

# An Introduction to Stroke Voices in Research

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The Stroke Association is the UK's leading stroke charity. We provide **specialist support**, fund critical **research** and **campaign** to make sure people affected by stroke get the very best care and support to **rebuild their lives**.

You can find out more about the research we fund and its effect on people's lives [at the bottom of this document](#).

It is important to us stroke that research is done in collaboration with **people affected by stroke, who are the experts in the reality of stroke**. We call this Research Involvement.

This means carrying out research 'with' or 'by' people affected by stroke. rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

We think people affected by stroke should be involved in research and use their experience to **inform and improve** research. This will give research **the best chance of making a difference** to people's lives.

## Stroke Voices in Research

Stroke Voices in Research is a group of people affected by stroke who **shape the research we fund**. They contribute their experiences and perspectives to inform how research is **developed, selected and delivered**.

The group's contributions help to:

- Decide **what research we fund**.
- **Support researchers** as they develop and carry out their projects.
- Support us to make **involvement work better** for everyone.

## How Does it Work?

We will send **opportunities** to **advise and collaborate** in research around the group **by email**. You can let us know if there are particular types of opportunity you would most like to receive when you first join the group.

You can find **examples** of just some of types of involvement that come through the network **later in this document**.

If you are interested in an opportunity you will be able to **sign up** to take part using the **details included**, with support to get involved where needed.

It is important that our **opportunities are accessible** to everyone. This helps to make sure research is informed by people who represent the true national picture of people affected by stroke.

We will **work with you** to **understand any needs** you have to take part.

There is information about the role in the profile below.

If you have any questions about how the group runs and what it involves please get in touch with Dan Taylor, Research Involvement Lead

Email: [research@stroke.org.uk](mailto:research@stroke.org.uk) Tel: 0161 742 7474

# Stroke Voices in Research - Role Profile

<b>Role:</b>	<b>Stroke Voices in Research Member</b>
<b>Key Contact:</b>	Daniel Taylor, Research Involvement Lead Email: <a href="mailto:daniel.taylor@stroke.org.uk">daniel.taylor@stroke.org.uk</a> Tel: 0161 7427474

The purpose of this role is to involve perspectives and insights of people affected by stroke in shaping research activities at the Stroke Association.

## Who Can Take Part?

- All Stroke Voices in Research members **must** have experience of stroke as a stroke survivor, carer or former carer (informal or professional), family member or spouse or partner.
- You can be based **anywhere in the UK**. You can be involved from home via email, post or video chat. Where opportunities involve require travel, expenses will be reimbursed.
- You **do not** need a background in science, medicine or research. It is your experience of stroke that is key.
- There is **no minimum time commitment**. How much involvement you have is completely up to you. You get to choose which opportunities you would like to take part in.
- We will work with you from the start to **understand what support** you might need. We will try to provide **additional support where required**.

## What will we offer?

- **This role is unpaid** but we will reimburse reasonable out-of-pocket expenses you incur while carrying out your role. We do also recommend that research teams pay for your time where possible.
- When you become a member **we will offer you training** to introduce you to the Stroke Association and involvement in research, and support you to get involved in stroke research.
- We will work with the group to understand how your contributions can be recognised and rewarded in a way that means something to you.

### Involvement opportunities available for members:

- **Reviewing applications** as part of the Stroke Association's decision making process for funding awards, with the **choice** to **attend meetings** discussing where funding should be allocated.
- **Working with researchers** in group workshops and meetings to **collaborate on a range of research topics and questions**. These might be one-off or involve ongoing meetings or workshops.
- Helping to **plan, develop and/or deliver activity and materials** to help people affected by stroke, research and medical professionals and Stroke Association staff to take part in involvement
- Helping to **develop new processes and materials** for Stroke Voices in Research and the Stroke Association Research Team

You can be involved in **as many or as few of these opportunities as you want**. We will ask you what you're interested in when you become a member.

### To become a member of Stroke Voices in Research you need to:

- Complete the short **opportunities form** sent with this profile, letting us know more about you and your involvement preferences.
- Return the form to [research@stroke.org.uk](mailto:research@stroke.org.uk). Alternatively call 0161 7427474 to speak to Dan Taylor if you need this in a different format.
- You will then be invited to have a short, informal introduction to explain more about the group and learn more about how you would like to be involved.
- We'll adapt this process to meet individual needs.

