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Statement Summary: impact of the of research on Post stroke visual impairment carried out by Prof Fiona Rowe since 2013 at The University of Liverpool

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Job Title: Head of Stroke Support  
Date: 29/3/19

This statement was written after the respondent consented to be interviewed, this was transcribed and summarised and returned to the respondent for corroboration of fact and to give an opportunity to add any omitted details

I work for the Stroke Association, my role is Head of Stroke Support and I cover Cheshire and Merseyside. I'm responsible for our commissioned services in this area, working directly with commissioners, CCG's, local clinicians. Developing local partnerships and supporting with the wider strategic work for the stroke association.

I've worked here for ten years; I started as a volunteer, worked as a stroke support coordinator, then moved into management. I've got a good knowledge of working on the front line with stroke survivors and the bigger picture of the importance of supporting stroke survivors to make the best possible recovery.

The stroke association is the UK's leading stroke charity; we want every stroke survivor to have access to the best possible support, to make their recovery as good as it can be. This is the priority for us. We also campaign, support research and fundraise as well.

We provide stroke recovery services that are commissioned by the CCG or local authority. These services provide direct support to stroke survivors, from the start of the stroke journey when they first have the stroke, the coordinators will visit people in

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Chief Executive Juliet Bouverie BA Hons (Oxon), DMS  
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hospital, and then they'll follow that journey through after discharge from hospital. It is a person centred approach with the aim of identifying needs and supporting the person to meet their needs, therefore supporting their recovery.

I probably first came into contact with Fiona when I was a coordinator, so it's probably going back, maybe 6-7 years now, initially there was a lot of work going on about the pathway for vision and stroke. Fiona is involved with the UK stroke forum, a yearly conference aimed at all health professionals that work in stroke. Fiona was on the steering group at some point over the last few years so was very much involved. Also some of the research Fiona and colleagues were doing was funded by the stroke association.

More recently over the last couple of years, we've had a few meetings about the VISION resources and how we can work more closely together, so we can make sure that our coordinators have access to really good quality information around vision and we know it's been tried and tested, and that it's the right information. We're also talking about the VFAST screening tool, looking at how we can utilise that for stroke survivors. We're looking to test a pilot using the screening tool with our six month post stroke reviews in Liverpool working with Fiona directly. This will enable any stroke survivors with a vision problem to be supported with referrals to the correct service and also allow support with management.

I think Fiona's work has really brought vision to the forefront of stroke, it's often something that's not initially talked about, we talk about people with physical disability after stroke and we even talk about aphasia after stroke, communication difficulties. Vision is often forgotten about because it's not always something people identify with as a need, that's what we are finding at the six month point, when all the acute side of things and all the therapies finished that vision does then becomes a bigger need.

Fiona's work has made sure vision is always on the agenda after stroke. Really raising the profile, making sure people are talking about vision and stroke, the stroke pathways as well, nobody else has been looking at that. Some of our peer support groups have been visited by Fiona and her researchers, so it's about that patient involvement too and listening to the people who are directly affected. That's what I think has been really important. Talking to the people that it really matters too, that's made a huge difference. To get it right and involve the patient voice!

It's not just about identifying what type of visual impairment; it's actually how somebody is managing that visual impairment. There will be other areas that don't have such good provision for vision problems after stroke, I definitely think the profile is higher locally because of the work Fiona's done. Lots of the clinicians and the therapy teams have worked with Fiona. She's always really keen to have conversations to make things better. So it's not about, that's done, that's a tick box and everything's fine, it's always

how can we improve it, what's happening at one hospital that they can share with another hospital to make things better for stroke survivors.

The VFAST screening tool pilot is the most prominent conversation with Fiona at the moment. Making sure that vision after Stroke stays high priority. It's also important to raise awareness of Fiona's work on VFAST that vision can be a sign of stroke. How we talk about vision and stroke has definitely been influenced by the work Fiona's done. I've been working closely with Fiona to improve links with the North West CLAHRC.

We've had a couple of her researchers come out to one of our survivors groups and talk to staff about the research they are doing. It's great to have conversations with Fiona because she's so passionate about what she does. That comes across, not just with us but talking to survivors. What I really like about working with Fiona is that for her it's the people that have had strokes that matter that they get the support they need at the right time, which comes across in everything she does.

Kate Charles

A handwritten signature in cursive script, appearing to read 'K Charles'.