



Shaping stroke research to rebuild lives

The Stroke Priority Setting Partnership
results for investment

June 2021

Stroke
Association

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Foreword

When stroke strikes, part of your brain shuts down. Stroke is a leading cause of death and complex adult disability in the UK, and 1 in 5 people¹ will have a stroke in their lifetime. Every stroke is unique and there are as many different impacts of stroke as there are stroke survivors. This is because the brain, the control centre for who we are and what we can do, is complex and stroke can happen in any part of it.

There has been encouraging progress in stroke care, driven by research, over the last three decades. Thanks to advances such as the development of specialist stroke units and new emergency treatments, stroke deaths in the UK have almost halved². However, the number of people living with the effects of stroke is forecast to double to 2.1 million by 2035³.

Despite progress, there is still so much we don't know, and the breadth of individual stroke experiences makes finding out the limits of our knowledge difficult. The field of stroke research has many disciplines and we need to achieve equivalent breakthroughs in stroke rehabilitation and long-term care to those we've seen in emergency treatment. This will enable the increasing numbers of people living with the long-term effects of stroke to live the best lives they can.

The James Lind Alliance (JLA) Stroke Priority Setting Partnership (Stroke PSP), led by the Stroke Association, brought stroke survivors and carers together with professionals across the stroke pathway, including GPs, neurologists, occupational therapists and physiotherapists. Together, they submitted and prioritised almost 4,000 questions about stroke. This process has given us two lists of 10 priority areas: the first in prevention and acute care, and the second in rehabilitation and long-term care, ranked in order of importance.

The Stroke Association, the UK's leading stroke charity, has been funding stroke research for over 30 years, but we're one of only a few dedicated stroke research funders. Current funding levels, badly affected by the coronavirus pandemic, do not go nearly far enough to address the uncertainties that stand in the way of saving and rebuilding lives after stroke. The latest analysis of public and charity health research spend reveals that only £23 is dedicated per stroke survivor in a year⁴. This compares to £161 per person living with cancer^{4,5}. Research is vital and we desperately need more investment in stroke research to save and rebuild lives.

This report calls on funders, system decision-makers and researchers to significantly increase investment in stroke research to address these priority areas, where uncertainties are a road block to reducing the devastating effects of stroke. We urge people affected by stroke and healthcare professionals to advocate for these priority areas and get involved in research to address them.

Investing in research will improve treatment and care where people affected by stroke need it most. It will also tackle the need to reduce the impact of stroke on health and social services, and wider society. For example, investing £10 million into stroke cognitive rehabilitation research could save £725 million over 20 years⁶, saving over 71 times the amount invested. Stroke costs the NHS and social care £8.6 billion per year⁷, so significant investment in stroke research and resulting interventions will save lives and money.

Thank you to everyone who has contributed to the Stroke PSP, in particular to the 1,400 stroke survivors, carers and professionals who shared their views. We are committed to making sure that the current underfunding of stroke research is prioritised and addressed as a matter of urgency. And we will advocate tirelessly for our vision to become a reality, namely for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.

Juliet Bouverie OBE
Chief Executive
Stroke Association



Why did the Stroke Association lead the Stroke Priority Setting Partnership?

Stroke is a leading cause of death and complex adult disability in the UK⁸. As the UK's largest stroke charity, the Stroke Association's vision is for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.

The Stroke Association has funded research to drive improvements in stroke treatment and care for over 30 years. However, the charity is one of few organisations providing these vital funds. Stroke research receives just 1.2% of public and charity health research spend (£30m of £2.56bn). This is compared to 18.9% (£483m) for cancer and neoplasms, and 9.7% (£248m) for other neurological conditions⁴. Investing in stroke research can generate savings for health and social care⁶, as well as improve quality of life for stroke survivors and their families.

The Stroke Priority Setting Partnership (PSP) follows the robust James Lind Alliance process that brings together people affected by stroke, and health and social care professionals in stroke to establish priorities for research. Although most affected by stroke, these groups of people rarely get the opportunity to set the research agenda. The process identifies priority areas of evidence uncertainty, where there are questions about healthcare that cannot be answered by existing research.

Due to stroke's complex and long-term effects, stroke research has many disciplines across the stroke care pathway from acute treatment in hospital to rehabilitation in the community. Stroke researchers, funders and decisions-makers need a clear idea of the research that can most benefit people affected by stroke. Significant investment in research is also needed to understand stroke's diverse effects, and develop effective treatments and care.

