Open-source data management system for Parkinson's disease follow-up

João Paulo Folador [Corresp., 1], **Marcus Fraga Vieira** [2], **Adriano Alves Pereira** [1], **Adriano de Oliveira Andrade** [1]

[1] Centre for Innovation and Technology Assessment in Health, Postgraduate Program in Electrical and Biomedical Engineering, Faculty of Electrical Engineering, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil

[2] Bioengineering and Biomechanics Laboratory, Federal University of Goiás, Goiânia, Goiás, Brazil

Corresponding Author: João Paulo Folador
Email address: jpfolador@gmail.com

Background. Parkinson's disease (PD) is a neurodegenerative condition of the central nervous system that causes motor and non-motor dysfunctions. The disease affects 1% of the world population over 60 years and remains cureless. Knowledge and monitoring of PD are essential to provide better living conditions for patients. Thus, diagnostic exams and monitoring of the disease can generate a large amount of data from a given patient. This study proposes the development and usability evaluation of an integrated system, which can be used in clinical and research settings to manage biomedical data collected from PD patients.

Methods. A system, so-called SIDABI (Integrated Biomedical Data System), was designed following the model-view-controller (MVC) standard. A modularized architecture was created in which all the other modules are connected to a central security module. Thirty-six examiners evaluated the system usability through the System Usability Scale (SUS). The agreement between examiners was measured by Kendall's coefficient with a significance level of 1%.

Results. The free and open-source web-based system was implemented using modularized and responsive methods to adapt the system features on multiple platforms. The mean SUS score was 82.99 ± 13.97 points. The overall agreement was 70.2%, as measured by Kendall's coefficient ($p < 0.001$).

Conclusion. According to the SUS scores, the developed system has good usability. The system proposed here can help researchers to organize and share information, avoiding data loss and fragmentation. Furthermore, it can help in the follow-up of PD patients, in the training of professionals involved in the treatment of the disorder, and in studies that aim to find hidden correlations in data.

1   **Open-source data management system for Parkinson's disease follow-up**

3   João Paulo Folador[1], Marcus Fraga Vieira[2], Adriano Alves Pereira[1], and Adriano de Oliveira

4   Andrade[1]

6   [1] Centre for Innovation and Technology Assessment in Health, Postgraduate Program in

7   Electrical and Biomedical Engineering, Faculty of Electrical Engineering, Federal University of

8   Uberlândia, Uberlândia, Brazil

9   [2] Bioengineering and Biomechanics Laboratory, Federal University of Goiás, Goiânia, Brazil

11   Corresponding Author:

12   João Paulo Folador[1]

13   290, João Benedito da Silva, Uberaba, Minas Gerais, 38071110, Brazil

14   Email address: jpfolador@gmail.com

16   ## Abstract

17   **Background**. Parkinson's disease (PD) is a neurodegenerative condition of the central nervous

18   system that causes motor and non-motor dysfunctions. The disease affects 1% of the world

19   population over 60 years and remains cureless. Knowledge and monitoring of PD are essential to

20   provide better living conditions for patients. Thus, diagnostic exams and monitoring of the

21   disease can generate a large amount of data from a given patient. This study proposes the

22   development and usability evaluation of an integrated system, which can be used in clinical and

23   research settings to manage biomedical data collected from PD patients.

24   **Methods**. A system, so-called SIDABI (Integrated Biomedical Data System), was designed

25   following the model-view-controller (MVC) standard. A modularized architecture was created in

26   which all the other modules are connected to a central security module. Thirty-six examiners

27   evaluated the system usability through the System Usability Scale (SUS). The agreement

28   between examiners was measured by Kendall's coefficient with a significance level of 1%.

29   **Results**. The free and open-source web-based system was implemented using modularized and

30   responsive methods to adapt the system features on multiple platforms. The mean SUS score was

31   82.99 ± 13.97 points. The overall agreement was 70.2%, as measured by Kendall's coefficient (p

32   < 0.001).

33   **Conclusion.** According to the SUS scores, the developed system has good usability. The system

34   proposed here can help researchers to organize and share information, avoiding data loss and

35   fragmentation. Furthermore, it can help in the follow-up of PD patients, in the training of

36   professionals involved in the treatment of the disorder, and in studies that aim to find hidden

37   correlations in data.

