

Patients as partners: Development of the post-stroke 'Easy Access Toolkit'

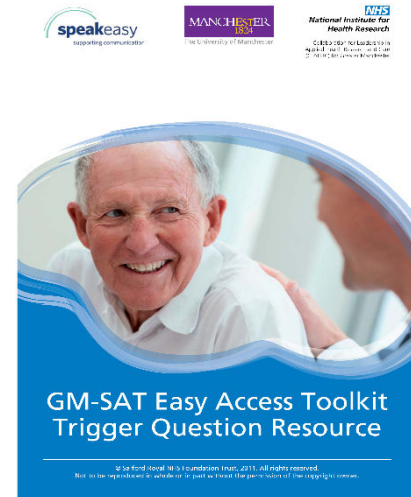
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Stroke six month reviews are a key requirement of the 2007 English National Stroke Strategy. The aim of this study was to work with patients to develop and implement the 'GM-SAT Easy Access Toolkit', a comprehensive resource that can be used to identify and address the long-term needs of people who have complex communication problems as a consequence of stroke.

"The GM-SAT is easy to use and go through with clients during their review and the easy access version is helpful for patients with all levels of language and cognitive difficulties. Even for patients whose aphasia is mild and who may understand the question verbally, it can really help them express themselves and keep track of the conversation"



Background and objectives

Aphasia is a complex and highly individual language processing disorder which affects speaking and writing, and also understanding both the spoken and written word. It is estimated that a third of all stroke survivors will experience some degree of aphasia after their stroke and an estimated 50,000 people become aphasic due to stroke every year in the UK. Those people who personally experience aphasia are often excluded from decision making processes and discussions which may affect them. This directly conflicts with the drive to place the patient at the heart of the decision making process.

The 2007 English National Stroke Strategy requires all stroke survivors and their carers to receive regular reviews of their health and social care needs post-stroke, including a review six months post-hospital discharge. However, for the 12% of stroke survivors who are still aphasic six months after leaving hospital, understanding and effectively participating in such reviews can be 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 within a review, particularly in relation to questions regarding the emotional and cognitive effects of their stroke.

Working with Speakeasy, a communication support charity based in the North West of England, we therefore set out to work with in partnership with stroke survivors with aphasia to develop an 'easy access' version of the GM-SAT: the Greater Manchester Stroke Assessment Tool, an assessment tool purposely developed for six month post-stroke reviews.

The specific objectives of the study were:

- To use a user-led strategy to develop a post-stroke assessment tool accessible for people with aphasia.
- To implement the assessment tool in the community to ensure that the needs of this specific stroke population are appropriately identified and addressed in a timely manner, leading to more equitable service provision, improved outcomes and increased quality of life for patients and carers.

Methods

A 'Stroke Assessment Tool User Group' was created comprising of eight people with varying degrees of severity, complexity and impact of aphasia post-stroke. This group was supported by three expert facilitators and was tasked with leading the development of a version of the Greater Manchester Stroke Assessment Tool (GM-SAT) that was appropriate and accessible for people with aphasia post-stroke.

The group met for 2 hours biweekly for a period of approximately six months and worked to identify and agree upon the important characteristics of accessible information, such as the use of simple words, short sentences and relevant images, symbols and pictures. Using this as a basis, during subsequent meetings, the group then worked through the original version of the GM-SAT section by section, applying these principles and making the information appropriate for people with aphasia. Notably, all changes made to the GM-SAT was driven solely by the members of the user group.

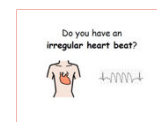


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Results and Conclusions

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

- Trigger Question Resource (TQR):** 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 resource covers the full content of the GM-SAT, from medication management and pain, through to fatigue and depression.
- 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 GM-SAT Easy Access Toolkit has been adopted by a number of health, social and voluntary care sector organisations across the United Kingdom. While requiring significant planning and resource, adopting a user-led approach was key to ensuring production of a quality resource that is appropriate and capable of meeting the needs of people with aphasia after stroke.

Application of the GM-SAT Easy Access Toolkit has ensured that the post-stroke needs of people with aphasia are as effectively identified and addressed as those of their non-aphasic peers.