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Development of user-friendly and interactive data collection system for cerebral palsy

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Abstract

Cerebral palsy (CP) is a permanent motor disorder that appears in early age and it requires multiple tests to assess the physical and mental capabilities of the patients. Current medical record data collection systems, e.g., EPIC, employed for CP are very general, difficult to navigate, and prone to errors. The data cannot easily be extracted which limits data analysis on this rich source of information. To overcome these limitations, we designed and prototyped a database with a graphical user interface geared towards clinical research specifically in CP. The platform with MySQL and Java framework is reliable, secure, and can be easily integrated with other programming languages for data analysis such as MATLAB. This database with GUI design is a promising tool for data collection and can be applied in many different fields aside from CP to infer useful information out of the vast amount of data being collected.

I. INTRODUCTION

Cerebral palsy (CP) is a group of neurological disorders that appear in infancy or early childhood and affect body movement and muscle coordination [1]. It affects one in 323 children in the United States [2], altering not only the children's physical but also their mental health. Other diseases relating to cognitive and behavioral functions often accompany cerebral palsy, such as speech problems and short attention spans. Healthcare professionals utilize various tests such as Child Health Questionnaires [3] and the Stanford-Binet Intelligence Scales [4] to assess the state of these accompanying disorders and patients' overall mental health. This condition creates a need for a database to record and host the test results, which can be used in the future to infer clinically meaningful patterns. These patterns could potentially promote better assessment of patients' current conditions and indicate any impending regressions.

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Currently, paper-based and existing electronic medical record (EMR) systems, e.g., EPIC, are the most commonly used data collection methods at the hospital. Studies have shown that existing EMR systems are hard to be seamlessly integrated into clinical workflow; prolonged data entries mainly happened after moments of patient care [5]–[6]. In addition, these EMR systems were generally designed for generic practices. It is difficult to tailor the database and interface to specialized cares (e.g., CP) [7]. It means that the data collected in specialized cares is cluttered with unrelated information fields. Several other database storage solutions, such as Cloud-based storage, have been identified, but these software packages are currently still limited in terms of applications in the bioinformatics domain [8] and the issues of complexity and sensitivity [9].

To overcome the limitations of the current systems, we developed a flexible and customizable database system with an intuitive graphical user interface (GUI). It allows healthcare professionals to store CP patients' information and test results electronically. The GUI only contains the relevant data input fields for CP. The data is stored within the hospital's secured network, leading to easier data extraction and analysis for yielding useful information about the CP population. The interface allows users to input, retrieve, and update patient information and test scores as well as updating diagnoses and test sets in an efficient and secure manner.

II METHODS

A. Database

The database used to store patients' information and test results needs to be reliable in data storage and retrieval. It should also be able to handle potential errors, store vast amount of data, and provide easy interaction with other programming languages for data analysis purposes. For these reasons, it is decided that the database should be built using My Structured Query Language, or MySQL for short. It is a relational database that utilizes tables and relationships between tables to store a vast amount of data without redundancy; this is done by relating data entries in one column to rows in other tables. Many other programming languages such as MATLAB and Java contain libraries that allow easy data query from MySQL.

Recently, NoSQL databases, which are designed to store a vast amount of data efficiently in an unstructured manner (unlike MySQL), were deemed to be the state of the art for databases [10]. Nonetheless, it was found that NoSQL databases do not have the necessary security level to protect information that is stored [11]. Therefore, MySQL is a better alternative regarding security, especially with the nature of the data being stored. MySQL was preferred over other relational database systems such as Oracle since it is free of cost, making our solution low-cost and more amenable to open sourcing.

B. Graphical User Interface (GUI)

Java was the language used to create the GUI for users to have access to the MySQL database. Nearly all computer devices have the necessary built-in platforms to run Java

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applications, which makes Java a suitable language for GUI development. It also contains a SQL package that allows Java to execute SQL queries to modify data in the database.

III. RESULTS

A. Database

A total of ten tables were created to store necessary information used to describe cerebral palsy patients' health status; the number of tables was determined based on nature of the information that needs to be stored, arranged in a logical manner. This database is to be stored within the hospital's network. Information stored in the database includes the list of possible diagnoses and the categories they fall under, basic biographical information of patients and the results of the various tests administered. The name of the ten tables are as follows: categories, disorders, education_level, occupations, participants, scores, scores_conversions, test, test_parts, and users. Relationships between tables are shown in Figure 1.

Cerebral palsy patients' biographical information will be stored in the 'Participants' table. The only required information is the patients' medical record number and diagnosis, which can support ICD-9 and ICD-IO codes. Unlike other databases, other information is not relevant to cerebral palsy and therefore not required to be entered. The biographical information needs to be reviewed by appropriate users once it is administrated into the database. Data with binary value will be stored in the database and will be reflected in the GUI with a checkbox component that indicates whether this information has been reviewed.

The 'disorders' table lists all possible diagnoses such as obstructive hydrocephalus and Down syndrome that a cerebral palsy patient can be identified with. Currently, the database has been tested using 30 different disorders, which can be expanded via the GUI. The index numbers of the rows of this table are related to the 'disorder _primary _id' column in the 'participants' table. Therefore, only the disorder identification number needs to be stored in the 'participants' table. The complete information of each disorder can be found by looking up its identification number in the 'disorders' table.

