# 

### PLORAS Interaction Aid for first stage consent

Version 1.0 | October 2023

**Prior to** using this Aid for the first time, please refer to our helpful guide, which includes clear instructions and demonstration videos:



This Aid is designed to complement supported communication strategies.

- 1) Refer to model phrases on left pages
- 2) Guide participant through corresponding images on pages on the right.
- 3) Emphasise words in **bold**, using **intonation**
- 4) **Point to corresponding images/titles** as you say the word (simultaneously)
- 5) Make meaningful **gestures** as you say the word (simultaneously).

Refer to the back page of this Aid for a handy strategy and set up reminder checklist.

Before starting, you **<u>need</u>**:

- 1) pens and blank paper
- 2) printed 'PLORAS Participant First Stage Summary' sheet' (to give to each participant)
- 3) printed 'Initials' page (for participant to practice signing their initials)
- 4) printed 'Participant Consent Form' (for participant to sign and CRN records)

For your convenience, we have included three extra page holders at the back of the Interaction Aid for storing spare copies of these documents.

## Aphasia

Phrase	Gesture
"This is about " <b>aphasia</b> "	Point to title.
" <b>You</b> had a <b>stroke</b> " " <b>Stroke</b> "	<ul> <li>Gesture towards participant.</li> <li>Point to own head, then point to picture.</li> </ul>
"A <b>stroke</b> can make it <b>difficult</b> "	<ul><li>Point to 'stroke' picture.</li><li>Point to 'difficult' picture.</li></ul>
"Difficult to <b>understand</b> "	<ul> <li>Point within 'difficult' picture.</li> </ul>
"This is called <b>aphasia</b> " " <b>Aphasia</b> "	<ul> <li>Gesture whole page.</li> </ul>

#### Reminder:

- emphasise **bolded** words.
   point to the corresponding word/image on the opposite page as you say them.
   Some words are repeated for emphasis.



## **Brain scan**

Phrase	Gesture
"In the <b>hospital</b> "	<ul> <li>Point to 'hospital' picture.</li> </ul>
" <b>You</b> had a <b>brain scan</b> "	<ul> <li>Gesture towards participant.</li> <li>Point to own head, then point to 'brain scan' picture.</li> </ul>
" <b>Brain</b> scan"	<ul> <li>Point to 'brain scan' picture</li> </ul>

#### Reminder:

emphasise bolded words.
 point to the corresponding word/image on the opposite page as you say them.
 o some words are repeated for emphasis.



## **Medical records**

Phrase	Gesture
"The hospital has your medical records" "Medical records"	<ul><li>Point to title</li><li>Gesture whole page.</li></ul>
" <b>Medical records</b> are information"	<ul> <li>Point to 'medical records' picture.</li> </ul>
"About <b>you</b> …"	<ul> <li>Gesture towards participant.</li> </ul>
"About your <b>health</b> "	<ul><li>Gesture towards participant.</li><li>Point to 'your health' picture.</li></ul>
"About <b>you</b> and <b>your</b> health"	<ul><li>Gesture towards participant.</li><li>Point to 'your health' picture.</li></ul>
"Medical records are <b>confidential</b> "	<ul> <li>Point to 'confidential' picture</li> </ul>

#### Reminder:

★ emphasise **bolded** words.

point to the corresponding word/image on the opposite page as you say them.
 Some words are repeated for emphasis.

## **Medical records**



## your health





## confidential



## Questions

Phrase	Gesture
"We want to ask <b>questions</b> "	<ul> <li>Gesture towards yourself (we).</li> <li>Then point to 'questions" picture.</li> </ul>
"Ask you questions"	<ul> <li>Gesture towards participant.</li> <li>Gesture for questions (e.g. shrugging)</li> <li>Point to 'questions' picture</li> </ul>
"In a <b>questionnaire</b> "	<ul> <li>Point to 'questionnaire' picture.</li> </ul>

#### Reminder:

- emphasise bolded words.
   point to the corresponding word/image on the opposite page as you say them.
   Some words are repeated for emphasis.

