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A Unified Data Architecture for Assessing Motor Symptoms in Parkinson's Disease

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Abstract. Introduction The diagnosis and treatment of Parkinson's disease depend on the assessment of motor symptoms. Wearables and machine learning algorithms have emerged to collect large amounts of data and potentially support clinicians in clinical and ambulant settings. **State of the art** However, a systematical and reusable data architecture for storage, processing, and analysis of inertial sensor data is not available. Consequently, datasets vary significantly between studies and prevent comparability. **Concept** To simplify research on the neurodegenerative disorder, we propose an efficient and real-time-optimized architecture compatible with HL7 FHIR backed by a relational database schema. **Lessons learned** We can verify the adequate performance of the system on an experimental benchmark and in a clinical experiment. However, existing standards need to be further optimized to be fully sufficient for data with high temporal resolution.

Keywords. Parkinson's disease, motor symptoms, inertial sensors, acceleration data, machine learning algorithms

1. Introduction

1.1. Background

Parkinson's disease (PD) is one of the neurodegenerative diseases with the greatest implications for contemporary societies [1]. While PD also manifests in non-motor symptoms with significant burdens on the patient, research mainly focuses on the characteristic motor symptoms [2]. The causes of the disease are relatively well understood, but effective treatment remains a challenge. Consequently, computer-aided support for managing medical assessments and therapies is an active area of research [3].

Various kinds of sensors are currently under investigation for their clinical feasibility [1]. Inertial sensors of so-called wearables have emerged to effortlessly collect large amounts of data. These portable computers are worn as smartwatches, fitness bracelets, or similar devices on different body parts. Developed for the consumer market, the collected data is usually used to measure activities and sleep quality. However, the miniaturization of the necessary sensor technology also enables its usage in clinical and

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ambulant settings. However, the vast amount of generated data in the process poses a challenge.

Machine learning algorithms have emerged as valuable tools for analyses of motion data acquired in monitoring motor symptoms. In research, classification of severeness, differential diagnosis, medication management, and similar tasks are nowadays evaluated accordingly [1]. These techniques can analyze large amounts of data with high accuracy. Therefore, these tools may reduce subjective differences in perception between clinicians and simplify daily clinical routines. Given the potential of machine learning algorithms, development and evaluation of such technologies increased in recent years.

However, multiple authors also stated limitations and pitfalls requiring consideration within that use case [4,5]. The accuracy and effectiveness of machine learning algorithms largely depend on the quantity and quality of the data. Many studies investigating the use of wearables for motion monitoring in PD often have small sample sizes and short study durations limiting the quantity. Symptoms and progress of PD can differ significantly between affected individuals. Accordingly, procedures primarily based on population statistics may result in a bias to the detriment of an individual. Other limitations result from the available variety of wearable devices, machine learning algorithms, and evaluation criteria preventing comparability. Apart from this, the use of artificial intelligence in healthcare raises several ethical and legal concerns, such as privacy, bias, and accountability. Most of these challenges could be managed by a secure, sufficiently large, and diverse collection of standardized data from suitable sources for ensuring proper generalization.

1.2. Objective and Requirements

This work aims to develop a unified data architecture for research on accelerometer data acquired in PD studies. A central goal is the interoperability and combination of different datasets according to the findable, accessible, interoperable, and reusable (FAIR) principles. Two research questions can be formulated:

1. Do existing studies keep their data in a format that allows easy interoperability and combination?
2. Which kind of structure is needed to optimally link different datasets and make them accessible for future research?

The data architecture aims to serve as a basis for future research with wearables in PD motion monitoring.

2. State of the art

Giannakopoulou *et al*. identified 53 publications using inertial sensors for various analyses in PD research [1]. To assess data availability and formats, all referenced publications were systematically searched for related statements. Most of the included studies provided no access to the raw data. Naturally, sensitive samples are commonly protected by data protection acts. At the same time, further research might be limited due to missing access. A minority of the included publications allow access to the underlying measurements through a transparent authorization process. The most popular examples are the mPower study [6, e.g. used by 7], the MJFF Levodopa Response Study [8], and suitable parts of the UK Biobank dataset [9, e.g. used by 10]. Another notable dataset without any access regulation is Daphnet [11, e.g. used by 12].

