A co-created and personalised digital support package for stroke survivors and their families: 'My Stroke Companion'

Louis Stokes^{1*}, Daisy Allington¹, Alice Wood¹, Mala Rai², Arvind Chandratheva³, Rob Simister³
¹Cognitant Group Ltd, Oxford, UK, ²East Kent Hospitals University Foundation Trust (EKHUFT), ³National Hospital for Neurology and Neurosurgery Queen Square and UCLH, Hyper Acute Stroke Unit (HASU), London, UK



Case study here!

RATIONALE

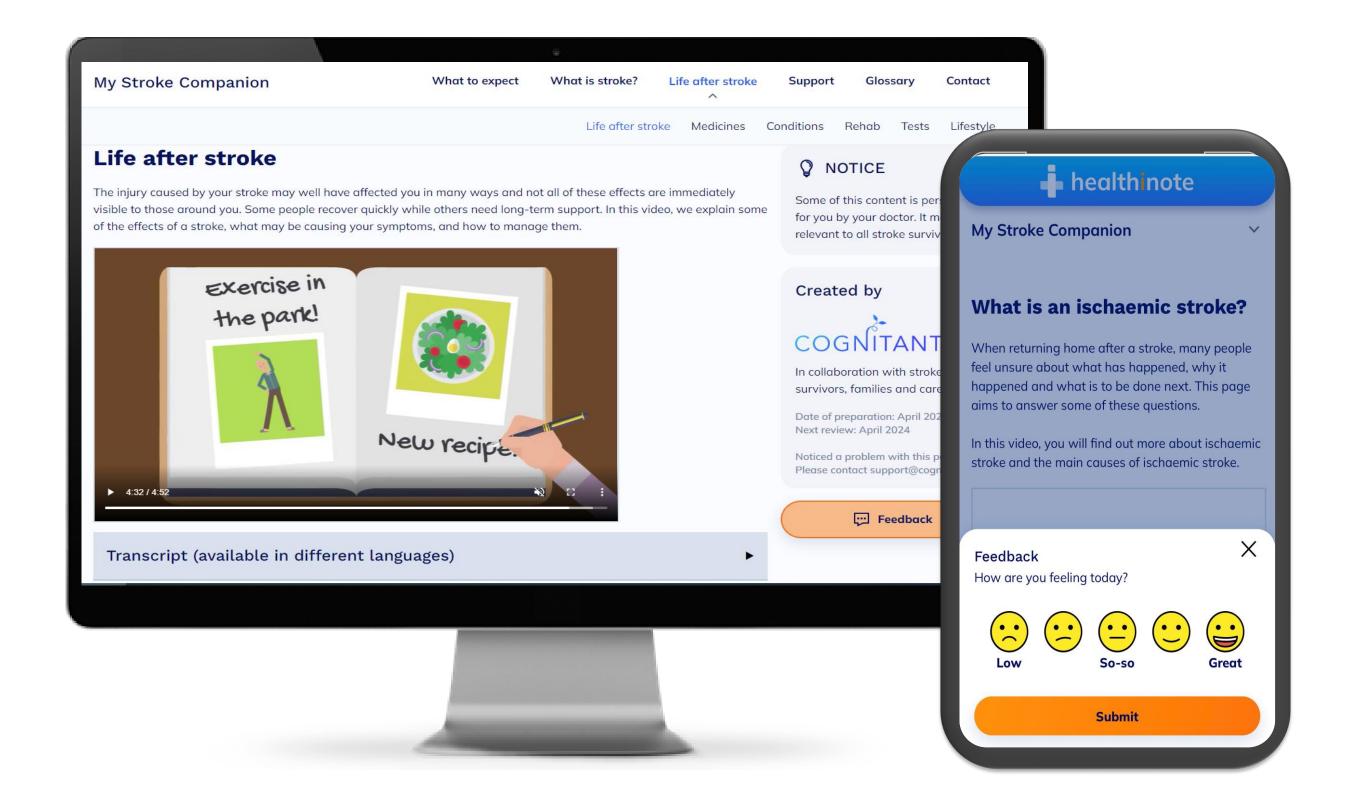
It is well-established that many stroke survivors lack a comprehensive understanding of their diagnosis, care plan, or treatment^{1,2}. Patients, therefore, have less control over their care and are at higher risk of non-compliance to treatment regimes, increasing stroke recurrence risk and long-term disability³. Additionally, patients and families often encounter unreliable or irrelevant information whilst seeking information independently.