## Questionnaire



## **Contact details**

Phrase	Gesture
"We want to know your contact details" "Contact details"	<ul><li> Point to title.</li><li> Point to picture.</li></ul>
"For <b>example</b> "	Gesture whole page.
"Your <b>home address,</b> where you live" "Your <b>postal address</b> " "Your <b>address</b> "	<ul> <li>Gesture towards participant.</li> <li>Point to 'address' picture.</li> </ul>
"Your <b>email address</b> " "Your <b>email</b> "	<ul> <li>Gesture towards participant.</li> <li>Point to 'email address' picture.</li> </ul>
"Your <b>phone number</b> " "Your <b>number</b> "	<ul> <li>Gesture towards participant</li> <li>Point to 'phone' picture.</li> <li>Gesture phone (e.g. hand to ear.)</li> </ul>

#### Reminder:

\* emphasise **bolded** words.

point to the corresponding word/image on the opposite page as you say them.
 o some words are repeated for emphasis.



## Introducing "PLORAS"

Phrase	Gesture
"We work with <b>PLORAS</b> " " <b>PLORAS</b> "	<ul><li>Gesture 'air quotes'.</li><li>Point to title.</li><li>Gesture whole page.</li></ul>
"PLORAS is a <b>research</b> team" " <b>Research team</b> "	<ul> <li>Point to 'research' word.</li> <li>Point to 'research team' picture.</li> </ul>
"From <b>UCL</b> " "University College London" " <b>UCL</b> "	<ul> <li>Point to 'UCL' picture.</li> <li>Point to 'University College London' word.</li> <li>Point to 'UCL' picture</li> </ul>
"They research <b>stroke</b> recovery"	<ul><li>Gesture own head.</li><li>Point to 'stroke' picture.</li></ul>

#### Reminder:

★ emphasise **bolded** words.

point to the corresponding word/image on the opposite page as you say them.
 o some words are repeated for emphasis.

## "PLORAS"

## research team



## **University College London**



stroke



## **Sending Information to PLORAS**

Phrase	Gesture
"This is <b>your information</b> "	Gesture participant. Gesture whole box.
"We want to <b>send</b> …"	Gesture yourself (we). Gesture 'send' (e.g. passing something with both hands away from you)
"your information to PLORAS"	Gesture whole box. Drag your finger along the arrow "to". Point to 'PLORAS' picture.
"Send…" "Your contact details" "Contact details"	Drag your finger along the arrow. Gesture towards participant. Point to 'contact details' picture.
<ul><li><b>"Send</b>…"</li><li>"Your <b>answers</b> to questions"</li><li>"The <b>questionnaire</b>"</li></ul>	Drag your finger along the arrow. Gesture towards participant. Point to 'questionnaire' picture.
" <b>Send</b> …""Your <b>brain scan</b> " " <b>Scan</b> "	Drag your finger along the arrow. Gesture towards participant. Point to 'brain scan' picture.
"Send" "Your medical records" "Records"	Drag your finger along the arrow. Gesture towards participant. Point to 'medical records' picture.
"We want to <b>send</b> this <b>information</b> to <b>PLORAS</b> "	Gesture whole box. Drag your finger along the arrow.



-15

## **Contact from PLORAS**

Phrase	Gesture
"PLORAS want to <b>contact</b> you"	Gesture title.
" <b>PLORAS</b> want to <b>contact</b> you"	<ul> <li>Point to 'PLORAS' picture.</li> <li>Point to 'contact' picture.</li> <li>Gesture towards participant.</li> </ul>
"Contact you"	<ul> <li>Gesture 'contact' (e.g. hand as phone to ear).</li> <li>Gesture toward participant.</li> </ul>

#### Reminder:

★ emphasise **bolded** words.

✓ point to the corresponding word/image on the opposite page as you say them.

U some words are repeated for emphasis.