The 'categories' table contains different test categories, while 'test' and 'test_parts' tables contain all tests and their test parts that can describe the health status of cerebral palsy patients. These tables are related to each other, as some tests fall into certain categories and have multiple test parts associated with it.

The 'scores' table contains participants' test scores, and the 'score-conversions' table provides the conversion between score scales for each of the tests. The score scales include the standard score, percentile, t-score, z-score, and scaled score.

The 'Education_level' and 'occupations' tables contain the basic classification for education and occupation of the patients' parents. These tables are linked to columns in 'participants' table, similar to the 'disorders' table.

The table 'Users' stores all user accounts that are given access to the database. There are three types of users: administrators, supervisors, and normal users. Administrators will have

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access to all functionalities in the GUI while supervisors and normal users have limited access. For example, normal users are allowed to input only new patient information to the database but supervisors are allowed to review previously stored patient information. All users are required having a username and a password for accessing the database. F or security reasons, the encrypted password, generated by hash function in Java, is stored in place of the actual password.

B. Graphical User Interface

The GUI design allows users to access the database securely using their personal account information (the username and the password). The main functionalities of the GUI can be accessed via the main panel, including inputting scores to the database, reviewing existing patient information, adding new tests to the database, and modifying personal login information. The interface will warn users with a pop-up when certain invalid inputs are entered, reducing errors in data collection. The following section will discuss these use cases in detail (Figure 2).

Input Scores—The input scores' functionality allows users to enter patients' biographical information and test scores. Only the patients' medical record number (MR) and at least one diagnosis are required while other information is optional. The MR serves as an important patient identifier that does not contain sensitive information such as social security number. Diagnosis of patients' health status, a description of patients' condition based on symptoms, is required because of its usefulness for data analysis. For example, in the future, a group of test results may be able to give information about patient's health status without relying on symptoms that are not always accurate. Users can select a diagnosis from a drop-down list or add a new diagnosis if it has not existed in the database. Other information such as blood pressure and heart rate that are normally included in the EMR is not required in this configuration due to its irrelevance to cerebral palsy.

When users are inputting test scores, they can conveniently customize which tests, out of more than 100 available tests, are intended for data input (Figure 3). The tests are separated by categories and are alphabetically ordered. This customization makes the field of input easier to navigate, and, therefore, entries are less prone to error. Users can enter the test results in any of the score scales and generate a text report based on the score scales with a filename of their choosing.

Review Scores—The review scores' functionality is very similar to input scores, where users can input biographical information and test results of patients. The functionality can only be accessed by supervisors or administrators, to ensure that the information is reviewed by higher-level users. The database requires users to enter the medical record number to retrieve patients' information from the database. The patient"s information and selected test scores should be edited as necessary, and a checkbox should be ticked to indicate that the information has been approved by a supervisor.

Add New Test—Users can add new tests to the database if there are new indicative tests for cerebral palsy. Only supervisors and administrators are allowed to access this

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functionality. A list of tests that already existed in the database under a selected category is shown to ensure that users do not duplicate any tests. Users should include all the test parts along with an export name for the text report when entering a new test into the database.

User Setting—The user setting functionality allows administrators to add or remove user access to the database and allows all levels of users to change their password. The password is hidden with bullet characters to prevent a security breach. The interface requires users to input the password twice to avoid any mistake in typing the password.

IV. DISCUSSION

This database with the GUI design has been developed for healthcare professionals to collect data easily from patients with CP using the interface and reliably store them. It also promises future data analysis, which can be done effortlessly due to a broad application of the SQL language used. Its advantage over current EMR systems, e.g. EPIC, includes its design that is geared specifically for clinical research in CP, its robustness in storing a vast amount of data, and its ability to communicate with various other programming languages. After rigid test, the database will be located within the hospital campus network; accessible only to personnel in patient care, and no personally identifiable information will be included when exporting the data.

Usability testing and comparisons with other existing systems will be performed at the Children's Healthcare of Atlanta to evaluate the ease of use after receiving approval from the Institutional Review Board (IRB). For the pilot stage, around 5–10 care providers who will be involved in the cerebral palsy test data collection will try to use the interface. Based on their feedback, improvements for the design will be made to the database and interface design. Technology acceptance model [12] will be considered for evaluating the system usability.

Currently, the design is geared towards data collection for the cerebral palsy population. However, the design can also be modified to meet the needs of other disease data collections. For example, mental disorders contain several major categories of diseases that are often evaluated through various psychological tests after initial diagnosis [13]. Similar data collection methods can be employed for patients with mental disorders, with relevant information including the diagnosis and the test scores. In the future extensions of this system, communicationwith existing systems will be considered using HL 7 and FHIR standards.

