



NUI Galway
OÉ Gaillimh



Data Science Institute
Institiúid Eolaíochta Sonraí



Project Title: Personal-independent Emotion Detection Model for Children with Level 1 Diagnosis of Autism
Researcher: Annanda Sousa
Supervisors: Prof. Mathieu d'Aquin, Dr Manel Zarrouk and Dr Jennifer Holloway

**Information Sheet for parent/guardian of children participating in the research study
titled “Personal-independent Emotion Detection Model for Children with Level 1
Diagnosis of Autism”**

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ABOUT THIS RESEARCH

You and your child are being invited to participate in a research study. Scientists do research to answer questions and learn new information. Some research might help change or improve the way we do things in the future. This information sheet will give you information about the study to help you decide if you want your child to participate. Please take as much time as you need to review this information before agreeing to allow your child to be in the study. If there is anything that you are not clear about or any questions you have, I will be happy to discuss these with you.

This research has been fully approved by the Research Ethics Committee in National University of Ireland, Galway.

TAKING PART IN THIS STUDY IS VOLUNTARY

You may choose not to allow your child to take part in the study or may choose for your child to leave the study at any time. Deciding not to allow your child to participate, or later deciding to remove your child from the study, will not result in any penalty or loss of benefits to which you and/or your child are entitled and will not affect your or your child's relationship with NUI Galway.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to collect data on how children with Level 1 diagnosis of autism express emotions to create a computer system that can identify emotions from children with Level 1 diagnosis of autism using video and audio. Today, because children with autism express emotions differently than the neurotypical population, emotion identification technology does not work well for them.

Emotions of children with ASD are very important. Their emotional state usually determines how willing and ready they are to learn and to interact with the world around them. When the child is anxious or agitated, it is harder for them to learn or process instructions. When the child is calm, it is easier to guide them to learn and/or engage in social interactions. Having an Emotion Detection systems specifically for children with ASD can bring a benefit when using a computer

program as part of the intervention treatment for ASD, for example, when using a game that teaches children with Level 1 Diagnosis of Autism how to start a conversation in a school cafeteria. If the game identifies that the child is anxious, agitated or angry, it would automatically present a calming activity to relax the child, so they would be in a state of calming readiness to learn again and to continue engaging with a tool that is a treatment for them.

Also, creating an emotion identification computer system that works well for children with autism will increase inclusion for them because they will be able to use a technology that also works well for them.

Your child was selected as a possible participant because they have Level 1 Diagnosis of Autism and you might have demonstrated interest in participating in research involving emotions.

WHO ARE THE RESEARCHERS?

The study is being conducted by Annanda Sousa (a PhD candidate in the College of Science and Engineering, Data Science Institute - NUI Galway) under the supervision of Prof. Mathieu d'Aquin (from Data Science Institute/NUI Galway), Dr Jennifer Holloway (from School of Psychology/NUI Galway) and Dr Manel Zarrouk (from Institut Galilée - Université Paris 13). This project is funded by the Science Foundation of Ireland (SFI).

WHO CAN TAKE PART?

Children with age of 8-12 years with a previous diagnosis of Autism Spectrum Disorder (ASD) without a history of intellectual and language disability, also known as Level 1 diagnosis of autism.

HOW MANY PEOPLE WILL TAKE PART?

If you agree to allow your child to participate, your child will be one of 12 participants taking part in this study.

WHAT WILL HAPPEN DURING THE STUDY?

If you agree to allow your child to be in the study, your child will be asked to attend online study sessions to do the following things:

- Engage with computer-based activities that will stimulate them to go through different emotional zones, example of activities is, watching video, solving a math worksheet and playing a game.

The sessions will be held online through a video conference software, i.e. Zoom. The video conference session will be recorded.

You are also asked to be part of this study by doing the following:

- Before the first session, answer questions about the special interests of your child, what usually calms and upset them. The questionnaire is expected to take less than 5 minutes. This will help us to define specific activities to your child do during the online session.
- To attend an online session to watch the recorded video of your child and identify your child's emotions from the video. This will also be done online. We will schedule a video call with you to give you instructions on this.
- After having identified your child's emotion from the recorded video, answer a questionnaire about how your child expresses emotions. It is expected to take less than 5 minutes.

