





Project Title: Personal-independent Emotion Detection Model for Children with High-Functioning ASD

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Information Sheet for parent/guardian of children participating in the research study titled "Personal-independent Emotion Detection Model for Children with High-Functioning ASD"

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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 and the support group for social skills.

# WHY IS THIS STUDY BEING DONE?

The purpose of this study is to collect data on how children with high-functioning autism express emotions to create a computer system that can identify emotions from children with high-functioning autism using video, audio and heart rate records. 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 high-functioning ASD 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 high-functioning autism and you demonstrated interest in participating in research involving emotions.

## WHO ARE THE RESEARCHERS?

The study is being conducted by Annanda Sousa (a researcher PhD student in the College of Science and Engineering and Informatics, 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 without a history of Intellectual and language Disability, also known as High-Functioning ASD.

# 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 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.
- Use a wristband device to record their heart rate during the visit.

They will be recorded (audio and video) by a camera during the visit.

You are also asked to be part of this study by doing the following, after and/or during your child's sessions:

- To use a computer-based software to watch the recorded video of your child and identify your child's emotions from the video.
- Before the first visit, 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 visits.

You and your child will be asked to attend on 3 different days. The study will happen in the NUI Galway School of Psychology in a room yet to be defined. We will schedule a date/time that is most convenient for you and your child to attend.

## **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 sessions in different days.

#### WHEN AND WHERE WILL THIS HAPPEN?

The sessions will take place at School of Psychology - NUI Galway at a date to be yet agreed.

# 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 in be part of this study, they won't, even if you had already agreed with it. For your child 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 too 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 visit will be divided, and calming activities will be done to help the child to regulate their emotions. Some examples of calming activities can include breathing exercises, observing a moving object between others.
- A therapist specialising in autism will be present all the time to provide timely comfort or take any further measure to guide your child to a calming state.
- Your child will have physical access to an image indicating STOP with the instruction that at any moment if they want to stop, they can touch the image and 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 high-functioning 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/heart rate records from 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/heart rate 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/heart rate records will not be used or distributed for future research studies without your consent.

This research involves processing the original audio/video/heart rate 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. However, we can provide, if needed and under request, financial support for travel expenses.

## 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 fill the online form on the website at [URL OF WEBSITE] 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 fill the online form on the website at [URL OF WEBSITE] 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, fill the online form on the website at [URL OF THE WEBSITE] 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.defreitassousal@nuigalway.ie. We can also arrange a face-to-face meeting in office hours at the Data Science Institute. 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

# **GENERAL INFORMATION ON YOUR RIGHTS**

On the website [PROJECT'S WEBSITE URL] you can find a copy of all your rights under the GDPR. We are also providing you with a printed version of the document, 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 <a href="https://www.dataprotection.ie/en/individuals/rights-individuals-under-general-data-protection-regulation">https://www.dataprotection.ie/en/individuals/rights-individuals-under-general-data-protection-regulation</a>.

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