will generally be the main way of communicating, unless you specify otherwise.

## How much time will you need to give?

It is up to you how much time you would like to spend on Insight Group activities.

Some activities may take a few hours, others may ask for longer commitments. We will contact you to let you know about activities on offer. You can choose which activities you would like to be involved in.

## Will I need to attend in person?

Many Insight Group activities can be completed in your own home. If you would prefer not to attend activities in person, just let us know.

## How will you be supported in this role?

Autism Insight Group members are compensated for their time at

- £150 per full day
- £75 per half day (3.5 hours)
- £20 for 1 hour

and expenses (e.g.: travel and subsistence) covered. This is in line with [INVOLVE](#) payment policies.

**Bethan Davies**, Discover Coordinator, will be available if you have any queries about the role.

## How can I apply?

1. Fill in the form on the next page, or online \_\_\_\_\_
2. Return the form to us by **emailing** it to Bethan Davies, Discover Coordinator, at [bethan.davies@autistica.org.uk](mailto:bethan.davies@autistica.org.uk)

## What will happen after I apply?

1. Bethan Davies, Autistica's Discover Coordinator will email you to confirm that your application has been received.
2. Bethan will send you an email with a few follow-up questions to ask you, to find out more about your preferences in terms of the activities you may like to get involved in. This will also be an opportunity for you to ask any questions of your own.
3. After speaking to Bethan, if you both agree ***that the Insight Group is suitable for you***, you will be ready to undertake an e-training course. This course is hosted on an external site and is 4 weeks long (taking 3-4 hours a week). The course is optional, but we find it helps build Insight Group members' confidence in taking part in Clinical Research
4. Once you have completed the e-training course you can get start on some Insight Group activities!

The first point of contact for the Autism Insight Group will be the Discover Coordinator at Autistica in London. If you have any questions about the application form, or the role, please feel free to contact Bethan Davies at [bethan.davies@autistica.org.uk](mailto:bethan.davies@autistica.org.uk)

**If you are no longer able to take part in the Insight Group, please let me know, so I have a record of how many people we have, and so you don't keep getting emails from me about Insight Group activities.** This will in no way affect your Discover Membership or any other Autistica communications that you may get.

## Autism Insight Group - Application form

This form is 5 pages long.

Thank you for your interest in joining the Autism Insight Group.

These details will not be shared with researchers but will be used to monitor the Insight Group, to make sure we are representative of the autism community, and to select the relevant people needed for different opportunities. Unless specified in the question, please answer the questions about yourself.

### 1. Personal Details

<b>Name</b>	<b>Title</b>
<b>Surname</b>	<b>Gender</b>
<b>Address</b>	<b>Your age range</b> (please highlight in bold) 18-24 years old 25-34 years old 35-44 years old 45-54 years old 55-64 years old 65-74 years old 75 years or older
	<b>Phone Number*</b>
<b>Post Code</b>	<b>Email Address</b>
<b>Are you</b> (please select both if relevant): <ul style="list-style-type: none"><li>• An autistic adult</li><li>• A parent or carer of one or more autistic children (including those who are now adults)</li></ul>	
<b>If a parent or carer, how old is your child/ children:</b>	
<b>At what age were you, and/ or your child diagnosed as autistic?</b>	
<b>Do you identify as LGBTQA+?</b>	
<b>What is your (if autistic adult) and /or your autistic child's (if over 18) current employment status?</b>	
Full time employment Part time employment Agency/ temp work Internship or Apprenticeship Voluntary work	Full time education Part time education Unemployed Prefer not to say Other (please specify):

<b>Ethnicity:</b>
<b>Is English your and/or your child's first language?</b>
<b>Do you and/ or your children have any co-occurring conditions, including physical and learning disabilities?</b>
<b>Would you identify yourself, and / or your autistic child as disabled?</b> You: Autistic child/ children:

\*After receiving your application we will contact you via email, we will not call you on the phone.

### **Autistica Contact Options**

In addition to regular mailings, Autistica will occasionally want to contact you with updates and news about the research programme and volunteering opportunities. Please indicate how you would prefer to be contacted.

**Which is your preferred contact method?** (Tick all that apply)

☐ email   ☐ post   ☐ phone

## 2. About you

The questions below ask about your background. ***It is not necessary for you to have a particular background in order to join the Autism Insight Group. We ask these questions simply to find out more about you.*** Please write a few paragraphs of background information about yourself below (use an extra sheet if necessary):

**We'd like to hear a bit about who you are and your experience of autism. Tell us your story.**

If you are registering as a parent, please include details of your child as well.

*For those who don't enjoy open questions, some points to consider include*

- *formative life events*
- *education and/or employment*
- *key relationships (family and other)*
- *diagnosis (Autism or other)*
- *any personal interests*
- *how you have gotten engaged with Autistica*

**What issues or areas around Autism research are particularly important to you?**

Mental health ☐ Aging/ Physical health ☐ Language and communication ☐  
Learning Difficulties ☐ Epilepsy ☐ Social Care ☐ Gender ☐

**Others, or any further comment:**

**Is there anything you definitely don't want to be involved in? Areas or activities.**

**Please tell us about your experience of autism research, if any.**

*For example, if you have taken part in a research study yourself, what was the experience like for you? Would you have changed anything? If you have not taken part in research yourself, is there a way research could have been made more appealing for you to take part in?*

**What do you hope to gain out of the experience of being an Autism Insight Group member?**

*For example, skills, networking, experience (for employment or otherwise), access to information*

**Is there anything you feel you can add to the Insight group, and autism research more generally?**

*Skills, experiences, or interest areas for example*

**As part of the Insight group, which is integral to the work we do at Autistica, is there anything you would like to see from Autistica that would make you feel engaged and appreciated?**

**Are there any adjustments that we can make (in terms of access requirements, or anything else) to support you in this role?**

### **3. Remote or in-person activities**

Some of the activities offered to Insight Group members will require in-person input. Other activities can be completed remotely, such as in your own home. Please indicate whether you are happy to take part in opportunities that are

In person (yes/no)

Remote (yes/no)

If you selected that you are happy to take part in in-person opportunities, how far would you be willing to travel? Please make sure you have put your postcode down (Section 1) or I don't know where you are.

I am happy to take part in local face-to-face opportunities (travel approximately half an hour – one hour) (yes/no)

I am happy to take part in long-distance opportunities (travel may be longer than one hour) (yes/no)

If you are registering as a parent of a child under 18 years of age, or of an adult with medium to high support needs, would you be interested in attending occasional activities together?

Yes

Only during weekends and (school) holidays

No

#### **4. Data Declaration**

I would like to join Autistica's Autism Insight Group. I understand that my personal details will be kept securely and entered onto a computer. I understand that this information will be kept in accordance with data protection law.

**Typed signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

*We regard your privacy as important and comply with the Data Protection Act 2018. We will only use any personal information you send us for the purposes for which you provide it. In the case of this registration form, information you provide will only be used by Autistica for the purposes of organising and administering the research programme and associated activities. We will only hold your information for as long as necessary and will not pass it to any other parties, other than the researchers you are paired with. All employees who have access to your personal data and are associated with the handling of that data are obliged to respect the confidentiality of your personal data.*

**Details:**

**Typed signature:**

**Date:**