38

39   **Keywords:** Data Management, System Usability Scale, Parkinson's Disease

40

Introduction

Parkinson's disease (PD) is a neurodegenerative condition of the central nervous system that affects the basal nuclei, because of a progressive loss of dopaminergic neurons of the substantia nigra. The decreasing of these neurotransmitters causes motor and non-motor dysfunctions, postural and cognitive disorders [1].

PD affects about 1% of the world population of individuals over 60 years old, and it is among the five most expensive neurological disorders in European Countries. The Brazilian National Health System spends an average of US$ 5,853.50 with an annual cost of PD per patient, including 53.4% direct costs and 46.6% indirect costs [2]. The PD diagnosis is not simple, however, symptoms such as tremor, stiffness, bradykinesia, and postural instability are cardinal signs of the presence of the disease. Monitoring the symptoms that affect the individual with PD can bring better living conditions to the patients since the disease remains cureless [1,3].

The evaluation of PD symptoms is commonly performed using clinical scales such as the Movement Disorder Society - Unified Parkinson Disease Rating Scale (MDS - UPDRS) and Parkinson's Disease Questionnaire (PDQ-39). Several exams are also used to further assess the condition of the patient over time, for instance, the electrocardiogram, electromyogram, electroencephalogram and medical imaging exams (e.g., Magnetic Resonance Imaging). Recently, inertial data, measured by inertial sensors, have been widely used to study the motor condition of patients [1].

As a consequence of the technological advancement in PD evaluation, there has been an increase in the volume and types of available data. In this sense, the organization and management of data are essential to obtain useful information from a large amount of data [4]. Consequently, it is necessary to know the technologies used to optimize data collection and storage [5]. This amount of generated data presents new challenges in the areas of information management, storage, security, and difficulty in understanding the produced data [4–6].

The multimodality and complexity of data concerning PD evaluation have been increasing, as shown in several studies. For instance, Klinger et al. [7] developed a virtual environment that simulates a supermarket on the personal computer (PC) through which the volunteer performs planned tasks to purchase goods. The authors recorded the trajectory of the patient in the virtual environment to assess the cognitive deficit of task planning.

Cunningham et al. [8] implemented a desktop software to assess the level of hand and finger control in PD patients. The participants performed the tasks of clicking buttons that alternated on the software screen. The authors collected and stored data such as personal information, speed of clicks, the coordinates, and the trajectory of the movement to evaluate the rigidity and dexterity.

Pastorino et al. [9] recorded inertial data from the upper and lower limbs and the waist of people with PD in the ON and OFF periods of medication. Similarly, Caldara et al. [10] proposed a network of wireless inertial sensors attached to the limbs and body to assess the gait, posture, and tremor of individuals with PD. The desktop software captured data via Bluetooth and saved information in a text file. The cadence, step length, and stride length of PD patients

