Research information for people with aphasia

Culturally and linguistically diverse aphasia rehabilitation: the experiences of people with aphasia.

LA TROBE UNIVERSITY

Centre of Research Excellence in Aphasia Recovery and Rehabilitation

NSW GOVERNMENT Health Sydney Local Health District

Who is doing the research?

Professor **Miranda** Rose Miranda is a **speech pathologist** Miranda works in **research** at La Trobe University	
Dr **Lucette** Lanyon Lucie is a **speech pathologist** Lucie **lectures** in speech pathology and works in **research** at La Trobe University	
Chelsea Larkman Chelsea is a **speech pathologist** Chelsea is a **PhD student** at La Trobe University	

Amanda Judson. Amanda is a **speech pathologist**. Amanda is a local investigator at **Concord Repatriation General Hospital**.	
Annie Dent Annie is a **speech pathologist**. Annie is a local investigator at **Royal Prince Alfred Hospital**.	
Karen Blazquez Karen is a **speech pathologist**. Karen is a local investigator at **Concord Repatriation General Hospital** and **Royal Prince Alfred Hospital**.	
Kristen David. Kristen is a **speech pathologist**. Kristen is a local investigator at **Balmain District Hospital**.	

Rachel McKenzie. Rachel is a **speech pathologist**. Rachel is a local investigator at **Canterbury Hospital**.	

1. What is the study about?

This **study** will **ask** about your **experience** of **aphasia treatment**.

The study is being conducted within **Sydney Local Health District** by **Chelsea Larkman** as part of her **PhD**.

This **Participant Information Sheet** will tell you what is involved in the study.

It will help you **decide if you wish to participate**.

Please **ask us** any **questions**.

You can also talk about the study with a relative, a friend or your doctor to help you decide.

Who is being asked to participate?

You have been asked to participate because:

- You are **over eighteen** [18] years of age
- You **have aphasia** due to **stroke**

  Aphasia is a **communication disability** which impacts on your ability to **speak, understand, read**, and **write**.

- You have been living with aphasia **for more than two [2] months**
- You speak a **language other than English** and have a **different cultural** background
- You have received **aphasia therapy** from a speech pathologist in the **last two years**
- You can **consent** to participating
- You can **communicate your story**. You can use talking, drawing, writing, gesture or other communication.
- Your **vision** and **hearing** are **ok**
- You **do not have** a **progressive neurological disease e.g., dementia or multiple sclerosis**

What will I be asked to do?

First, we will ask you for **information about yourself**, your **stroke**, your **language**, your **culture**, and **other medical conditions**.

If you are eligible, you need to provide **consent** to participate.

This means **you understand what the study is** for and **what you need to do**.

If you want to participate, we will ask you to **sign a consent form**.

The form will be available **in English** as well as your **preferred language**. There will be **an interpreter** available.

After you **consent** to participate, the **study begins**.

2. Information about the study

A **speech pathologist** will interview you with the help of an **interpreter**.

The **interview** can be done at **your home**.

Or it can be at **Concord Hospital**.

If we cannot meet face-to-face, we might interview you in a Zoom **videocall** 💻.

You can tell us your story about:

- The **treatment** and **services** you received. Or, **not getting** the right treatment and services.

- What it was like working with an **interpreter**.

- How appropriate the therapy was for your **language** and **culture**.

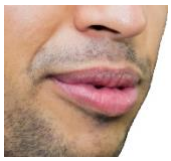
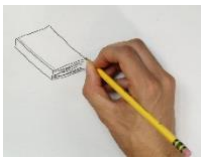
- Things that **would have helped when** you were having therapy.

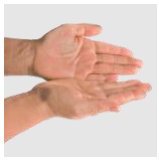
You can choose **not to talk** about things that **upset** you.

The interview will be **about one [1] hour**.

The speech pathologist can **help you communicate** your story.

You can use **speech**, **drawing**, **writing**, **gesture,** or other communication.




You can **pause** and take **rest breaks** during the interview. If you are **very tired**, we can **stop** the interview. The speech pathologist can come back **a week later** to **finish** the interview with you.