You and your child will be asked to attend on 3 different days each. We will schedule a date/time that is most convenient for you and your child to attend. The sessions will be held online through a video conference software, **so you will need a computer with camera, microphone and internet connection to be able to attend the sessions.**

Your child's sessions are separated from yours. We will schedule different times for them.

HOW LONG WILL IT TAKE?

Each session is expected to take around 30 minutes. You and your child are required to attend to 3 different online sessions in different days. Your child's sessions are separated from yours. We will schedule different times for them.

WHEN AND WHERE WILL THIS HAPPEN?

The sessions will be held online through a video conference software, i.e. Zoom at a date to be yet agreed.

ARE THERE REQUIREMENTS TO BE PART OF THIS STUDY?

Yes. Because the study will be held online through a video conference, it is necessary that your household has a computer equipped with camera and microphone to be used to connect to the study sessions. Also, your child will need to wear a headset or earplug to listen the audio during the session.

WILL MY CHILD'S ASSENT TO BE PART OF THIS RESEARCH BE REQUIRED?

Yes. If you agree to allow your child to participate, we will talk to them using age-appropriate language and ask if they desire to be part of this study. If your child doesn't agree to be part of this study, they won't, even if you had already agreed with it. For your child to be part of this study, both you and they need to agree. If you request, the researchers will show you the material that will be used to seek for your child's assent.

WHAT ARE THE RISKS OF TAKING PART IN THE STUDY?

While participating in the study, because it involves evoking emotions from your child, the potential risk includes:

- A risk of the child feels emotional discomfort and gets agitated or lose control of their emotions during the activities they engage with.

To minimise this risk the following measures will be employed:

- The time of each session will be divided, and calming activities will be done to help the child to regulate their emotions. Some examples of calming activities include breathing exercises, observing moving objects between others.
- A psychology student with experience supporting children with autism will be present all the time to provide timely comfort or take any further measure to guide your child to a calming state.
- At the beginning of the session, we will agree with your child a code of a movement they can perform if they feel like stopping the session. During the time of the session, if they indicate they want to pause, the study will be immediately paused. After taking a few

minutes, we will ask your child if they desire to continue. If not, the current session will be finished immediately.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THE STUDY?

We don't expect your child to receive any direct benefit from taking part in this study, but we hope to learn things that will help children with Level 1 Diagnosis of ASD in the future. By accepting to allow the participation of your child, you will be collaborating to the advance of this research and any other based on it, which can lead to future discoveries and development of tools to help children like yours.

WHAT WILL BE DONE WITH MY CHILD'S RECORDS?

We will transform the original audio/video records of your child into a numerical representation (set of numbers) to be used to create the emotion identifier computer system. When this process is complete, identifying information from your child will not be present anymore. In other words, it will not be possible to identify your child from this numerical representation.

The records will only be accessible to members of the research team and will be kept securely, in strict accordance with the General Data Protection Regulation (GDPR).

Your child's data **will not** be used for any kind of profiling or marketing content. Arrangements are in place so that yours and your child's personal data will be processed only as is necessary to achieve the objective of the research and will not be processed in a way that damage or distress will be caused to you and your child.

HOW WILL MY CHILD'S INFORMATION BE PROTECTED?

With your permission, we are recording audio/video of your child as a part of the study. Every effort will be made to keep your child's personal information confidential. This project is compliant with the recommendation of the General Data Protection Regulation (GDPR), a European regulation to protect the rights of people regarding their personal data. We created a plan with measures to protect yours and your child's personal data which was approved by both the NUI Galway's Data Protection Officer and the NUI Galway's Ethics Committee (an ethics committee that helps protect people involved in research).

