A Preliminary Case Study of Developing A Web-based Digital Portal for Stroke Survivors using Synthetic Personal Health Data

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***Abstract*—Stroke survivors often encounter numerous challenges in managing their health in a long term, primarily due to the complexities of the stroke disease and the presence of multiple comorbidities. Patient portals are recognised as a promising solution, offering stroke survivors a centralised platform with access to their personal health records, support resources, and tools for managing their health status. In this study, we present a co-designed patient portal system using web technology through stakeholder involvement. This portal uses data from the South London Stroke Register (SLSR) data centre, and a synthetic database was created to simulate the access of personal health records. Featuring user-friendly interfaces (UIs), this portal provides self-management tools such as blood pressure monitoring, risk assessment for stroke recurrence, and quality of life questionnaires to facilitate self-assessment in home settings. Future work will focus on this patient portal interactions, usability test and pilot feasibility study.**

***Index Terms*—Personal health records, Synthetic database, Web development, Digital portal**

I. Introduction

Patient portals have gained increasing attention in healthcare with a focus on supporting self-management for patients. A patient portal is defined as a mechanism that offers new opportunities for patients to actively engage in their healthcare journeys, providing access to health data and enabling communication with healthcare practitioners [1]. Patient portals are increasingly recognised as essential tools for delivering patient-centred care in both outpatient and inpatient settings [2], [3].

However, designing an effective and practical patient portal presents a multitude of challenges that must be carefully navigated to create a user-friendly platform. Accommodating diverse user demographics, including various levels of digital literacy and accessibility requirements, poses a significant challenge [4]. Most importantly, the portal requires features with clinical evidence supporting health self-management, such as the monitoring and understanding of blood pressure observations in home settings [5], [6]. Furthermore, while the focus often lies on creating a user-friendly and feature-rich interface for patients, it is equally important to ensure that the underlying technical infrastructure is robust, secure, and scalable. Active involvement of stakeholders is essential throughout the iterative process of design and development to accommodate these challenges.

This study presents a preliminary development of a co-designed patient portal for stroke survivors affiliated with the South London Stroke Register (SLSR) centre. The co-design process involves a diverse array of stakeholders, including clinicians, stroke survivors, caregivers, social scientists, human-computer interaction experts, and policymakers [7]. Participation comprises three stakeholder meetings and two patient group meetings, supplemented by initial insights from qualitative interviews with stroke survivors and caregivers. The portal operates on a web-based platform, with its system architecture depicted in Fig. 1. The framework facilitates the integration of various services such as supporting access to in-

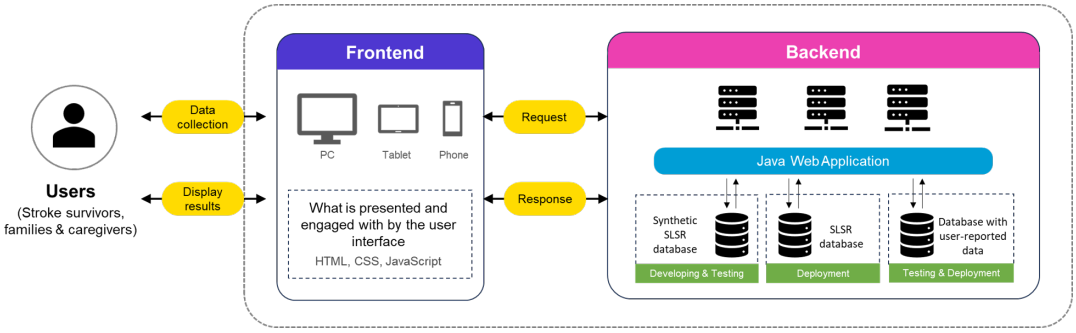

Fig. 1. Architecture of web-based patient portal: users can access services through laptops, tablets, and smartphones, all of which feature interactive user interfaces. During the development phase, the portal's web server utilises synthetic health records of stroke survivors from the SLSR database for testing purposes. In parallel, a database for archiving user-reported data has been established and communicates with the web server. Subsequently, the server will establish a connection with the real database in the deployment and evaluation stages.

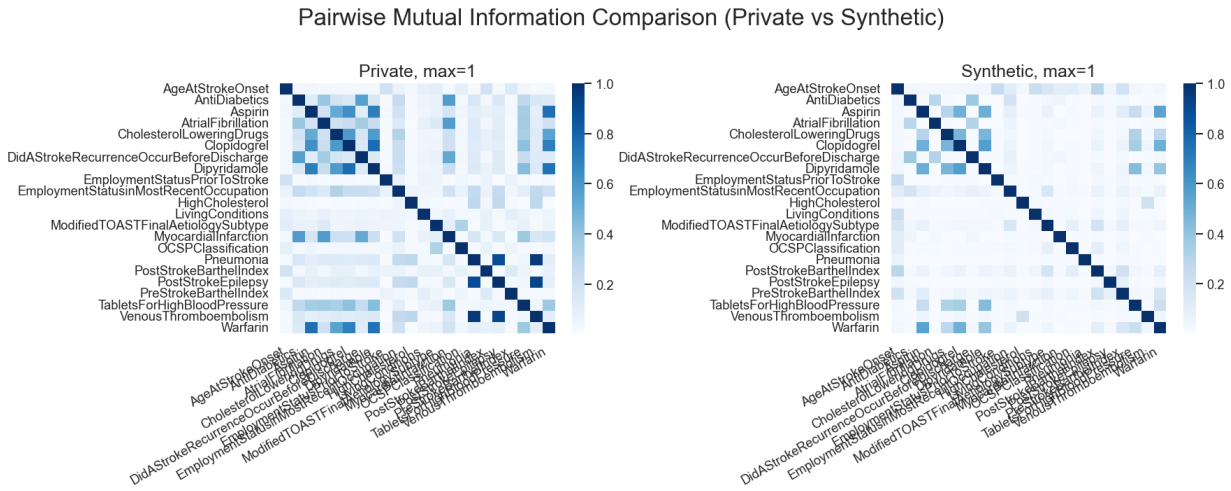

Fig. 2. Mutual information comparison: The left side illustrates the correlation matrix of the original dataset, while the right side reveals the correlation structure within our synthesised data. Confusion matrix helps in understanding how well the synthetic data replicates the patterns present in the original data.

