



**UCL**

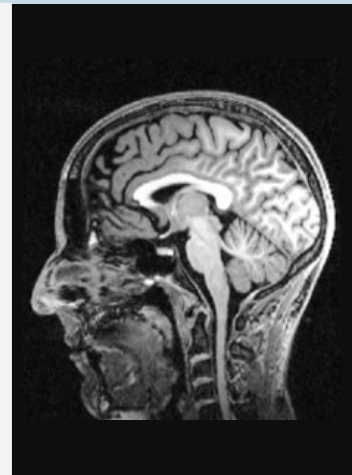
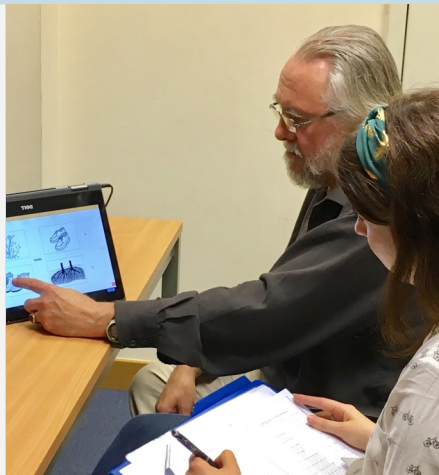
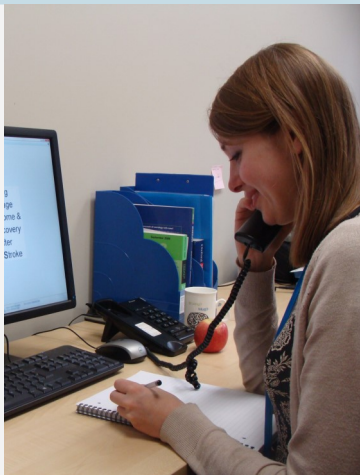
# **P L O R A S**

**Predicting Language Outcome and Recovery After Stroke**

## **Participant Information Booklet**

**Version 6.0**

**Date: 13.10.2022**





**Audio version** of this booklet: [www.ucl.ac.uk/ploras](http://www.ucl.ac.uk/ploras)

Find it on the '**Quick links**' section of **homepage**.

# Invitation

---

- This is an **invitation** to **take part** in **PLORAS**.
- **PLORAS** is a **stroke research study**.



The PLORAS Team want to:

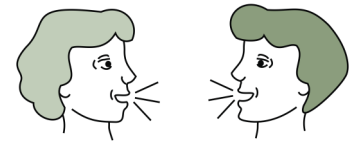
- **include you** because your **stroke** has **affected** your **speaking**
- **look at** your hospital **brain scan**
- **monitor** your **speech and language recovery**.



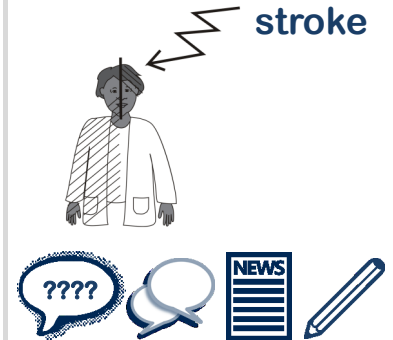
# Study background

---

- **Language** is an **essential human skill**.
- We use language to **share needs, ideas, knowledge, feelings** and **humour**.



- **Aphasia** is a **language disorder**.
- A **stroke** can **cause aphasia**.
- Aphasia can affect **speaking, understanding, reading** and **writing**.



- **Patients** and their family **want to know**:

“**how much** will I recover?”

“**how long** will it take?”

- Currently, **no one** has the **answers**.
- **Aphasia recovery varies** from patient to patient.



There is **not enough information** about **links** between:

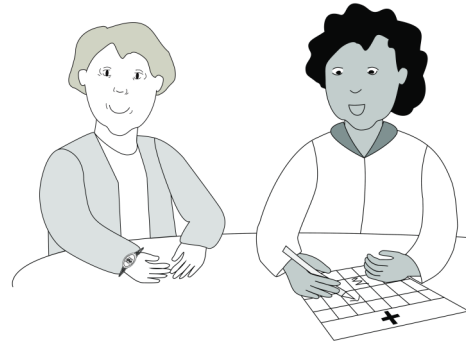
- **where** the **stroke** is in the **brain**
- **speech and language skills**.
- the **time** and **amount** of **recovery**.



# PLORAS goals

---

- PLORAS **aims** to:
  - **collect** the **information** needed
  - **tell future patients** about their likely **speech and language recovery**.
- The information will **help patients** to **plan** their **future**.
- The information will **help patients** and **therapists plan treatment**.