Our charity is uniquely placed to lead this project as:

- An established partner in the stroke community including delivering stroke services, which reach out to people affected by stroke, health and social care professionals and partners.
- A dedicated funder of stroke research.
- An influencer of stroke research, and health and social care policy.

We are pleased to announce the results – the top 10 priorities for research in:

- Prevention, diagnosis, pre-hospital and hospital care.
- Rehabilitation and long-term care.

Prior to the Stroke PSP, the stroke community had a limited idea of where to focus resources and increase investment so that research can make the greatest improvements in stroke treatment and care. The stroke community must now increase investment in research to address these priority areas, leading to better outcomes for stroke prevention, treatment and long-term care.





Brin Helliwell

Stroke survivor and Steering Group member.

"I had a stroke in 2005 at the age of 47. Soon after, I got involved in stroke research as I saw how important it is in driving improvements in treatment and care.

"Getting involved in the Stroke PSP was an obvious way for me to use my first-hand knowledge, understanding and experience of stroke to influence future research. It has allowed me to turn around a life-changing negative experience into a positive response that will benefit others."



Professor Rustam Al-Shahi Salman

British Association of Stroke Physicians President (2019-2021) and Steering Group member.

"Research over the last two decades has identified treatments that prevent stroke and improve its outcome. But the number of people struck down by stroke is rising in the UK as the population ages, because older people are at the highest risk. Although survival after stroke is improving, this leaves more people living with complex disability after stroke.

"Research is needed to address the many uncertainties about how stroke prevention, treatment, and recovery can be further improved. However, funds are limited. This Priority Setting Partnership was needed to identify the areas of greatest need.

"These lists of uncertainties are wish lists for people affected by stroke and to-do lists for funding agencies that want to improve outcomes and reduce the burden of stroke."



Jennifer Crow

Chair of Royal College of Occupational Therapists Specialist Section Neurological Practice Stroke Forum and Steering Group member.

"As an occupational therapist in stroke, my colleagues and I rely on research evidence to guide treatment and care for our stroke patients. But there are gaps in the evidence.

"With limited funds for research, it's important that the people most affected by stroke; the patients, carers and health and social care professionals get their say to direct and increase funds in the areas of research that can make the biggest difference to their experience of stroke treatment and care."



Priorities for stroke research in the UK

The priorities are areas of evidence uncertainty in stroke policy and practice. 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 exists⁹.

The priorities must guide research investment to address the issues that matter most to people affected by stroke.

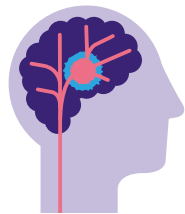
The Top 10 priorities: Stroke prevention, diagnosis, pre-hospital and hospital care



1. What are the best interventions* to **stop stroke happening for the first time** (ie primary prevention)?



2. How can the public, paramedics and other health care professionals **recognise and respond to stroke or TIA*** better and more quickly?



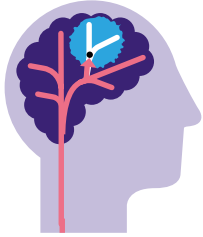
3. What are the benefits and risks of **acute treatments for intracerebral haemorrhage*** (eg surgery and medications)?



4. What are the **benefits and risks of new therapies for stroke** (eg stem cell therapy) and those that work to **protect the brain from damage** (ie neuroprotection)?



5. What is the risk of **recurrent stroke**, how does this risk change over time, and what can stroke survivors do to reduce the likelihood of having another stroke (ie secondary prevention)?



6. How can the proportion of patients with ischaemic stroke who get **clot retrieval (thrombectomy)** be increased either by using new ways to identify more patients that are eligible, or by increasing the number of specialist healthcare professionals who can carry out thrombectomy?



It is estimated that around **9,000 patients** a year could benefit from thrombectomy in the UK. Currently only a fraction of those eligible for the thrombectomy get it¹⁰.



7. What are the processes that cause **delayed changes in brain function (neurological deficit) after subarachnoid haemorrhage*** caused by an aneurysm?



8. How can **complications* of stroke** be reduced (eg pneumonia)?



9. What are the risks and benefits of using **blood-thinning treatments** (antiplatelet and anticoagulants) to stop stroke happening after TIA*/haemorrhagic/ischaemic stroke? Is **personalised decision-making** possible for the timing and types of antiplatelet and anticoagulant therapy used?



10. Do patients' **other health conditions, and characteristics** such as age, ethnicity and frailty, affect stroke symptoms, outcomes*, interventions* and care pathways?

