



# Patient/public involvement in a feasibility Study of Prisms and Therapy in Attention Loss after stroke (SPATIAL feasibility). Why, What, and How?



A. Bamford<sup>1</sup>, M. Savin<sup>1</sup>, P. Dawson<sup>1</sup>, S. Hunt<sup>1</sup>, K. Woodward-Nutt<sup>2</sup>, M. Checketts<sup>3</sup>, V. Longley<sup>4</sup>, J. Haigh<sup>3</sup>, S. Hulme<sup>2</sup>, K. Stocking<sup>3</sup>, P. Moule<sup>5</sup>, A. Vail<sup>3</sup>, A. Turton<sup>5</sup>, A. Bowen<sup>3</sup>



1- SPATIAL PCPI Advisory Group; 2- Salford Royal NHS Foundation Trust; 3- Faculty of Biology, Medicine and Health, The University of Manchester, Manchester Academic Health Science Centre; 4- Manchester Metropolitan University; 5- Faculty of Health and Applied Sciences, University of the West of England, Bristol.

The study of Prisms and Therapy In Attention Lost after stroke (SPATIAL) is a **feasibility study** about **spatial inattention**, a cognitive problem that affects **awareness of one side of the body and surrounding environment**. The **eyes work** but the person **does not see**. It is the **brain** that is **not sending the messages**. SPATIAL is a **collaboration** with researchers in Manchester and Bristol and at Salford Royal Hospital. **Central** to the study is the **strong patient, carer and public involvement (PCPI)** which began 7 years before the first patient was recruited to the study.

## WHY have PCPI in SPATIAL?

To harness the **expertise** of people with **lived experience of stroke** and to **ensure patient voice** is **actively heard** throughout the study.

## HOW were patient, carers and public involved in SPATIAL?



PCPI Lead

- Study **co-applicant**
- **Chair** of PCPI group
- Member of **trial management group**

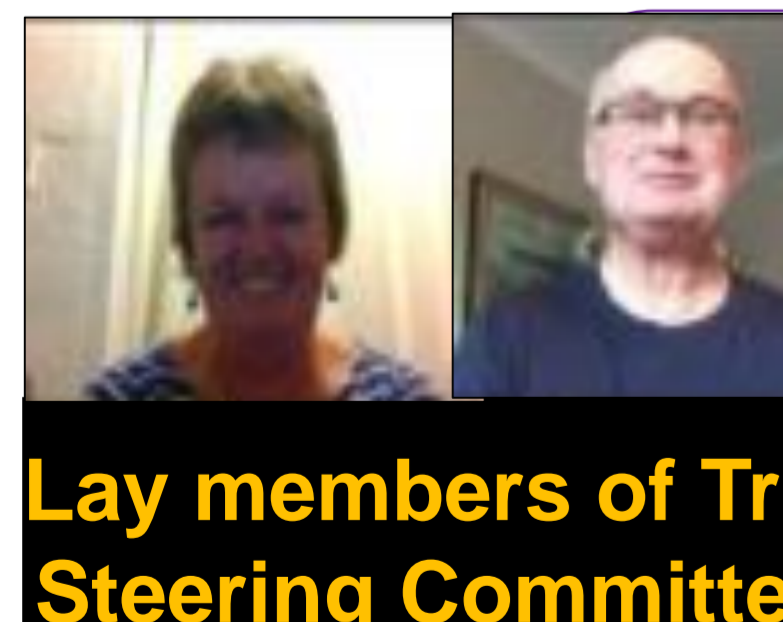
### How was involvement supported?

- Accessible **documentation**
- Accessible **environment**
- Pre-meeting **contact** face to face or by phone to discuss issues
- **Access** to research team as required
- **Payment** of expenses and time
- Research team **attended meetings** at groups request



PCPI Advisory group

- **Stroke survivors**
- Experience of **inattention**
- Experience of **rehabilitation**



Lay members of Trial Steering Committee

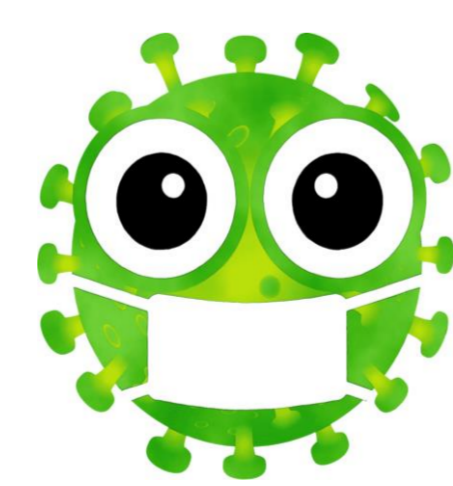
- **Stroke survivors**
- Experience of **involvement** in stroke research

## WHAT was PCPI in SPATIAL?

- Worked with the research team to **develop study proposal**
- Ensured **patient-facing documentation** was **accessible**
- Attended **ethics committee** and considered **ethical issues**
- Reviewed **equipment** and **materials**
- Ratified **changes** to criteria
- Developed **training video** and **materials**
- Reviewed anonymised **participant feedback**
- **Met with site teams** to explore differences between sites
- **Presented** at local and national **conferences**
- Reviewed and ratified **results** and **future plans**
- Co-designed **easy access summary report**
- Provided **oversight** of **study conduct**



### Covid-19 Implications



Processes and **strategies to maximize PCPI contribution** needed to be refined.