While the underlying platforms ensure authenticated and authorized access to the data, we were unable to identify a platform for receiving and storing datasets complying with the FAIR principles. Instead, the data are mainly stored in study-dependent formats requiring customized preprocessing for individual research. Such semantic incompatibilities are amplified by differing research questions and various paradigms in the data acquisition of inertial sensors. Since the platforms are primarily built to publish static data and do not offer real-time interfaces, they are not suitable for storing data with high temporal resolution encountered during experiments. Consequently, providing an alternative appears as an efficient way to simplify research.
Generally, only "very few studies or research projects have investigated [appropriate data standardization for wearable data] or proposed standardization procedures" [13]. The publications focus primarily on harmonizing general movement data on local systems powered by MATLAB [13,14]. While those approaches are powerful in their range of supported data modalities, they are neither tailored to the specific requirements of Parkinson´s disease nor optimized to be used as platforms.

In summary, sustainable use of the data published remains conditionally possible. The formats currently in use are neither standardized nor capable of real-time analyses. A unified data architecture would enable the integration of data from different sources, such as databases, individual files containing tabular data, and external research data platforms, into a single system. Consequently, developed data processing pipelines can be used independently of the actual data origin. In the following, we present a possible concept and implementation of a unified data architecture for heterogeneous datasets containing accelerometer data.

3. Concept: Designing a uniform data architecture

The conception and implementation of the uniform data architecture for the monitoring of motor symptoms in PD can be divided into separate steps. After the identification of feasible data sources in the literature, a classic Extract, Transform, Load (ETL) process was applied. This was followed by the definition, development, and testing of a suitable interface standardized for data storage, modification, and retrieval.

The datasets of Daneault *et al*. and Bot *et al*. were included to exemplary create a unified data architecture [6,8]. After receipt of the datasets, their content and metadata were analyzed. In the second step, we defined the transformation rules. In contrast to classical ETL processes in existing data warehouses, a unified data architecture was identified based on the analysis of the included data, the information from the previously mentioned literature review, and the discussions with clinicians. The three central structures identified in this process are (1) the subjects, (2) the inertial data, and (3) the medical assessments.

3.1. Integration of the subjects

Similar to existing standards, the unified data model is subject-centered. For reasons of data minimalization, their description is by default rudimentary. In addition to an internal identification number, classification to a certain cohort is primarily relevant. The original study can only be identified at this point within the architecture. The possibility of assigning further descriptions can also be used to ensure further connections.

3.2. Integration of acceleration data with a high temporal resolution

The central element of motion recording is the data with high temporal resolution collected by inertial sensors of wearables. The movement data are complex and can be collected using sensors from different manufacturers. Accordingly, they may differ in temporal resolution, measurement ranges, and associated measurement errors [13]. The impact of these variances may potentially influence further analyses. Therefore, the sensor type and group structure must be reflected by the data architecture. Depending on the manufacturer, the inertial sensors can use only accelerometers or combinations of accelerometers, gyroscopes, and other sensors. Due to its popularity in research regarding PD [1], we only consider the first type of sensor within this study. The unit of those measurements can vary; both the SI unit m/s^2 and the mean acceleration due to gravity are common. Since conversion between both units is possible, the proposed architecture needs to ensure its integration. Of greater relevance is the measurement site on the body. The placement of sensors differs between studies and might reflect differences in manifestations of motor symptoms on distinct body sites in PD patients [3].

Based on the resources described, the storage of the actual acceleration data is relatively simple: Both, the identification numbers of the sensor used on a specific body part and the identification number of the patient in combination with a timestamp function as the key element for the measured sample. This sample is serialized in the standardized SI unit m/s^2 in all three dimensions with timestamps transferred from the time zone of their recording to the Coordinated Universal Time (UTC). Consequently, the data become easily comparable across studies. This enables the efficient mass storage of the data with high temporal resolution and provides the basis for subsequent analyses.

3.3. Integration of medical assessments

The unified data model specified so far is suitable for making acceleration data recorded over a course of time available and easily retrievable. This enables, for example, continuous monitoring of motor symptoms in an ambulant setting. In terms of machine learning models, unsupervised methods can thus already be applied. In literature, however, supervised methods are more frequently used. The integration of medical assessments appears to be necessary and represents the third central structure of the unified data architecture.

The basis of any assessment is the use of a test procedure as standardized as possible. In this context, they are commonly represented as physical exercises highlighting specific motor symptoms in PD. However, different options are available often based on the personal experiences of clinicians or individual hospital guidelines. A certain standardization can be achieved by using rating scales, for example, the motor section of the unified Parkinson's disease rating scale (UPDRS). While both reference datasets supported this classification, the schema optionally allows the use of proprietary exercises. With this design decision, we choose flexibility and straightforward applicability for custom studies over inter-study comparability.

