

P4: I'm one of the recent stroke victims and I can say apart from one ophthalmologist, this group is the only contact I have with people that really understand the condition that I have. I come from another health system in Scotland, where as far as I can tell there's nothing like this; there's nothing like this in England as far as I understand as well. To me it's an absolute lifeline, and it's not just that Fiona's turning up lots and lots of research with her colleagues, it's the fact that I have a personal contact with this group, and with her and Claire. It's an absolute lifeline for me.

P5: I think one of the differences with Fiona, Claire and Lauren is that they are clinicians, as well as being researchers and academics. So they have at least two strings to their multi-talented bow, which in terms of evaluating and analysing professionally, sight loss, that's their job, they give us so much practical information. I went from September to the following May with no one talking to me about hemianopia and even when I went privately to see an ophthalmologist because he's a surgeon, he's not interested, and I think it's a really misunderstood condition.

P6: I'm not a stroke survivor I'm P1's wife, so I'm seeing it from a different perspective, but coming to these meetings and knowing Fiona outside the group as well and reading all her research papers, it's clear to me that disseminating this sort of information across the wider health care professionals makes them much more aware that stroke can and does effect vision significantly. It's quite clear from our experience that clinicians, maybe in the past, haven't always acknowledged it. People are becoming more aware, having survivors give talk at large conferences, seeing the perspective of people living with conditions to a huge group of wide ranging professionals, suddenly it was- oh god so stroke does effect vision! And so the work she's been doing is really starting to disseminate information across the wider sector.

P7: I think in terms of Fiona's presentation skills, she is phenomenal; her depth of knowledge, Fiona has got everything at her fingertips. You've not just got her satisfying us personally, she's exceptional.

P3: It's really hard to put your finger on, has Fiona, herself, influenced what's going on now? Its fourteen years since I had my stroke and nobody took any notice of what was wrong with my vision, I had major, left field. Visual neglect. I was even assessed okay for driving, and I was driving, yet I was processing no information on my left side. Now it's all okay, don't worry I have vision today.

I got involved through volunteering for her IVIS project because I was aware through my optometrist that I'd got this visual neglect, I heard about the IVIS project and volunteered and Fiona said why don't you join the Visible group? I'd already got involved with stroke research, being involved with Fiona just took that to another level because it gave me more confidence. On one level I see that with the group, when new members come, people like P3, he's been a member of the group about three years now, seeing how his confidence has grown is amazing. Fiona's done that by making this group what it is, we've now got, with Fiona's work, such a critical mass that guidelines are changing nationally, the stroke guidelines have changed because of Fiona quite categorically, so now peoples vision is being assessed, in HAS units, in hyper acute stroke units, now that wasn't happening five years ago.

P3: my experience is very different to maybe P1. I just go to a stroke group on a Tuesday morning because I'm local, and Fiona sent a researcher to the stroke group to talk about vision problems and that's how I became involved, and without being overly dramatic, it's given me a reason to get out of bed. Maybe two or three years ago I would sit here, I wouldn't understand everything and I wouldn't really contribute, now it's a lot better than that, on a very personal, individual basis, nothing to do with academic papers, being part of the group has helped me.

P3: I agree, for me one of the most important things, apart from the research and everything else Fiona's done, she's actually made our quality of life better. The knowledge that we have gained; we're aware of what's out there, making other clinicians aware of what's out there, who can then pass that back to their patients, by the knowledge that you have allows you then to take some control back in your life. If we didn't have that, where would we be?

P4: one of my goals on this two day visit to Liverpool, I haven't spoken to Fiona about this yet, I would like to see if I can get her to come to my local hospital in Scotland, I talk to clinicians, and my personal experience of being on the patients side is that their understanding of my condition is really very limited, with a very few exceptions, if I can get Fiona to speak to 50 or 60 of them at once I think that's going to be a tremendous step in the right direction.

P7: We almost minimise a lot of what goes on behind the scenes, because we don't see it, you remember the FAST advert? As a result of Fiona we now have VFAST which stands for Vision, face, arms, speech, time- how significant is that? That a major stroke campaign about understanding that you might be having a stroke now includes vision and I think that's really big.

