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| **Name** | **How many years have you been involved with VISable?** | **Are you a stroke/acquired brain injury survivor, carer, or both?** | **In what ways do you benefit from being member of VISable?** | **Have you used any of the free patient resources available? If yes, which ones and how were they useful?** | **In your view, what influence does Prof. Rowe’s work have on post-stroke screening and patient care/ experience?** | **Do you support other stroke survivors with vision impairment who are not members of VISable? If yes, is Prof. Rowe’s research useful in your activities, and how?** |
| MB | 3 | Stroke survivor | Interesting opportunity to interact with other survivors and professionals. Encouraged me to further research on treatments and rehabilitation. | The resources are useful and I have recommended them to other patients. I have an academic background (psychology) so tend to go to source publications. However I have shared stroke and visual impairment with local opthalmologists. | Some extremely useful research projects are currently underway and these will undoubtably have a positive influence on identifying and managing disabilities related to stroke. | Not yet actively engaged in support work. |
| GT | 8 | Stroke survivor | Peer Support, giving a receiving knowledge I can pass onto other stroke survivors particularly with eye problems post stroke | I have used all the patient resources, particularly the scanning sheets and information on hemianopia for stroke survivors and driving and PIP claims. Very helpful. | I think she has had a massive impact, healthcare workers seem much more aware of eyesight problems post stroke. | I am a peer support worker for the Charity Different Strokes and I attend a Different Strokes support group in Northampton. At DS I am the go to peer support worker to advise patients with eye problems, I share the research, activity sheets and advice I learn from being a member of the Visible panel. |
| BH | 10 | Stroke survivor | sharing expertise and experience of stroke vision research and other stroke relate research activities | Information on stroke  Advice on driving post stroke: helped stroke survivors at a local stroke support group to understand how to get back to driving and regain some independence after their stroke | Without effective screening, patients and carers may be unaware of their post stroke vision deficiencies resulting in significant problems if they try to return to their previous employment where they may make errors when using VDUs as part of their job | Yes, I often run sessions on how to get involved with stroke research at my local Different Strokes and Headway ABI support groups where I encourage stroke survivors to engage with research teams to help them to regain their dignity and self-confidence. Prof. Rowe’s work forms a linchpin to those sessions because of my own highly positive experience of being involved in her research along with many other stroke research trials throughout the UK |
| JC | 6 | Stroke survivor | The understanding of my own vision loss. I am able to use my personal experience from having a stroke and the issues my vision loss has had on my quality of life and rehabilitation as part of patient involvement.  By being a coordinator of a peer support stroke group, I am able to make other people aware of the assistance/treatment/information that is available to stroke survivors with visual problems. | Activity Books – Scanning/eye movement  Driving information – What is required by DVLA (Answers some of the questions you may have)  Dry eye – treatment  Sight impairment registration – information. | Professor Rowe’s professional and personal knowledge, empathy and genuine interest in improving the life of stroke survivors has been key in informing her research projects. She is always focused on the wellbeing of the survivor and patient involvement helps to form her work, ensuring she is always open and welcome to suggestions and ideas from those whose lives have been affected by stroke. | Yes, as previously mentioned I am the coordinator of Whitstable Different Strokes Group and I am able to pass information to those members who have visual problems from their stroke. |
| SR | 7 | Stroke survivor | So many ways, but it has definitely improved my confidence and motivation. | I am aware of them but not been able to make much use of them myself as my stroke was 10 years ago. I have been able to direct some other stroke survivors to them. | I know that Prof. Rowe (and her team) work tirelessly to make improvements to the system. I can only imagine that things would be worse without her efforts. | It would be a bit grand to say that I support others but if I bump into other stroke survivors with vision problems, I direct them to the website. |
| KD | 3 | Carer | It can feel very isolating being a carer as my life and structure changed to support my partner since she had her strokes and became blind, so I lost some of my identity of feeling like I was contributing to something useful or meaningful outside of what I would already help a partner with, so to have something like this research group where my lived experience as a carer to someone who has gone through life changing strokes and vision loss it made me feel like I had some important input into something bigger than me, Also seeing my partner feeling more confident and having a sense of purpose and pride in being involved in something useful too is really helpful to me as it helps her mental health to feel useful in society | The hints and tips were invaluable because when you are thrown into the deep end with so much information about medical situations which change your whole life it can feel really confusing as what to do to help, so having this information to help guide you on things to make my partners life more easier was a great help. Finding other information sheets for my partner to help her understand what she is going through was helpful too, especially in a format she can access herself as most information isn’t in a format which is accessible to her from NHS staff and sights and other service providers. | Prof Rowes work is vital to helping others who have had vision loss from brain injury or strokes because as a carer for my partner who has 3 strokes while in her early 30’s I was left to figure out our lives now as a carer and help her to figure out how to live her life blind and the hints and tips are vital because I had no idea what to do and felt helpless and having help from others who have experienced this already makes it feel like you aren’t so alone and confused. | I tell other carers at the local stroke rehab and social group at Stoke City football club where my partner attends about the research and resources from the group and they find it helpful and interesting. |
| JR | From start | Stroke survivor | I personally have learnt a lot from the group. When I first join the group, I learnt a lot about vision and how different people can be impacted. Learning with this group is lifelong and I have enjoyed learning from the research projects.  It has helped me with my confidence, I now feel happy to talk and work with health care professionals.  Also, I really enjoy seeing how beneficial the group is to new members and over time I can see how the group helps support their confidence. I love seeing people ‘blossom’ in confidence.  I work as an Accessibility Assistant at the Stroke Association and the knowledge and skills I have gained from this group have helped my professional development.  I am very grateful for the team who are so approachable and have answer many of my questions over the past few years. I appreciate that they will talk to me on the phone rather than email as my aphasia has impacted my writing. They have been flexible to my needs. When we have a face-to-face meeting, they are great at accommodating the whole groups needs to ensure everyone gets the best out of the meetings. The in-person meetings have been so beneficial for us as a group to support building relationships, sharing learning and working through projects.  The team has taken on feedback over the years and the meetings are now more accessible than ever. | In my stage of my stroke journey, I don’t need these resources anymore, but I do still signpost others to them. Especially the aphasia-friendly materials. | It is clear to see that Prof Rowe is a leader in stroke and vision and her work not only impacts the research world but also has real world implications when research findings are put into practice.  I have taken part myself in many vision projects and have seen firsthand the excellent work Fiona and her team are working on. | I run a specialist involvement group at the Stroke Association called Aphasia and Accessible Voices. The knowledge I have gained from this group I used in my job daily. |