

# Participant Information Sheet

**Title of Project:** Establishing Benchmarks of Important Change in Post-Stroke Aphasia Care

**Lay title:** Measuring Meaningful Changes in Aphasia Care

## Researchers:



**A/Prof Sarah Wallace**

The University of Queensland



**Prof David Copland**

The University of Queensland



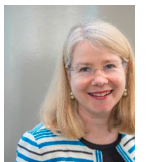
**A/Prof Monique Kilkenny**

Monash University



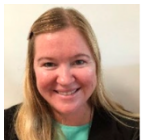
**A/Prof Erin Godecke**

Edith Cowan University



**Prof Carolyn Unsworth**

Federation University



**Dr Kirstine Shrusole**

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**A/Prof Robyn O'Halloran**

La Trobe University



**Dr Muideen Olaiya**

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**Dr Annie Hill**

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**Prof Deborah Hersh**

Curtin University



**Dr Sam Harvey**

The University of Queensland



**Marissa Stone**

The University of Queensland



**Dr Sally Zingelman**

The University of Queensland

**You are invited to take part in research as a person with  
aphasia after stroke.**

## What is this research about?



- Clinicians use aphasia tests to measure how aphasia affects patients.
- Sometimes tests are done before and after treatment.
- Changes in aphasia tests before and after treatment can help patients and clinicians to understand if a treatment is working.
- But we don't know if these changes are meaningful to people with aphasia.



This **research aims** to identify which test scores represent meaningful change to people with aphasia.

## What would I need to do?

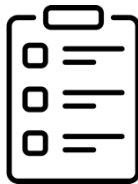


Participate in **three (3) online meetings**.



### Meeting One (1)

- We will collect **information** about **you** and **your aphasia**.
- We will ask you to **nominate** a significant other (**a family member, friend, or carer**), **who often communicates with you**.
- This meeting will take up to **one (1) hour**.



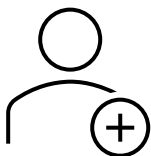
### Meeting Two (2)

- You will **complete three (3) aphasia tests** with a research **speech pathologist**.
- Your **significant other** will complete a **questionnaire** about your **communication in everyday situations**.
- This meeting will take up to **two and a half (2.5) hours**.
- The tests **can be completed over more meetings** if you are tired.

### Meeting Three (3)



- You will **complete the same three (3) aphasia tests** with a research **speech pathologist**.
- You will **rate your change** on a short **scale**.
- Your **significant other** will complete a **questionnaire** about your **communication** in **everyday situations**. We will ask about **aphasia treatment** you have done **since Meeting Two (2)**.
- This meeting will take up to **two and a half (2.5) hours**.
- This **can be completed over more meetings** if you are tired.



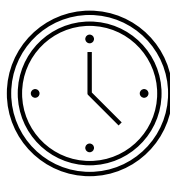
- **You can invite a family member or support person** to come to the research **meetings with you**.

## Where will the research take place?



- The research will be conducted **online**.
- You can **participate from home** using a **computer**.
- You will need an **internet connection**.
- **If you live in Brisbane or the Sunshine Coast, the research can be conducted in-person.**

## How long will the research take?



- **Six (6) hours** in total.



- You will be **paid \$300 for your time** if you consent to the study.

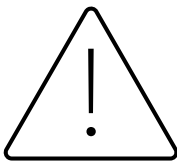


- Payment will be made **directly** to an **Australian bank account**.



- If you **leave** the study **early**, you will be **paid \$50** for **each hour** that you participated in the study.

### Are there any risks?



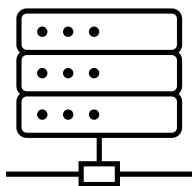
- There is **no danger** in doing this research.
- You may get **tired** participating in this research.
- If you get tired, you can **take a break**, **finish** the task **later**, or **withdraw** from the research.

## Are there any benefits?



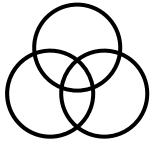
- This study **may help to improve aphasia services.**
- This may help **people** living with aphasia.
- There may be **no direct benefit to you.**

## What will happen to my data?



- Your data will be **stored in a secure database** at The University of Queensland.
- Your data will be **stored for a minimum of five (5) years.**
- Your data will be **de-identified.** This means **personal information** like your name and birthdate **will not be stored** in the database.

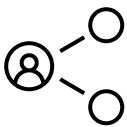
## How will be my data be used?



- Researchers will **combine your de-identified results with results** from participants in **other studies**.
- The **combined data** will identify **changes on aphasia tests** that **represent meaningful change** to people with aphasia.



