PLORAS Privacy Notice

Version 2.0 | Date: 13.10.2022

Predicting Language Outcome and Recovery After Stroke

The **PLORAS Team collect, store** and **analyse information from you** and your **medical records.**

This **information** is **needed to:**

- **include you in the study**
- **predict language outcomes for future stroke survivors**

This **booklet** is about the **information** we **collect.**

Audio version of this booklet: **www.ucl.ac.uk/ploras**

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

Data we collect

Name **Date of birth**	
Contact details and preferences Including **additional contact details** (e.g. friend or family)	
Relevant medical information: • **stroke date** and **type** • **brain scans** and **reports** • other **brain diagnoses** • **NHS number** • National Institute for Health **Stroke Scale Scores**	

Speech and language information

- **speech and language therapy records** and department details

- your **speech and language abilities**

- **languages** you speak

'About you' information

- **vision** and **hearing**

- **hand** and foot **dominance**

- **education** and **work**

- **sex** and **gender**

- **ethnicity** and **place of birth**

- **dyslexia** diagnosis

Other studies you are **taking part in**.	
Your access to **technology**.	
If you also **consent** to this: **Audio and video recordings** of you doing a **language assessment**.	

How we look after your data

Your data will be **looked after by:**

- **University College London (UCL)**
- **Professor Cathy Price** – Chief Investigator of the study.

Your **data** 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**.
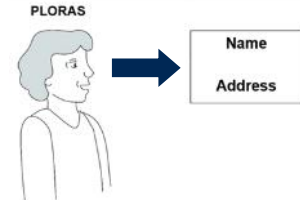
Your data will be **looked after** in accordance with:

- **General Data Protection Regulation (GDPR)**
- **Data Protection Act 2018**

Who can see your data

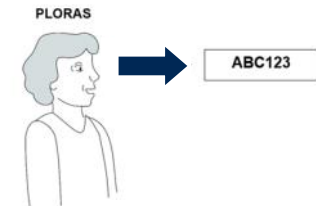|	
Authorised members of the **PLORAS** Team can access **data that identifies you** (i.e. name and contact details).	
This is because they need to: • **check** you can be **included** in the study or • **contact you** about the study.	
Other members of the **PLORAS** Team will access a **coded version of your data** for **analysis**. This **does not include** your **name and contact details**.	

University College London and **your NHS trust** might **audit** or **monitor** the **research**.	
They can **look at relevant sections** of **your medical notes** and **other data** collected.	
Your identity will **not** be **shared** with **anyone else unless** you have **consented** to this.	

Your choices about what happens to your data

Taking part in this study is **your choice.**	
Your consent to take part is needed **before** any **information** about you is **collected**.	
You **can stop** processing of your data **at any time**.	
If you stop, the **researchers** will **keep your data** and continue to **use it confidentially**.	

You **can ask** for **your data** to be **deleted.**

There **may be limits** to this.

For example, **anonymised data cannot be deleted** (as it will **no longer** be **linked to you**).
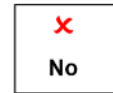
You **may not be able** to:

- **access** your data

- **change** your data

- **move** your data

This is **because** it may affect the **accuracy** of the **research**.

You can **choose which data** can be shared and **who** it can be **shared with.**
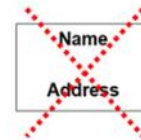
✓ Yes	✗ No

Except for **anonymous data** (as it will **no longer** be **linked to you**).

Data that **does not identify you** may be used for:

- **other research projects**
- **future research** after this study has ended.

What happens to your data

Research data will be **stored securely** for **20 years** after the study has ended.

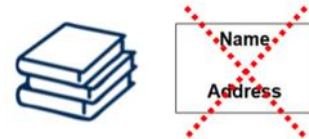This is in case the **researchers** need to **check it**.

20 years

After this time, any **data** that **identifies you** will be **destroyed.**

You will **not be identified** in **any publication** from this study.

Name
Address

Who to contact to discuss the use of your data

PLORAS Research Team See PLORAS Information Booklet for details.	
UCL Data Protection Officer ✉ data-protection@ucl.ac.uk	
If you are **still unhappy**, you can contact the Information Commissioner's Office (**ICO**) ☏ 0303 123 1113 ✉ https://ico.org.uk/global/contact-us/	

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