Plain English definitions of words with an asterisk (*) are at the end of this report.
A full list of submitted questions will be available at jla.nihr.ac.uk/priority-setting-partnerships/stroke.
The project did not include questions about childhood stroke because they were out of scope of this PSP.
Any received were passed onto the **Childhood Neurological Conditions PSP**.

The Top 10 priorities: Rehabilitation and long-term care



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, wellbeing 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 and understand the impacts of these, 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 subarachnoid 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 everyday life**; what interventions* can be made available to facilitate these abilities, and how? For example, impact on and interventions including education, assessment, treatment and support for return to work, driving, relationships and financial wellbeing.



7. What is the best **time, place and amount of therapy** (eg 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**?

How did the Stroke Priority Setting Partnership agree the priorities?

The Stroke Association worked in clear stages with the JLA, a non-profit initiative established in 2004. The process brings patient, carer and clinician groups together on an equal footing with the principles of equality, transparency, and using and contributing to the evidence base. It provides a rare and valuable opportunity for patients and clinicians to shape the health research agenda⁹.

1

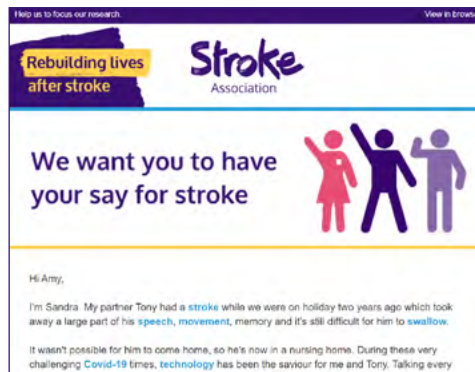
July 2019

First meeting of stroke community stakeholders



February - August 2020

Unanswered questions about stroke collected. Surveys were shared by our charity, Steering Group members and partners.



There was involvement at many stages:

A Steering Group of people affected by stroke and representatives from UK stroke healthcare professional bodies and charities input to decisions.



Partner organisations such as charities and healthcare professional bodies supported throughout.

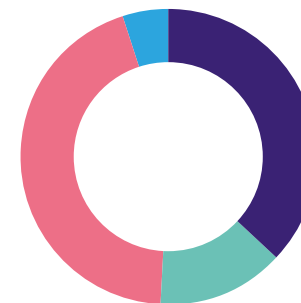


People affected by stroke, and health and social care professionals took part.



2

Number of respondents by role at stage 2



37% Stroke survivor ■
14% Carers ■
44% Professionals ■
5% Not stated ■



Total responses = 1,407

3

August 2020 - February 2021

Questions checked against the Stroke PSP scope and existing evidence, and combined and sorted. 93 questions were formed from 3,905.

Evidence-checking



Total original questions = 3,905

The future

The Stroke Association and the stroke community continue to:

- Focus research in priority areas by understanding evidence uncertainties, and developing research to address them.
- Influence health and social care decision-makers to improve stroke treatment and care.

4

February - March 2021

Most important questions chosen from lists

There were three lists, 'Prevention, diagnosis, pre-hospital and hospital care', 'Rehabilitation and long-term care' and 'General'.

Online survey was shared by our charity, Steering Group members, partners and Equality Health on social media, in presentations, and emails.

Number of respondents by role at stage 4



29% Stroke survivor ■
 12% Carers ■
 59% Professionals ■

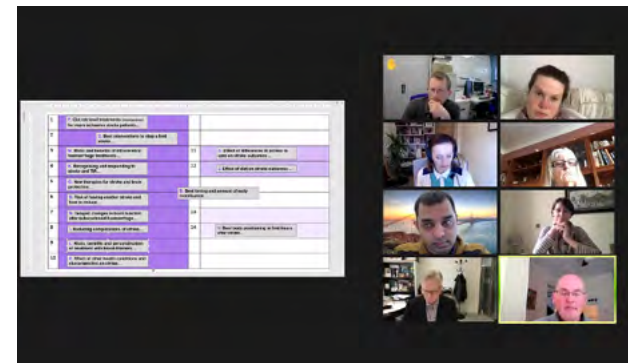


Total responses = 1,154

5

April 2021

Online workshops decided on the top 10 priorities.



