
Cognitive functioning and its relationship with identity and future thinking in stroke

A Data Management Plan created using DMPonline

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Assessment of existing data

Existing databases of active participants will be contacted to participate in this study. Existing data collecting from these participants will then be used (such as scans already collected, behavioural data).

Additional participants will be recruited for this work for power reasons, and additional data will need to be collected (detailed below).

Information on new data

- Approximately 40 stroke patients will take part. Participants will be asked various questions regarding background demographics regarding themselves and their stroke
- Neuropsychological tests will be used to establish the level of language, memory and executive impairments in participants with stroke.

1. For language assessments, our research will include tasks such as the Boston Diagnostic Aphasia Examination (Goodglass, 1983) and the Psycholinguistic Assessments of Language Processing in Aphasia (Kay, Lesser, & Coltheart, 1992b). These tasks will provide an assessment of language fluency, repetition and comprehension.

2. For semantic processing assessments, our research will include tasks such as the four tasks from Cambridge semantic battery (Bozeat, Lambon Ralph, Patterson, Garrard, & Hodges, 2000). These involve naming, matching items or pairing associations which are either verbal or non-verbal (e.g., pictures).

3. To assess semantic control, we will include tasks such as the ambiguity test, presenting homonyms in dominant and subordinate conditions (e.g., bank goes with money or river, Noonan et al., 2010). These will include verbal and non-verbal assessments.

4. In our assessment of more general neuropsychological and executive functioning, our research will include tasks such as forwards and backwards digit span (Wechsler, 1987), and Raven's Coloured Progressive Matrices test of non-verbal reasoning (Raven, 1962).

5. Participants may also be invited to have a MRI brain scan at CUBIC in Royal Holloway, when this is required to establish their pattern of brain damage. All of the standard MR safety procedures will be followed and a researcher who is familiar to the patient will be present during the scanning. Participants are not required to have a scan to participate in other aspects of our research.

6. Identity will be measured using questionnaires, which, where necessary, will be adapted to be aphasia friendly. A number of published scales have already been adapted for use in brain injury patients, including the Head Injury Semantic Differential Scale – III (pre stroke, current self), allowing for self-discrepancy to be calculated. Additional scales include the Self-Concept and Identity Measure (SCIM, Kaufman et al., 2015).

7. Self-awareness will be measured using questionnaires such as the Awareness questionnaire (AQ, Sherer, 2004), comparing post- and pre-injury functioning (e.g., 1 = much worse, 3 = about the same, 5 = much better). These will be compared to caregiver ratings on the same items. Self-awareness is the discrepancy between these scores.

8. Future thinking will be tested using a task such as the Autobiographical Interview (protocol in Levine et al., 2002), probing events using nouns, such as in Addis et al., 2008) adapted for patients using a method similar to Irish et al. (2012). This probes both past and future event construction, followed by the interview (Levine et al., 2002), to elicit further details.

We will employ a battery of cognitive tests to determine the degree of impairment to different language, executive and memory processes for each individual. To assess clinical outcome, we will run a series of questionnaires. The cognitive assessments typically be pencil and paper-based tests; for example, participants may be asked to read words aloud, to name pictures of objects, to repeat short lists of words or to make judgements about the meanings of words. Some assessments may be presented on a laptop, and some in booklet form. Where remote testing is required (for example, due to social distancing in light of COVID-19), we will use Zoom to share our screen to present items which are usually shown to a participant face-to-face. Questionnaires may be shared in paper format to be sent back, or via an internet link (using a questionnaire software such as Qualtrics). It may also be run through with the participants face-to-face (or via a virtual meeting such as via zoom). The method used will be in relation to the participants preferences.

Participants will be invited to have an MRI scan at CUBIC, the imaging centre based at Royal Holloway when this is necessary to determine which brain structures are damaged (e.g., where a previous scan does not exist). MRI brain scanning will allow deficits to be related to specific aspects of brain damage.

Quality assurance of data

Data that is collected via Zoom when quantitative (e.g., selecting an item), will be typed directly into a spreadsheet for storage. When data is collected in person, this will be noted onto paper and translated to an electronic spreadsheet upon return to the office. When data are more complex, such as verbal responses to a more general question, an audio recording will be taken (with consent), or when on zoom, a video recording of the session (with consent). All files will be kept, securely, where consent allows.

Backup and security of data

Data from the study will be stored in secured offices (if paper files) or on protected drives if electronic. Any details containing personal information such as names will be stored separately from data sheets. Data sheets will be coded so participants are anonymous. Electronic files with anything personal such as names will be password protected. Any participant who wishes to withdraw data will be able to do so, until the point at which data are published. In this case, all personal information will be deleted and data files for that individual will be destroyed.

Management and curation of data

All data will be recorded, where applicable, on standardised score sheets. When handwriting occurs (such as during face-to-face testing of fluency tasks), responses will be typed up by the researcher upon return to the office. All anonymised data will be input onto the same spreadsheet, to allow for direct comparison.

Difficulties in data sharing and measures to overcome these

Due to the sensitivity and individuality of the structural brain scans obtained from stroke patients, consent will not be gained for public archiving of data. Researchers who wish to access this data should contact the researcher and all data to replicate results will be released, when this is possible under the terms of GDPR (General Data Protection Regulation EU, 2016/2017) and subject to approval from the Research Ethics and Committee of the University of Surrey.

Consent, anonymisation and strategies to enable further re-use of data

We will never recruit anyone who doesn't have the capacity to consent themselves (as described in the Mental Capacity Act). The PI will always be present during the first visit and take consent prior to testing. The consent form has been specifically adapted to minimise the amount of language used for these patients with language impairments, whilst still covering all the necessary points. Where testing is done remotely (in light of COVID-19), forms will be sent electronically, whichever is the participants preference to the participant in advance. In this instance, we will regard a typed name on the form as consent.

For some testing, it will be helpful to gain a caregivers perspective to assess potential discrepancies between perception of the impact of stroke by the patient and caregiver (and therefore insight into the stroke participants' condition). For this testing, live-in unpaid caregivers (typically a relation - usually a spouse, but may be a sibling, parent or child) will be asked for their consent to complete questionnaires regarding the stroke participant. If a caregiver is unavailable, unable or does not wish to consent to take part, this does not stop the stroke participant continuing participation in all other aspects of the research.

Copyright and intellectual property ownership

Behavioural data will be provided in the Open Science Framework (OSF; <https://osf.io/cxubp/>). Digital materials where possible will also be available

in the OSF (<https://osf.io/6s7fg/>) and any that are inaccessible due to the programme used can be released by contacting the PI.

The background neuropsychological materials are not provided on OSF since these included published and copyrighted tests, and because they were administrated as 'paper and pencil tests'. Researchers who wish to access these materials should contact the PI.

Responsibilities

The PI is responsible for all data management at the University of Surrey. Where data is collected at the University of York, all consent forms and data will be stored in accordance with this DMP and kept securely under the responsibility of Prof Beth Jefferies.