The research team enabled strategies to keep valuable input from group members who **could not usually access the technology** to do this.

### Impact on Patient Advisors

Patient advisors reported that **involvement built confidence** and gave them a feeling of worth.

*"You feel quite useless when you've had a stroke and lose the ability to do the things that make you feel like you. So this is an opportunity to help somebody else and help you feel like you again."*

### Impact on Research Team

Members of the research team felt more **confident approaching patients** with the knowledge that the PCPI group have reviewed all aspects of the study.

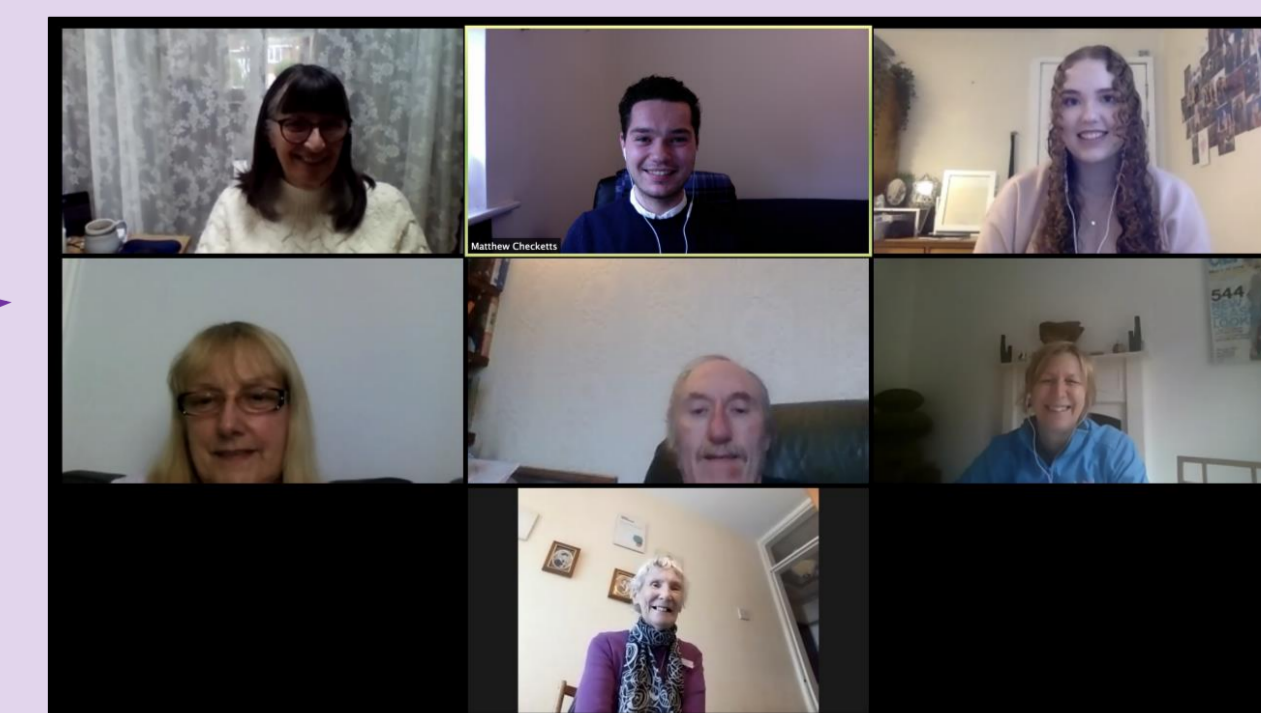
*"This group kept us going to the end, validating our aims and our efforts."*

*"The feedback...was extremely useful and certainly made me feel better about going onto a ward and asking patients to participate..."*

### Impact on Research Community

SPATIAL demonstrates the **mutual benefits of involving stroke survivors to support research**. Learning from PCPI is being fed back into teaching of future researchers.

*"As a result [of PCPI feedback], we decided to use the alternative term 'spatial inattention' ... We are also trying to change the vocabulary used in practice to this effect. I have taken this message to other stroke projects and to teaching."*



SPATIAL final report and publications available soon at: <https://sites.manchester.ac.uk/spatial/>



@SPATIALstroke



SPATIALstroke@manchester.ac.uk

This poster presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0816-20016) with financial support from Stroke Association (TSA LECT 2015/01) and a University of Manchester Research Impact Scholarship. The views expressed are those of the authors and not necessarily those of the NIHR, the Department of Health and Social Care or the Stroke Association.