Participation of people affected and professionals in stroke

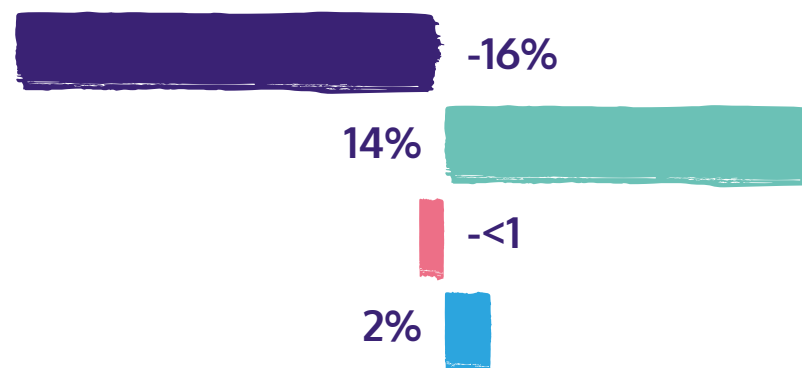
The project involved various stages and levels of participation. The Stroke Association, Steering Group and partner organisations worked hard to be inclusive. Where possible, aphasia-friendly, Welsh translation and printed versions of materials were available.

The Stroke Association monitored responses, and with the Steering Group and partner organisations worked to reach out to people affected by stroke, and health and social care professionals for a representative sample of geographies and ethnicities. The charity worked with Equality Health, an organisation focused on improving diversity in health research and clinical trials in the UK to broadcast the second survey through five partner organisations.

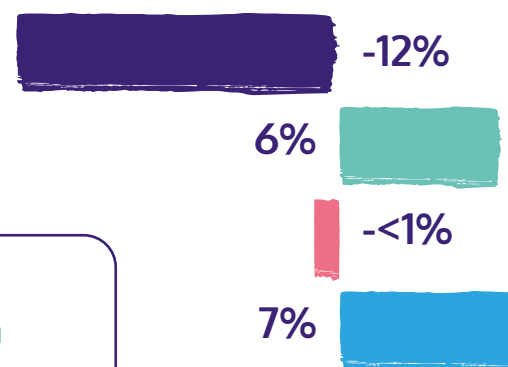
Future work will require participation of the stroke community to understand priority areas and develop research to address them.

Response from people affected by stroke compared to 2011 census data By nation

First survey (Stage 2)

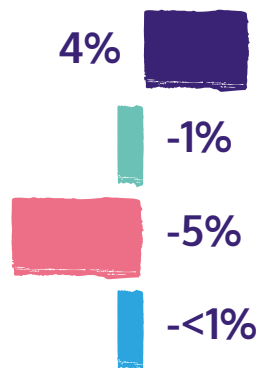


Second survey (Stage 4)



By ethnicity

First survey (Stage 2)



Second survey (Stage 4)



- White ■
- Black/African ■
- Asian ■
- Mixed/multiple ■



Ade Adebajo

Stroke survivor, Steering Group member and MBE recognised for service to promoting inclusive patient and public involvement in health research.

"I'm passionate about inclusivity and am proud to be a part of this project where inclusivity is a priority. Stroke survivors and their carers are given an equal voice to professionals. A huge effort was made to reach out to communities that are traditionally less involved in health research.

"The results reflect my, and my peers' experience of stroke, and unmet needs in care. I hope that together we can continue to raise awareness and direct funds into research in these areas to improve treatment and care for the future."

The impact of the coronavirus (Covid-19) pandemic

From March 2020 the Covid-19 pandemic in the UK impacted the Stroke PSP. The table below summarises the main challenges faced due to the pandemic, and solutions.

Challenge caused by pandemic	Stroke PSP solution
Public health measures in the UK such as lockdown and social distancing stop face-to-face contact.	<ul style="list-style-type: none"> • First survey collecting unanswered questions about stroke extended. • Second survey and workshops choosing most important questions online only. • Targeted approach to engage groups traditionally less heard from.
Health care professional redeployment and increase in workload.	<ul style="list-style-type: none"> • Extended project timeline. • Flexible working with Steering Group members.
Disruption to services and the lives of people affected by stroke.	<ul style="list-style-type: none"> • Extended project timeline. • Navigation of opportunities to reach out through services as they respond.
Fall in funding for health research.	<ul style="list-style-type: none"> • Continue work to establish priorities that can direct limited funds to areas of greatest need.