A separate resource is created for each exercise. It contains the test procedure used and the patient examined. It also offers the possibility to define a precise start and end point of the exercise. As a result, a patient's exercise documentation can overlap, even if they are in principle performed sequentially to each other. In the context of diagnoses, several motor symptoms including tremor, dyskinesia, and bradykinesia can be assessed

in parallel during each exercise. Their expressions are encoded on different scales. Hence, the joint encoding of the motor symptom and the scale demonstrate comparability and differences.

The final classification can be used as a label for machine learning. It is distinctively defined as a rating of a specific instance of a task and can be particularized to individual body parts. The value then encodes the severity of the motor symptom defined within the applied scale.

3.4. Formalization of a relational database schema

Based on the previously described definitions, a relational database schema was formalized which is shown in Figure 1. The resulting definition of resources represents the lowest common denominator between the different data sources extracted. According to clinical requirements, the relational database scheme possesses the necessary flexibility to be compatible with a wide range of study designs and evaluation methods. Furthermore, the use of an optimized database management system enables a performance that is sufficient for large amounts of data and can handle a range of workloads. The SQL definition of the schema should be compatible with most available systems. The actual data storage can thus take place within stable and well-tested systems.

To finalize the ETL process, the two exemplary datasets of Daneault *et al*. and Bot *et al*. were loaded into the unified architecture [6,8]. To perform the required syntactic and semantic transformations, we developed independent command-line tools.

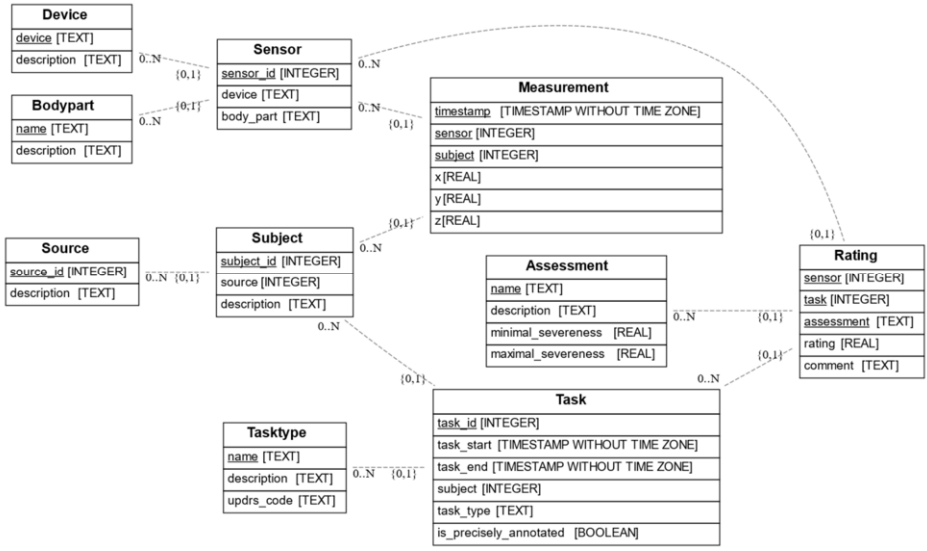

Figure 1. Visualization of the proposed relational database schema

4. Implementation: FHIR as an interface to the uniform data architecture

After applying the appropriate schema and the ETL process, the data are available in a relational database management system. They can be added, edited, and retrieved via SQL. This forms the foundation for efficient storage and retrieval of the acceleration data acquired in studies. However, this type of data management is insufficient to ensure a reusable and expandable data architecture. Therefore, fast healthcare interoperability resources (FHIR), established by Health Level Seven International (HL7), was introduced as an interface to approach the optimized data management formulated at the beginning.

HL7 FHIR is a standard for data exchange between different software solutions in healthcare. By design, it is defined to be compatible with FAIR principles. The associated overhead not strictly required for fulfilling the interoperability aspect of the latter might not be necessary for every use case. In our case, providing an FHIR-compatible interface while referencing the SQL database schema in the background facilitates the integrability into existing systems. In addition, the development of the customized front end enables a more defined integration of machine learning algorithms and models. Accordingly, there are numerous possible integrations within clinical infrastructures.

For creating an appropriate interface for data insertion and querying, we developed a Java-based server. The HAPI FHIR library was used as the technical foundation to ensure proper and well-tested parsing and conformity to the standard. Inside the software, the values are mapped on-the-fly to and from PostgreSQL as the underlying database management system. Easily deployable through Docker, the code is available under a permissive open-source license and available to research groups interested in PD[2].

