

Involving aphasic stroke survivors in development of an ‘aphasia-friendly’ post-stroke assessment tool

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What was the problem?

No one is better qualified to answer the question “How have you been recently?” than the stroke survivor themselves. However, for the 12% of stroke survivors who are still aphasic six months after leaving hospital, understanding and effectively responding to such questions can be difficult. This can make the delivery of effective post-stroke reviews challenging. Service providers often rely on the presence of a carer or family member which can not only have negative consequences for stroke survivors’ self-esteem but can also impact on the quality of responses received, particularly in relation to questions regarding emotions and feelings. Working with **Speakeasy**, a communication support charity based in the North West of England, we therefore set out to develop an aphasia-friendly version of GM-SAT: the Greater Manchester Stroke Assessment Tool, an assessment tool purposely developed to review the long term needs of stroke survivors six months post hospital discharge.



What did we do?

- A ‘**Stroke Assessment Tool User Group**’ was formed, comprising of nine aphasic stroke survivors and three expert facilitators. The members of the group with aphasia represented a wide array of aphasia classifications.
- **Six, two hour group meetings** were held.
- Each group member was provided with transport to and from all meetings, refreshments and an honorarium.
- At each meeting, the group worked through GM-SAT, discussing and agreeing on how it should be made aphasia-friendly. This included, **rephrasing questions, adding pictures and symbols, highlighting individual words and modifying the text size and font.**

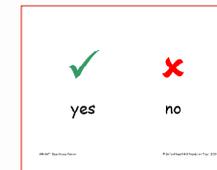
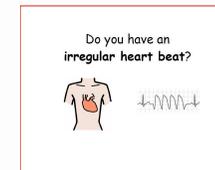


- After each meeting, **GM-SAT was modified** in accordance with the discussions had and decisions made at the meeting.
- Materials were taken back to the meeting the following week to be **approved and signed off** by the user group.
- Notably, all changes made to GM-SAT were solely driven by the members of the user group with aphasia.

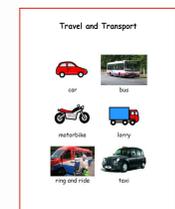
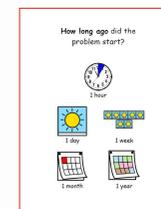
What did we achieve?

The group developed an **Easy Access GM-SAT Toolkit**, comprising of two resources:

1. **Trigger Question Binder:** a set of 38 close-ended questions used to quickly and efficiently identify any long term, post-stroke problems a stroke survivor may be experiencing. The binder covers the full content of GM-SAT, from medication management and pain, through to fatigue and depression.



2. **Conversation Support Resource (CSR):** a comprehensive resource designed to enable the reviewer to explore any presenting problems, identified using the trigger questions, in more detail. For example, when the problem started, what caused the problem, how often the problem occurs and how severe the problem is. It can additionally be used to offer explanations and reassurance in relation to any problems identified and to engage individuals in decisions regarding their future care.



Impact

- The **Easy Access GM-SAT Toolkit** is a resource produced **by** people with aphasia **for** people with aphasia.
- Whilst working with aphasic stroke survivors can be time consuming and present its own challenges, having these individuals at the heart of this piece of work ensured production of a high quality resource.
- Implementation of the Toolkit in practice has ensured that aphasic stroke survivors receive a more personalised experience of care and, crucially, that their long term post-stroke needs are identified and addressed as effectively as those of their non aphasic peers.