

Participant Information Sheet for consent(Full version)

EUCAP 2021 Survey

Please read this text before you decide to take part in this study. You can mail us in case you need additional information.

What is the purpose of the study?

This study wants to collect the viewpoints from autistic people on

- Various types of autism studies
- Various types of treatment and support
- How autistic people should be represented

The results will be used to identify priorities for improvements within Europe as a whole as well as individual countries.

Who is organising the research?

The research is organised and funded by the European Council of Autistic People (EUCAP). EUCAP is an umbrella organisation for 16 autistic-led national and regional organisations in Europe. EUCAP aims to promote the welfare of autistic people in Europe through participation in public discourse, by networking and engaging with decision-making bodies, and by supporting co-operation between autistic-led groups across borders.

Who can participate?

Autistic people (formally diagnosed as well as self-identified) living in Europe.

Languages:

The survey is available in Czech, Danish, Dutch, English, Finnish, French, German, Italian, Romanian, Spanish, Swedish. Please complete only one version.

What will the study involve?

It is an online survey.

You will need approximately 10-15 minutes to complete.

We will ask non-identifiable questions about general characteristics such as age, education and country of residence. The main questions in this survey are about your viewpoints, needs and wishes. The topics were chosen with input from 16 autistic-led organisations across Europe.

Finally you can supply a free-format message that our member-organisations can use a quotes in their communications.

Only 3 questions are mandatory, but ask you to complete as many as possible.

Completing the survey is voluntary and you may stop at any point.

What are the possible benefits of taking part?

By taking part you will help 16 autistic-led organisations in the identification of priorities for autism policies on a national and European level. The findings from the study may also be shared with policy makers, the scientific and research community. Benefits should be expected only a medium to long term.

What are the possible disadvantages of taking part?

Thinking about the issues mentioned may cause feelings of frustration.

Who will have access to my data?

The survey is executed using the SoSci Survey tool which ensures secure access, anonymised data entry and server storage in the EU. The information that we collect is anonymous, it will be stored on the EUCAP computers and will be accessible to named EUCAP researchers only. Other researchers may request the EUCAP Board to obtain access to the anonymous data as well. The analysis of the data will be shared publicly via EUCAP and its member organisations.

Quotable messages will be stored separately from the questionnaire for publicity purposes by EUCAP and its member organisations.

All data collected will be retained and analysed in compliance with GDPR and the Freedom of Information Act. The study data will be stored securely for 5 years and then destructed.

Research team:

Silke Lipinski (D), Annikka Suonen (FI), Diederik Weve (NL)

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Contact for further information

If you require any additional information or have any questions about this project, please contact the research team via survey@eucap.eu

Consent

By participating in this survey:

- I confirm that I have read and understand the Participant Information Sheet
- I confirm that have had the opportunity to ask questions and have them answered
- I agree that data I supply in this study may be stored anonymously and securely, may be used for research and that the research may results published on the internet.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. However, because my data are collected anonymous, I will be unable to withdraw my data after I have started to participate in the survey
- I understand that I am free to provide a quotable message that can be published on the internet and also free to decide to provide my name that would be displayed together with that quote; I give permission to EUCAP and its member organisations to use my quotable message and the name I supply for publicity purposes in line with the aims of EUCAP

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