4.1. Results

At least two quality measures are important for assessing the appropriability of the proposed tool. The general correctness of the underlying transformation processes and the stored data are ensured through a battery of integration tests. However, if the system should be used for data collection in real-time, an appropriate insertion performance is required. Accordingly, we benchmarked our server against a reference server developed by the team behind the HAPI FHIR library. While the FHIR interface and parsing functionality are the same, the reference implementation used a general-purpose database schema instead of our proposed backend.

The corresponding benchmark results of four parallel threads and data payload of 100.000 requests without network overhead are stated in figure 2. The boxplot of insertion timings indicates an asymmetrical data distribution skewed towards lower writing times. The median of the proposed system (0.005 seconds per insertion) is substantially lower than the reference HAPI server (0.01 seconds per insertion). However, our naïve and unoptimized implementation shows a larger spread in the interquartile range. Summarizing, the proposed FHIR interface implementation appears useful for real-time applications.

[2] Corresponding Git repository: https://github.com/UKEIAM/de.uke.iam.parkinson_on_fhir

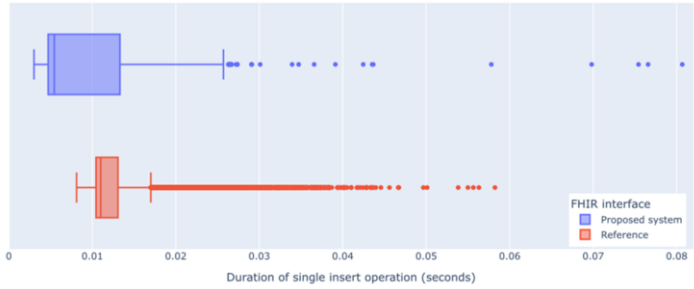

Figure 2. Boxplot of insertion times of the proposed and reference system

4.2. System in use

The proposed relational database schema and FHIR interface are already deployed for storing acceleration data within a PD study currently conducted at the University Medical Center Eppendorf. Utilizing two applications for smartwatches with the popular operating systems iOS and Android OS, the accelerometer data of up to 50 patients are recorded for various movement tasks with a temporal resolution of 50 samples per second. By the time of writing, more than 107.068.493 of these samples have been recorded from up to five subjects simultaneously. Subsequently, the data will be used to research solutions for the optimized treatment of PD.

5. Lessons learned

As demonstrated in both, the lab and the pilot study, storing motion data of patients according to FAIR principles is possible. A hybrid system with a relational backend optimized for performance and a FHIR-compatible frontend can handle requests in real-time. Consequently, integration of such systems is possible within existing clinical environments.

Current limits are set not by the technology itself but by the use of FHIR for this kind of data modality. As an example, encoding each recording sample as an individual observation might appear verbose. FHIR supports sampled data as a type of value stored within this resource. However, such a storage format may hinder the application in the real-time setting as easy insertion is not possible and render longitudinal studies hard. It will be interesting to see if and how future releases may induce further opportunities.

The medical vocabularies used for interoperability are not readily applicable, either. While there exists a LOINC code 80493-0 for an aggregated form of acceleration, individual gravitational components could not be specified. The FHIR specification does neither allows possible alternatives like SNOMED-CT concepts with post-coordination within the Measurement resource. Accordingly, our implementation falls back to not-yet-standardized codes. Getting those codes standardized through the official process remains future work. The code under a permissive open-source license allows adaptation for the required changes in the future. We hope the unified data architecture can further boost research activity regarding PD.

6. Conclusion

The current research landscape in the sensor-based recording of motor symptoms in PD is diverse. Accordingly, existing studies do not maintain data in a format that easily allows interoperability and a combination of different datasets. Within the scope of this project, a uniform data architecture was developed to represent the multitude of possible paradigms for recording movement data in patients with PD. It enables reusable storage of research data, allows interoperable communication between systems, and effective training of machine learning algorithms. The data architecture can be used for primary data acquisition or serve as an endpoint for decentral collected measurement data. Using FHIR as an interface for optimized data management offers the possibility for extensions depending on the requirements of future research projects. For example, in addition to the measurement data, medication data can be stored and included in analyses via the multiple resources provided by the standard.

In summary, the designed, implemented, and tested data architecture can provide a basis for future PD research. By standardization of popular yet inhomogeneous datasets, and by providing sufficient data management with an expandable data architecture, it offers the opportunity to link machine learning methods to daily clinical routines and further boost research activity regarding PD.

Declarations

Conflict of Interest: The authors declare that there is no conflict of interest.

Contributions of the authors: CG and QZ were involved in the planning and implementation of the project. AD, MR, TG, CL, SN, and MB contributed significantly to the clinical study. CG, QZ, LT, AD, MR, TG, CL, SN, MB, and FÜ were involved in the writing and/or revision of the manuscript.

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