**For more information visit our website:**

<https://www.stroke.org.uk/research/get-involved-research>

# Involvement Opportunities

Involvement can look many different ways but should always involve **active collaboration** between people **living and working** with stroke to **meaningfully influence and shape research**.

You can find information about some of the types of opportunity that come through the network below.

- You can select as many or as few as you would like.
- We will try to tailor the information we send you based on your interests. You're free to change your mind about your choices at any time.
- Choosing a certain opportunity doesn't commit you to being involved in it.

## Being part of short-term consultations, workshops and meetings

These will be a chance to **discuss important questions** and topics related to stroke.

- These usually focus on a **specific area or milestone** of a project, such as informing a funding application, clinical trial or how to share results.
- These usually involve **1 – 3 meetings** which mainly take place **remotely** (e.g. via email or video call).

We'll invite you to be part of these as and when the opportunity arises.

## Working with researchers to design, develop and deliver their research

These opportunities can look **many different ways**, but it could involve:

- **Collaborating** with research teams **throughout a research project** to inform its focus, design and implementation

- Helping to **develop and decide on ideas** for **new areas** of research or which **outcomes** will be **important to people** affected by stroke.
- Suggesting ways that researchers could **recruit participants** and/or how to **design research methods** so taking part is easier.
- Collaborating to **deliver aspects of research**, such as analysing results or co-interviewing people affected by stroke
- Commenting on **what the results mean** from your point of view and recommending ways to share results with people affected by stroke.

We'll contact you with details of opportunities to get involved in research projects as and when they arise. These can last anything from a few months to years.

The researchers may only wish to involve people with **certain experience**, for example of aphasia. In these cases we'll only send the details to people who have the experience needed.

## Reviewing applications for research funding

As a member of Stroke Voices in Research **you can review research funding** applications we receive. This helps decide which research we fund **through our [funding schemes](#)**.

You do not need any scientific expertise to take part, this is about contributing your lived experience of stroke.

You will be asked questions about aspects such as the **clarity** and **relevance** to you, **plans to involve and collaborate** with people affected by stroke and plans for **sharing results publicly**.

If you tick the 'reviewing applications' box on the sign up form, we will contact you when we need reviewers to ask if you are available:

- You'll have around **four weeks** to submit your reviews, by email, post, or in conversation with our Research Involvement Lead.

- We will **randomly allocate** applications to review based on how many people are available. You will usually be sent between two and four of these.
- We provide **support and training** to complete your reviews, we can discuss how to help new reviewers try this for the first time

Stroke Voice members represent your comments at funding panel meetings, where people living and working with stroke decide what research to fund.

## Attending funding panel meetings

Once the review process is complete an independent group of scientists, healthcare professionals and people affected by stroke meet to recommend which research funding applications the Stroke Association should fund.

Your comments are sent to the whole panel and **represented** at the meeting by **two Stroke Voice members**.

**You can volunteer** to be one of these panellists, with **support** from more experienced members and our Research Involvement Lead.

- Meetings usually place at Stroke Association House in **London**. You will need to attend **in person**.
- Panel meetings usually last between **four and six hours** (including breaks). You will need to attend the **whole meeting**.
- You'll need to do **some preparation** ahead of the meeting (for example, re-reading applications, reading other reviews).
- Everything discussed during the panel meeting is completely **confidential** and should not be discussed with anyone outside of the panel.

# Research at the Stroke Association

Stroke research saves lives. You can find out more about how the research we have funded has made a difference on our [website](#).

The findings from research are vital in the search for new ways to:

- **Prevent strokes** from happening.
- **Treat stroke.**
- Provide the best **care for stroke survivors**, including rehabilitation.

We fund many types of stroke research, including:

**Acute care:** Research exploring how hospitals diagnose and treat stroke patients immediately following stroke onset.

- **Applied Neuroscience:** Research aimed at furthering the understanding of how the brain and nervous system work in relation to stroke.
- **Community care:** Research looking at how long term care of stroke survivors in the community can be improved.
- **Secondary prevention:** Research into how to stop people who have already had a stroke or Transient Ischaemic Attack from having further strokes.
- **Rehabilitation:** Research aimed at identifying ways in which a stroke survivor's independence and quality of life may be improved.

The research that we fund is driven by [our Research Strategy](#) and the results of the [Stroke Priority Setting Partnership](#).

The most important principle of our approach to research is that it is **driven by** the voices of **those affected by stroke**. We believe this leads to better quality research that can be more effectively applied in practice.