The measures include the following:

- Keep yours and your child's personal data stored in a secure, encrypted and password-protected server within NUI Galway premises (Data Science Institute/NUI Galway) for no longer than 3 years.
- Keep the storage server isolated from the internet, the only possible connection being from inside the building of Data Science Institute/NUI Galway.
- The only people who will have access to yours and your child's personal data records are the researchers listed above.
- After 3 years, all the personal data will be deleted.
- We are not going to share yours and your child's personal data with anyone else.
- No information which could identify you or your child will be shared in publications about this study.

Please bear in mind that your child's personal information may be disclosed if required by law.

WILL MY CHILD'S INFORMATION BE USED FOR RESEARCH IN THE FUTURE?

Your child's audio/video records will not be used or distributed for future research studies without your consent.

This research involves processing the original audio/video records from your child into a numerical representation to be used to create the emotion identifier computer system. This processed numerical representation may be used for future research studies or shared with other researchers for future research. If this happens, information which could identify your child will be removed before any information is shared. Since identifying information will not be present, we will not ask for your additional consent.

WILL I BE PAID FOR PARTICIPATION?

Your child will not be provided with any payment to take part in the research.

CAN I HAVE ACCESS TO MY CHILD'S RECORDED DATA?

Yes. It is your right to request and have access to this data. If you desire to have a copy of your child's records, please check the website at <http://emotion-asd.datascienceinstitute.ie/> on how to request it and we will hand you an encrypted DVD media with a copy of your child's records.

WILL I BE INFORMED OF THE OUTCOME OF THIS RESEARCH STUDY?

If you want, you can receive information about this research study's results. Please check on the website at <http://emotion-asd.datascienceinstitute.ie/> how to request it and we will contact you with general and anonymised results from this research by the end of its lifetime, around 3 years.

WHAT IF I CHANGED MY MIND AFTER THE STUDY AND DON'T WANT MY CHILD'S PERSONAL DATA STORED ANYMORE?

In general, you have the right to request your child's data to be deleted before the 3 years of retention time. However, other law conditions may also apply. So, if you desire to have your child's records deleted, please, check the website at <http://emotion-asd.datascienceinstitute.ie/> on how to request it and we will deal with this request on a case-by-case basis, in accordance with the law.

WHO SHOULD I CALL WITH QUESTIONS OR PROBLEMS?

For questions about the study, contact me at any time by email at annanda.sousa@insight-centre.org or a.defreitassousa1@nuigalway.ie. We can also arrange a video conference meeting, I will be happy to answer any question you have about the project. You can also contact my supervisors Prof. Mathieu d'Aquin at manthieu.daquin@insight-centre.org or Dr Manel Zarrouk at zarrouk@lipn.univ-paris13.fr.

For questions about your or your child's rights as a research participant, to discuss problems, complaints, or concerns about a research study, please contact the NUI Galway Data Protection Officer, details provided below:

Peter Feeney
The Data Protection Officer
NUI Galway, Room A129,
The Quadrangle,
NUI Galway University Road,
Galway
Email: peter.feeney@nuigalway.ie or dataprotection@nuigalway.ie
Phone number: +353 91 493673

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, by phone at +353 91 495312 or by email at ethics@nuigalway.ie.

You also have the right to lodge a complaint with the Data Protection Commissioner of Ireland, details provided below:

<https://www.dataprotection.ie/en/contact/how-contact-us>

Phone numbers:

+353 578 684 800 or +353 761 104 800 09:15 - 17:30hrs (17.15 Friday)

Postal Address:

Data Protection Commission
21 Fitzwilliam Square South
Dublin 2
D02 RD28
Ireland

GENERAL INFORMATION ON YOUR RIGHTS

On the website <http://emotion-asd.datascienceinstitute.ie/> you can find a copy of all your rights under the GDPR. Please, take the time to read it whenever you want to be aware of yours and your child's rights.

You can also find your rights under the GDPR on the Irish Data Protection Commission website at <https://www.dataprotection.ie/en/individuals/rights-individuals-under-general-data-protection-regulation>.

Thank you kindly for taking the time to read this Information Sheet and considering for your child to participate in this study.