

Designing User-centred Patient Portal for Stoke Patients: Challenges in Accessibility, Engagement, and Interpretability

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Stroke is a major public health concern, ranked as the second leading cause of death worldwide. According to the World Stroke Organization, one in four adults over the age of 25 will experience a stroke in their lifetime, affecting over 110 million people globally. This has significant implications for the delivery of healthcare and the provision of medical services. In light of this, recent studies have demonstrated that patient portals can have a positive impact on the health outcomes of individuals who have suffered a stroke. These portals allow patients to take control of their personal health records, which could improve their understanding of their medical condition and the progress of their recovery, leading to improved outcomes and a better quality of life. This increased understanding can lead to better health self-management and increased adherence to medication or therapy plans, particularly for those with chronic diseases [4]. While patient portals offer potentially transformative opportunities for empowering stroke survivors to access and manage their health, designing a personalised and user-centred patient portal is a substantial challenge [1]. This is particularly the case in stroke – which often leads to cognitive, language, and physical impairments, which are not only major barriers to using portals but also to participating in portal design. We must consider designs which afford not only user engagement and accessibility, but also must address the substantial challenges of interpretability and visualisation of complex healthcare data. In our EPSRC-funded project, “Improving the lives of stroke survivors with data”, we aim to consider how we might design personal health records portal, with highly accessible visualisation/interpretation of health data, working closely with stroke survivors. We will focus on:

- (1) **Engaging users in design:** how might we engage stroke survivors in co-designing technologies? Building upon prior work on accessible design techniques [5], we will develop new accessible co-design techniques to support stroke survivors to be designers.;
- (2) **Accessibility of dashboard data visualisations:** how might we build upon prior accessible design accessible technologies for stroke survivors (e.g. [2]) who might experience cognitive and language impairments;
- (3) **Supporting accessible data collection:** How to build upon accessible visualisation approaches (c.f. [3]), to support users in reporting their health data;
- (4) How to support stroke survivors in **understanding, reflecting and acting** upon their health data;
- (5) how to best **integrate current care practices** into the portal to support carers.

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