

CAASD-WS: Participant Information Sheet & Informed Consent for Online Studies on CA, ASD and WS

We would like to invite you to take part in our research project, **CAASD-WS**, “**Cracking the pitch code in music and language: Insights from congenital amusia (CA), autism spectrum disorders (ASD) and Williams syndrome (WS)**”. You should only participate if you would like to. Choosing not to take part will not disadvantage you in any way. Before you decide whether you would like to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Please contact us if there is anything that is not clear or if you would like more information. We are happy to answer any questions you may have.

What does the study involve?

This study aims to find out how people with and without congenital amusia (CA), autism spectrum disorders (ASD) or Williams syndrome (WS) understand and produce speech and music differently. To take part, you will complete online task(s) at a given URL. The tasks may include one or more of the following:

- Make judgements about and respond rapidly to words or images you see and sounds you hear
- Complete questionnaires about your feelings and experiences
- Make judgements about social stories or social videos describing everyday events
- Remember and recall sounds, items, or events
- Produce speech sentences, musical melodies, or sing familiar songs from memory
- Repeat or imitate speech/song based on a model

Please note that all these tasks use speech, music, or environmental sounds, or everyday items and situations, which are not emotionally stressful or scary.

Who can participate?

We are recruiting children and adults aged 7 and above to take part in this study.

Reimbursement

You will receive 0.5 credits through SONA.

What are the possible benefits of taking part in this research?

You are not likely to have any direct benefit from being in this research study. In the long term this study may aid our understanding of how speech and music are processed and represented in the brain of different individuals. This information may help develop effective treatment programs for individuals with musical or language disorders, or effective teaching programs in music learning or second language instructions.

What are the possible risks of taking part in this research?

There are no or only minimal risks involved in our tasks, such as possible fatigue. To reduce your discomfort, you can take as many breaks as necessary during the tasks. You can also choose to terminate the experiments at any point.

Do I have to take part?

No. We would like to emphasize that participation in this research is voluntary and does not in any way affect your human rights. If you choose not to participate, you will not be penalized in any way or lose any benefits to which you are otherwise entitled. If you decide to take part, please retain a copy of this information sheet and consent form. Even if you decide to take part, you can withdraw at any time, without giving a reason.

What data will be collected from me?

When you take part, we collect non-personally identifiable data (apart from your name and e-mail address if you'd like to enter the prize draw) about you and what you did in the tasks, such as:

- Name (if you'd like to enter the prize draw)
- E-mail address (if you'd like to enter the prize draw)
- Age
- Gender
- Medical history, including history of learning disability and attention deficits if applicable
- Information related to your speech, language, music, and hearing abilities, and current and past treatment/habilitation/rehabilitation enrolment
- Current and past medications or therapies
- Information from past or recent audiological evaluations or screenings.

What will happen to my data?

We are committed to respecting your privacy and keeping your personal information confidential. All data will be handled according to the UK Data Protection Act 2018 and the EU General Data Protection Regulation (GDPR) 2016.

Data such as responses you make in tasks and questionnaires, your age, language, and musical background are kept in our CAASD-WS database and used in an anonymised way. With your permission, we would like to allow other researchers in the world to access and reuse the anonymised data from this study and future studies, as part of the Open Research Data Pilot (ORD Pilot) of Horizon 2020, our funding source. This means that your anonymised data will reach more people and have a greater impact for science and society.

With your permission, we may want to use the audio recording we make in some of the speech or music tasks you perform for research, teaching, conferences, presentations, publications, and/or thesis work. These materials will be used in an anonymised way, and they will not be used in any way that will violate your confidentiality and privacy.

What if I want to withdraw from the study?

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary

for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes. You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>. You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer at imps@reading.ac.uk in the first instance.

What will happen after the study?

We will put the results from all the volunteers together for publication. They will be published in reputable scientific journals. Data are typically published for groups (e.g., an average of 20 people) rather than individuals. All data will remain entirely anonymous in the final research papers.

What should I do now?

- If you want to take part in the study, please read the following statements. If you consent to taking part, please continue by clicking the URL link to the task(s) where you will be asked to provide consent to the statements below.
 - ☐ I have read the Information Sheet and Informed Consent document and understand what the study involves.
 - ☐ I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.
 - ☐ I understand that if I decide at any time that I no longer wish to take part in this study, I can notify the researchers involved and withdraw immediately.
 - ☐ I consent to the processing of my non-personally identifiable information for the purposes of this research study.
 - ☐ I agree that my anonymous research data may be used by other researchers. This data will be anonymised to maintain confidentiality.
 - ☐ I understand that parts of my participation may be audio recorded, which I will be notified prior to recording, and I consent to use of this material as part of the project.
- If you do not want to take part, you do not need to do anything. We will not contact you about this study again.
- If you want to be removed from our database, please contact Dr Fang Liu.
- If you have any questions about the study, please contact Dr Fang Liu.

We hope that you feel able to help us with this study. If at any time you decide that you do not want to continue to take part in the study, you are free to withdraw.

Further information.

This study is part of the CAASD project, supported by the European Research Council through an ERC Starting Grant to Dr Fang Liu.

All proposals for research using human participants are reviewed by an ethics committee before they can proceed. This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

All investigators on this project have obtained criminal record clearances through enhanced DBS (Disclosure and Barring Service) checks that cover vulnerable adults and children, and they have also been approved by the School to work with children.

If you have any comments or concerns about this study, you should discuss these with the project leader, Dr Fang Liu (E-mail: f.liu@reading.ac.uk; Tel: 0118 378 8122).

If you want to speak with someone who is not directly involved in this research, or have questions about your rights as a research participant, please contact the University Research Ethics Committee at the University of Reading (<http://www.reading.ac.uk/internal/res/ResearchEthics/reas-REethicshomepage.aspx>).

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: Information Management & Policy Services, University of Reading, Whiteknights, P O Box 217, Reading, RG6 6AH.