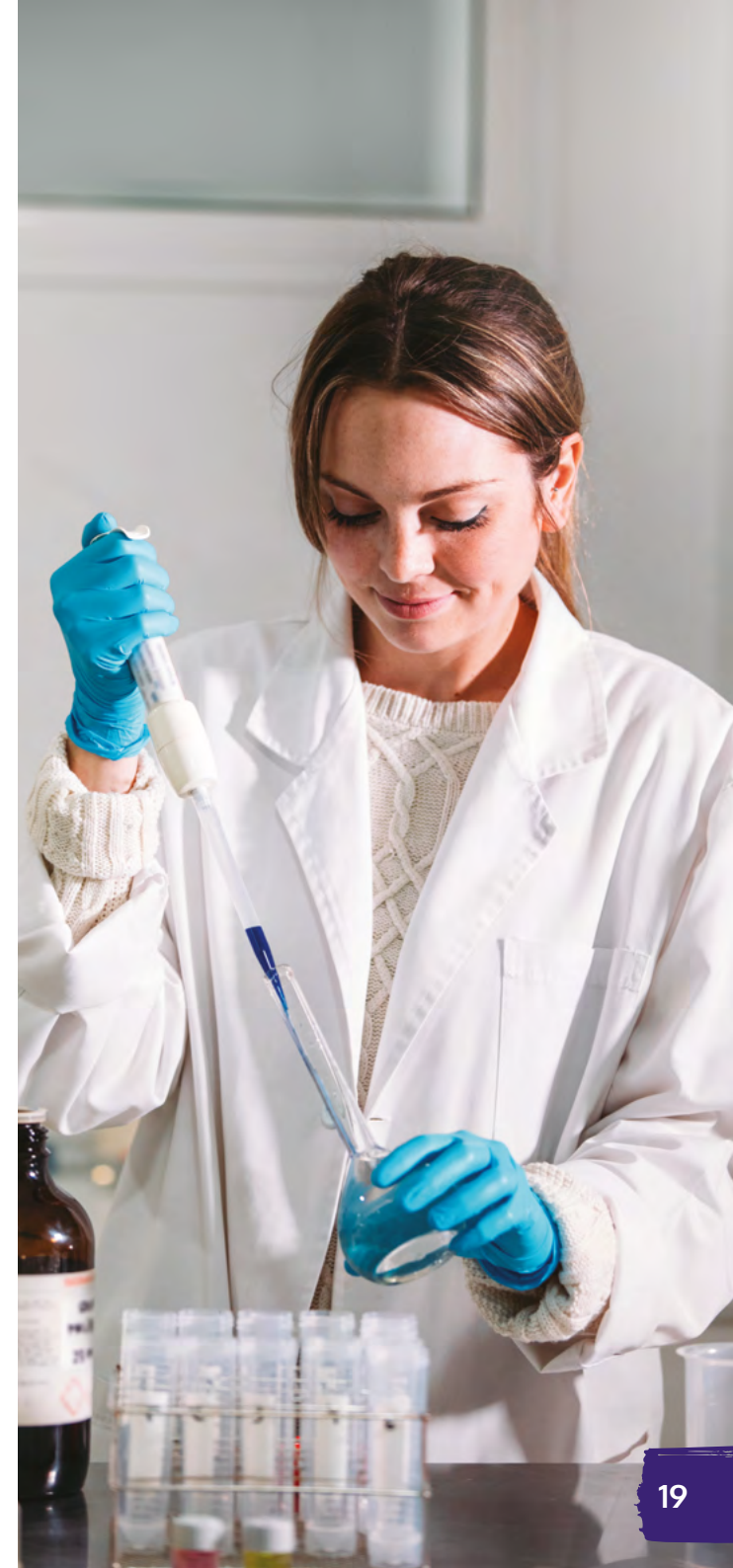


What needs to happen **now?**

The priorities tell us the areas where research is most needed to improve treatment and care. This is the first step. The stroke community must continue to invest in these areas so research can make the biggest difference to the lives of people affected by stroke.

Our charity calls on:

- **Funders and research institutes** to significantly increase investment in research that can address these priority areas.
- **Researchers** to address these priority areas in their work, and involve people affected by stroke.
- **Health and social care policy and decision-makers** to significantly increase investment in, and enable stroke research to address these priorities, and use research evidence to inform policies and practice.
- **People affected by stroke and professionals** in stroke to advocate for priority areas, and get involved in research to address them.



The Stroke Association commits to:



Engaging with the stroke community and wider system to drive increased funds for, and progress in these priority areas.



Investing in priority areas.



Facilitating involvement of people affected by stroke in research.





Sandra

Carer of her partner who had a severe stroke in 2019 and Steering Group member.