V. CONCLUSION

The data collected from patients with cerebral palsy are very rich with information that can be used to help improve the diagnosis and treatment methods of the disease. To address the limitations resided in existing EMR systems, such as EPIC, this database with a personalized GUI is a promising data collection tool that is intuitive and reliable for storing a high volume of data. It allows the data to be directly extracted to other programming languages for bioinformatics data analysis purposes without the need of additional software. This data

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collection method is applicable to a wide range of diseases, such as mental disorders, and can greatly contribute to a better understanding of these diseases.

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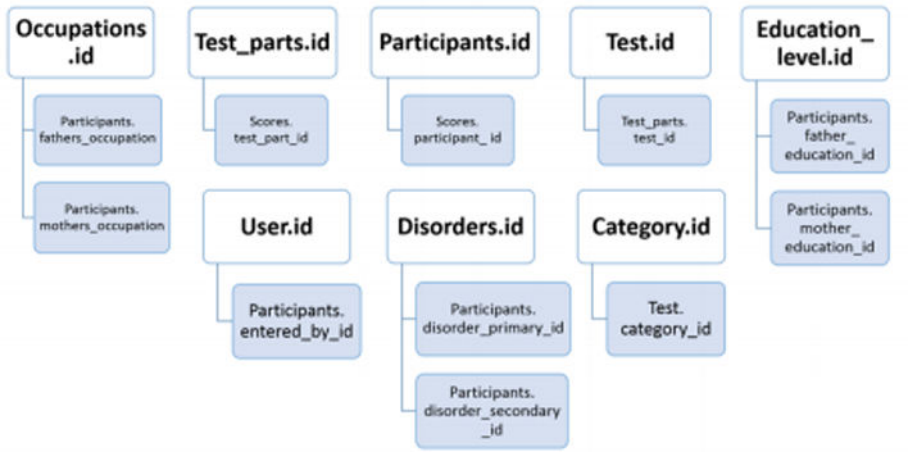

Figure 1.

Relationships between tables in the database. The main, colored boxes represent the primary reference table name with the corresponding column, and the boxes connected below them are tables that have columns related to the reference table. The format for the table and column name is [tabte_name] [column_name].

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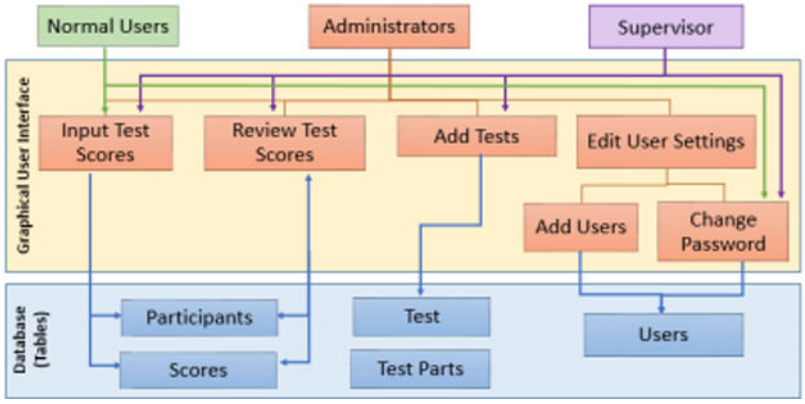

Figure 2.

Use cases of different types of users of the GUI functionalities and the corresponding tables that are modified or reviewed via the GUI.

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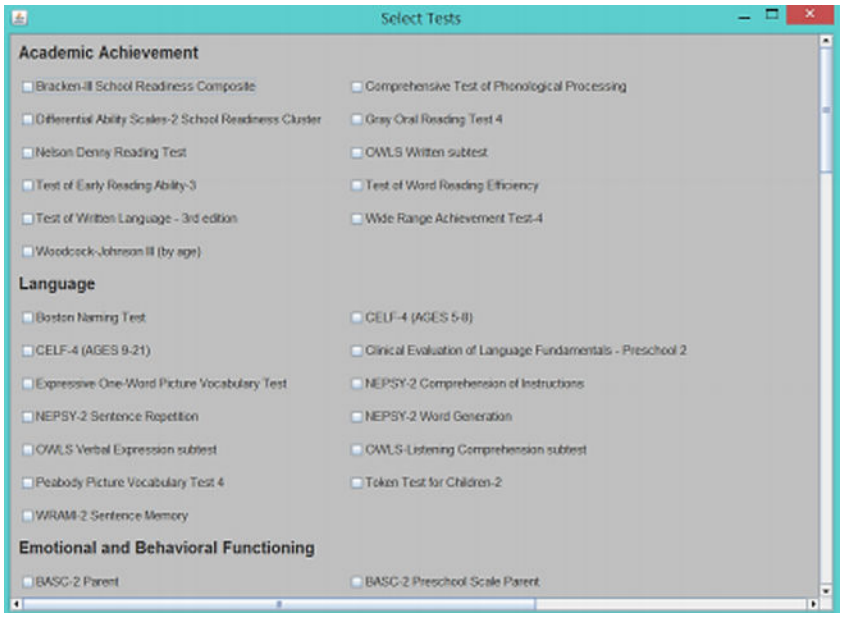

Figure 3.

Select Tests panel, listing all available tests in the database. Users can customize which tests arc of interest, and the following panel will only show input boxes for the selected test with its test parts.