

**Participant information sheet** – Individual diagnosed with Asperger’s Disorder (Autism Spectrum Disorder)

**Study Title:** Living with a psychiatric categorisation: Negotiation of identity, by individuals diagnosed with Asperger’s Disorder (Autism Spectrum Disorder)

**Lay title:** Experiencing Asperger’s Disorder (Autism Spectrum Disorder)

**Lead Researcher:** Sari Mangru

PhD candidate, School of Social Science, University of Queensland

Contact email: [s.mangru@uq.edu.au](mailto:s.mangru@uq.edu.au)

**Supervisory team:** Dr Rebeca Olson – Senior lecturer the University of Queensland, School of Social Science, Faculty of Humanities and Social Sciences

Dr Fernanda Claudio - The University of Queensland.

This Participant Information Sheet tells you about the research project. It explains the purpose of the research, procedures and risks involved. It also describes information about you that will be obtained, how that information will be used and with whom it will be shared. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you may want to ask for further information from the Lead Researcher, Sari Mangru, whose contact details are provided above.

Participation in this research is voluntary. Participation will not affect your relationship with your support organisation, support group, the researcher or The University of Queensland. If you don’t wish to take part, you don’t have to.

If you decide you want to take part in the research project, you will be asked to sign the Consent Form. By signing the Consent Form, you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to the use of interview data as described.

**Purpose of the study** - This study is interested in exploring the experiences and viewpoints of individuals diagnosed with Asperger’s Disorder, recently re-categorised as Autism Spectrum Disorder. We would like to know how you see the world, your place in it and would like to hear about your

experiences growing up, in school, and with family and friends. Your viewpoints are important to this study.

**What will you be asked to do?** - Consenting to participation in this qualitative research project means agreeing to take part in the following form of data collection:

A 30-60 minute semi-structured interview with the lead researcher of how you view yourself; your experiences of social interaction, and with health professionals.

Interviews will be recorded using a digital voice recorder. However, should a participant choose to, they can request to turn off the recorder temporarily or stop the interview permanently. The location can be of your choosing e.g. the offices of support organisations.

**Risks to you** - There are no risks involved in participating. It is not anticipated that your decision to withdraw or not take part in this project will have any impact on your relationship with your support organisation, support group, the researcher or The University of Queensland.

**Benefits of the study** - Improved understanding of how interpersonal practices works for those diagnosed with Asperger's Disorder will inform strategies for improved policy development in the workplace, education and health system.

**Your participation is voluntary** - Your participation is entirely voluntary: you are not obliged to be involved and – if you do participate – you may freely withdraw from the project at any time without giving any reason and without any consequences. If you agree to take part in this study but change your mind later, you are free to withdraw consent for your participation at any time, without comment or penalty. Withdrawal or refusal to participate will not impact your relationship with a support organisation or group.

Only the Lead Researcher Sari Mangru will have full details of who decides to participate. You can tell other people about the study by providing them with Lead Researcher Sari Mangru's contact details (listed above).

**Your confidentiality** - All information gained from this study will be handled in a strictly confidential manner. It will only be disclosed with your permission, except as required by Law or as required for ethical research conduct auditing or adverse event reporting. Transcribed interviews will be de-identified prior to analysis. Only the Lead Researcher (Mangru) will have access to the identifiable data collected.

If you withdraw from the study after interviews have been recorded then your recording and any transcripts will be destroyed and an email sent to you to confirm this action.

All data will be stored securely in the School of Social Science, the University of Queensland, for the duration of the study and then destroyed. Results will be disseminated through journal article(s); conference presentation(s) and the PhD thesis as required by the doctoral program at the University

of Queensland. However, individual participants will not be identifiable in any publications or the thesis. Participants may ask to receive information about the findings of the research by contacting Lead Researcher Sari Mangru: s.mangru@uq.ed.au.

**Research funding** - This study is being funded by the Australian Government Research Training Program and supplementary grants from the Graduate School and the School of Social Science at The University of Queensland.

**Ethics statement of this research – Approval # 2017001100**

*"This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (contactable on s.mangru@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on 3365 3924."*