

# Top ten research priorities relating after stroke

By Alex Pollock and Bridget St George

A collaborative project, carried out by researchers from the Nursing Midwifery and Allied Health Professionals (NMAHP) Research Unit at Glasgow Caledonian University, has identified the Top Ten shared research priorities of stroke survivors, carers and health professionals relating to life after stroke.

We carried out this two-year project in collaboration with the James Lind Alliance (JLA), a national organisation (funded by the National Institute for Health Research), which aims to ensure meaningful patient involvement in research priority setting. The JLA supports the development of Priority Setting Partnerships (PSPs), which bring together patients, health professionals and their representative groups within equal partnerships. These PSPs identify and prioritise unanswered questions ('treatment uncertainties'). Central to the PSPs is the equal involvement of everyone at all stages of a prioritisation process.

Our 'Life after Stroke' PSP was led by a representative steering group which included a stroke survivor, carer, physician, nurse, allied health professional and researcher. In order to gather our treatment uncertainties, as well as using postal and electronic surveys, we used methods specifically designed to reduce barriers to equal participation. Many stroke survivors have impairments which could prevent or limit ability to get involved, such as difficulties with communication, movement or understanding. Also, we wanted to enable involvement of stroke survivors and health professionals from across the whole of Scotland, including the many remote rural areas and islands. Our specially designed methods included face-to-face visits at

stroke support groups and clubs across Scotland. We also produced information in a variety of formats, including written information, presentations, audio versions and information sheets specifically for people with aphasia (a common communication impairment after stroke). During our visits to stroke survivor groups / clubs the standard presentation was delivered using the most appropriate mode for the venue and group. We were pleased that the methods we used were successful in achieving roughly equal involvement in terms of numbers of stroke survivors / carers and health professionals.

Through this process, we gathered a total of 548 treatment uncertainties, 54% of which were submitted by stroke survivors and carers and 46% of which were submitted by health professionals. After checking and merging similar questions, we involved stroke survivors, carers and health professionals in setting 24 interim priorities. We then held a consensus meeting (of stroke survivors, carers and health professionals), where these priorities were discussed until consensus was reached on a shared Top Ten.

The Top Ten were:

1. What are the best ways to improve cognition after stroke? [Cognition: the function of processing information and applying knowledge. Functions include processes requiring thought and intelligence, such as attention, perception, learning, memory, comprehension, judgment and decision making]
2. What are the best ways of helping people come to terms with the long term consequences of stroke?
3. What are the best ways to help people recover from aphasia?
4. What are the best treatments for arm recovery and function, including visual feedback, virtual reality, bilateral training, repetitive task training, imagery / mental practice, splinting, electromechanical and robot-

assisted arm training, and botulinum toxin [a type of injection to relax muscles, commonly known as 'botox']?

5. What are the best ways to treat visual problems after stroke?
6. What are the best ways to manage fatigue?
7. What are the best treatments to improve balance, gait and mobility, including physiotherapy, gait rehabilitation, visual and auditory feedback, electrical stimulation, different types of ankle foot orthoses [splints] and electromechanical assisted gait training?
8. How can stroke survivors and families be helped to cope with speech problems?
9. What are the best ways to improve confidence after stroke, including clubs / groups, offering support, one-to-one input and re-skilling?
10. Are exercise and fitness programmes beneficial at improving function and quality of life and avoiding subsequent stroke?

Interestingly, the views of stroke survivors appear to have had slightly greater impact on the final Top Ten than the views of health professionals. Stroke survivors and carers made eloquent and convincing arguments in support of some key questions that appear in the Top Ten, including several that health professionals would not have placed there independently. The consensus meeting provided an opportunity for both stroke survivors and health professionals to debate their opinions on research priorities, to reach understanding of the opinions of others, and to successfully reach consensus on the shared top priorities.

We feel that we achieved equal involvement of stroke survivors, carers and health professionals at all stages of this process. These Top Ten shared research priorities should ensure that future research targets the issues which are most important to those directly affected by stroke.

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