81   were recorded by Paredes et al. [11] through a Kinect, a motion-sensing technology based on
82   RGB cameras, infrared projectors, and detectors.
83   Eskofier et al. [12] used wearable inertial sensors in PD patients to detect bradykinesia. The
84   authors used Deep Learning on the sensor data and reported an accuracy of 90.9% in the
85   classification of the individuals. Kassavetis et al. [3] evaluated the symptom of bradykinesia and
86   tremor in PD patients using software developed for mobile devices, which employs the
87   capacitive screen and the accelerometer to collect and store the data through a smartphone.
88   The investigation of speech problems in people with PD was proposed by Dimauro et al.
89   [13], who used the Google Speech-To-Text tool to assess speech intelligibility. The authors used
90   reading exercises to perform the speech evaluation to assist specialists in improving PD
91   treatments. In another study, Haddock et al. [14] proposed a tool to control the parameters of
92   deep brain stimulation devices automatically. The authors used inertial sensors from a
93   Smartwatch that captures, via Bluetooth, the tremor on the most affected hand.
94   Specific systems developed to manage people with PD and other neurological disorders have
95   been previously reported. For example, Astakhov et al. [15] showed a way of integrating
96   interinstitutional databases focused on studying medical images. The system uses a server, an
97   application programming interface, and a query builder to ease the exchange of information
98   between researchers and their databases.
99   Pepa et al. [16] developed an application on the smartphone to monitor the gait of patients
100   with PD. The data were stored periodically on the device and synchronized with web-based
101   software. Similarly, Patel et al. [17] monitored patients at home using wearable sensors that
102   transmitted the data via a mobile device to a web application. Garzo et al. [18] developed a web-
103   based system to monitor and record gait and freezing episodes in people with PD. The type of
104   monitoring [16–18] can produce a large amount of data.
105   The development of any system for the management of biomedical data should be followed
106   by evaluating its usability, which aims to understand whether a such system is easy to use and
107   has the appropriate functionality for the users. A method commonly employed to assess usability
108   is the System Usability Scale (SUS), which has been applied in several situations such as the
109   evaluation of a mobile application that helps to improve gait in people with PD [18], an
110   augmented reality game to evaluate the extremity of upper limb impairment in stroke [19] and
111   PD patients [19,20], evaluating a mobile application for mental health monitoring that collect
112   physiological signals, activity, and environmental data [21], testing the usability of augmented
113   reality software in food advertising via smartphone [22], learning evaluation of a management
114   web system [23], evaluation of a multimedia interface for learning English [24], and also to test
115   e-commerce application on smartphones [25].
116   In this scenario, the amount of collected data may have a large volume, increases fast and
117   assumes a variety of data formats [4]. Furthermore, if these data are not organized and secure,
118   being in any place such as clinics, hospitals, and research centers, the information can be lost,
119   fragmented, poorly analyzed, and the resources invested are wasted. In addition, it is crucial
120   controlling of sensitive personal information and guarantee the privacy rights formalized as in

121   California Consumer Privacy Act [26], Data Protection Law Enforcement Directive of European
122   Union [27], and General Personal Data Protection Act in Brazil [28].
123   From the literature review, it is possible to identify the lack of systems capable of managing
124   biomedical data related to the knowledge and follow-up of PD patients. Besides that, many
125   philanthropic institutions and PD associations that help people with PD in countries such as
126   Brazil have limited technical resources to manage their basics services. In this context, it is of
127   utmost importance to develop free and open-source systems.
128   This research presents different aspects to the management of information of people with
129   Parkinson's disease: (1) development of a system that integrates information and research files,
130   (2) assessment and clinical monitoring through customizable scales and questionnaires, (3)
131   learning and training about Parkinson's disease, (4) control at distinct levels of security in a
132   modularized and multiplatform format, (5) the usability test (SUS) of the system performed by
133   36 examiners, and (6) a free and open-source initiative to assist, mainly, philanthropic
134   institutions and PD associations that help people with PD.
135
136   **Materials & Methods**
137
138   **Requirement analysis**
139
140   The development of the system was based on the Rapid Application Development (RAD)
141   concept. RAD is an approach based on agile project, and it was chosen because this methodology
142   is incremental, emphasizing rapid and reusable coding for the development of application
143   modules. It can be understood in four main steps: (i) requirement planning: developers, software
144   users, and team members discuss the objectives and expectations of the project and address the
145   requirements; (ii) design: in this step, a prototype is drawn up and discussed with software users
146   and refined until an acceptable design is reached; (iii) construction: this step is mainly related to
147   database development and coding of the prototypes. (iv) cutover: final coding, tests on the
148   system, and the system users are trained. Bugs can be reported for correction, and new
149   requirements will reinitialize step (i). This concept focuses on lean documentation, relying on the
150   essentials for coding the functionality of the system, but requires an experienced programmer
151   [29–31].
152   In line with the RAD concept, several functionalities were analyzed to construct an integrated
153   system providing an adequate tool. To reach this objective, the process was guided by the
154   expertise of seasoned professionals in research on PD, interviews with specialists in PD
155   diagnosis, and professionals specialized in software development. Furthermore, the development
156   of the system took into consideration all aspects and conditions of PD patients (biological, social,
157   and cultural), and a complete study of well-known questionnaires and clinical scales to evaluate
158   PD patients [1].

