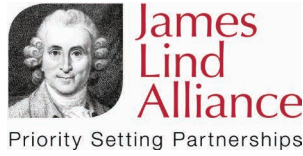


Priorities in stroke rehabilitation and long-term care



The priorities are areas of evidence uncertainty in stroke policy and practice established by the James Lind Alliance Stroke Priority Setting Partnership.

This means there are no up-to-date, reliable reviews of research evidence to guide treatment and care, or that up-to-date reviews show that uncertainty exists (James Lind Alliance, 2021). The priorities can guide research investment to address the issues that matter most to people affected by stroke.

1. Mental and emotional (psychological) problems can be caused by stroke/TIA.

How common are psychological problems and what impact do they have on the lives of people affected by stroke (including the children of stroke survivors); what factors and interventions can best prevent psychological difficulties, support adjustment, and improve motivation, well-being and engagement; how cost-effective are these interventions and how can they be made available to people affected by stroke?

2. Thinking and memory (cognitive) problems can be caused by stroke.

What is the best way to assess for, understand the impacts of and track progression in all areas of cognition – including using standardised measures – across the stroke pathway; what and how can interventions and services involving multidisciplinary teams and families be made accessible, and how can information on these problems be provided?

3. Stroke can affect communication abilities, such as reading, speaking and listening as well as social and related 'thinking' skills (cognitive communication disorder).

What are the effects of, and best assessments and interventions for, the range of communication difficulties in stroke survivors?

4. People with stroke/TIA can experience fatigue.

How common is fatigue; what and why are there various types, causes/triggers and experiences of its effects? What are the best ways to recognise, reduce, treat and self-manage fatigue - including in young stroke survivors and for all types of stroke, including sub-arachnoid haemorrhage - to minimise the impact on recovery and life after stroke?

5. How can community stroke services best be resourced and organised in all regions to provide effective home/community-based rehabilitation that meets the needs of all groups of stroke survivors such as ethnic groups, young people, stroke severities and those with multiple health conditions?

6. What and how common are the long-term impacts of stroke on abilities necessary for every-day life; what, and how can, interventions be made available to facilitate these abilities?

For example, impact on and interventions including education, assessment, treatment and support for return to work, driving, relationships and financial well-being.

7. What is the best time, place and amount of therapy (e.g. speech and language therapy, physiotherapy, occupational therapy) to get the best outcomes for stroke survivors, and is this different than advised in the Stroke Guidelines (5 times a week for 45 minutes)?
8. How can people supporting stroke survivors work best with the stroke care team, and what personalised training and support is available for carers to enable them to support stroke survivors and their recovery, including those with communication, cognitive and engagement difficulties?

For example, the roles of family members, volunteers, stroke liaison workers and young carers.

9. What are the best interventions including exercise to improve strength and fitness, promote recovery and prevent further stroke in stroke survivors?
10. What do stroke survivors think and feel works well, or needs improvement as they move through the stroke pathway, including the intensity of rehabilitation; what can be done to improve the stroke survivor and carer experiences?
11. What is the best intervention to improve outcomes for people with severe stroke and long-term disability, and what can be gained from longer-term rehabilitation provided at home and in nursing homes?

Outcomes include measures of physical ability (functional outcomes) and of well-being (quality of life outcomes).

12. What are the factors that best predict, and make a difference to the speed, amount and timing of recovery, and how can healthcare professionals help early in the rehabilitation process to guide expectations for stroke survivors and families?
13. What are the causes of different types of pain in stroke survivors, and what interventions are most effective in the prevention, treatment and management of pain?

Types of pain such as musculoskeletal including shoulder pain, and neuropathic.

14. Is there a fixed time period after which stroke survivors make no measurable improvement with an intervention; if improvements can continue, what type and intensity of treatment is effective at a later stage?
15. What interventions improve arm function after stroke and when should they be provided?
16. What is the best way to increase the availability of on-going physiotherapy for stroke survivors?
17. Stroke can cause disabilities and effects that may not be visible to other people, for example fatigue, emotional, communication and thinking problems.

What are the public thoughts and feelings (perceptions) on these disabilities; what are the best ways to help people to understand these and improve attitudes toward, and support, stroke survivors?

18. How can training for healthcare professionals be made the same to ensure the best outcomes for all stroke survivors and their carers?

The full report can be found at stroke.org.uk/psp.

All submitted questions will be available at jla.nihr.ac.uk/priority-setting-partnerships/Stroke/.
