

Administration

The SAQOL-39g is applicable to people who have experienced a stroke, including people with aphasia. It can be used with people with any severity of expressive aphasia. For people with receptive aphasia, we have established that those with a score of $\geq 7/15$ on the receptive domains of the Frenchay Aphasia Screening Test (FAST, Enderby et al., 1987) (moderate or mild receptive aphasia) are able to self-report reliably on the SAQOL-39 (Hilari et al., 2001; 2003).

Before you administer the SAQOL-39g for the first time, we recommend that you:

****PRINT THE SAQOL-39g PRESENTATION FORM AND SCORE SHEET TO REFER TO WHILST READING THESE ADMINISTRATION INSTRUCTIONS****

Interviewer-administration vs. self-completion

The SAQOL-39 is a self-report measure. It is intended to be interviewer-administered with people with aphasia. This way people with receptive aphasia can benefit from a multi-modal presentation. For example, they can both read and listen to the questions, they can see the interviewer's gestures or facial expression. People with expressive aphasia can just point to their responses. People with stroke without aphasia may be able to self-complete. We generally recommend that interviewers score the SAQOL-39 on the scoring form, but some respondents may prefer to do it themselves (use self-complete hard copy form).

For people with severe aphasia who are not able to self-report on the SAQOL-39, a proxy person (a significant other who knows them well) may report for them (on the proxy form).

If a person with stroke completes the SAQOL-39 on a self-complete form or if a proxy form is used, clinicians/researchers would still need to use the scoring form to calculate the SAQOL-39 scores.

Overall set-up

During administration, both the SAQOL-39 presentation form and the scoring sheet are used. The interviewer overall follows the SAQOL-39 presentation form as, apart from the questions, it includes general instructions, transition sentences (e.g., '*the first set of questions ask how much trouble you have had with daily activities*') and practice items. Once the respondent has given his/her response, the interviewer marks it on the scoring sheet.

Starting the administration - practice items and response options

It is recommended that prior to the administration the interviewer explains to the respondent what the SAQOL-39 covers and what the purpose of the assessment is.

The administration starts with the interviewer showing the SAQOL-39 presentation form to the person with stroke/aphasia and reading the general instructions. Then the first transition sentence is given and the interviewer goes through the first example/practice item. Practice items *are not scored*. Their aim is to familiarise the respondents with what the questions look like and with the response formats.

For the first practice item, the interviewer reads the item and the alternative response options and asks the respondent to point to their response. For people with reading difficulties it is useful to highlight the anchor points (*✗* = couldn't do it, *✓* = no trouble). The interviewer makes sure that the respondent understands the response options and can point to their response before moving on to the actual questions.

The response options of the second practice item (page 11, 'Did you feel hopeless about your future?') require some clarification. After reading this item the interviewer should explain the response options by saying:

“Definitely yes, if you *really* felt hopeless about your future.
Mostly yes, if *often* you felt hopeless about your future.
Not sure, if you are not sure how you felt.
Mostly no, if *occasionally* you felt hopeless, and
Definitely no if you *did not* feel hopeless at all about your future”.

Thereafter if the participant looks unsure on specific items the interviewer should give similar prompts.

Asking the questions

The interviewer asks each question in turn. After a few questions, the interviewer can use discretion and not repeat the 'DURING THE PAST WEEK' phrase or the lead-in questions (e.g., 'how much trouble did you have..') before every single item as this can affect the flow of questions.

BEAR IN MIND: two questions require an extra oral prompt:

- UE1 on trouble with writing/typing requires a clarification that it refers to the mechanics of writing (i.e., the interviewer needs to say “*i.e., using your hand to write or type*”);
- T4 on writing things down to remember them requires an alternative question for people who have difficulty with writing (the interviewer needs to say “*or ask somebody else to write things down for you to remember*”).

Facilitation strategies

During administration, the interviewers can use various facilitation strategies to help people with aphasia.

- They can point to the item they are saying.
- On the hard copy, they can cover the other questions on the page to facilitate concentration.

- If a respondent looks unsure after a question they can check their understanding (e.g., “Is this clear?”) and repeat the question.
- For people with moderate comprehension problems they can use total communication techniques to facilitate their understanding. For example, they can gesture or mime for demonstrable items (e.g., ‘doing buttons’, ‘climbing stairs’, ‘opening a jar’). They can also use natural gesture and facial expression (e.g., to express degree like ‘*little confidence*’, ‘go out *less often* than you would like’ or to express moods/emotions like ‘have *no interest* in other people’, ‘feel *withdrawn* from other people’).

Trouble shooting respondents’ difficulties in choosing a response

‘How much trouble did you have’ questions: Overall, respondents find the ‘how much trouble did you have..’ questions and the relevant response options straightforward.

‘Yes-no’ questions: In answering a few of the ‘yes-no’ questions, some people may require an overall reminding of what the response options mean (see last paragraph in ‘Starting administration and practice items’ above).

Alternatively, some people may choose an option but look unsure. For example, a respondent may choose ‘mostly yes’ in response to ‘did you have no interest in other people or activities?’ but look unsure. The interviewer can then confirm this choice by saying e.g., ‘so often you had no interest in other people or activities?’.

Questions including a comparative (SR1, 4, 5): For the three items that include comparative (e.g., ‘did you go out less often than you would like?’), the prompts given above, which are based on frequency, may be confusing. An example will be used to illustrate how to facilitate a respondent who seems to have difficulty answering one of these questions. Suppose a respondent points to ‘mostly no’ in response to the question on going out less often than he would like, but looks unsure about it. The interviewer can:

- Point to the ✓ anchor point and say something like “so overall it was alright?”
- Ask a question to confirm the respondent’s choice, e.g., “so you went out more or less enough?”

If, following such prompts, the respondent changes their mind and points to ‘mostly yes’, the interviewer can confirm this is the intended choice by saying something like ‘so you wish you’ d gone out more?’ or ‘so more would have been better?’