159   All the identified requirements were used to develop the system architecture and
160   organization, to design the graphical user interface, and to model data structure. The system was
161   developed incrementally, i.e., it was tested and improved as the unit was developed [30].
162

163   **Integrated Biomedical Data System Architecture**

164

165   The aim of the Integrated Biomedical Data System (in Portuguese, SIDABI, Sistema Integrado
166   de Dados Biomédicos) is to manage and secure data from PD patients and research volunteers.
167   Fig. 1 depicts the architecture and structure of the system.

168

169   **Figure 1. Access, security, and system structure flowchart**. The system requires user
170   authentication (A) and user profile verification (B) to access the modules (C). The modules of
171   the system are connected to a security module (D). The system architecture is based on the
172   model-view-controller pattern (E). The system is hosted on the Apache webserver, and the data
173   are stored in the PostgreSQL database (F).

174

175   Figure 1 shows the security levels that a system user or administrator has to go through to
176   access the distinct modules of the system. Fig. 1A illustrates the first security barrier to
177   authentication. The access to specific screens and modules is released according to the user's
178   profile (Fig. 1B). Users may have permission to create, view, update and delete records. Each
179   module of the system is presented in Fig. 1C. The system has five interconnected modules that
180   can share information among them: Clinical Assessment, Data Management, Idea Collection and
181   Sharing, Education and Training, Data Query. All the modules of the system are connected to a
182   security module, Fig. 1D.
183   The system architecture is based on the Model-View-Controller (MVC) pattern (Fig. 1E).
184   The Apache web server was used to host the system because it is the most used web server.
185   Apache web server is an open source project, easy to customize environments, fast, reliable, and
186   highly secure [32,33] and the Apache web server can be set up to accept distinct programming
187   languages and databases. The data are stored in the PostgreSQL database that also is open-source
188   software, secure, robust, works with relational and no relational data, highly concurrent, and the
189   most popular database system [34]. The Apache web server and the database are illustrated in
190   Fig. 1F

191

192   **Design Pattern**

193

194   In general, the design pattern provides best practices in a framework of solutions for common
195   problems in the context of designing software. The Model-View-Controller (MVC) is a pattern
196   used to build interfaces in three separated logic layers: the Model manages the data and rules of
197   the application; the View is the representation and appearance of the data on the screen such as
198   text, tables, charts; the Controller handles the requests from View or Model layers validating and

199 processing these data, and sending commands to execute the appropriate action (e.g., store data,
200 retrieve data, show some information in a table) [29,30,35].
201   In the literature, it is possible to find recent patterns based on MVC such as Model-View-
202 ViewModel (MVVM) in which the ViewModel layer controls the functions of presentation,
203 sending commands, automating communication between View and ViewModel layer, and
204 supporting the View state. MVVM supports multiple views. It was created to facilitate
205 interactions between the View and ViewModel layers of graphical user interfaces. The Model-
206 View-Presenter (MVP) is more flexible about layer's responsibilities, and the pattern also was
207 based on MVC. The Presenter layer is responsible for supervising the View and Model layers,
208 handling user events, listening to the View layer, making changes to the View layer, and
209 maintaining the application synchronized. In general, the Model and View layers in MVVM and
210 MVP follow the principles of the MVC pattern [35].
211   Despite some improvements in MVVM and MVP, the MVC design pattern was used to
212 construct the proposed web system because it is the most acceptable standard used to develop
213 custom applications on the Web in different programming languages [29,30]. Additionally, MVC
214 gives more focus on the Controller layer [35] that is suitable for this study once the main idea is
215 based on controlling requests made by the software user and verifying its permissions of access
216 in a module, page, and data manipulation. These verifications can slow the response of requests
217 in some milliseconds, MVC can result in additional classes and objects, and in more complex file
218 organization, however, the MVC pattern also allows reliable access to the database, providing a
219 clean, organized, reusable, scalable, and efficient code [29][30].
220   The MVC pattern is used by a number of well-known frameworks and companies such as
221 Django (National Geographic, Instagram, Pinterest, Open Stack, Mozilla) [36], Ruby on Rails
222 (GitHub, Airbnb, Basecamp, Shopify) [37], Spring (Netflix, VMware Tanzu, Alibaba, Amazon,
223 Google, Microsoft) [38]. Despite this, software that uses the MVC pattern in the medical field
224 related to Parkinson's disease is still rare. Studies found in the literature showing software
225 development, such as the use of a mobile and web application to improve gait in patients with
226 PD [18], an augmented reality game to assess upper limb impairment in stroke [19] and PD
227 patients [19,20], and a mobile mental health monitoring application [21], did not describe any
228 pattern of development used.
229   Figure 1E illustrates the MVC adopted, in which the interaction between the user and the
230 system's response to the user is represented. The View layer contains the elements presenting
231 information to the software user, and these elements can be built using HTML5 (the language
232 used to create the structure of the elements shown on web pages), Cascading Style Sheets
233 (CSS3), which is the mechanism for formatting the pages, and JavaScript (JS) that is the
234 programming language used on the client-side to make it possible the interaction between the
235 user and the components presented on the screen [29,39]. The JS library JQuery 3.1.1 was used
236 to optimize interactions.
237   Therefore, when the user interacts with the system, for example, by clicking on a button, JS
238 handles this event and passes it on to a controller. The controller layer uses the PHP