## Contact

## PLORAS



contact



17

## **Summary of Conversation**

Phrase	Gesture
"This is a <b>summary</b> of our conversation" " <b>Summary</b> "	<ul> <li>Gesture whole page.</li> <li>Gesture conversation (e.g. hand moving between you)</li> <li>Point to title.</li> </ul>
"You had a <b>stroke</b> " "A <b>stroke</b> can make <b>communication difficult</b> "	<ul> <li>Gesture 'stroke' (e.g. towards own head).</li> <li>Point to 'stroke' picture.</li> <li>Point to 'communication difficult' picture.</li> </ul>
"You had a <b>brain scan</b> "	<ul><li>Gesture 'brain scan'</li><li>Point to 'brain scan' picture.</li></ul>
"We'll ask you some <b>questions</b> "	<ul> <li>Gesture yourself (we).</li> <li>Gesture 'questions' (e.g. shrugging).</li> <li>Point to 'questions' picture.</li> </ul>
"We <b>send</b> your <b>information</b> to <b>PLORAS</b> "	<ul> <li>Gesture yourself (we).</li> <li>Gesture 'send' (e.g. passing something with both hands away from you).</li> <li>Point to 'information' box.</li> <li>Drag finger along from 'information' box to 'PLORAS' (to).</li> <li>Point to 'PLORAS' picture.</li> </ul>
"PLORAS will contact you"	<ul> <li>Point to 'PLORAS' picture.</li> <li>Point to 'contact' picture.</li> <li>Gesture towards participant</li> </ul>
"This is a <b>summary</b> " "You can <b>keep</b> this"	<ul><li>Gesture whole page.</li><li>Gesture for them to keep.</li></ul>
Give participant a copy of the summary sheet to keep.	

# Summary



## Questions

- Participants may have questions.
- You may need to be creative getting their message 'out', paying close attention to clues they give you (gestures, facial expressions, etc.).
- The opposite page offers some picture/word support for possible questions. There is a 'something else' option for the participant to indicate that the options provided are not what they want to ask. You can write/draw other options you might think of, using key words, on a separate piece of paper.

Phrase	Gesture
"Do you have any <b>questions</b> ?"	<ul> <li>Gesture towards participant.</li> <li>Use a sweeping gesture across the page.</li> </ul>

#### Step 1: Offer page to participant to choose options

- Demonstrate options one at a time using gesture and facial expressions to support their meaning.
- Give the participant time to process what you are saying, and to answer.

#### Step 2: Double check

- E.g. participant indicates 'hurt':
  - Point to 'hurt', look at them, whilst saying 'you want to know if it will hurt?'
  - Get confirmation from them, either through nodding or other indication.

#### Step 3: Answer question

- When you are confident in the participant's question, answer it.
- A simple spoken response may be sufficient, however if more support is needed to understand the question, you can use a separate piece of paper to write the key words and draw symbols/pictures.
- Give the participant time to process what you are saying, and time to respond or follow up.

# Your questions



## Involving someone else

This is a very important step. Even if (and especially if) no other interaction is

successful, you should prioritise this page.

- You will likely complete this with **every** participant who requires support (not only for permission for liaising with consultees).
- It is crucial in acknowledging the participant's competence and **our** limitations as communicators.
- It empowers the participant to choose whether another person is involved.

Phrase	Gesture
"I need to ask <b>someone else</b> "	<ul><li>Gesture towards yourself</li><li>Point to title.</li></ul>
"I know <b>you know</b> what you want to say…"	<ul> <li>Gesture towards yourself (I)</li> <li>Gesture towards participant (you).</li> <li>Gesture 'know' (e.g. own head)</li> <li>Gesture "say" (e.g. own mouth)</li> </ul>
"I know you are <b>intelligent</b> "	<ul> <li>Gesture towards yourself (I).</li> <li>Gesture towards participant.</li> <li>Gesture 'intelligent' (e.g. own head.)</li> </ul>
"Aphasia can make it <b>hard</b> "	<ul><li>Gesture 'hard' (e.g. frowning/frustrated)</li><li>Point to picture 'difficult'.</li></ul>
" <b>I'm</b> finding it <b>difficult</b> "	<ul> <li>Gesture towards yourself (I).</li> <li>Point to 'difficult' picture.</li> <li>Gesture 'difficult' (e.g. frowning)</li> </ul>
"l'm <b>sorry</b> "	Gesture towards yourself.
"If I ask <b>someone else</b> …"	<ul> <li>Gesture towards yourself.(I)</li> <li>Gesture towards 'someone else' picture</li> <li>(someone else may be in the room – indicate them).</li> </ul>
"It will <b>help</b> me"	Gesture towards yourself.
"We can <b>work together</b> "	<ul><li>Gesture between the two of you.</li><li>(or three of you if someone else is there)</li></ul>
"Is it <b>OK</b> if I ask someone else?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>

