

The research is being carried out by the following researchers:

Elly Greenwood

The research is being carried out in partial fulfilment of PhD (Doctor of Philosophy) under the supervision of Associate Professor Amanda Cooklin, Associate Professor Josephine Barbaro, and Dr Charne Miller and Perrin Date. The following researchers will be conducting the study:

Role	Name	Organisation
Student Researcher	Elly Greenwood	Judith Lumley Centre Olga Tennison Autism Research Centre School of Nursing and Midwifery La Trobe University
Co-Investigator	Associate Professor Amanda Cooklin	Judith Lumley Centre
Principal Investigator	Associate Professor Josephine Barbaro	Olga Tennison Autism Research Centre
Co-Investigator	Dr Charne Miller	University of Melbourne
Co-Investigator	Perrin Date	Olga Tennison Autism Research Centre
Research Funder	This research has received in-kind funding from Latrobe University.	

1. What is the study about?

You are invited to participate in this study with the aim to

- Understand the lived experience of parents/caregivers with Autistic children during their child's admission to emergency department.
- Understand the experiences of Autistic patients (children) as described by their parents/caregivers during their admission to emergency department.

2. Do I have to participate?

Being part of this study is voluntary. If you would like to be part of the study, we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end that you do not wish to be involved. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation, or your relationship with the hospital that recently cared for your child.

3. Who is being asked to participate?

You have been asked to participate because:

- You are a parent/caregiver of an autistic child who is less than 18 years of age and you are the main caregiver.
- Your Autistic child was admitted to the emergency department within the last 12 months.
- Your child has a confirmed autism diagnosis by healthcare professional/s.

4. What will I be asked to do?

If you want to take part in this study, we will ask you (i) to complete a brief 10-minute online questionnaire with some questions about you and your child (e.g., names, age, recent hospital visit, contact information); and (ii) to participate in a 45–60-minute interview either via ZOOM recorded as audio files or telephone depending on your preference. You will be asked questions about you, your Autistic child and your family's experiences during admission at the emergency department. There will be a remuneration of a \$30.00 voucher as a gratitude of your time and taking part in this study.

5. What are the benefits?

The benefit of you taking part in this study is that with this evidence, we will be able to better understand the experiences of parents and their children during admission to emergency departments. The goal of this study is to improve admission experiences and support for patients and families by improved communication and care planning in the future.

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6. What are the risks?

For some families, reliving these experiences, may be upsetting. If this happens to you, you may stop the interview at any time, ask to skip questions, or withdraw from the interview and study participation. If you have other questions or issues with the study that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. Our contact details are below:

Name/Organisation	Position	Telephone	Email
Elly Greenwood	PhD Research Student	9 479 1929	E.greenwood@latrobe.edu.au
Amanda Cooklin	Associate Professor, ARC Principal Research Fellow	9 479 8803	A.cooklin@latrobe.edu.au
Josephine Barbaro	Associate Professor, Principal Research Fellow, Psychologist	9 479 5135	J.barbaro@latrobe.edu.au
Charne Miller	Director of Teaching and Learning/Senior Lecturer	83444456	Charne.miller@unimelb.edu.au
Perrin Date	Research Operations Manager	94795055	p.date@latrobe.edu.au

Other support services available to you are as follows:

- Lifeline: Call: 13 11 14, text: 0477 13 11 14 or use their online chat, 24/7.
 - Headspace: Call: 1800 650 890 or chat online from 9.00 am–1.00 am, 7 days a week.
 - Area Mental Health Service Triage: <http://www3.health.vic.gov.au/mentalhealthservices/>
 - Parent line Victoria: Call: 132289
 - Carer Gateway: <https://www.carergateway.gov.au/about/person-phone-counselling#a3>
- To minimise the inconvenience, the interviews will be arranged at a time and location that is suitable for you.
 - There is no risk that you or your child or family will be identifiable from the evidence from this study. Only the interviewer will have access to identifiable data. All other information from the questionnaire and interviews will have a code number only; with all identifying information (names, contact information, child's name, hospital name) removed and stored separately.

7. What will happen to information about me?

We will **collect** information about you in ways that will reveal who you are.

We will **store** information about you in ways that will initially reveal who you are, but we will separate out all identifying information (i.e., names, child's name, contact information, hospital visited) and store this separately to the data you provide (in interview and brief online survey).

We will **publish** information about you and other participants as a group only, in ways that will not be identified in any type of publication from this study.

We will **keep** your information for 7 years after the project is completed. After this time, we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

8. Will I hear about the results of the study?

If you would like to know about the results of the study, we will send you a summary copy of the results. We will ask you about this at the registration survey and use your email details for this purpose in 12-18 months' time.

9. What if I change my mind?

You can choose to cancel or stop the interview at any time. For one month following the collection of your data, you are free to withdraw the data (survey and interview) that you provided to us. You can do this by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us; or
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

When you withdraw, we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed, we can only withdraw information, such as your name and contact details. If results haven't been analysed, you can choose if we use those results or not.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details provided below.

Name/Organisation	Position	Telephone	Email
Elly Greenwood	PhD Research Student	9 479 1929	E.greenwood@latrobe.edu.au
Amanda Cooklin	Associate Professor, ARC Principal Research Fellow	9 479 8803	A.cooklin@latrobe.edu.au
Josephine Barbaro	Associate Professor, Principal Research Fellow, Psychologist	9 479 5135	J.barbaro@latrobe.edu.au
Charne Miller	Director of Teaching and Learning/Senior Lecturer	83444456	Charne.miller@unimelb.edu.au
Perrin Date	Research Operations Manager	94795055	p.date@latrobe.edu.au

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC24060	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

Please click on this [LINK](#) to provide digital consent and complete your Registration Survey.

Participant Information Statement

Project Title: Understanding the experiences of Autistic children and their parents or caregivers during emergency department admission

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been de-identified.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

*[Delete if inapplicable] **if you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data.

- Destroyed and not used for any analysis.
 Used for analysis.

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

Student Researcher	Elly Greenwood
Email	E.greenwood@latrobe.edu.au
Phone	9 479 1929
Postal Address	School of Nursing and Midwifery Latrobe University, Bundoora 3083