



INFORMATION LETTER – Interviews

Researcher Information

Title of the project: How does the school community understand inclusion?

Department: School of Psychology, University of Galway, Ireland

Principal Investigator and Data Controller:

Esther Mercado-Garrido; e.mercadogarrido1@universityofgalway.ie

Supervisors: Dr. Anne O'Connor (aconnor@universityofgalway.ie); Dr. Aoife McTiernan (aofemaria.mctiernan@universityofgalway.ie)

Data Controller: University of Galway Data Protection Officer (dataprotection@universityofgalway.ie; 091 524411)

Thank you for your interest in this study. You are being invited to take part in a research study being carried out by Esther Mercado Garrido (PhD candidate in the University of Galway); Dr Anne O'Connor and Dr Aoife McTiernan.

Before you decide whether you wish to take part or not, you should read the information provided below and, if you wish, discuss with (family, friends etc.). Take your time and ask questions – don't feel rushed and don't feel under pressure to make a quick decision. You should be clear about the risks and benefits of taking part in this study so that you can make a decision that's right for you. This process is known as 'Informed Consent'.

What happens if I decide not to participate?

Participating in this study is completely voluntary. Choosing not to take part will not have any consequences. You can also change your mind about taking part in the study even after commencement. You don't have to give a reason, and be assured that if you do opt out, there will be no consequences.

Why is this study being done?

Research has shown that despite all the time and effort done to promote inclusion, most of the time it is not achieved. It has been observed that one group of people that tend to be excluded from active participation in secondary education are autistic adolescents¹. We believe that this may be related to a lack of understanding of what inclusion is and what does it mean to be included for autistic people. As a result, we want to know what your opinion is, and what suggestions do you have to make school a more enjoyable experience. With this information, and with the views from other members of the School Community (families, neurotypical peers, and professionals), we would like to understand how the School Community defines inclusion, aiming to create an *inclusive* definition of inclusion, where all the active agents are involved. By involving everyone, we expect to transfer that definition to research and practice, to potentially develop effective and efficient interventions to promote inclusion.

1. We acknowledge currently there is a debate about this topic, but identity-first language (i.e., autistic adolescent) is being used instead of person-first language (i.e., adolescents with autism), since recent research (Bury et al., 2020; Taboas et al., 2022) highlights the preference of identity-first language by the autistic community. However, if you have a different preference, please, let the researchers know so we can adapt our language and documents.



Who is organising and funding this study?

There is no organisation funding this project directly. However, the first author is partially funded by the Mutua Madrileña Foundation.

Why am I being asked to take part?

As an autistic adolescent and part of the School Community, we acknowledge your expertise on the topic of inclusion and autism. Because of that, we would like to know what is your opinion on inclusion and what could be done to promote inclusion and to make high school a more enjoyable situation. In addition, we would like to know how you would define inclusion. Your insights on the topic are really important to us and could have a big impact on how future research is conducted.

Unfortunately, you cannot take part in the interviews if you:

1. Do not have a diagnosis of Autism Spectrum Disorder (ASD)
2. Are under 12 years of age or over 18 years of age

However, if you are between 12-18 and do not have a diagnosis of ASD, but would like to give your opinion on the matter, we also want to hear from you! Please, contact the main researcher (e.mercadogarrido1@universityofgalway.ie) so she can give you more information.

What can I expect if I agree to take part?

If you decide to take part, you will be expected to take part in an interview with the researcher. The interview will last up to an hour, but you will be the person deciding the rhythm and length. We want the interview to be a comfortable experience so we will contact you and your parents/legal guardians beforehand to ask you about if you would like to have any accommodations during the interview (e.g. asking about your preferred method of communication and sensory supports).

You can also decide if you want a family member to be present during the interview or if you prefer to answer the questions on your own. We will also send you a list with questions before the interview. However, this will be a semi-structured interview. That means that, even though the questions sent will be asked, the phrasing and order may change. In addition, depending on the conversation, it is possible that some extra questions related to the topic may arise.

Interviews will be offered to be done in the School of Psychology in the University of Galway. However, if that is not suitable, they can be conducted in a setting that suits you and your family.

The interview will be audio recorded so the researcher can transcribe the conversation after the group discussion. However, once all the transcriptions are done, those audios will be securely deleted. Your participation in this study will remain confidential.

What are the benefits for me taking part?

There are not direct benefits to taking part in this research. However, the potential benefits will include reflecting about topics such as neurodiversity, education and inclusion. The aim of this study is to provide reliable and empirical data to researchers and educators about the inclusion of autistic students, so another potential benefit of their participation would be the design of new procedures and to favour the inclusion of autistic adolescents in education, following the Convention on The Rights of Persons with Disabilities (2008) legislation.



What are the risks?

There is no direct risk expected from participating on the focus group. However, due to the sensitive nature of the topic, there is a small risk that some participants may find the discussions distressing. In the case that you feel uncomfortable or distressed, or if you need to, you will be able to take a break or leave the discussion group without any consequences.

Confidentiality

Your participation in this study will remain confidential. Neither your name nor any identifying details (e.g., your birthplace or study/workplace) will be included in any reports on this study.

However, in the case that there is any data breach, the matter will be redirected immediately to the University of Galway Data Protection Officer.

