

ONLINE PARTICIPANT INFORMATION STATEMENT

Characterising the use of Specialty harnesses and vests by children in motor vehicles in Australia & New Zealand (ChareS)

1. What is the research study about?

The ChareS study aims to investigate the access to, and the use of specialty harnesses and vests commonly used by children with disabilities and medical conditions when travelling in motor vehicles. The goal of this study is to gain a holistic understanding of when, why, and how parents/carers in Australia and New Zealand are accessing harnesses and vests and their overall experience of using harnesses. The study is funded by Austroads, a not-for-profit organisation of Australia and New Zealand transport agencies representing all levels of government, to assist the development of guidance and standards for the safe adoption and use of harnesses and vests in Australia and New Zealand.

If you are a parent or carer of a child who currently uses a harness or a vest while travelling in a motor vehicle, you are invited to take part in this study because we want to understand your experience of accessing and using harnesses and/or vests.

2. Who is conducting this research?

The study is being carried out by the following researchers:

| Role | Name | Organisation |
|--------------------|---|---|
| Chief Investigator | A/Prof Julie Brown | Neuroscience Research Australia The George Institute for Global Health |
| Co-Investigators | Helen Lindner Emma Clarkson | Mobility and Accessibility for Children in Australia Ltd |
| Study Personnel | Catherine Ho Yaojia (Wennie) Dai Rebecca Szabo Amelia Thomas | The George Institute for Global Health University of New South Wales |

Research Funder: This research is being funded by Austroads.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Aged 18 years or older.
- Parent or carer of a child (under 16 years) who currently uses a specialty harness or vest when travelling in a motor vehicle.

4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study by discontinuing the survey at any stage before you submit your survey response. However, please note that once you have submitted your survey response, we will not be able to identify and remove your response from our database as all responses are anonymous and cannot be linked back to you.

If you decide you want to take part in the research study, you will be asked to:

- Read the information here carefully (ask questions if necessary);
- Complete the online survey.

5. What does participation in this research require, and are there any risks involved?

ONLINE PARTICIPANT INFORMATION STATEMENT

Characterising the use of Specialty harnesses and vests by children in motor vehicles in Australia & New Zealand (ChareS)

If you decide to take part in the research study, we will ask you to complete an online survey: the Australian and New Zealand Harness and Vest Survey. This survey will ask you questions about your experiences and/or knowledge about transporting children in motor vehicles using a harness or vest. During the survey, you will be asked to upload a picture of the specialty harness/vest you are using and a picture of your child using the harness/vest. If you do not wish to upload any pictures, you can skip the applicable question and can still participate in the rest of the survey. Note: Please avoid uploading any pictures that include your child's face or anything that may be linked to a person's identity. This survey should take approximately 10-15 minutes to complete.

Aside from giving up your time to participate, we do not expect that there will be any risks associated with taking part in this study. However, if you experience discomfort or feelings of distress while participating in the research, you can stop participating at any time. You can also tell a member of the research team and they will provide you with assistance, or alternatively a list of support services and their contact details are provided below in section 10.

6. What are the possible benefits to participation?

We hope to use information we get from this research study to develop guidance and standards for the adoption and use of harnesses and vests in Australia and New Zealand. This will benefit parents and carers of children who require the use of harnesses and vests when travelling in motor vehicles.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid.

7. What will happen to information about me?

Submission of the online survey is an indication of your consent. By responding 'Yes' to the question, 'Do you agree to participate in this study' and clicking the 'Start survey' button you are providing your permission for the research team to collect and use information about you for the research study.

The research team will store the data collected from you for this research project for a minimum of 5 years after the publication of the research results.

The data collected from you (including your responses and pictures that you upload) will be initially stored on a highly secure Qualtrics server protected by high-end firewall systems and encrypted using Advanced Encryption Standard (a strong and robust industry encryption standard). The data will then be directly transferred to a highly secure server hosted by The George Institute for Global Health for storage. Upon transfer, if the research team detects a picture containing identifiable features (e.g. child's face) or anything that can be linked to a person's identity, the picture will be cropped to remove these features.

The information about you will be stored in a non-identifiable format where your identity will be unknown.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that will be an extension of, or closely related to, the original project; or is in the same general area of research. Your information will only be shared in a format that will not identify you.

8. How and when will I find out what the results of the research study are?

The research team intend to publish and/ report the results of the research. All Information will be published in a way that will not identify you.

ONLINE PARTICIPANT INFORMATION STATEMENT

Characterising the use of Specialty harnesses and vests by children in motor vehicles in Australia & New Zealand (ChareS)

If you would like to receive a copy of the results you can let the research team know by providing your email or mailing address details in the consent form at the bottom of this page. We will only use these details to send you the results of the research.

9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time before you submit your survey response by closing the survey window or tab. Please note that due to the anonymous nature of the survey, you will only be able to withdraw from the study before submitting your survey response. Once you have submitted your survey response, we may not be able to remove your answers as it will not be linked to you and will be kept in an unidentified format. Your decision not to participate or to withdraw from the study, will not affect your relationship with UNSW Sydney, The George Institute for Global Health, or Mobility and Accessibility for Children in Australia.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact

| | |
|------------------|-----------------------------|
| Name | Wennie Dai |
| Position | Research Officer |
| Telephone | +61 2 8052 4828 |
| Email | wdai@georgeinstitute.org.au |

| | |
|------------------|-------------------------------|
| Name | A/Prof Julie Brown |
| Position | Chief Investigator |
| Telephone | +61 2 8052 4420 |
| Email | jbrown@georgeinstitute.org.au |

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Support Services Contact Details

| | | |
|----------------|--------------|-------------------------------------|
| Beyond Blue | 1300 224 636 | Open 3pm to midnight, 7 days a week |
| Lifeline (AUS) | 13 11 14 | Open 24 hours a day, 7 days a week |
| Lifeline (NZ) | 0800 543 354 | Open 24 hours a day, 7 days a week |

ONLINE PARTICIPANT INFORMATION STATEMENT

Characterising the use of Specialty harnesses and vests by children in motor vehicles in Australia & New Zealand (ChareS)

What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

| | |
|----------------------------|--|
| Position | Human Research Ethics Coordinator |
| Telephone | + 61 2 9385 6222 |
| Email | humanethics@unsw.edu.au |
| HC Reference Number | HC220818 |

ONLINE PARTICIPANT INFORMATION STATEMENT

Characterising the use of Specialty harnesses and vests by children in motor vehicles in Australia & New Zealand (ChareS)

Consent Form – Participant providing own consent

Declaration by the participant

By checking 'Yes' in response to the question 'Do you agree to participate in this study' and clicking the 'Start survey' button below:

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Statement, or it has been provided to me in a language that I understand;
- I provide my consent for the information collected about me to be used for the purpose of this research study, or for the purpose of future research that will be an extension of, or closely related to this project; or is in the same general area of research;
- I understand that if necessary, I can ask questions and the research team will respond to my questions.
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form from <https://www.georgeinstitute.org/chares>
- [OPTIONAL] I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

[OPTIONAL] Name: _____

[OPTIONAL] Address: _____

[OPTIONAL] Email Address: _____

Do you agree to participate in this study?

- Yes
- No

Start survey