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| The research is being carried out by the following researchers by Dr Dana Wong and Professor Jacinta Douglas. The following researchers will be conducting the study: | | |
| **Role** | **Name** | **Organisation** |
| Chief Investigator | Dr Dana Wong | La Trobe University |
| Associate Investigator | Professor Jacinta Douglas | La Trobe University |
| Research Assistant | Nick Sathananthan | La Trobe University |
| **Research funder** | This research is supported by in kind support by La Trobe University. | |

1. **What is the study about?**

People living with acquired brain injury (ABI) can experience changes to their health, wellbeing, and ability to complete their usual daily activities. The COVID-19 pandemic, and its associated social distancing measures and lockdowns, has had a significant impact on many aspects of health, wellbeing, and functioning for most individuals. However, it is possible that the impact of the pandemic may have been greater or different in those with ABI and their family members and caregivers.

The broad aim of this study is to understand how the COVID-19 pandemic has impacted individuals with ABI and their caregivers/family members in Australia. We seek to understand how the pandemic and lockdowns have affected your health, mood, relationships, work, general behaviour, and overall rehabilitation and recovery from ABI. We also seek to understand what you may have learnt from the experience of living through a pandemic. The findings of this study may help in the development of recommendations on how to best support those with ABI, both in future global crises and more generally.

1. **Do I have to participate?**

Being part of this study is voluntary. We ask that you read the information below carefully and decide at the end whether you would like to participate in this research. If you decide not to participate this won’t affect your relationship with La Trobe University or any other listed organisation.

1. **Can I participate?**

You are eligible to take part in this study if you are:

* 18 years of age or older

Living in Australia and you are either:

* An individual with an ABI (e.g. stroke, traumatic brain injury, brain tumour, hypoxic brain injury) OR
* A carer/family member of an adult with ABI

You must be able to provide consent and complete the survey independently. If you are an individual with an ABI who also has a family member/carer who would like to participate, then both of you can complete *separate* versions of the survey. You will each need to complete this consent form separately.

1. **What will I be asked to do?**

You will be asked to complete an online survey that will take you between 20 – 30 minutes to complete. If you are an individual with an ABI, the survey will ask about your own experience. If you are a caregiver of someone with ABI, the survey will ask about your experience AND the experience of the person you care for. The survey will ask information about:

* Demographic characteristics
* Information about the brain injury
* Your response to the pandemic
* The impact of the pandemic on different aspects of your life
* Any learnings or positive changes that you experienced during the pandemic

At the end of the survey you will be asked if you would like to register your interest to participate in an interview about your experiences during the pandemic. The interview will take 20-30 minutes and will ask you additional questions about your experience of the pandemic. If you are interested in this, you will be asked to provide your contact details. If you do this, you are not obliged to participate in the interview and you can change your mind later. You will be asked again for your written consent before you participate in the interview.

1. **What are the benefits?**

It is unlikely that you will receive any direct benefit by participating in this research. However, by participating in this survey you may be helping others with brain injury and disability by improving our understanding of how to best support people with ABI.

1. **What are the risks?**

It is possible that completing this survey may trigger uncomfortable feelings relating to how you feel about your ABI or the experience of the pandemic. If you feel upset or distressed as a result of your participation in this research, please contact us immediately so we can discuss the best way to manage your concerns.

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| Dr Dana Wong/La Trobe University | Chief Investigator | (03) 9479 5079 | d.wong@latrobe.edu.au |

You can also contact Lifeline on 13 11 14 for 24/7 support if you wish to speak to someone outside of La Trobe University.

1. **What will happen to information about me?**

By clicking on the ‘I agree, start questionnaire’ button, this tells us you want to take part in the study. You can download an electronic copy of this participant information statement for your records by clicking the button below. This option will be provided again at the end of the survey.

We will **collect** and **store** information about you in ways that will not reveal who you are. This means that you cannot be identified in any type of publication from this study. We will keep your information for 7 years after this 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/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

1. **Will I hear about the results of the study?**

The results of the study can be made available to you at the completion of the study. If you would like them sent to you, please email Dr Dana Wong at d.wong@latrobe.edu.au. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be not be provided in such a way that would identify you, except with your permission.

1. **What if I change my mind?**

If you no longer want to complete the questionnaire, simply close the web browser. If you change your mind after clicking on the ‘Submit’ button, we cannot withdraw your responses because we cannot link who you are with your questionnaire responses.

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

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

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

| **Name/Organisation** | **Position** | **Telephone** | **Email** |
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| Dr Dana Wong/La Trobe University | Chief Investigator | (03) 9479 5079 | d.wong@latrobe.edu.au |

1. **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** |
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| HEC21043 | Senior Research Ethics Officer | +61 3 9479 1443 | [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) |