

## Participant Information Sheet

### Autism and Healthcare Experiences Project

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It is important that you understand why this research is being done and what will be asked of you before you make a decision to participate. Read through this document thoroughly and feel free to discuss it with others if you like. Please reach out to our team if you have any further questions or would like additional information.

#### ***What is the purpose of the study?***

The purpose of the study is to gather information on the experience of individuals with and without Autism Spectrum Conditions and the healthcare system. The findings of the questionnaire will be used to determine if individuals with autism spectrum conditions have different healthcare experiences than others. We hope that this study will allow us to better establish a comparison of experiences regarding healthcare for those with and without autism.

#### ***Why have I been chosen?***

You have been invited to take part because you are 16 years of age or older, with or without an autism diagnosis. You may have been sent the link to this page in an email or seen it on an advertisement on a website or social media encouraging you to participate.

#### ***Do I have to take part?***

No. This survey is entirely optional. You are not required to participate and may stop participating at any time during the survey by closing your website browser. We are not recording any personally identifiable data and will not be able to identify your responses to the questionnaire. As such, once you have consented to completing the survey, all partial or complete responses to the survey may be included in the data analysis.

#### ***What will I have to do?***

If you decide to take part in the study you will be asked to complete an online survey. The survey should take between 15 and 25 minutes to complete. Each participant will be asked questions regarding their healthcare experiences in general, as well as

specifically about their most recent experience with a healthcare professional. The survey includes one section that asks questions about mental health and healthcare experiences, which may be distressing for some individuals. As such, individuals have the ability to skip this section without being forced to review the questions.

### ***Confidentiality - Who will have access to my data?***

The information that we ask for in the online survey is **anonymous** and no personally identifiable data will be collected. This means we will not know which answers you gave and will not be able to contact you about anything you say in survey.

If you do provide us with information which identifies you or your family members (e.g. by writing a name or address in an open text box in the survey, emailing us, or including your email address in order to receive information about the results of the study), we will keep your identity confidential. The only situation in which we would break confidentiality is if you tell us your identity (name or address) **and** tell us that you or someone else is at risk of harm. In this situation we would be required to inform the relevant authorities.

We will keep all of your data safe by storing it in password-protected files that only the researchers can access. All data collected will be retained and analysed in compliance with the Data Protection Act and the Freedom of Information Act. Identifying information (names email addresses) will be deleted at the end of the study (December 2020). Anonymous study data will be stored securely for 5 years.

General information about how the University uses personal data can be found at <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>.

### ***How can I hear about the results of the study?***

As this survey is anonymous, we will not be able to automatically contact you about the results of the study. If you would like to receive information about the results of the study, please complete this form with your email address [Contact Form for Healthcare Experiences Survey](#). A link to this form is also provided to participants in the “End of Survey Message” after the completion of the questionnaire. Please note that this contact form is entirely optional and is not linked to your survey responses in any way. Thus, your specific questionnaire responses will remain anonymous whether or not you fill out this contact form.

You can also look at our website for updates on our research projects and any published scientific papers: <https://www.autismresearchcentre.com/>

### ***Ethical review of the study***

This project has been reviewed by the Psychology Research Ethics Committee of the University of Cambridge.

### ***Contact for further information***

If you require any additional information or have any questions about this project, please contact the research team on: [AutismPhysicalHealth@medschl.cam.ac.uk](mailto:AutismPhysicalHealth@medschl.cam.ac.uk)