'My Stroke Companion': a collaborative approach to designing a personalised digital support programme for stroke survivors and their caregivers

Louis Stokes¹, Daisy Allington¹, Alice Wood¹, Tim Ringrose^{1*}, Arvind Chandratheva², Rob Simister² ¹Cognitant Group Ltd, Oxford, UK, ²National Hospital for Neurology and Neurosurgery Queen Square and UCLH, Hyper Acute Stroke Unit (HASU), London, UK

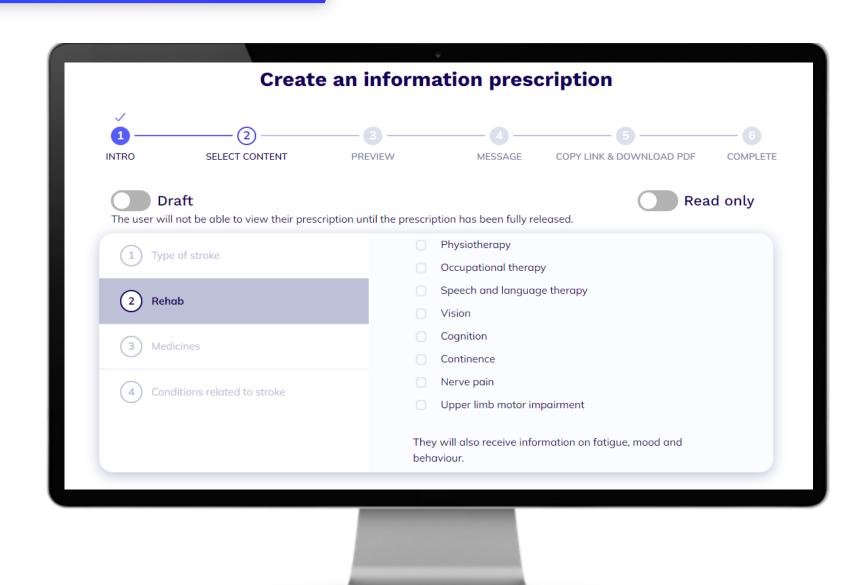


Case study here!

BACKGROUND

Many stroke survivors lack a comprehensive understanding of their diagnosis, care plan or how to navigate life after stroke^{1,2}. Poor understanding may be associated with less engagement with care and treatment regimes, potentially increasing adverse health outcomes including mental health challenges, long-term disability, and stroke recurrence³.

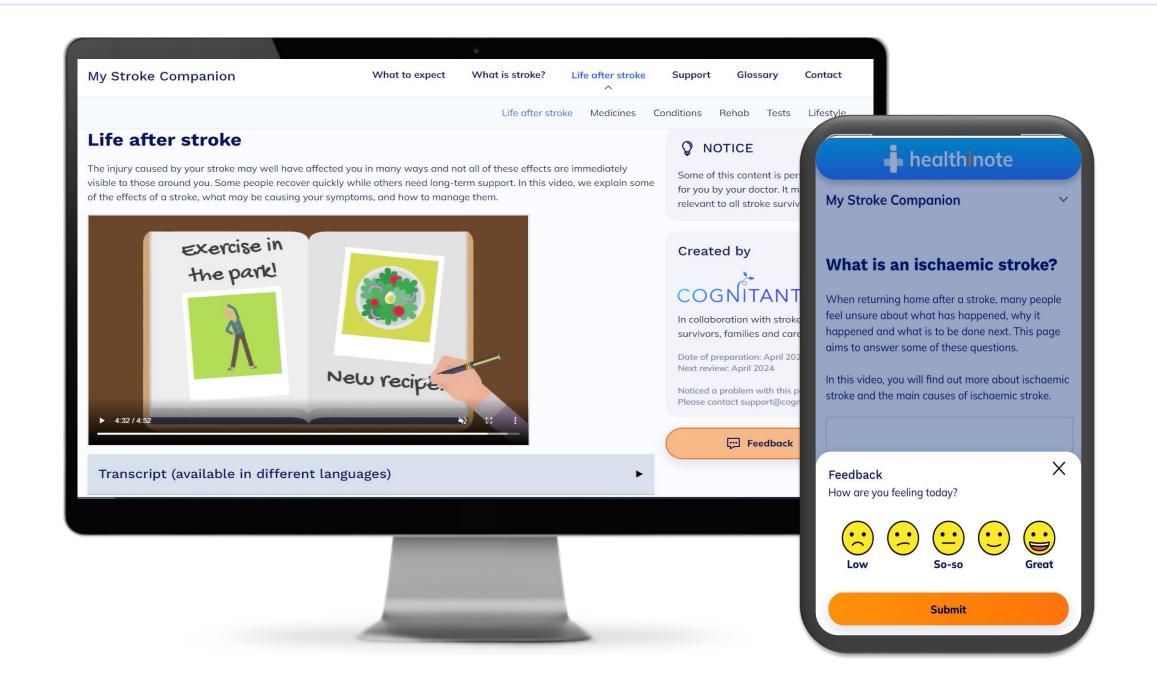
Although a wealth of information is available about stroke, it can be challenging to identify resources that are relevant, accessible, and reliable⁴. 'My Stroke Companion', designed through ongoing collaboration with hospitals, charities, stroke survivors, and caregivers in the United Kingdom, is an accessible digital support platform. It provides personalised, local, and trustworthy information to stroke survivors and their families, helping them to understand and navigate life after stroke.



Creating an information prescription: Healthcare professionals create a bespoke information prescription using Healthinote Pro, enabling them to curate an individual package of personalised information about type of stroke, prescribed medicines, and subsequent care plans.

METHODS

Through engaging with groups including young stroke survivors, traditionally underserved ethnic groups, and those in rural locations, alongside multidisciplinary clinical teams, the first iteration of 'My Stroke Companion' was iteratively and collaboratively developed. Over an eight-week period, we piloted "prescription" of the platform to stroke survivors presenting to the University College Hospitals London (UCLH) Comprehensive Stroke Service. Patient and clinician acceptance was assessed through analysing platform engagement and questionnaire feedback.



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

During the pilot phase, 127 unique users accessed 'My Stroke Companion', and spent an average of 14-minutes per session (compared with a 2-minute industry standard).



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

Information about type of stroke was most viewed. Stroke survivors felt their understanding of their stroke and subsequent care plan increased after accessing the platform and clinicians provided favourable feedback, noting direct benefits to patient recovery.

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. Our approach to developing the platform demonstrates the value of collaborating with all relevant stakeholders when designing digital health solutions. We are now undertaking Phase 2 of the project which 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 using highly visual content in 2D and 3D animations





View an example of our animated content here





- 1. 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. 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.
- . 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.