teractive User Interfaces (UIs), real-time interactions between different databases and user-reported data management. A synthetic database is developed to simulate personal health data access archived in the South London Stroke Register (SLSR) data centre in the testing phase. Concrete UIs of prioritised functions are presented, along with accessible design elements tailored to the stroke survivor users.

II. Methods

The SLSR is a population-based cohort study established in 1995 to examine stroke causes, incidence, and outcomes. The SLSR seeks to estimate both the incidence and the acute and long-term needs of a multi-ethnic, inner-city population, with the follow-up up to 20 years [8].

This portal system aims to provide personal health records (PHRs) in the SLSR data centre; however, PHRs contain highly sensitive and confidential medical information, where sensitive or confidential information must be protected in the development stage.

In this work, we applied a Python library named "DataSynthesizer" [9] to create synthetic stroke-related health records for patients who encountered first or recurrent stroke onsets. Particular settings are:

- Epsilon Value (Privacy Control): $\epsilon = 5$
- Degree of Bayesian Network: $degree_{bayesian} = 2$
- Number of Synthetic Data Tuples: $Num_{tuples} = 1000$

By generating synthetic data that closely resembles the original patient health records while masking specific identifying details, it allows developers to create secure and privacy-compliant access systems for patients. Fig. 2 presents a comparison of correlation matrices between original and synthetic database. When presenting results to stakeholders, a synthetic database provides a tangible demonstration of the system's capabilities and usability without exposing real patient data to risks.

Fig. 3 shows the dashboard of patient portal with an overview page. Through a collaborative team and patient and public involvement , we were able to prioritise the needs and preferences of stroke survivors in the co-design of the portal. Three critical functionalities were priorities and developed in the portal: *i*) allow patients access and manage personalised individual health-related data on their stroke; *ii*) assist stroke

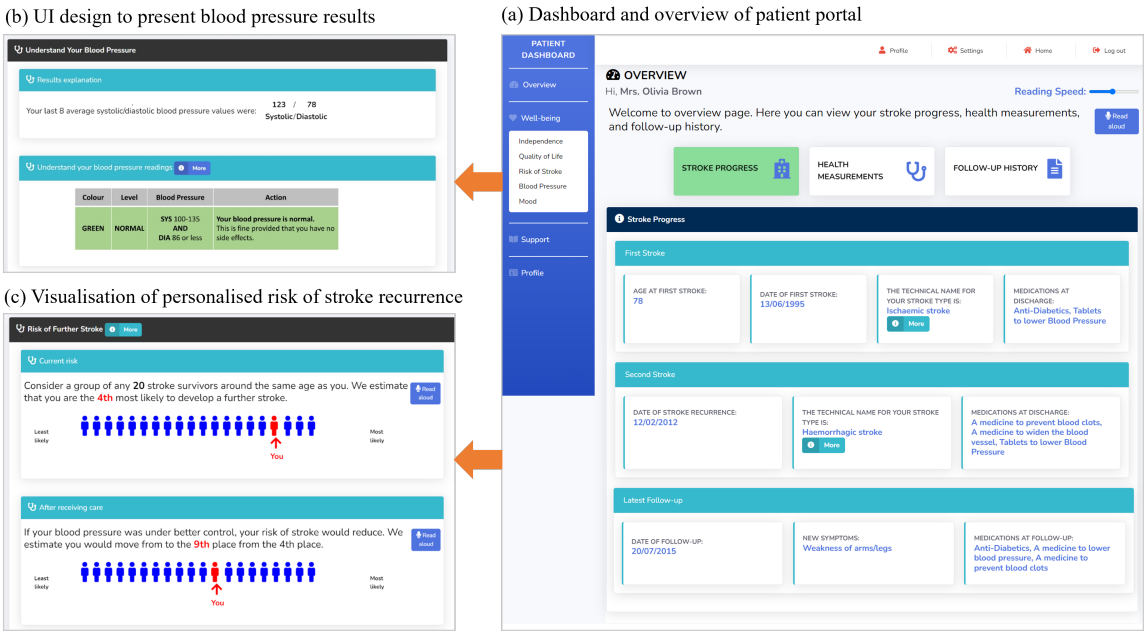

Fig. 3. Snapshots of (a) the overview page after user login; (b) the UI design for presenting blood pressure results and assisting in the interpretation of normal/abnormal levels, along with clinical advice following guidelines; (c) the presentation of individual risk of stroke recurrence and improved blood pressure if appropriate medication or rehabilitation is involved.

survivors in recording their health conditions and tracking recovery, including physical and psychological health; *iii*) help understand and address the risk of stroke recurrence [10].

III. Conclusions & Future Works

This research presents a novel web-based patient portal, which utilises a client-server system architecture and integrates databases. A synthetic personal health database was developed and employed to ensure data privacy throughout the development and testing phases. The design of the patient portal dashboard was a collaborative effort, featuring user-friendly components derived from a co-design approach. Subsequent efforts will focus on improving the usability of the portal and enriching the user experience.

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