239 programming language to code the server-side system. The view controller assembles the results
240 brought by the model controller or simply assembles the response of a specific request and
241 returns it to the browser. The model controller is responsible for interacting with the model layer,
242 which has classes that interact directly with the database [29,40].
243   In addition to the MVC pattern, the Responsive Web Design (RWD) concept was also used
244 to design the layout with optimized experience, good ergonomics, and usability while using the
245 system on different devices. The Bootstrap Framework 3.3.7 was used to ensure proper
246 functioning on different platforms [40].
247
248 **Usability Evaluation**
249
250 Usability is a term used to define how easy people can employ a tool or object in order to
251 accomplish a specific task. Usability is also related to the evaluation of a system with the aim to
252 improve (i) human computer interaction, and (ii) the social and practical acceptance of the
253 system [41,42]. Thus, the usability of an interface should be good enough allowing the users to
254 perform the system's tasks easily.
255   In this way, the usability of a system should focus on developing interfaces that are easy to
256 handle and quick to learn. The functionality of the layout should avoid and deal with operational
257 errors efficiently and with appropriate feedback to the user. In addition, usability must address
258 user satisfaction and provide an effective solution to the problem that the system was designed to
259 solve [41,42].
260   In this sense, SUS was used to evaluate the usability of the system. The scale has ten
261 questions, $q = \{q_1, \cdots, q_{10}\}$, and each of them can assume a value, w, ranging from 1 (strongly
262 disagreement) to 5 (strongly agreement) (Table 1). The calculation of the scores for a specific
263 question, S_q, is given in (1). The final scale score, SUS_{score}, ranges from 0 to 100 points, with 68
264 points being an acceptable score [43], and this final score is given in (2).
265

$$S_q = \begin{cases} w - 1, & \text{if } w \text{ is odd} \\ 5 - w, & \text{if } w \text{ is even} \end{cases} \qquad (1)$$

266

$$SUS_{score} = \left(\sum_{q=1}^{10} S_q \right) * 2.5 \qquad (2)$$

267
268   Bangor, Kortum, and Miller [44] proposed an adjective rating scale according to the average
269 points obtained from SUS, with the usability classified as worst imaginable (12.5), awful (20.3),
270 poor (35.7), ok (50.9), good (71.4), excellent (85.5), and best imaginable (90.9).
271
272 **Table 1**. **SUS questions.**
273

