

# The Stroke Priority Setting Partnership (Stroke PSP) results

Rebuilding lives after stroke

**Stroke**  
Association



# The Stroke Priority Setting Partnership (Stroke PSP) results



These are the **most important areas in stroke that need research.**



They are questions from:

- **People affected by stroke.**
- Health and social care **professionals.**

These **questions** can **help future research.**



The questions could help **improve:**

- **Treatment.**
- **Rehabilitation.**
- **Prevention.**

This report tells you :

1. Why the Stroke Association led the Stroke PSP?
2. Top 10 priorities:
  - Stroke prevention, diagnosis, pre-hospital and hospital care.
  - Stroke rehabilitation and long-term care.
3. How did the Stroke PSP agree the top priorities?
4. What people say about the Stroke PSP?
5. What needs to happen now?
6. Where to find more information?
7. Thank you to all who were involved.

# 1. Why the Stroke Association led the Stroke PSP?



Stroke is a leading cause of death and disability in the United Kingdom.

**Research can improve stroke treatment and care.**

Stroke research is complex as each person's stroke is different and can have long-term effects.



The Stroke PSP will help the stroke community.

There is limited funding available for stroke research.

It is **vital that money is increased** in topics which are important to people affected by stroke and the professionals that support them.



The **Stroke Association** is well placed to lead this project as:

- A dedicated **funder of stroke research.**
- A well-known **partner in the stroke community** which supports people affected by stroke, health and social care professionals and partners.
- An **influencer** of stroke research, and health and social care policy.



## 2. Top 10 priorities



The priorities are areas where there are unanswered questions about stroke treatment and care.

The priorities can help research to address the questions that matter most to people affected by stroke.

Some of the priorities are long as there may be many questions.

This report has summarised the priority areas.

You can find the full version at [www.stroke.org.uk/psp](http://www.stroke.org.uk/psp).

These are the **top priorities in stroke prevention, diagnosis, pre-hospital and hospital care.**

1. Best interventions to stop a first stroke.
2. Recognising and responding to stroke and TIA.
3. Risks and benefits of intracerebral haemorrhage treatments.
4. New therapies for stroke and brain protection.
5. Risk of having another stroke and how to reduce.
6. Clot retrieval treatments (thrombectomy) for more ischaemic stroke patients.
7. Delayed changes in brain function after subarachnoid haemorrhage.
8. Reducing complications of stroke.
9. Risks, benefits and personalisation of treatment with blood-thinners.
10. Effect of other health conditions and characteristics on stroke.

These are the **top priorities in stroke rehabilitation and long-term care.**

1. Impact of psychological problems and how to reduce them.
2. Understanding cognitive problems and how to reduce them.
3. Effects of communication problems, how to assess and reduce them.
4. Understanding fatigue and how to reduce it.
5. Organising community stroke services to meet all survivor needs.
6. Long term impacts on everyday abilities and availability of interventions.
7. Time, place and amount of therapy for best outcome.
8. Working with the stroke care team and support for carers.
9. Strength and fitness for recovery and stroke prevention.
10. Stroke survivor and carer experience of stroke pathway.

### 3. How did the Stroke PSP agree the top priorities?



The Stroke PSP followed the James Lind Alliance (JLA) process.

This means the Stroke PSP:

- Had **clear stages**.
- Gave **equal voice** to people affected and stroke professionals.
- Makes **all information** about the process **available to the public**.
- Used and adds to **evidence** on stroke care and treatment.



The Stroke PSP started in 2019.

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

Other partner organisations such as charities and healthcare professional bodies were identified and supported the project.

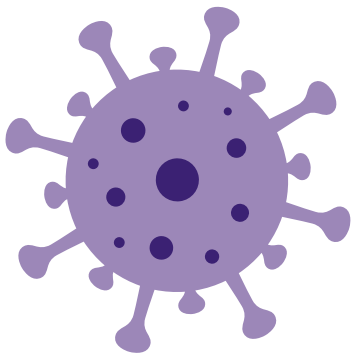


In February 2020, February 2021 and April 2021, **people affected by stroke and health and social care professionals took part.**

They told us the questions they think research needs to answer.

They chose the questions most important to them from lists.

They also took part in workshops to decide on the top 10 priorities.



The Covid-19 pandemic caused challenges for the Stroke PSP.

For example, it was more difficult to reach out to people affected and professionals.

The Stroke PSP made changes so the project could continue.

For example, the project timeline was extended.

**The pandemic has reduced funds for research overall, so the Stroke PSP priorities are even more important** to understand the areas of greatest need.

## 4. What people say about the Stroke PSP?



**Brin Helliwell, a stroke survivor and Steering Group member.**

“Getting involved in the Stroke PSP... has allowed me to turn around a life changing negative experience into a positive response that will benefit others.”



**Associate Professor Shirley Thomas, Rehabilitation Psychology at the University of Nottingham, and Stroke PSP Steering Group member.**

“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 to inform improvements in treatment and care that will bring the most benefit to people affected by stroke.”



## 5. What needs to happen now?



The Stroke Association wants **the stroke community and decision-makers to invest in research** to address the priority areas.



**The Stroke Association will work with the stroke community** to address the priority areas.

The Stroke Association will also:

- Publish all the questions submitted to the Stroke PSP.
- Invest more into the priority areas.
- Help people affected by stroke get involved in research.

## 6. Where to find more information?

Stroke Association website: [www.stroke.org.uk/psp](http://www.stroke.org.uk/psp)

JLA website: [www.jla.nihr.ac.uk/priority-setting-partnerships/Stroke/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/Stroke/)

# 7. Thank you to all who were involved.

**A large number of people and organisations made the Stroke PSP possible.**  
The Stroke Association want to thank all who were involved.

This includes:

- Steering Group members
- The JLA
- Partner organisations
- People affected and professionals in stroke who participated
- People that shared information about the project in the stroke community

**Images credit:**

Speakeasy-Aphasia <http://speakeasy-aphasia.org.uk/>

A **stroke** happens **every five minutes** in the UK.

Stroke **changes lives**.

**Recovery** is tough.

But with the **right specialist support** the brain can **adapt**.

Our **specialist support, research and campaigning** are only possible with the support of the **stroke community**.

With more **donations and support** we can **rebuild** even more **lives**.

## Contact us

---

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**

---

Rebuilding lives after stroke

**Stroke**  
Association

Item code: **A08C19** © Stroke Association 2021

The Stroke Association is a company limited by guarantee, registered in England and Wales (No 61274).

Registered office: Stroke Association House, 240 City Road, London EC1V 2PR.

Registered as a charity in England and Wales (No 211015) and in Scotland (SC037789).

Also registered in the Isle of Man (No. 945) and Jersey (No. 221), and operating as a charity in Northern Ireland.