Edinburgh Cognitive and Behavioural ALS Screen

Standard Operating Procedure SOPHIA July 2013

A. Instructions below.
B. Guidelines for administration and translation (separate file).
C. Data entry file (separate file).

A. Instructions

1. ALS Patients: The number of ALS patients to be tested per centre is 40.

Exclusion criteria: people in the terminal stages of ALS, severe diabetes, epilepsy, pre-existing psychiatric disorder, or alcohol/substance-related disorders, severe head injury that has required hospitalisation in an intensive-care setting, traumatic brain injury including subarachnoid haemorrhage, significant cerebrovascular disease or stroke, significant childhood developmental delay, reading or writing developmental problems including dyslexia.

2. Healthy Controls: The number of healthy controls to be tested per centre is 40.

Recruitment of healthy controls is essential to produce local normative data to determine appropriate cut-offs for abnormality. These are best selected from the same social grouping as the ALS patients, e.g. spouses or non-blood relatives or friends.

20 of the healthy control should undertake the written version of the verbal fluency test and 20 undertake the spoken version. This will enable separate normative data to be produced for each measure. See guidelines for detailed explanation.

3. Place of testing: The clinic is the optimal place of testing in a quiet room with just the patient and the tester. Testing can take place in the patient's home if need be in quiet space without distractions. Testing can be done by an MND nurse specialist. The carer interview should be undertaken separately and confidentially.

4. Length of interview: The patient interview takes 20 minutes to perform and should be performed in one continuous period. The carer interview can take place on a separate occasion.

5. Test performance: The patient can respond verbally, written or using a speech aid as long as the predictive text is switched off. If a patient finds a subtest too difficult a score of 0 is given. In the rare occurrence that a patient stops the test before the end of the interview, the participant data should be excluded.

6. Repeated Testing: Repeatable parallel versions for longitudinal assessment are not yet available. Repeated assessment using the current version should leave a 6 month period between assessments.

7. Data Entry: Data should be entered into the attached excel file and e-mailed back to Dr Sharon Abrahams (s.abrahams@ed.ac.uk). Data processing (patient and normative control data) will be undertaken by Dr Sharon Abrahams.

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