**Experiences of post-stroke vision care services in Australia**

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| The following researchers will be conducting the study: | | |
| **Role** | **Name** | **Organisation** |
| Principal Investigator | Associate Professor Connie Koklanis | Discipline of Orthoptics, School of Allied Health Human Services and Sport, La Trobe University |
| Co-investigator | Associate Professor Meri Vukicevic | Discipline of Orthoptics, School of Allied Health Human Services and Sport, La Trobe University |
| Student Investigator | Lauren Batchelor | Discipline of Orthoptics, School of Allied Health Human Services and Sport, La Trobe University |
| **Research funder** | This research is supported by in kind support by La Trobe University. | |

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

You are invited to participate in a study investigating the experiences of post-stroke vision care services in Australia. This research can enhance our understanding of the challenges faced by stroke survivors in accessing and receiving adequate vision care, leading to potential improvements in service provision.

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

Being part of this study is voluntary. If you want to be part of the study, we ask that you read the information below carefully.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won’t affect your relationship with La Trobe University or any other listed organisation.

1. **Who is being asked to participate?**

Participants should have internet access and be able to read and respond to online survey questions in English, either independently or with assistance. There are no restrictions on the age of the stroke survivor, the timing or type of stroke, or the presence of post-stroke vision difficulties.

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

If you want to take part in this study, we will ask you to complete an online anonymous survey hosted on RedCap. It will take approximately 15 minutes of your time to be part of this study.

1. **What are the benefits?**

The benefit of you taking part in this study is that you will be contributing to our understanding of the experience of stroke survivors with vision impairment and orthoptists in stroke care and to identify any issues with services. Your experiences can contribute to improved post-stroke vision care, and potentially influencing positive changes in healthcare practices, leading to enhanced quality and accessibility of services.

1. **What are the risks?**

With any study there are (1) risks we know about, (2) risks we don’t know about, and (3) risks we don’t expect. If you experience something that you aren’t sure about, please contact us immediately so we can discuss the best way to manage your concerns.

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| Associate Professor Connie Koklanis | Principal Investigator | 03 9479 1903 | [k.koklanis@latrobe](mailto:k.koklanis@latrobe).edu.au |

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

It is possible that you may find some questions difficult to answer as you reflect on challenging moments in your stroke journey. If so, you can stop the questionnaire at any time without giving a reason. If you require support, we encourage you to contact Beyond Blue on 1300 22 4636.

If you would like further advice regarding stoke treatment, recovery and prevention you can call StrokeLine on 1800 787 653.

If you are having post-stroke vision difficulties that have not been addressed, we recommend you contact Guide Dogs Australia on 1800 484 333 or Vision Australia on 1300 847 466 for an eye assessment.

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.

We will **collect** information about you in ways that will not reveal who you are. This may occur if you voluntarily provide your email address at the end of the survey to receive a summary of the research outcomes. If you do not provide an email address, information will not reveal who you are.

We will **store** information about you in ways that will not reveal who you are.

We will **publish** information about you 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/>.

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?**

If you would like to receive the results of the study, please email the Principal Investigator, Associate Professor Connie Koklanis, at [k.koklanis@latrobe.edu.au](mailto:k.koklanis@latrobe.edu.au) by 30 June 2025. We expect to have results ready at this time.

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** |
| --- | --- | --- | --- |
| Associate Professor Connie Koklanis | Principal Investigator | 9479 1903 | k.koklanis@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** |
| --- | --- | --- | --- |
| HEC24100 | Senior Research Ethics Officer | +61 3 9479 1443 | [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) |

**Consent Form – Declaration by Participant**

I (the participant) have read understood the Participant Information Statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time until I submit the survey. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

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| **I agree, start questionnaire** |