The material gathered will be treated with strict confidence, but this is subject to legal limitations. If you disclose that you or someone else is in immediate danger or risk of harm, the researcher may have to report this to the relevant authorities.

What do I need to know about how the data will be used?

This research will be part of a PhD thesis, and results are expected to be published on a peer-reviewed journal. It is very likely that we include literal quotes from the interview on the paper and the thesis. However, your name will be modified to maintain your confidentiality.

We will record the interview so we can transcribe the conversations. However, once the transcriptions are finished, they will be securely deleted by the researcher.

All the information will be stored on a Shared OneDrive folder from the University of Galway and password protected. Only the researcher (Esther Mercado-Garrido) and supervisors (Dr. Anne O'Connor & Dr. Aoife McTiernan) will have access to the password protected files. Information will be retained in the University of Galway servers for seven years after the conclusion of a project. After seven years all information will be destroyed safely by the research supervisors.

As this research is part of a PhD thesis, it is likely that your data will be used in future research related to this study. If that happens, we will not ask for your consent again, but we will require for approval from the University of Galway Ethics committee. An Ethics committee is a group in charge of ensuring that research is conducting in an ethical manner.

Where can I get further information?

If you would like to get further information, please, feel free to contact the main researcher, Esther Mercado-Garrido, via email: e.mercadgarrido1@universityofgalway.ie

If you wish to contact a neutral third party, email ethics@universityofgalway.ie to communicate with the Coordinator or Chair of the University of Galway Research Ethics Committee.



ASSENT FORM – ADOLESCENTS

Research Study Title: How does the school community understand inclusion?

Name and Contact Details of Researcher(s): Esther Mercado Garrido (e.mercadogarrido1@universityofgalway.ie)

Name and Contact Details of Supervisors: Dr Anne O'Connor (aoconnor@universityofgalway.ie) & Dr Aoife McTiernan (aoifemaria.mctiernan@universityofgalway.ie)

School / affiliated Centre: School of Psychology, University of Galway

University Data Protection Officer: email - dataprotection@universityofgalway.ie / Tel - (091) 524411

	Please initial the box
1. I confirm that I have read (or had read to me) the information letter for the study I am going to participate in. I have had the opportunity to reflect about the information, ask questions and have had these answered at least one day (24 hours) before deciding to participate in the study.	
2. I understand that my participation is voluntary and that I am free to leave at any time without giving any reason.	
3. I understand that the information collected during this study will be managed following the appropriate European laws.	
4. I confirm that I am aware of the possible risks and benefits of participating in this research.	
5. I give permission for my interview to be audio recorded. The recording will be transcribed (<i>written</i>) and analysed for the purposes of the research and will be deleted after the transcription is done.	
6. I consent to literal quotes being used in publications; My name will not be used, but I understand there is a small possibility that I could be identified.	
7. I understand that all information I give for this study will be confidential but with legal limitations. For example, if I tell the researcher that I or someone else is in immediate danger or risk of harm, the researcher may have to report this to the relevant authorities (e.g. garda or TUSLA). The researcher will discuss this with me first, but they may be required to report with or without my permission.	
8. I understand that in any report on the results of this research (thesis, conference presentation, published paper, etc.), my identity will be hidden. To do so, my name will be changed in any type of report.	
9. I give permission for my <u>anonymous</u> information to be stored for <u>possible future research related</u> to the present study <u>without giving consent again</u> but only if the research is approved by a Research Ethics Committee.	
10. I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Researcher

Date

Signature



CONSENT FORM – PARENTS/LEGAL GUARDIANS

Research Study Title: How does the school community understand inclusion?

Name and Contact Details of Researcher(s): Esther Mercado Garrido (e.mercadogarrido1@universityofgalway.ie)

Name and Contact Details of Supervisors: Dr Anne O'Connor (aoconnor@universityofgalway.ie) & Dr Aoife McTiernan (aoifemaria.mctiernan@universityofgalway.ie)

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	Please initial the box
1. I confirm that I have read (or had read to me) the information letter for the above study. I have had the opportunity to consider the information, ask questions and have had these answered at least 24 hours before deciding to participate in the study.	
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason.	
3. I understand that the data collected during this study will be processed in accordance with data protection law as explained in the participant information letter.	
4. I confirm that I am aware of the potential risks and benefits of my child participating in this research.	
5. I consent for my child's interview to be audio recorded. The recording will be transcribed and analysed for the purposes of the research, and will be deleted after the transcription is done.	
6. I consent to literal quotes being used in publications; My child will not be named, but understand there is a risk that they could be identified.	
7. I understand that all information my child provides for this study will be treated confidentially with legal limitations. For example, if they tell the researcher that them or someone else is in immediate danger or risk of harm, the researcher may have to report this to the relevant authorities.	
8. I understand that in any report on the results of this research (thesis, conference presentation, published paper, etc.), my child's identity will be disguised and remain pseudonymous. To do so, their name will be changed in any type of report.	
9. I give permission for my <u>anonymous</u> data/material to be stored for <u>possible future research related</u> to the current study without further consent being required but only if the research is approved by a Research Ethics Committee.	
10. I agree for my child to take part in the above study.	

Name of Participant

Date

Signature

Name of Researcher

Date

Signature