Chris Welburn shares her experiences of being a service user taking part in a research project

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hris Welburn had a stroke four years ago. After six months, she left hospital with severe aphasia. Since then Chris has made remarkable progress. In 2013, she began working with the University of Sheffield’s Dr Rebecca Palmer as part of a service user group. The group has been meeting for five years and has helped with the design and dissemination of a National Institute for Health Research (NIHR) National Institute for Health Research (NIHR) Early Career Investigator Fellowship: ‘The Patient Benefit’ pilot study – Cost effectiveness of computerised aphasia treatment versus usual stimulation long-term, post stroke (CACTUS).

The NHS ethics committee commended the research team for the level of patient and public involvement the project demonstrates. Here, Chris uses email to share her experiences of being a service user involved in research with Dr Emma Aguamahna.

How have you been involved in the project?
I was going to a group thinking that I was going to a group thinking the meeting was about aphasia. It was typical – made up with people with aphasia together with some carers. But the group I joined did seem a little different. I didn’t know why, maybe they had been together for some time – they all had confidence in what they said and the way they expressed it. Usual carers do most of the talking and those of us who find speech difficult – we just smile. But this time the organisation were different – they had a real interest in what the group members had to say, even if some people take a little bit longer to say it. It was super!

Why did you get involved?
I was looking for people to communicate so important. I can’t begin to tell you – having something here inside your head or your heart that you are unable to speak – it’s unbearable. It’s the same for ordinary things, you just need to express yourself in everyday life. So with Rebecca and Madeleine Harrison doing research to help people with aphasia it is wonderful – and if I can help I would love to!

Why is it important to involve people who receive speech and language therapy in research?
People receiving speech and language therapy will have their own views about things, but it’s true that the important things will be similar. If you are attempting to make something better for somebody it is so useful to ask them if it is good and if they know anything that would make it better. Sometimes it is so tempting for the researcher to do things their way and they don’t do the things that are more obvious to the people having therapy.

What have been the benefits to you personally?
I have such an increase in confidence! I have always enjoyed meetings where I will learn something, but I would never say anything. I just would be the same in larger groups, but I think I’m a little bit better in smaller meetings. I have met some really good people by going to the meetings. I would never have had the opportunity of talking to them and they have got the same language problem as I have.

How did the research project benefit?
This is the most difficult question to answer. I feel that I’ve done only the least that the other participants have done, some do a lot more. But being there and saying my thoughts and ideas seemed to be adequate. I was made to feel that it was good and the work that we did was so very useful.

At a recent meeting we looked at the project that had been done so far. We were supposed to be critical – but I found that the whole project was great! The only thing that I could wonder about was what if I was just out of hospital, would it mean as much to me as it does now? My speech and language were so poor. I know now that I needed the Big CACTUS so much – but the written word didn’t mean much to me. I would do my work set by Big CACTUS, but I would do it not really knowing what it was about. So at our meeting we discussed having a one-page picture summary about the project – which is super! Rebecca says the ethic committee loved it!

What have you found challenging?
It is where we have to do things – even if you are awful at doing it, maybe other people with a similar stroke to you would also find it difficult. But what I find really hard is giving my opinion about things that are equally alike. At the last meeting we were looking at the use of photographs or line drawings. I loved the drawings – they clearly illustrated what was intended. But the photos were so engaging! Gosh... it’s so challenging when everything is good! I also have great difficulty in walking. The researchers are very good and have found a very suitable room with no trouble in getting there.

Any tips for SLTs carrying out research?
For SLTs wanting to involve service users in research, it couldn’t be easier! SLTs wanting to find out more about this frightening disability! And it’s the same. They understand our own difficulty in speech and they want our opinions. It would be good if there have a room which is easy to get to and a nice cup of tea waiting! I think service users would depend upon the level of speech SLTs were working with – the level of language in the group Rebecca and Madeleine are working with is quite good. I was without speech for a long time – at six months when I left hospital. I hadn’t much other than ‘yes’ and ‘no’. I don’t think I would be able to see groups doing at getting everybody to participate. The service users want to feel useful and how their involvement has helped and they need to know what has happened since the last meeting.

I was talking to my communication partner this morning. He had a stroke six months ago and whilst he was in hospital he helped some research. He said how upset he had been because they never told him how it had developed. It reminded me that I have been involved with a couple of research projects and I would love to find out how they ended. I think it would be useful if SLTs had some way they could let all the participants know the research had ended and if it was useful or if negative. It was interesting! It wouldn’t need to be big – just half a page saying ‘thank you’.

So what would you say to others about getting involved in research?
I would say to other people who have communication difficulties that it is so good being involved in speech and language research! I have been involved and I have enjoyed meeting some lovely and very interesting people and to have my mind stimulated! We met in some lovely places – it’s a wonderful treat! It is good to get involved in health research also. The health researchers are not necessarily people who are experienced with aphasia but with a little help they’ll improve! Maybe they won’t be as understanding as Rebecca and Madeleine.■

References & Resources
Palmer R, Paterson G. To what extent can people with communication difficulties contribute to health research? Nurse Researcher 2013; 20:3, 23

Find out more about the work of the CACTUS service user group at http://clahrc-sy.nihr.ac.uk/resources-videos.

html and in Palmer and Paterson 2013.