- You will **receive a report with your individual test results**.



- The **research findings** will be **shared**.
- The **Queensland Aphasia Research Centre** will **share** the **research results** in the **aphasia-friendly QARC Matters newsletter**.
- You can ask for a copy of the **research results**.



- Your **de-identified data** may be used for **related research** in the **future**.

## Who can I contact if I have any concerns about the project?



- This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research.
- You can **discuss your participation** in this study with the lead researcher **Associate Professor Sarah Wallace**.

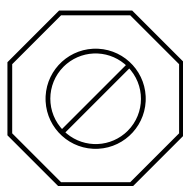


Phone: 07 3346 7453

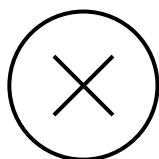


Email: [s.wallace3@uq.edu.au](mailto:s.wallace3@uq.edu.au)

## What if I decide I do not want to be involved?



- You do not have to participate. **It is your choice.**
- You can ask **questions** at any time.
- Saying no will **not affect** your **relationship** the **University of Queensland.**
- You can **change** your mind.



- You can **stop participating in the research at any time.**
- To **stop** participating in the research, contact Associate Professor **Sarah Wallace:**



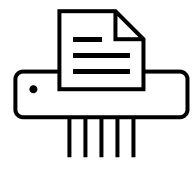
Phone: 07 3346 7453



Email: [s.wallace3@uq.edu.au](mailto:s.wallace3@uq.edu.au)




Or tell us during a meeting.



- If you **stop participating in the research** you can decide to **withdraw your data** from the research.
- This means **any data collected about you** will be **destroyed** and **not used** in the research.

If you would like to **speak to an officer** of the University **not involved** in the study, contact the Ethics Coordinator.

 Phone: 07 3365 3924

 Email: [humanethics@research.uq.edu.au](mailto:humanethics@research.uq.edu.au)

This research Ethics ID number: 2025/HE000912

### What if I have more questions?

- We are happy to give you **more information**.
- Please contact **Associate Professor Sarah Wallace**:

 Phone: 07 3346 7453       Email: [s.wallace3@uq.edu.au](mailto:s.wallace3@uq.edu.au)

## Consent form

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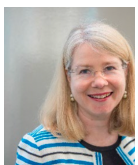
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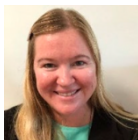
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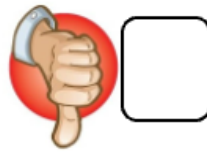
**Dr Sally Zingelman**

The University of Queensland

Please mark



or

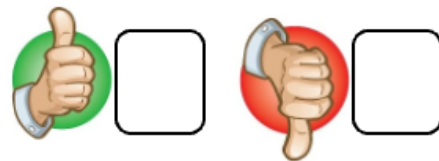


for each statement

yes

no

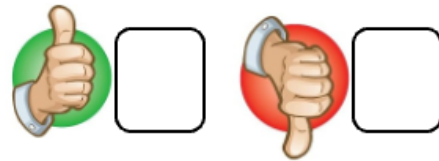
The **information sheet** has been explained to me. I understand what this research is about.



yes

no

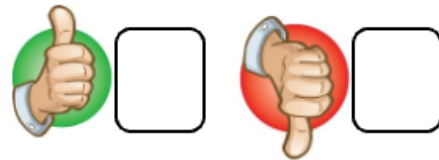
I have had the chance to **ask questions**.



yes

no

I understand that there is **no danger** in doing this research.

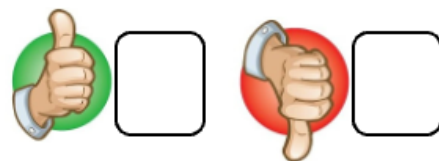


yes

no

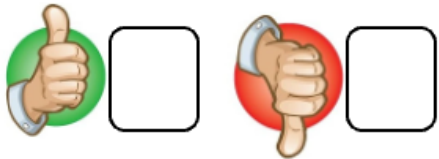
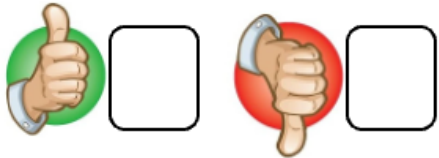
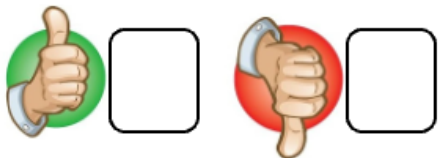
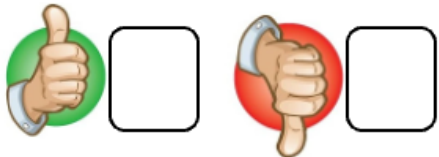
I understand the benefits of this research:









- This research may help to **improve aphasia services**
- This research may **not benefit me directly**



yes

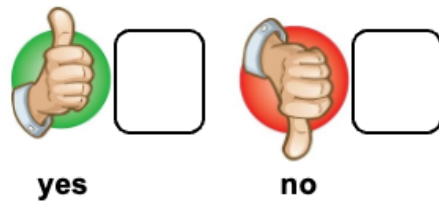
no





|  |   |
|--|---|
| <p>I understand that <b>I do not have to participate</b>. It is my choice.</p> <p><b>I can change my mind</b> at any time.</p>   |  <p><b>yes</b>                      <b>no</b></p>   |
| <p>I understand that I can <b>stop participating in the research</b> by <b>contacting Associate Professor Sarah Wallace</b> (Speech Pathologist).</p> <p>Phone: 07 3346 7453</p> <p>Email: <a href="mailto:s.wallace3@uq.edu.au">s.wallace3@uq.edu.au</a></p> <p>I understand if I <b>stop participating in the research</b> I can decide to <b>withdraw my data</b> from the research.</p> <p>If I choose to do this <b>any data collected about me</b> will be <b>destroyed</b> and <b>not used</b> in the research.</p> |  <p><b>yes</b>                      <b>no</b></p>   |
| <p>I understand that <b>information</b> about me will be <b>kept safe</b> and not shared with <b>anyone outside the research team</b>.</p>   |  <p><b>yes</b>                      <b>no</b></p> |
| <p>I understand that <b>my data</b> will be <b>kept</b> for a <b>minimum of five (5) years</b>.</p>  |  <p><b>yes</b>                      <b>no</b></p> |

|   |   |
|---|---|
| <p>I understand that I can ask to <b>access my data</b>.</p>  |  <input data-bbox="1031 293 1118 394" type="checkbox"/>  <input data-bbox="1259 293 1347 394" type="checkbox"/> <p><b>yes</b>                      <b>no</b></p>     |
| <p>I know that when <b>results</b> are shared the researcher will <b>not use my name</b>.</p>   |  <input data-bbox="1031 526 1118 627" type="checkbox"/>  <input data-bbox="1259 526 1347 627" type="checkbox"/> <p><b>yes</b>                      <b>no</b></p>     |
| <p>I know that I am welcome to bring a <b>family member or support person</b> to the research <b>meetings</b>.</p>  |  <input data-bbox="1031 759 1118 860" type="checkbox"/>  <input data-bbox="1259 759 1347 860" type="checkbox"/> <p><b>yes</b>                      <b>no</b></p>     |
| <p>I know that to ask <b>questions</b> I need to contact <b>Associate Professor Sarah Wallace</b> (Speech Pathologist).</p> <p>Phone: 07 3346 7453</p> <p>Email: <a href="mailto:s.wallace3@uq.edu.au">s.wallace3@uq.edu.au</a></p> |  <input data-bbox="1031 992 1118 1093" type="checkbox"/>  <input data-bbox="1259 992 1347 1093" type="checkbox"/> <p><b>yes</b>                      <b>no</b></p> |

**I agree:**

- I will have **aphasia tests at two time points.**
- I understand the tests will include **questions about my change.**
- I understand there will be **questions about any speech and language treatments** I am doing.
- I understand my **significant other** will **answer a questionnaire** about **my communication in everyday situations.**



|   |   |
|---|---|
| <p>I <b>consent to participating in this study</b></p>  | <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  <input data-bbox="1038 443 1134 555" type="checkbox"/> <p><b>yes</b></p> </div> <div style="text-align: center;">  <input data-bbox="1278 443 1374 555" type="checkbox"/> <p><b>no</b></p> </div> </div> |
| <p>I would like <b>my data</b> to be <b>used</b> for <b>related research</b> in the <b>future</b></p>                   | <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  <input data-bbox="1038 678 1134 790" type="checkbox"/> <p><b>yes</b></p> </div> <div style="text-align: center;">  <input data-bbox="1278 678 1374 790" type="checkbox"/> <p><b>no</b></p> </div> </div> |
| <p><b>My name</b></p> <hr/>   |   |
| <p><b>My signature</b></p> <hr/>  |   |
| <p><b>Today's date</b></p> <hr/>  |   |
| <p>I would like to receive a <b>written copy of the research findings.</b></p> <p>My postal/email address is:</p> <hr/> |   |