'My Stroke Companion' is an accessible digital support package cocreated alongside NHS hospitals, charities, stroke survivors and caregivers. The platform is designed to provide personalised, reliable, and localised information to stroke survivors and their families, including about type of stroke, prescribed medicines, rehabilitation, and navigating life after stroke.

PROCESS

This work aimed to measure patient response to, and acceptance of, 'My Stroke Companion' following discharge from hospital after a stroke, by analysing engagement with the tool and by using a simple patient feedback questionnaire. Qualitative insights were also captured from the care team.

We piloted "prescription" of the first iteration of the DSP to selected patients presenting to the UCLH Comprehensive Stroke Service over a four-week period. Above traditional printed information leaflets, we found that providing interactive and animated content, with signposting to local support services, resulted in a positive user experience and high engagement levels.



Receiving reliable and personalised information: Patients and caregivers receive a unique web link or QR code which enables them to access their personalised digital support package; containing information about the type of stroke, prescribed medicines, rehabilitation, and much more.

RESULTS

The impact of this digital intervention was assessed through patient feedback and engagement metrics. During an eight-week pilot phase, 127 people accessed the tool with a 14-minute average session duration, compared with a 2-minute industry standard. The most viewed information related to type of stroke. Patients felt their understanding of their stroke and subsequent care plan increased after using the hub, and feedback from clinicians was favourable, noting direct benefits to patient recovery.



127 people accessed the digital support package during the pilot phase



People spent an average of **14 minutes** on 'My Stroke Companion'



Patients felt their understanding of stroke and their care improved

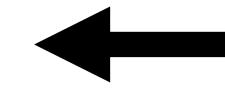
WHAT NEXT?

Following a stroke, information should be accurate, tailored, and accessible. Pilot data from 'My Stroke Companion' suggests the benefits of, and appetite for, curated digital resources. We are now undertaking Phase 2 of the project which, across 5 NHS pilot sites including East Kent, aims to:

- ensure information remains **personalised** by a clinician, removing the burden of searching for relevant, credible and reliable information
- be **localised**, signposting to local resources and support networks, connecting people to a local community of stroke survivors
- develop a dedicated area for caregivers
- remain current, updating content as the patient progresses through the clinical pathway
- incorporate notifications and reminders
- be **accessible**, translated into different languages to suit the local population, and highly visual content in 2D and 3D animations



View an example of our animated content here



References

- L. Knight, K., Worrall, L. and Rose, T., 2006. The provision of health information to stroke patients within an acute hospital setting: What actually happens and how do patients feel about it?. *Topics in Stroke Rehabilitation*, 13(1), pp.78-97.
- 2. O'Connell, B., Baker, L. and Prosser, A., 2003. The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience Nursing*, 35(1), pp.21-28.
- Nursing, 35(1), pp.21-28.
 Mohd Zulkifly, M.F., Ghazali, S.E., Che Din, N., Singh, D.K.A. and Subramaniam, P., 2016.
 A review of risk factors for cognitive impairment in stroke survivors. The scientific world journal, 2016.
- 4. Wallengren, C., Segesten, K. and Friberg, F., 2010. Relatives' information needs and the characteristics of their search for information—in the words of relatives of stroke survivors. *Journal of Clinical Nursing*, *19*(19-20), pp.2888-2896.