P8: Can I say from the clinicians side, I'm an (allied health professional) as well as having a post stroke vision issue but getting into this led to me getting involved with Fiona's PAVE trial. The PAVE trial, while not a great success due to workload has been a great success in getting people to understand that vision is a sign of stroke, and this is paramedics who you would think would know and be clued up, and it's changed their whole perception. There are discussions in the backs of ambulances and on the station and that, between each other about it, develops further going out and identifying it on the street and taking them to the right place to get treatment. That then has a knock on effect because it benefits the patient, and the families and everyone else supporting them and then they share that information with everyone they're dealing with. I find I tell so many people this background stuff that's going on, that it changes their lives. One of my colleagues had a stroke just before Christmas and he was really struggling with everything, Fiona's been able to help, I went to see him and suddenly his whole view and vision of his future was changing because of the input of Fiona, it doesn't just change for him, but his wife too, and it's just huge, just that little bit is all it takes.

P5: It's a bit like a ripple effect and Fiona's at the heart of the ripple and sending them out and they start to just get bigger and bigger and bigger.

P7: no disrespect to paramedics down south but they haven't had the insight of any clinical trials into vision and paramedics are rolled out a lot to do PIP assessments and what does a paramedic know about sight loss? Which means that most often with people who have some degree of sight loss, you don't stand a chance of getting your PIP because they don't understand so you have to go through the appeals system. We are looking at producing a benefits leaflet which will come through Fiona.

It's critical that the group are able to guide the research agenda and the possibilities are endless, it's from the clinical academic research that change happens for patients. Fiona's invited me on several of her applications to be a co-applicant, that's given me the confidence to support other researchers as a co-applicant. Any of us can do that.

P5: I'm involved in research partly because I have the confidence from attending this group, and that is demystifying research and that's getting better research. We know PPI improves recruitment and retention now so it's breaking down those barriers, improving research and improving outcomes. I think Fiona is one of the best practitioners for PPI in the country.

P2: About 40% of people after stroke have the problem I've got that is aphasia; it means that your written skills are effected etc. I've been involved with Fiona, Claire and Lauren making aphasia friendly leaflets. That means that people can get involved that couldn't previously and that makes me feel all goosepimply. That can be the way in and then they get the strategies to actually deal with things in lots of ways.

It's a symbiotic relationship; us working with Fiona benefits her research and benefits us personally and also how we impact others through her, through the group, the tentacles have gone out, but it had to start somewhere. So it starts with Fiona, information comes in, we sit here as a group, we discuss, we learn things, then we go off and we take them away with us and then it goes out there, we add to that, other people then become more enlightened as to what's happening.

P7: It's definitely a two-way thing because this group, from what I've observed, is very influential in how Fiona takes her research forward because she always asks, what do you think? Should we be doing this? What's your personal experience? She's got open ears and thinks ways through from the feedback back up

P7: I think in my experience of seven years dealing with clinicians, doctors, whoever it might be, researchers, Fiona has the most open heart to accepting people who have lived the life of someone with sight loss and she doesn't look down at us, she doesn't speak down to us and we are elevated to a level of importance that she understands is critical to her research being the best it can be. A lot of researchers don't treat patients that way.

If Fiona's research hadn't happened, we would be poorly off, floundering.

P5: I use twitter and I tweeted that I was here today and someone at York replied about their visual assessments, now in previous years nobody would have given me that feedback straight away. People are proud that they are doing what they are supposed to be doing.

I think she's putting the word out there and she works tirelessly to put the word out there, and we do that too, and I think the best people to do it is us. Who can argue with someone who has hemianopia or any other kind of vision problem?

I would say she has prevented people from taking their own lives and she has enabled people to have quality of life through access to screening and the right kind of support. So they aren't closed off from the world, we can feel so misunderstood and part of society that's been neglected in terms of our medical needs. Fiona's work, its life changing.



Jim Currie,

Chair, VISable panel