**EU Research Dissemination 2021**

**For translation:**

**Involving stroke survivors in research**

**Introduction**

2020 has been a difficult year for people across the globe and has had a negative impact on running clinical research trials in Europe.

Stroke Alliance for Europe wanted to learn from some of the EU-research trial participants about why they agreed to be involved in this important research.

v

**PRECIOUS - Using everyday drugs to treat stroke complications**

In the first days after stroke, about half of the patients have complications, including **infections**, **fever** and **swallowing** problems. The occurrence of these complications is strongly associated with a higher risk of death or future disability.

The PRECIOUS research assesses the impact of pharmacological prevention of these frequent complications. The study uses cheap, off-the-shelf medications that are simple, safe and readily available.

**Interview with a PRECIOUS clinical trial patient, Utrecht**

**SAFE: Why did you think it was important to take part in the PRECIOUS clinical trial?**

PATIENT: For us (me and my family) the stroke diagnosis and treatment was a nerve-racking experience, however we think research is important, and this trial did sound like a potential beneficial treatment.

**SAFE: Did you have any fears or reservations before making the decision?**

PATIENT: Not really no, the trial was clearly explained by the physician, and we recognised the importance of it, so we wanted to take part.

**SAFE: Do you think participation has benefited you? (eg did it make you feel more positive about the future, more confident, happier?)**

PATIENT: At the moment, I am doing really well. I have been improving steadily the last three months. I hope off course, part of this is due to my participating in this trial, because that would mean the treatment could work.

**SAFE: What are your hopes after taking part?**

PATIENT: I hope it provides valuable information for the researchers, to improve care for patients with stroke. I have recovered quite well, but I know from other stories this is not always the case.

**SAFE: What would you say to someone who is considering participating in a trial?**

PATIENT: Do consider it! Research and clinical trials are usually well thought-out, and it could potentially be beneficial for you or future patients

**SAFE:** **If you were asked to take part in a trial now, would the pandemic influence your decision**

PATIENT: Off course, at this moment everything is influenced by the pandemic. It would off course depend on the type of trial, but yes I would still participate in a trial.



**SVDS@target - Targets for intervention for the prevention of stroke and dementia**

SVD is small vessel disease. It affects small arteries in the brain and accounts for most cases of haemorrhagic (bleeding) stroke, a quarter of ischaemic (blockage) strokes, and contributes to at least 40% of dementia cases. There are currently no treatments for SVDs and they are only partially understood. This project looks at the common factors in multiple SVDs and will try to develop new treatments for the particular diseases that lead to dementia and stroke.

**Interview with a patient in her 70s, who participated in the SVDS trial, Scotland**

SAFE: Why did you think it was important to take part in the Treat SVDs@Target clinical trial?

PATIENT: I thought it would be beneficial for me as it meant that my blood pressure was being monitored twice a day for the duration of the trial.

**SAFE: Did you have any fears or reservations before making the decision?**

PATIENT: No, I had no concerns at all.

**SAFE: Do you think participation has benefited you?**

PATIENT: Yes, it made me feel more confident, knowing that my blood pressure was being checked every day.

**SAFE: What are your hopes after taking part?**

PATIENT: I’ve felt more comfortable since taking part.

**SAFE: What would you say to someone who is considering participating in a trial?**

PATIENT: Go for it. It’s a wonderful idea. It made me feel at ease knowing that people were looking at my blood pressure every day during the trial.

**SAFE: If you were asked to take part in a trial now, would the pandemic influence your decision?**

PATIENT: It didn’t really affect me as it was all done from home. I’d take my blood pressure reading myself and it was monitored remotely so I didn’t have to worry about coming in to contact with anyone during the trial.

**Interview with Stuart, 52-year-old man, who participated in the SVDS trial in the UK**

Stuart is a fit and healthy active person who had a minor stroke last August (2020)

‘I started to feel unwell and had a tingly sensation in my arm on the Friday. I was still feeling unwell by Monday so I rang the NHS and after a hospital visit and scan, I was told I had had a minor stroke probably related to the fact that I was overweight causing high blood pressure. I couldn’t drive for a month and I had 5 weeks off work.

I was asked if I wanted to participate in a clinical trial and after speaking to my family I decided to sign up. I had no concerns about being exposed to COVID-19. The study took place in a separate building from the hospital and involved having an MRI scan and review check-up.

My main concern was having time of work. I made the decision to participate in the trial because I thought it would be both beneficial to me and hopefully help future treatment for others affected by stroke.

Being part of the trial meant that I was being monitored for 4-5 months. Having regular check-ups and MRI scans meant that I felt reassured that if there were any further problems with my health, they would be picked up quickly. It gave me reassurance.

I am determined to make sure I do all I can to prevent another stroke. I’ve lost 2 stone already and hoping to shift another this year. Everything seems to be fine. The stroke has changed my life – I'm now fitter, healthier and lighter than before and on blood pressure tablets. Participating in the trial was nothing but a positive experience for me and I would recommend anyone approached to participate to do so.’

**Interview with Tony who had a stroke in June 2020 and participated in the SVDS trial in England**

‘I checked out the research on their website and any questions or concerns were answered by one of the principal researchers. She was fantastic and explained everything step by step so I had no worries going in to the trial.

‘It involved going the university unit at the hospital and having four MRI scans over four months. My blood pressure was also taken and I was put on different blood pressure medication during the trial. The last tablets worked out the best for me and I’m still taking them now.

‘I was having problems with my left eye and the MRI scan picked up the lesion in the part of the brain that affected my sight.

‘I didn’t see anyone from the stroke unit during COVID-19 – only my physio every two weeks. I didn’t have any concerns going to the site for the trial to have the MRI scans. I felt completely safe as it was separate from the main hospital so I didn’t feel worried about being exposed to the virus.

‘I was looked after extremely well by the research team during the trial. They were all fantastic including the radiographers. I feel lucky to have had the opportunity to participate in SVDS. I’m now on the right blood pressure medication thanks to the trial.

‘I would highly recommend participation in a clinical trial. If you’re unsure, do your research and ask questions about any concerns you may have before you decide. If asked again, I would have no hesitation in considering participating in a future trial.’