



The VISable group is a national patient and public involvement (PPI) group comprising 15 stroke survivors who have, or had, visual impairment, along with two family/carer members.

Members state the following as benefits they have felt by being involved in VISable:

- ❖ Acquiring and sharing knowledge of effects of stroke and supporting other members to use their knowledge and understanding to improve stroke research
- ❖ It has helped my recovery. In the early days after my stroke I taught myself to move again (walk, swim etc) this activity helps me to think again. Rehab for the brain?!
- ❖ Networking with other stroke survivors and learning more about the world of research from their past experiences of involvement. Makes me feel useful again as I have knowledge and experience as a stroke survivor. I feel like I'm giving something back to the hospital doctors/nurses who helped me to maybe help others in the future with similar things I have been through
- ❖ Networking, learning many projects, helping with the confidence, go to conferences, helping with new interesting tangents in my life
- ❖ Feel that my opinion is valued, being a service user I feel my lived experience helps the group and myself by networking with others
- ❖ I like the idea of linking up with other stroke survivors. I have an interest in stroke and low vision. It is good to know about what research that is going to help stroke patients
- ❖ Interesting, educational and social contact

When stating what are the benefits to others (e.g. other stroke survivors or their family) of them being involved in VISable:

- ❖ Improvements in personal attributes such as: self confidence, independence, motivation
- ❖ I hope that helping with research helps people who have a stroke today
- ❖ I feel better in myself when I am contributing to something useful which in turn helps my mood and just general outlook in life which helps others I am in contact with. Also if my input can help other stroke survivors then that is a huge benefit and worthwhile
- ❖ Letting people know about the group if you've got vision problems after a stroke. Lovely seeing peoples' confidence start to blossom again with the help of this group
- ❖ I use what I learn at the group in my interaction with work colleagues and stroke survivors who use the charities services
- ❖ I can share experience as an orthoptist and a stroke survivor
- ❖ Hopefully sharing knowledge and experiences to give greater understanding if stroke

Final summary comments from VISable members include:

- ❖ Membership of the VISable team restores life choices to the Patient, family and carer members. It improves their quality of life by making them feel more useful and valued

- ❖ I struggle with open questions. A thought that has occurred to me is that it is easy for Stroke Survivors to feel abandoned but VISable demonstrates that this is not absolutely the case
- ❖ Very grateful for my personal medical info and letters when dealing with benefits and appeals etc. I've really enjoyed being involved with this group with the health professionals and the group members who have had a stroke
- ❖ I hope that by being part of a group like this that I can help improve the care of stroke survivors who are coming through the system now
- ❖ I was suffering from neurological symptoms for 12 hours before I was testing my own vision to then shout to say I am an orthoptist I know something neurological was going on I want a scan, only then I was listened to. I was diagnosed to have an intracerebral brain haemorrhage. I feel eye movements and visual fields to confrontation should be part of a neurological assessment by all trained doctors
- ❖ Keen to be involved in whatever way would be helpful to the group