Inside DO-IT: A Participant Shares Her Experience

"In an emergency, you simply cannot take in everything"

Why we did this interview

As part of the DO-IT trial's Patient and Public Involvement activities, we interviewed one of our trial participants about her experience of being approached for research during an acute stroke. We wanted to understand what worked well, what could be improved and what matters most to patients when study participation has to be discussed in an emergency. We are sharing the key points with all DO-IT sites because her perspective offers practical lessons for how we communicate with and support participants across the trial.

DO-IT participant with the Bern Team of Study Nurses and Research fellows

“I had a safe feeling about the study”

She remembers being surprisingly calm in the emergency department. Her mother had previously suffered a severe stroke, so she knew how much worse the situation could have been. Her first contact with DO-IT was in the emergency department. Despite the stressful circumstances, she felt confident about the study and the team:

“*I had a safe feeling about the study. I did not feel that people were simply doing ‘something’*.”

For her, transparency was key. She wanted to understand what the study was about, what the options were and what would happen next. She felt this had been explained clearly and competently.
Randomisation was not a major concern either. Although she understood that nobody wants to feel disadvantaged by being randomly assigned to a treatment group, she personally never had the feeling that this had happened to her.

Keep it short when every minute counts

Perhaps the strongest message from the interview was about how to explain a study during an acute stroke. Her advice: do not overload patients with information.

“*In such an emergency situation, you cannot process all the information*.”

She liked that the study team initially explained only the essentials. A long and detailed discussion at that moment, she felt, could easily become overwhelming.

The next day, she personally felt ready to hear more. But she also noticed that other patients on the stroke unit were still struggling to process what had happened. Her suggestion was therefore simple: the detailed conversation does not necessarily have to happen at exactly the same time for everyone. For some patients, waiting another day or two might make a big difference.

She was also happy with a simple face-to-face explanation rather than a complicated information format. And if a patient cannot decide for herself, she sees an important role for relatives or another trusted person.

Would she accept a higher bleeding risk?

DO-IT addresses a difficult question: how should a possible benefit be weighed against the risk of serious bleeding?
For her, the answer was closely linked to independence:

“*For me, the potential treatment benefit would be decisive - the probability that I would be independent afterwards*.”

She said she would be prepared to accept some additional bleeding risk if the treatment also offered a chance of a better recovery.

Recovery is also about the small steps

One of the most memorable parts of the conversation was her definition of a successful treatment.

Her mother had experienced a severe stroke with hemiparesis, and she herself had previously gone through rehabilitation after major heart surgery. Both experiences shaped how she thinks about recovery.
Success, she said, is not only about being completely independent again.
It can also mean walking a little further than yesterday. Doing something today that was impossible the day before. Seeing steady progress.

"*For me, it is about the small successes - improving from day to day and recovering step by step*."

Regaining independence in everyday life would still be the biggest success for her. But smaller improvements can already have an enormous psychological effect and provide motivation during rehabilitation.

And when DO-IT is finished?
She definitely wants to know the results.
In fact, her preferred option would not simply be a letter or email. She would like an event where the findings are presented and where participants can also meet and exchange experiences with each other.
And her single most important piece of advice to the DO-IT team?

"*For me, the interpersonal aspect is the most important thing.*"

She mentioned that if the personal interaction with the study team had not felt right, she probably would not have taken part at all. This is a powerful reminder that good research is not only about protocols, treatments and outcomes, but also about trust, clear communication and the people behind the study.

We would therefore like to sincerely thank all of you: DO-IT investigators, study nurses, coordinators and clinical teams for your continued commitment. Every patient you screen, approach and recruit brings us one step closer to answering this important clinical question, and your thoughtful interaction with patients is an essential part of making DO-IT a success.

Reach out to us with any questions, concerns of hurdles - we are happy to help you!

DO-IT Principal Investigators	Trial Coordination / Management	Contact details
Thomas Meinel Luciana Catanese Urs Fischer Aristeidis Katsanos David Seiffge Ashkan Shoamanesh	Freschta Zipser-Mohammadzada Nerea Fernandez Trigo Stefanie Abend	Email: do-it@insel.ch Phone: +41 31 632 60 83 +41 31 632 98 84 +41 31 632 67 80

Thank you for your continued commitment and collaboration.

Recruit. Care. Cure. DO-IT!

https://www.linkedin.com/in/do-it-trial-a5b76537a/

https://x.com/DOIT_trial

https://www.doit-trial.ch