## Someone else?

## difficult



someone else











No

## Yes

## **Participant Consent Question 1a**

- The following pages are to support you in getting the participant's message 'out'.
- The aim is to provide participants with a way of expressing whether or not they consent to statements in Participant Consent Form (Part 1).
- For each page, give the participant time to process what you are saying and to answer.
- See 'initialling' section for participants needing support to understand 'initial in the box'

Phrase	Gesture
Repeat part	s as needed
"Is it <b>OK</b> ?"	Point to title.
"Is it <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK</li><li>Make eye contact.</li></ul>
"Brain scan sent to PLORAS?"	• Drag finger along the arrow.
"Is that <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>

#### Step 1: Offer page to participant to choose options

• Demonstrate options one at a time gesturing thumbs up and thumbs down whilst saying "yes" or "no", and shrugging whilst saying "don't understand"

#### Step 2: Double check

- E.g. participant indicates 'yes':
  - Point to 'yes', look at them, nod/thumbs up whilst saying 'yes?'.
  - Get confirmation from them, either through nodding or other indication.

#### Step 3: Transfer answer to consent form

• When you are confident in the participant's answer, indicate the corresponding consent statement on the consent form, and allow them time to initial or mark in the box.

# Is it OK?



**PLORAS** 









## **Participant Consent Question 1b**

Phrase	Gesture	
Repeat parts as needed		
"Is it <b>OK</b> ?"	Point to title.	
"Is it <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK</li><li>Make eye contact.</li></ul>	
" <b>Medical records sent</b> to <b>PLORAS</b> ?"	<ul> <li>Drag finger along the arrow.</li> </ul>	
"Is that <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>	

#### Step 1: Offer page to participant to choose options

• Demonstrate options one at a time gesturing thumbs up and thumbs down whilst saying "yes" or "no", and shrugging whilst saying "don't understand"

#### Step 2: Double check

- E.g. participant indicates 'yes':
  - Point to 'yes', look at them, nod/thumbs up whilst saying 'yes?'.
  - Get confirmation from them, either through nodding or other indication.

#### Step 3: Transfer answer to consent form

• When you are confident in the participant's answer, indicate the corresponding consent statement on the consent form, and allow them time to initial or mark in the box.

# Is it OK?

## medical records

send

PLORAS









## **Participant Consent Question 1c**

Phrase	Gesture	
Repeat parts as needed		
"Is it <b>OK</b> ?"	Point to title.	
"Is it <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK</li><li>Make eye contact.</li></ul>	
"Questionnaire sent to PLORAS?"	<ul> <li>Drag finger along the arrow.</li> </ul>	
"Is that <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>	

#### Step 1: Offer page to participant to choose options

• Demonstrate options one at a time gesturing thumbs up and thumbs down whilst saying "yes" or "no", and shrugging whilst saying "don't understand"

#### Step 2: Double check

- E.g. participant indicates 'yes':
  - o Point to 'yes', look at them, nod/thumbs up whilst saying 'yes?'.
  - Get confirmation from them, either through nodding or other indication.

#### Step 3: Transfer answer to consent form

• When you are confident in the participant's answer, indicate the corresponding consent statement on the consent form, and allow them time to initial or mark in the box.

# Is it OK?





## **Participant Consent Question 1d**

Phrase	Gesture	
Repeat parts as needed		
"Is it <b>OK</b> ?"	Point to title.	
"Is it <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK</li><li>Make eye contact.</li></ul>	
"Contact details sent to PLORAS?"	<ul> <li>Drag finger along the arrow.</li> </ul>	
"Is that <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>	

#### Step 1: Offer page to participant to choose options

• Demonstrate options one at a time gesturing thumbs up and thumbs down whilst saying "yes" or "no", and shrugging whilst saying "don't understand"

#### Step 2: Double check

- E.g. participant indicates 'yes':
  - Point to 'yes', look at them, nod/thumbs up whilst saying 'yes?'.
  - $\circ$  Get confirmation from them, either through nodding or other indication.

