

“Developing a self-advocacy program for autistic youth”

Information letter

“Developing a self-advocacy program for autistic youth: an in-depth interview and survey study.”

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1. What is this study about?

This study is part of a European project called ACTIVATE.

In the ACTIVATE project we, a group of autism researchers and autistic community organisers, are developing an **Autism Advocacy Academy**. **This Academy is a training course for autistic people** between 16 and 29 years of age to learn how to advocate for your own and your fellow autistics' rights.

This Advocacy Academy will consist of a series of workshops to learn how to advocate. Following the workshops, there will be some discussion sessions with actual policymakers in the context of healthcare, education, workplace and politics to practice the advocacy skills participants have learned.

You can read more about the background of this wider project and the partners involved at our website: <https://neuroadvocacy.eu/>

In order to develop an Autism Advocacy Academy that suits the actual needs of autistic people, we are doing a set of interviews and a survey with autistic people. You can choose to take part in either an interview, or the survey. You cannot take part in both.

2. Can I participate?

You can take part if you are autistic (formal diagnosis or self-identification) and, living in the European Union and, between 16 and 29 years of age.
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To make this study more accessible, we offer different ways to participate (see below).

If there are any remaining **accessibility issues** which hinder your participation, please let us know at gertjan.vanaken@kuleuven.be. Our ambition is to have minimal obstacles to your participation.

3. Choice between interview or survey

You can choose to take part in an interview or in the survey, but not both.

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During both interview and survey, you will be asked questions on how to organize this Advocacy Academy (e.g. do you like this training to be online or offline?) and what the content of this Academy should be (e.g. what kind of knowledge and which skills do you hope to learn?).

We will also ask you about a few **demographic variables** (identification on the autism spectrum, gender identity, age and country of residence, experience in autism advocacy work, ethnicity).

Interview

The interview consists of a conversation between you and a researcher.

You can choose to take part via

a **face-to-face** interview,

video-interview or

via **an email correspondence**.

A face-to-face or video interview (via Microsoft Teams) will take **between 30 and 90 minutes**, depending on how much you would like to share with us. If you choose to answer our questions via email, you take as much time as you need and want.

At least three days before the interview takes place, we will send you the main **interview questions**. This way you can prepare the interview, if you want.

Survey

The survey is an **online questionnaire**.

In the survey, there will be both **closed questions** (for example, give a rating whether you prefer to follow the Academy online) and **open text boxes** where you can clarify your answer if needed.

The survey will take between **20-35 minutes** to complete.

At the end of the interview, we will query you about a few **demographic variables** (identification on the autism spectrum, , gender identity, age and country of residence, experience in autism advocacy work).

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4.How will my data be processed?

The text in *italics* below is quite technical but we are legally obliged to provide this. The main takeaway is that we will work in accordance with the General Data Protection Regulation (GDPR). This means

- your data will be pseudonymised when we process and store your data, it will be pseudonymised (see explanation below),
- you have a right to see, change and have deleted all the data you give us.
- the main contact person for any of your questions is Gert-Jan Vanaken (gertjan.vanaken@kuleuven.be).

*Your data will be processed in accordance with the General Data Protection Regulation (GDPR). You will be asked to share information that is considered **personal data, such as your gender identity, country of residence, identification on the autism spectrum and ethnicity**. These data are required and relevant for the purposes of this study, i.e. to assess the diversity of our group of participants.*

*Data collected for this study will be **pseudonymised**. This means that data that might identify you, such as your name and geographical references, will be separated from the other data in the study and replaced by a unique random code. In this way, the data can no longer easily be attributed to a specific individual. Only the researchers can link the data to a specific individual by means of the unique code. However, this re-linking will only happen in exceptional cases, for example if you wish to exercise your right to access, rectify or erase your data. **You will also not be identified in publications arising from the research.***

The data will be processed on the basis of public interest. This means that the research will lead to advances in knowledge and generate insights that (directly or indirectly) benefit society.

Your data will be stored by the researchers for 10 years after the end of the study at a secure storage location at KU Leuven. After this period, your personal data will be permanently deleted.

Your rights

You have the right to request more information about the use of your data. In addition, you have the right to access, rectify or erase your data unless exercising these rights would render impossible or seriously impair the achievement of the research objectives.

If you wish to exercise one of these rights, please contact the researchers using the contact details below.

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Contact details

For the purposes of this research, KU Leuven is the data controller. More specifically, only the researchers involved (see below) will have access to your personal data. Should you have any specific questions about this study, including the processing of your personal data, please feel free to contact us.

Research team:

dr. Gert-Jan Vanaken (post-doctoral researcher), prof. Ilse Noens

E-mail: gertjan.vanaken@kuleuven.be

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For any further questions and concerns regarding the processing of your personal data, please contact Toon Boon, KU Leuven's data protection officer for research (dpo@kuleuven.be). Please specify the study concerned by mentioning the title as well as the names of the researchers involved.

If, after contacting the data protection officer, you would still like to lodge a complaint about the use of your personal data, you can contact the Belgian Data Protection Authority (www.gegevensbeschermingsautoriteit.be).