"I hope that the Stroke PSP not only increases people's understanding of the experience of stroke survivors, but also those who are directly affected like relatives, close friends and carers. The fact that the process was participatory and took into account existing research evidence gives me hope that funding for research will be used in the priority areas to improve stroke treatment and care where it's needed the most."



Associate Professor Shirley Thomas

Rehabilitation Psychology at the University of Nottingham, and Steering Group member.

"One of the biggest challenges for myself, and my colleagues is securing funding. It's particularly challenging in stroke, a complex and underfunded area of health research.

"The Stroke PSP provides robust guidance to researchers and funders on the areas of greatest need. It's vital to direct funds to these areas so researchers can continue to work with people affected and professionals in stroke and generate research evidence. This research can inform improvements in treatment and care that will bring the most benefit to people affected by stroke. I look forward to using the Stroke PSP results in my research to increase evidence in these areas."



Thank you

A large number of people and organisations made this project possible. We want to thank Steering Group members and the JLA for guiding the Stroke PSP, and partners for supporting the project. We'd like to thank all of the people affected by stroke and professionals in stroke who participated in surveys and attended workshops. We'd also like to thank those, including researchers, that spread the word throughout the stroke community in the UK.

"It's only by working in partnership that we have established these priorities for research across the entire stroke care pathway. I'd like to thank each individual and organisation that dedicated their time to work with our charity and successfully build this project.

"I look forward to continuing to work with the stroke community to develop research and policy in these priority areas to improve stroke treatment and care. Far too many people affected by stroke do not receive the support they need to rebuild their lives and a lack of investment in research is part of the problem. It's my hope that by increasing investment in these priority areas more people can not only survive, but also rebuild their lives after stroke."

Juliet Bouverie OBE

Chief Executive of the Stroke Association

Stay in touch

If you're a researcher... Please keep us informed of research inspired by the priorities in stroke.

If you're someone that has been affected by stroke... You can find out how to get involved with our charity's research.

If you're looking for research funding, or influencing partners... Please get in touch to see how we could work together.

Email research@stroke.org.uk

Additional priority areas

Almost 4,000 questions were sorted and combined in the Stroke PSP. At the workshops (stage 5) people affected and professionals discussed and prioritised more than 10 priority areas. This section tells you the additional priority areas.

Additional priority areas: Stroke prevention, diagnosis, pre-hospital and hospital care

11. How do regional and other **differences in access to stroke care** affect outcomes* for stroke survivors and their families?
12. **What effect does diet have** on short- and long-term outcomes* for stroke survivors?
13. What is the **best timing and amount of early mobilisation*** for stroke survivors?
14. What is the **best body positioning** for patients with stroke in the first hours after stroke?

Additional priority areas: Stroke rehabilitation and long-term care

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 wellbeing (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 ongoing 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?

Plain English definitions

Word used in priority area	Explanation of word used in priority area
Interventions	<p>These are ways used to treat and support people affected by stroke. Interventions can also include ways to:</p> <ul style="list-style-type: none"> • Identify and assess stroke and its effects. • Educate and provide advice to people affected by stroke, and healthcare professionals in stroke, to improve treatment and care.
Intracerebral haemorrhage	A type of stroke caused by bleeding in the brain; a type of intracranial haemorrhage.
Subarachnoid haemorrhage	A type of stroke caused by bleeding on the surface of the brain. It is a type of intracranial haemorrhage.
Outcomes	<p>Information about a person's health that can be measured to understand how well they are.</p> <p>Outcomes can be used by healthcare professionals, and in research, to understand:</p> <ul style="list-style-type: none"> • The effects of stroke. • Stroke recovery. • Different types of treatment, support and care for people affected by stroke. <p>For example, survival from and severity of stroke, are outcomes that could be measured to understand if a medication can help treat stroke. How well someone can move their hand, and/or quality of life, can be measured as an outcome to find out if a therapy can help physical recovery.</p>
Complication	A negative effect of a disease, health condition, or treatment.
TIA	<ul style="list-style-type: none"> • This stands for transient ischaemic attack, sometimes called a mini-stroke. • Someone with TIA will experience symptoms of stroke, such as losing control of their muscles or speech. • These symptoms are only temporary, and the person will recover within a few hours. • TIA is caused by a loss of blood flow to the brain that does not cause permanent brain damage.
Rehabilitation	Treatment and care for people affected by stroke that aims to improve independence and quality of life.
Early mobilisation	This aims to help recovery by assisting and/or encouraging stroke survivors to move around in the first hours and days after stroke.

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When stroke strikes, part of your brain shuts down.
And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

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Rebuilding lives after stroke

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