

Participant Information Sheet

Autism and Neurodiversity in Faith Communities - Resource Creation 11066338

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Research Team: Dr Helena Cundill, Dr Zoe Strong,

Primary contact: (Research Intern): Gabreilla Noreikaite

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully, and please retain this copy for your personal records. Please ask if anything requires further clarification.

What is the purpose of the study?

The Centre of Autism and Theology (CAT) is creating a resource to educate faith communities about autistic and neurodivergent experience. The resource will consist of video-interviews with autistic and neurodivergent people, accompanied by written analysis and points for discussion. The video interviews are designed to communicate information about autistic and neurodivergent experience of being part of a faith community, and the importance of these communities to such individuals. The written analysis will be added by our researchers and will suggest ways that faith communities can better support autistic and neurodivergent individuals to feel safe, empowered and understood.

Why have I been invited to take part?

You have been invited because:

- You have expressed an interest in taking part;
- You identify as autistic or neurodivergent (either formally diagnosed or self-diagnosed);
- You are currently attending meetings with a faith community, or have previous experience of doing so.

Do I have to take part?

Participation in this resource-creation project is completely voluntary. This participant information sheet has been produced to help you decide if you wish to take part in a video interview. It is up to you (and you alone) to decide whether you wish to take part. If you do decide to participate, you will be free to withdraw from the project at any time without giving a reason, and with no detriment to you.

If you also decide you no longer want your contribution to be included in this project and the final published resource, you will be able to withdraw your video. However, due to the nature of the resource, it is impossible for CAT to control redistribution, copying, and continued circulation of the resource once it is published. Please note that if you ask to withdraw your video after publication of the finished resource some users may have already downloaded or circulated it somewhere else through a non-regulated channel, and this is out of our control.

How do I give my consent to participate in the study?

It is important that you give your informed consent if you decide to take part in this study, and you will have the opportunity to ask any questions in relation to the research before you provide your consent. We suggest to speak with someone you trust about the details of this study. If you are happy to participate in the study, you will be asked to complete and sign a consent form. Once you have completed the consent form on Microsoft Forms, you can download a copy of the consent form to retain for your personal records.

What does taking part involve?

If you decide to take part in an interview and your consent form has been submitted, a member of our research team will contact you by email. They will send you a copy of the proposed interview questions, and you will be able to change or omit any of them as you wish.

We will then schedule your interview at a date and time convenient both to you and to the interviewer (Gabriella Noreikaite). The interview will take place in the Multi-Faith Chaplaincy (25 High Street, Aberdeen AB24 3EE). The final recorded interview will be 25-30 minutes long, but the appointment may take around an hour – this allows time to welcome you to the venue, meet the interviewer, confirm that you are still happy to proceed and re-record any sections of the interview that you feel you are not happy with on the day. If you feel you need longer, we can extend your appointment time.

You can ask to skip questions during the interview, and the interview can be ended at any point. There is a possibility for you to be asked a follow-up question that was not on the initial list that had been agreed on. This is if you have talked about something that the interviewer believes is valuable information for the resource and would like you to say a little more. If you are uncomfortable answering unscripted questions in this way, you can decline to answer, or you can request before the interview starts that the interviewer asks only the predetermined questions.

After your interview has been conducted and recorded you will be sent an edited recording of your interview. This will be the final version that we intend to use in the published resource. You can approve this video, request further edits, or if you have changed your mind, you can ask for the interview to be withdrawn from the resource and deleted at no detriment to you.

Are there any risks associated with taking part?

The questions to be asked in the interview will relate to your experience of being in a faith community and of being an autistic or neurodivergent person. They may touch on personal experiences that you do not want to discuss. You will be given the proposed interview questions before your interview date you are able to omit certain questions or ask for them to be changed. There is nothing that you are obligated to talk about, and the interview can be terminated at any time before, during or after recording. If certain topics have caused you distress, you will be referred to appropriate support services.

Compensation

Are there any benefits associated with taking part?

By taking part in this interview, you are helping us to resource faith communities so that autistic and neurodivergent individuals to feel safe, empowered and understood. The final published resource is being created at our own cost, and will be available for free to users, therefore we are not able to make financial remuneration available to participants.

What will happen to my data?

Only the research team named above will have access to the un-edited version of your interview video. The edited video will not be made available more widely until after you have approved it for use.

All un-edited and un-approved video files will be stored in research specific drives on secure servers at the University of Aberdeen and only accessed or transported by encrypted and password-protected devices. Your video file will be retained in accordance with the University of Aberdeen Research Data Management Policy for 5 years after the project end date and thereafter permanently deleted in accordance with University IT data security procedures. You can also consult the University's Privacy Notice for Research Participants for further information on how we manage your data - <https://www.abdn.ac.uk/about/privacy/research-participants-938.php>.

Will my participation be confidential?

The final edited video interview that you approve for use will be used in the final, published resource. Therefore, your participation will not be confidential.

How will I find out about the results of the study?

The final resource will be available to view online by the participants and the wider public.

Who is funding and/or sponsoring the study?

This project is being conducted by the Centre of Autism and Theology, which is funded centrally by the University of Aberdeen.

Who has reviewed the study?

The research has been approved by the Committee for Research Ethics and Governance in Arts, Social Sciences & Business, University of Aberdeen on the 1 June 2031.

Contact Details

If you have any general queries, require further information about the study or would like to withdraw your consent to participate, please contact the research intern:

Name: Gabriella Noreikaite

E-mail: g.noreikaite.25@abdn.ac.uk

You may also wish to contact the Principal Investigator:

Name: Dr Léon van Ommen

E-Mail: leon.vanommen@abdn.ac.uk

If you have any concerns about the way in which the study has been conducted, you can contact the Chair of the Committee for Research Ethics & Governance in Arts, Social Sciences & Business:

Name: Dr Alessandra Cecolin

E-mail: (alessandra.cecolin@abdn.ac.uk)

Thank you for considering taking part in this study.