#### Step 3: Transfer answer to consent form

• When you are confident in the participant's answer, indicate the corresponding consent statement on the consent form, and allow them time to initial or mark in the box.

# Is it OK?









## **Participant Consent Question 2**

Phrase	Gesture	
Repeat parts as needed		
"Is it <b>OK</b> ?"	Point to title.	
"Is it <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK</li><li>Make eye contact.</li></ul>	
"PLORAS contacts you?"	<ul><li>Point to PLORAS picture</li><li>Point to contact picture</li></ul>	
"Is that <b>OK</b> ?"	<ul><li>Gesture thumbs up / OK.</li><li>Indicate options on page.</li></ul>	

#### Step 1: Offer page to participant to choose options

• Demonstrate options one at a time gesturing thumbs up and thumbs down whilst saying "yes" or "no", and shrugging whilst saying "don't understand"

#### Step 2: Double check

- E.g. participant indicates 'yes':
  - Point to 'yes', look at them, nod/thumbs up whilst saying 'yes?'.
  - Get confirmation from them, either through nodding or other indication.

#### Step 3: Transfer answer to consent form

• When you are confident in the participant's answer, indicate the corresponding consent statement on the consent form, and allow them time to initial or mark in the box.

# Is it OK?

## PLORAS









## Initialling

Some participants may have difficulty understanding instructions for marking their initials on the consent form. Use this separate page to illustrate 'writing your initials' to support participants' understanding of this step.

Phrase	Gesture
"Write your <b>initials</b> "	Point to title.
"Initials are your <b>name</b> "	<ul> <li>Gesture towards participant (your).</li> <li>Point to '<b>name'</b> picture.</li> </ul>
"[participant's first name]" "[participant's last name]"	• Write as speaking.
"Take the <b>first</b> letter"	<ul><li>Gesture holding up one finger.</li><li>Point to first letter of first name.</li><li>Drag finger along arrow.</li></ul>
"[participant's first letter of first name]"	• Write as speaking.
"Take the <b>first</b> letter…"	<ul><li>Gesture holding up one finger.</li><li>Point to first letter of last name.</li><li>Drag finger along arrow.</li></ul>
"[participant's first letter of last name]"	• Write as speaking.
"Those are your initials"	Point to initials.
"Write your <b>initials here</b> "	<ul> <li>Indicate actual place to initial on consent form Part 1.</li> </ul>

## Initials

### your name

[Write participant's first name below (with first letter in box), whilst saying it out loud]



### **Reminder Checklist**

### Set Up for Success

#### Set up the environment

- Sit side by side
- Make regular eye contact
- Read facial cues
- Limit group size
- Minimise visual distractions
- Minimise background noise
- Schedule at a quiet time
- Allow extra time

#### Set up the person with

#### aphasia

Dentures

- Visual aids
- Hearing aids
- Interpreter
- Fatigue

Memory/Cognition

Mood

#### Always acknowledge

#### competence

Use adult tone of voice
-------------------------

- "I know you know"
- Acknowledge frustrations
- Deal openly with limitations
- Make the conversation feel good use humour and connect
- Attribute breakdowns to yourself as a communicator

#### Strategies

Make your message clear – adjust your speech

#### Slow down

- Simplify words
- Short, simple sentences
- Emphasize key words
- Use intonation
- Use repetition

#### Help the person understand

- Use meaningful gesture
- Write key words
- Use pictures
- Use drawings
- New idea, new page

#### Help the person express

- Provide fixed choices
- Ask yes or no questions
- One thing at a time
- Ask for a clue
- Get creative
- Allow extra time for the participant to respond

#### Always double check (verify)

- Reflect
- \_ Expand
- Summarize

### **Consent Flow Chart**

