Impact Report

Event dates: 25th - 29th October 2021
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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.

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The 2021 Forum at a Glance

1,901 tickets booked across all events by stroke survivors, loved ones, and carers.

We forged new partnerships to include more collaborators than ever before:

15 Partners
9 Research Groups

77,080 total impressions across UCL WSD Forum social media pages.

112 tweets tagged #uclWSDforum.

Increase in website traffic in October 2021 versus September 2021: 98%
The primary focus was to enable two-way engagement between researchers and stroke survivors. Attendees left the events feeling empowered.

Sessions with highest attendance:
1. It’s Never Too Late for Recovery
2. Rehabilitation Apps: Aiding Recovery from Home
3. The Impact of Stroke on Identity, Relationships and Work

87% of participants enjoyed or really enjoyed the Forum.

81% of participants found the session topics relevant.

“I think the Forum’s strength was the ability to bring all sectors together. There was such a broad range of researchers, practitioners and patients all able to share & learn together.” - Attendee

Session voted most useful by attendees:
Staying Active After a Stroke

“Being in touch with patients and their main concerns for what needs to be better understood is inspiring for me as a scientist, who likes to believe my work is useful for patients living with stroke.” - UCL Researcher

Researchers and partners also were able to gain valuable insights from stroke survivors and carers to inform future research and public engagement opportunities.

What motivated our contributors to join the forum?

- To get ideas for research: 23.8%
- To hear from stroke survivors: 66.7%
- To share work more widely: 71.4%
Bringing people together

UCL World Stroke Day Forum brings stroke survivors and their carers together with others in similar situations, building a sense of community.

As well as introducing stroke survivors to peers, the Forum introduced stroke survivors to peers, as well connecting them with innovative research projects, resources, and services which they may otherwise be unaware of. It provided a platform and opportunities to interact directly with stroke researchers, clinicians and charities on a personal level.

The programme was designed to cover a wide range of topics in stroke research, from post-stroke fatigue to aphasia. This year also included sessions focused on emotional support, as well as a dedicated session for carers. The vast majority (80%) of attendees who responded to our survey found the sessions enjoyable and the topics relevant to them.

Connecting people with knowledge and resources

Most participants had multiple reasons for wanting to attend, including learning about stroke research, medical services and charity work. Some were drawn to the Forum because they were already familiar with the work of specific contributors.

Participants valued the extensive resources shared throughout the Forum week. These were collated into six themed Padlets, which are hosted on the Forum website. In sharing these resources, the Forum empowered stroke survivors and carers by providing them with the tools to have more control of their own rehabilitation and care.
Sharing lived experiences

A key part of the sessions was giving stroke survivors and carers the space to share their personal stories, experiences and insights. Participants felt comfortable sharing these intimate details, and this is a testament to the inclusive and safe environment created by session contributors and facilitators. This also left stroke survivors and carers feeling heard, and fostered a sense of solidarity when one person’s experience resonated with others.

Researchers and partners also gained valuable insight from stroke survivors and carers to inform future research and public engagement opportunities. In the contributor survey, 67% of respondents were motivated to take part in the event in order to hear from stroke survivors, while 24% hoped to get ideas for their research.

Contributors overwhelmingly reflected that they felt their sessions had gone very well, citing clear planning and insightful contributions from attendees as particular strengths. 81% answered that they would be interested in joining the Forum again next year.

“Being in touch with patients and their main concerns for what needs to be better understood is inspiring for me as a scientist, who likes to believe my work is useful for patients living with stroke.”

Reaching people online

The online format inevitably brings with it some technical issues and accessibility challenges.

Some participants mentioned they had difficulty keeping track of which individual sessions they had signed up for, and opening the correct Zoom links for each event. In future, using an alternative event management system and/or hosting platform that is clearer is a possible solution.
In addition, a focus group of participants who reflected on the Forum with our team, made us aware that the chat and Q&A functions on Zoom could sometimes be problematic for those with language or cognitive processing issues. Some people found it distracting when new messages appeared on the screen, diverting their attention from what speakers were saying. To alleviate these difficulties in future events, session facilitators should emphasise that the chat function is optional, and highlight the different ways people can contribute during sessions.

"Trying to follow the chat is hard. If you are also using Q&A it becomes almost impossible!"

However, others enjoyed using these functions and valued the opportunity to interact with other attendees. This helped to preserve the open atmosphere from previous, in-person Forums. Free-flowing conversations between stroke survivors and with researchers and clinicians can occur more organically at an in-person event. Therefore, in 2022, we hope to host some in-person events alongside the online programme.

In particular, the creative art workshops would function better as in-person events. Sending out artistic equipment in advance was time-sensitive and not all attendees received their parcels in time. Furthermore, many participants chose to keep their cameras off, making it difficult for the workshop leader to monitor their progress and engage with their creations directly.

"It really highlighted the positives of virtual workshops in terms of access but also how difficult it is to engage with making processes over the Zoom platform."

World Stroke Day Forum 2018
Conclusions

Overall, UCL World Stroke Day Forum 2021 was a success with overwhelmingly positive feedback.

This year saw a notable growth in attendance and online engagement from previous years. Participants and contributors both found the event valuable and enjoyable. Future plans should look at further increasing attendance by continuing to grow the Forum’s social media accounts and working with partners to promote the events to a wider range of participants.

In 2021, the organisers expanded on existing relationships and fostered new partnerships, including some smaller and regional organisations. Highlighting grassroots community work, as well as national projects and large research initiatives gave a breadth and depth to the coverage of stroke research and rehabilitation issues explored. These connections should be built upon for future Forums.

The digital format of the past two years has the event accessible to more stroke survivors and their loved ones from across the country and abroad, with fewer financial and physical barriers. This has been particularly important during a time when, because of the Covid-19 pandemic, in-person events would not have been possible. However, digital exclusion was an issue for some with specific needs that should be considered carefully in the planning for each year’s event. Additionally, some session formats, such as creative workshops, would be more effective as in-person events.

Next year, a hybrid mix of some smaller, in-person sessions (Covid-19 permitting) alongside the digital programme would capture the best of both worlds, and increase accessibility and reach further.

This report was generated using data collected through attendee and contributor surveys, a focus group of attendees, social media and web analytics as well as reflections from the events team.