

Involvement of stroke survivors in research proposals

We think it's vital that people affected by stroke are involved in research throughout the process, from setting priorities to helping to analyse results, to sharing findings. This will help ensure that the right research is being undertaken, that it meets a real need for those affected by stroke, and that it's shared with a wider audience.

Patient and Public Involvement (PPI) in research is when research is carried out 'with' or 'by' people affected by health conditions and members of the public, rather than 'to', 'about' or 'for' them. ([INVOLVE](#))

We expect all applicants who are seeking funding from us will have meaningful involvement, and we expect that it will continue, should the application be successful.

People affected by stroke are experts in what it's like to experience and live with stroke. When it's done well, PPI can:

- Improve the quality and relevance of research.
- Provide a different perspective on research.
- Ensure accountability for public or charity funding.
- Empower patients and carers, providing a route to influencing change and improvement in issues which concern people most.

Research has also shown that PPI in clinical trials leads to [improved patient enrolment](#), and that studies that involve people with lived experience to a greater extent are more likely to [achieve recruitment targets](#).

People affected by stroke can be involved [throughout the research cycle](#), including:

- Prioritising topics for research.
- Identifying relevant outcomes for studies.
- Developing plain English summaries of research.
- Identifying potential ethical issues a study may face.
- Developing participant facing information (participant information sheets and consent forms).
- Helping to manage the study (through membership of a Steering Group).
- Helping to analyse and interpret the result of a study.
- Sharing results with a wider audience.

If you would like any advice in conducting involvement, have any questions or would like to know more, please contact Richard Francis, Head of Research at the Stroke Association via research@stroke.org.uk

Please also see the [Stroke Association webpages on involvement in research](#).

We would strongly encourage you start planning any involvement activities as early as possible. This is to ensure there is sufficient time for you to consider and plan meaningful involvement ahead of the deadline.