# What do PLORAS participants do?



## In hospital/clinic

### 1. Sign a consent form

You **confirm** that you:

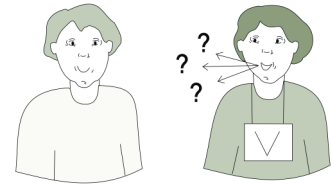
- **understand** this **information booklet**
- **agree** to **take part** in the study
- are **happy** to **share** with the **PLORAS Team**:
  - **brain scans**
  - **speech and language therapy records**
  - **relevant medical records.**



**PLORAS Team**

## 2. Complete a participant interview

- A **researcher** will **ask** you **questions**.
- The questions ask **how** the **stroke affected** you.
- The interview takes about **30 minutes**.



The **researcher** will **complete** all **questionnaires** and **forms** with **you**.



A **friend** or **family member** may be able to **help** you **answer** the questions.



**For participants who self-refer to PLORAS:** Forms will be done with you by the PLORAS Team, not in hospital.





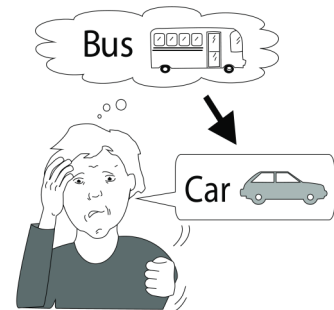
## At home

- Answer some **questionnaires**.
- We have listed them in **order of priority** for us (in case you do not want to do all of them).



### 1. Communication Recovery Measure

- This asks about how the **stroke affected** your **speaking, understanding, reading** and **writing**.
- The questionnaire takes about **20-45 minutes**.
- This is **essential** for you to be **included** in the study.



## 2. 'About You'

- This asks about your **vision** and **hearing**, **hand** and **foot dominance**, **education**, **work**, **ethnicity**, **sex** and **gender**, **dyslexia**.
- The questionnaire takes about **10 minutes**.



## 3. Language Practice Questionnaire

- This asks about any **speech and language therapy** you have had.
- It also asks about your **everyday use of language**.
- The questionnaire takes about **20-45 minutes**.



## 4. Your language history

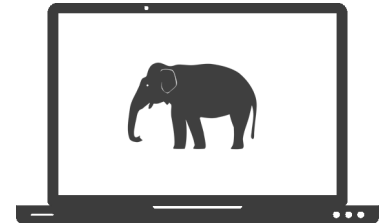
This asks about:

- any **other languages** you speak
- **how** the languages were **affected** by the stroke
- The questionnaire takes about **20-45 minutes**.



The **PLORAS Team** **may**:

- **invite** you to do other **speech and language assessments**. For example:
  - **pointing to pictures, naming pictures, reading and writing** (60-90 minutes)
  - **rating how aphasia affects your life** (20-30 minutes).



The **PLORAS Team** will:

- **contact you every 3 to 6 months to repeat** the:
  - **Communication Recovery Measure**
  - **Language Practice Questionnaire**



**3 - 6 months**

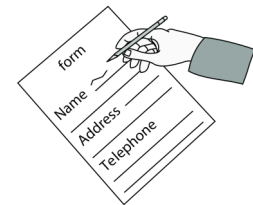
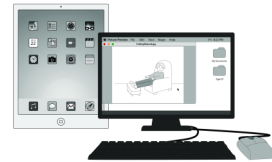


The **PLORAS Team** will:

- **ask your speech and language therapist to complete a questionnaire about your therapy.**



- All **questionnaires** and **assessments** can be done on a **computer** / **another device**.
- You can **communicate** with the **PLORAS Team** via **video link**.
- Participants **who do not have access** to a **computer** may:
  - use **paper forms**
  - have a **home visit**.
- All **appointments** will be **arranged** at a **time** to **suit you**.



## Other activities

The **PLORAS Team** **may**:

- **invite you to take part in other events and activities.** For example:
  - **study meetings**
  - **therapy studies**
  - **developing training resources**
  - **public engagement activities.**

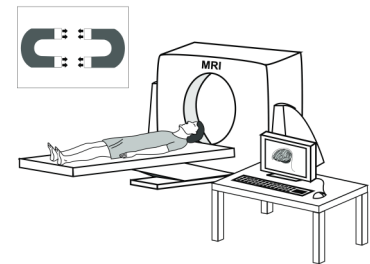


The **PLORAS Team** **may**:

- **invite you** to have a **functional MRI brain scan**
- this involves doing **language tasks inside** the **scanner**
- the scan would be at the **research centre in London**.

