Leveraging Cloud Technology for Personalized Multiple Sclerosis Care: A Comprehensive Data Management and Visualization Approach

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Abstract

This project develops a cloud-based solution for securely managing clinical data and patient-reported outcomes (PROMs) for multiple sclerosis (MS) patients. Utilizing REDCap for data collection, we incorporated clinical outcomes and PROMs from 300 MS patients over 18 months, supporting a machine learning (ML) based clinical decision support system. Our cloud architecture, featuring segregated data handling and enhanced security protocols using AWS, ensures robust data integrity and confidentiality. Key improvements include streamlined data ETL processes and an interactive online-based dashboard that facilitates the visualization of clinical data and PROMs, crucial for effective clinical decision-making. Initial results indicate a successful implementation in enhancing data management, with implications for personalized and predictive medicine. This framework not only elevates clinical data handling efficiency but also integrates PROMs into clinical practice effectively.

Keywords: Multiple Sclerosis; Data Visualization; Cloud Computing; Patient Reported Outcome Measures; Decision Support Systems

Introduction

Multiple sclerosis (MS) is an autoimmune, neurodegenerative disease with unpredictable progression, which complicates clinical decision-making and significantly impacts patient quality of life [1]. Addressing these challenges, digital solutions for clinical data management, as well as apps designed to collect PROMs, are common. Nevertheless, technological solutions that allow for the integration of these data and their appropriate visualization by healthcare professionals are scarce [2]. In this context, our project aimed to develop a comprehensive cloud-based solution to manage a wide array of data types involved in MS care. The primary objective of this initiative was to establish a robust platform that ensures thorough data checking, guarantees security and anonymity, and lays the groundwork for future integration of Machine Learning (ML) and Artificial Intelligence (AI) technologies. This platform will not only facilitate the advanced analysis needed to drive forward personalized medicine but also support more nuanced and data-driven clinical decision-making processes. The secondary objective revolved around the development of an interactive online-based dashboard, designed to enhance the visualization of both clinical data and patient-reported outcomes (PROMs), making it an essential component in the daily clinical management of MS [3]. By providing real-time data interaction capabilities, the dashboard serves as a critical support system for clinicians, enabling the effective incorporation of PROMs into routine clinical practice and ensuring that treatment decisions are informed by up-to-date and comprehensive patient data.



Materials and Methods

Data Collection and Management

Data for this study were systematically collected using the REDCap platform, tailored to gather both clinical outcomes (CROs) and patient-reported outcomes (PROMs) for a cohort of 300 multiple sclerosis (MS) patients over an 18-month period. We structured the data collection into two separate databases to maintain the anonymity and integrity of the data. A clinical database was developed to record baseline demographic information as well as clinical history, diagnostic details, and ongoing assessments of disease progression during biannual clinical visits. Separately, we created PROMs Database where patients could independently submit their responses to validated PROMs questionnaires through their electronic devices [4].

Data Anonymization and Security

Each participant was assigned a unique identifier at the point of inclusion, ensuring all data remained anonymous. This identifier linked the clinical and PROMs data longitudinally (captured in different time-points from every subject), allowing for comprehensive analysis without compromising patient privacy.

Cloud Architecture and Data Processing

The cloud architecture was designed for high security, operational efficiency, and scalability, as shown in Figure 1, using AWS [5]:

- Front-end and Back-end Segregation: The public front-end is protected with access controls via AWS
 Cognito and is separated from the backend, which is hosted in a private VPC. The interconnection
 between them is made through an API Gateway that controls access to the system's private services.
- User Interface: Developed in React and hosted on AWS Amplify, the interface provides secure access through authentication with AWS Cognito.
- Data Processing: The AWS Lambda function, which manages the ETL process, is responsible for importing data from S3 buckets into the Aurora MySQL database, where data validation and transformation tasks are also performed to ensure their coherence and prepare them properly for analysis.
- Data Storage and Backup: Uses dual instances of Aurora MySQL, one active and one standby, to ensure data availability and robustness against failures.

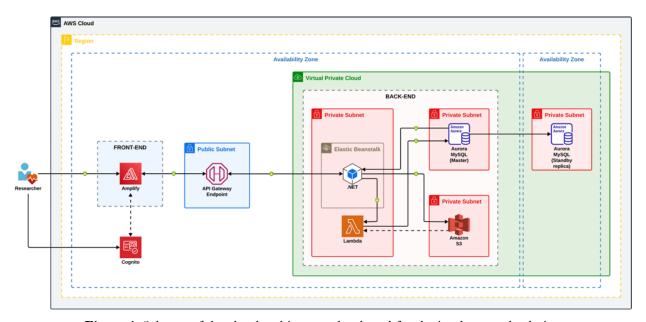


Figure 1. Schema of the cloud architecture developed for the implemented solution

Monitoring and Security Management

Continuous monitoring and advanced security measures, such as data encryption in transit and at rest and granular IAM policies, are implemented to protect data integrity and access. Tools like Amazon CloudWatch are used to oversee system performance and health.

Extraction, Transformation, and Loading Processes

Our ETL (Extraction, Transformation, and Loading) processes are designed to optimize the quality and structure of data for ML applications: during the Extraction and Preparation phase data from REDCap is extracted, checked for completeness, and validated. Transformation implies exporting data into a standardized CSV format, making it suitable for ingestion into a database. Finally, data is securely loaded into the cloud database using refined AWS Lambda processes to ensure integrity and alignment with our analytical needs.

Interactive Online-Based Dashboard

A key feature of our methodology is the development of an interactive dashboard hosted within the cloud infrastructure. This dashboard allows for real-time visualization and analysis of both clinical data and PROMs, enabling dynamic data interaction and clinical decision support by integrating data trends. Thus, we provide a powerful tool for clinical decision-making, facilitating the adoption of PROMs into routine practice.

Results

The implementation of our cloud solution has effectively managed comprehensive data collection and integration, ensuring high-quality data. Its scalable design supports robust data processing, enabling enhancements to our ML predictive models and facilitating ongoing research. The AWS-based platform is accessible to hospital staff via web authentication, allowing clinicians to view historical and updated patient information by simply knowing the assigned patient number. The interactive online dashboard has been especially impactful, offering real-time data visualization that aids clinicians and researchers in informed decision-making.

Discussion

Our solution represents a significant step forward in the management of MS, integrating clinical data with PROMs; other available solutions focus on clinical data or PROMs separately, which complicates the inclusion of patient perceptions in clinical practice. It supports rigorous data management with checks, security, and anonymity, enhancing the use of machine learning (ML) and artificial intelligence (AI) in clinical settings. The platform's interactive dashboard is vital for converting complex data into actionable insights, enabling real-time visualization of clinical data and PROMs. The major limitation of the platform is its design specific to a scientific study context, which will require modifications and adjustments for broader use.

Conclusions

The project has effectively met its objectives, establishing a secure and efficient cloud-based platform that enhances data management and lays the groundwork for future ML and AI applications in MS care. The interactive dashboard has proven useful in supporting clinical decision-making. As we advance toward a data-driven healthcare system, the technologies developed here are set to significantly improve patient management and care.

List of Abbreviations: MS - Multiple Sclerosis, ML - Machine Learning, AI - Artificial Intelligence, PROMs - Patient-Reported Outcome Measures, AWS - Amazon Web Services, ETL - Extraction, Transformation, and Loading, REDCap - Research Electronic Data Capture, VPC - Virtual Private Cloud, API - Application Programming Interface, IAM - Identity and Access Management.

Jose Manuel PINILLOS RUBIO and Minerva VIGUERA MORENO

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Conflict of Interest: The authors declare no conflict of interest.

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