Patient Involvement in the NIHR Stroke Research Network

The NIHR SRN has robust systems to support involvement at all levels of the organisation and all levels of the research process.

This leaflet gives examples of the ways in which we can support involvement in your studies.

Ideally involvement should begin at the ideas stage but any involvement is better than no involvement, as Dame Sally Davies states in the quote below:

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective.”

Professor Dame Sally C. Davies
Chief Medical Officer
Department of Health

NIHR Stroke Research Network (SRN)

Our purpose is to provide the health service infrastructure to facilitate the conduct of clinical trials and other well designed studies in stroke across the full spectrum of disease treatment and secondary prevention through our local research networks and national coordinating centre.

Case Studies

Here are some examples of how patients and carers have contributed to development, design, delivery and dissemination of studies in the NIHR SRN Portfolio.

The following group of case studies demonstrate that lay members can contribute in a meaningful way to all aspects of the research process. These are direct quotes from the researchers themselves.

Decision Support for Thrombolysis in Acute Stroke
Chief Investigator: Prof Richard Thomson, Newcastle University

This project has developed iPad and web based computerised support for clinicians to aid better selection of patients for thrombolysis and better communication of the benefits and risks to patients/family. Patients and families were actively engaged throughout the development, and usability and acceptance testing of prototype versions of tools. Interviews with patients and carers were incorporated into subsequent testing in the actual clinical setting.

ACT NoW Study (Assessing the effectiveness of Communication Therapy in the North West)
Chief Investigator: Dr Audrey Bowen, University of Manchester

People with stroke and their carers made a significant contribution to the successful completion of this challenging programme of research that contained a feasibility study, a randomised controlled trial with nested qualitative study and economic evaluation. Over seven years, the self-named RUG ‘Research User Group’, met regularly in their capacity as research partners. They provided general advice, monitoring of progress and working on specific tasks. For example, they designed aphasia-friendly patient information and consent materials, and provided insights into ways to facilitate communication for qualitative interviewing. The recruitment materials and other resources developed are freely available at http://www.psych-sci.manchester.ac.uk/actnow/outputs/resources/ RUG members are currently co-writing a paper on their experiences of long term research involvement.

BUCS (Attention and Executive Function after Brain Injury - the Birmingham University Cognitive Screen) Study
Chief Investigator: Dr David Werring, UCL Institute of Neurology

Following on from the involvement in the trial the following were developed:

i. the establishment of training CDs which have now been used in 5 training courses given to therapists, helping impact on therapist training;

ii. the development of a new research project which aims to develop a care pathway for stroke informed by cognitive screening - which, if successful, will support the adopting of cognitive screening as a regular part of stroke treatment.
Patient and Carer Involvement - An essential component of Stroke Research

Who is this leaflet for?
• This leaflet is for researchers
• It will tell you how patient and carer involvement can make a difference to your studies

CACTUS (Evaluating the cost effectiveness of computer therapy compared with usual stimulation for people with longstanding aphasia: a feasibility study) Study
Chief Investigator: Dr Rebecca Palmer, Sheffield University
The PPI group had particular impact on recruitment to the study. We were looking for people with aphasia who had been discharged from speech therapy, a hard to reach group. As a result of the PPI group’s assistance with knowing the best places to advertise the study and their help creating aphasia friendly flyers and distributing them, we identified a further 23 people to screen (25% of the total screened). The group also assisted with the production of aphasia friendly information sheets, procedures for teaching participants to use the computer treatment and contributions to the topic guides used to interview participants.

IMPROVE (Improving the perception of Vascular Events after Stroke or TIA)
Chief Investigator: Dr Martin James, University of Exeter Medical School
People with stroke were involved from the start in the design of the study - they contributed to the development of the intervention (a care pathway for risk factor management after a stroke or TIA) and to the qualitative methodology, and four people with stroke joined the trial management group. The quantitative study was redesigned with the involvement of lay members - specifically, non-pharmacological methods of risk factor management were given greater priority, and the length of follow-up was extended. The qualitative part of the study was expanded to collect the views of carers as well as participants.

Contact details for further information
If you are a researcher who wishes to discuss how to involve patients/carers in your study, or for more information, contact Zena Jones, NIHR SRN Patient, Carer and Public Involvement Manager:
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