This may happen if the PLORAS Team:

- **cannot access** or **use** your **hospital brain scan**
- want to **understand** how your **brain** has **helped** your **speech and language recovery**.



## Benefits

- The PLORAS Team will **monitor** your **speech and language recovery**.
- The PLORAS Team **may** be able to **offer** you a **prediction** for your **recovery**.
- You will be **helping future stroke survivors**.



## Risks

- There are **no risks** to taking part.
- Some participants **may be uncomfortable discussing** their **stroke**.
- You **do not need** to **answer** if you **do not want to**.





# Important!

---

- Taking part is **voluntary** – you can **stop**, have a **break** or **withdraw** at any time.
- PLORAS will **keep storing** and **using your data**.
- You can **withdraw consent** for **processing your data** at any time.



- The PLORAS Team **do not provide treatment**.
- The PLORAS Team can provide **information** to help you **find treatment**.
- Taking part **does not affect** your **clinical care**.

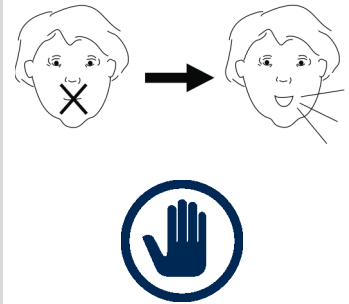


# Other questions

## How long will I be involved in the study?

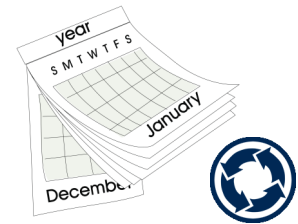
The PLORAS Team will **contact you until:**

- your **language difficulties recover**
- you no **longer wish to take part**
- **funding is not renewed.**



## How long will the study last?

- PLORAS will **include hundreds of stroke survivors.**
- PLORAS will **collect data for many years.**



## Will my information be kept confidential?

### Yes

- Your **information** will be **stored electronically** in the **PLORAS database**.
- **Data** is **encrypted** where appropriate.
- **Paper data** will be **stored** in a **locked cabinet** at the **research centre** or **archived** at the **UCL Records Office**.
- **Access** to the **PLORAS database** and **cabinets** is **controlled** by the **Chief Investigator**.
- See the **PLORAS Privacy Notice** for **more information**.

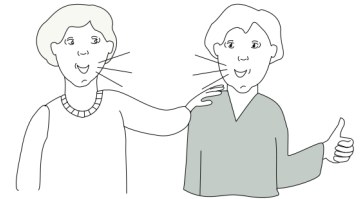


## What if the participant cannot understand the study information or complete the forms?

- The **participant** can **identify** a **consultee**.
- The consultee **advises** what the **participant's wishes** and **feelings** would be if they could consent themselves.

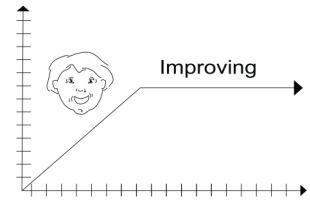
The consultee will be asked to:

1. **read** and **sign** a **consultee declaration**
2. **assist the participant** with **study activities**
3. raise any **concerns** or if they think the participant should be **withdrawn**.



## What will happen to the results of the study?

- **Final results** will be:
  - used to **help predict recovery** for **future stroke survivors**
  - **available** via the **PLORAS newsletter** and **website**
  - **published** in **scientific journals**.
- The **publication stage** could take **years**.
- **Publications do not contain details** that could **identify participants**.



## Who has funded the study?

- Wellcome
- Medical Research Council
- Stroke Association



## Who has reviewed the study?

London Queen Square Research Ethics Committee



## For further information or complaints:

- **PLORAS Team:** see back page
- **PLORAS Chief Investigator:** ✉ [c.j.price@ucl.ac.uk](mailto:c.j.price@ucl.ac.uk)
- **UCL** (if a complaint is not dealt with):  
✉ [complaints.officer@uclh.nhs.uk](mailto:complaints.officer@uclh.nhs.uk)






# Contact details


---

## PLORAS Team

 [ploras@ucl.ac.uk](mailto:ploras@ucl.ac.uk)

 0207 813 1538 or  
07984 111 585

 [www.ucl.ac.uk/ploras](http://www.ucl.ac.uk/ploras)

 PLORAS Research Team  
12 Queen Square, London  
WC1N 3AR

## Clinical Research Network

Picture credits: see [www.ucl.ac.uk/ploras/picture-credits](http://www.ucl.ac.uk/ploras/picture-credits)