We will record the interview with a **video camera**.

The recording will then be **transcribed** by the speech pathologist. There will be no details that will identify you.

3. 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.

You might feel **upset** after talking about your story.

If this happens, we can stop the recording.

We can also talk to your GP (doctor) if you are **very** upset.

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.

Name	Position	Telephone	Email
Professor Miranda Rose, La Trobe University 	Coordinating Principal Investigator	(03) 9479 2088	m.rose@latrobe.edu.au

4. What are the benefits of participating?

Likely **benefits to participants**

You might benefit from:

- **Telling your story**
- Taking part in something that will **help other people**

We cannot guarantee that you will benefit.

Likely **benefits to other people** in the future

Speech pathologists might be able to **learn from your experience** to help **other people** with aphasia from **different cultures and language** backgrounds.

5. Costs

Participation in this study **will not cost you** anything.

You **will not be paid** to participate in this study.

6. Do I have to participate?

You do not have to participate.

Being part of this study is **voluntary**.

If you want to be part of the study, please **read the information below** carefully.

You can **ask us** any **questions**.

Then you can **decide**:

👍"I **do** want to participate in this research."

👎"I **don't** want to participate."

Your decision to **participate**, **not** participate or **stop** participating will **not affect your relationship** with:

- La Trobe University
- The Aphasia CRE
- Sydney Local Health District
- The researchers

What if I change my mind?

Up until four weeks after the interview, you can choose to no longer be part of the study. You can let us know by:

- completing the '**Withdrawal of Consent Form**' (provided with the consent form)
- calling us
- emailing us

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

If you withdraw, we would:

- stop asking you for information
- withdraw any identifiable information about you from the research study.

If results **have not** been analysed you can choose if we use those results or not.

However, once the results have been analysed we can only withdraw information, such as your name and contact details.

7. What will happen to information about me?

We will **collect personal information** and **video recordings** of the interview. All information will be treated **confidentially.**

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

Information that can **identify** you by **name** will be stored within the **Sydney Local Health District REDCap database**. REDCap is a secure internet application. It is password protected. A **code** will be

generated and all other data about you will have this code. No other data will contain your name.

Information that **does not identify** you (e.g., country of birth, language spoken) will be stored on a **La Trobe University REDCap database**.

Videos and **transcripts** of the **interview** will be stored on a secure **La Trobe University research drive**. This is password protected.

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 5 years after** the project is completed. After 5 years we will destroy all of your data.

The storage, transfer and destruction of your data will follow La Trobe University Research Data Management Policy.

We will keep the information we collect for this study, and **we may use it in future research studies**. By providing your consent you are allowing us to use your information in future research. We don't know at this stage what these other studies will involve. We will seek ethical approval before using the information in these future studies.

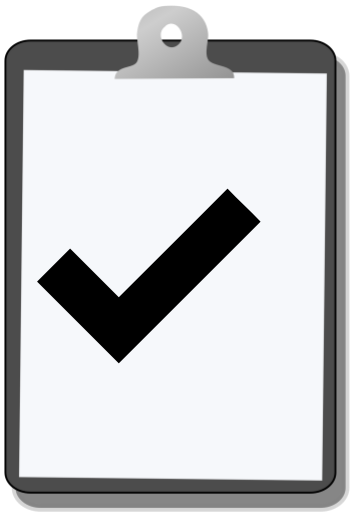
8. Who can I contact for questions or if I want more information?

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

Name	Position	Telephone	Email
Professor Miranda Rose, La Trobe University 	Coordinating Principal Investigator	(03) 9479 2088	m.rose@latrobe.edu.au

9. Ethics permission

We have **permission** to do this research.



It comes from the **La Trobe University** and the **Sydney Local Health District** Ethics Committees.

Ethics number HEC 2022/ETH00932

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
	Senior Research Ethics Officer	03 9479 1443	humanethics@latrobe.edu.au
2022/ETH00932	Concord Executive Officer	02 9767 5622	