Aims

Empower stroke survivors to contribute to and influence the future of stroke research and rehabilitation at UCL.

Provide researchers with an opportunity to engage openly with stroke survivors and carers.

The 2019 Forum at a Glance

14 contributing research projects, clinical services, and charities.  
100 attending stroke survivors and practitioners.  
30 staff on hand to make it all happen.

The Sessions

Best attendance:  
- Technology for Aphasia, Professor Alex Leff, UCL  
- Post Stroke Fatigue: a Result of Altered Effort Calibration? Dr Anna Kuppaswamy, UCL

Most mentioned by attendees:  
- Life as a Younger Stroke Survivor, Austin Willett, Different Strokes

Most interaction and observed participant engagement:  
- Hyperacute Stroke Research, Azra Banaras, UCL
The Feedback: Attendees

Attendees were motivated to attend by a range of factors, including a desire to continue treatment beyond the end of their NHS provision, particularly physical and speech therapy.

Attendees were seeking hope, for themselves or loved ones, that they had not been forgotten and that someone was trying to improve their situation.

Youth and stroke was a recurring theme in attendee feedback, with them wanting more emphasis in stroke treatment and discussions that strokes happen at a range of ages, and that it is not an “old person’s problem”. They felt that their treatment pathways and the services they were referred to made them feel older and unwanted by society.

“I worked for 10 more years after my stroke, that’s hardly geriatric, so why are we treated as such?”

The Feedback: Contributors

All contributor respondents indicated they would be likely or very likely to take part again next year. All but one indicated they would be likely or very likely to take part in related but new events next year.

Half of the contributor respondents indicated that a main reason to attend was to raise awareness of options for support.

Less than half responded that recruiting participants and informing attendees about new research were important to them.

About a third were hoping to gather attendees’ thoughts on their work.

Event contributors were surveyed for their opinions, which were overall very positive.

★ ★ ★ ★ ★
Overall opinion on the event

★ ★ ★ ★ ★
Overall success of interactions
Conclusions

Overall the event was well received, and addressed a range of needs from the community.

Future plans should look at how to maximise the impact of the event, by targeting specific survivor groups, working with contributors in advance to prepare their offerings and improving flow around the event. Significant change for all stroke survivors, including those not at the event, could be achieved by making use of the richness of contributions to inform policymakers of the needs of the community.

This report was generated using data collected through 13 contributor surveys, 9 public interviews and observation of all sessions and expo area.