274   The usability test (SUS) of the system was performed by 36 examiners, and the resultant data
275   is available in the supplemental information section. The data is organized in a comma-separated
276   file (usability-db-en.csv) in which the first four columns are related to the characterization of the
277   examiners, and the fifth to fourteenth columns deal with the SUS questions.
278   In addition, Kendall's coefficient of concordance was estimated to verify the overall
279   agreement between the examiners in the SUS questionnaire. It was used because it is a non-
280   parametrical statistic, more accurate to smaller sample sizes, which can be used for assessing
281   agreement among examiners considering ordinal data, and can be used for assessing agreement
282   among a variety of raters. This coefficient can assume values from 0 (without agreement) to 1
283   (complete agreement) [45].
284   The statistical analysis and data visualization were performed in R, a language and
285   environment for statistical computing [46], using the open-source integrated development
286   environment (IDE) RStudio for R, version 1.2.5042. Thus, an R file with the analysis presented
287   in this study (*data-analysis-usability-v01.R*) is also available in the online repository pointed at
288   the supplemental information section.
289
290   **Experimental protocol**
291
292   This research follows the Resolution 466/2012 of the National Health Council. The study was
293   conducted at the Centre for Innovation and Technology Assessment in Health of the Federal
294   University of Uberlândia (UFU), Brazil. The experimental protocol was approved by the Human
295   Research Ethics Committee (CEP-UFU), CAAE Number: 93993118.4.0000.5152. The
296   participants were informed about the data collection procedures and signed a consent form
297   before data collection.
298   During the experiment, the system was evaluated by 36 examiners and the examiners were
299   not trained on how to use the system before carrying out the proposed tasks. They remained
300   comfortably seated and accessed the web system through a computer. In order to evaluate the
301   usability of the system, the user was asked to execute several common tasks, such as logging in
302   to the user account, accessing specific software modules and filling in form data, uploading
303   experimental session data, using search fields, and others. The duration of the interaction tasks
304   was approximately 15 minutes.
305   The user was asked to inform the level of computer skills (1-2, 3-5, more than 5 years), age
306   (18 to 25, 26 to 35, 36 to 45, more than 46 years old), and the number of hours of computer use
307   per week (2 to 5, 6 to 10, over 10 hours). Subsequently, the examiner answered ten questions
308   about the usability evaluation questionnaire.
309
310   **Results**
311
312   **System description and visualization**
313

314 Figure 2 illustrates the authentication screen (A) and interface that provides access to the distinct
315 modules of the system (B). The ordinary user or administrator performs authentication using a
316 username and password. The security module validates access into screens, modules, and
317 information manipulation levels that the user has on each page, such as inserting new data, data
318 visualization, updating information, or data removal.
319
320 **Figure 2. Main graphical interfaces of the system.** (A) The viewing on a mobile device of the
321 authentication system screen. (B) The viewing on PC of the screen showing the modules of the
322 system (1 – 5).
323
324 Currently, the system contains five implemented modules (Fig. 2B) and a security
325 administration area to manage user permissions. Each module has its functionalities, and some of
326 them share data. The principal functions of the modules are described in Fig. 3 as a use case
327 diagram. Besides that, the complete system can be downloaded and is available in the
328 supplemental information section.
329 The use case diagram is a feature of Unified Modeling Language (UML) and is commonly
330 used to show the relationship between functionalities and system users. It is used for a high-level
331 view of the system and identifies the fundamental factors. The use case diagram utilizes some
332 notations such as an actor that performs a role (i.e., a user and an administrator of the system), a
333 system user can be researcher's labs, hospital staff, nonprofit organizations staff; an ellipse
334 drawing that is the use case representing a function or an action in the system. The system object
335 is represented as a rectangle, which defines the scope of the use case [30].
336 Besides that, as shown in Fig. 3, the relationships in a use case diagram are used to represent
337 the interactions between actors and use cases. A continuous line connects an actor to
338 functionality, a dashed line with an arrow and marked with an <<include>> word means a
339 necessity to add that use case (the arrow points to the use case included). On the other hand, a
340 dashed line with a <<extend>> label means a possible additional functionality but not mandatory
341 (the arrow points to the use case that extends the functionality) [30].
342 In this context, Fig. 3 represents the main use case diagrams of SIDABI modules shown in
343 this study. It is essential to emphasize the words *manage* and *control* presented in the use cases
344 meaning junction of some data manipulation functionalities such as insert, edit, delete, and find
345 information. Thus, Fig. 3A represents the security module with two actors, the administrator can
346 manage all the permissions functionalities, and the simple user can visualize its account and the
347 modules permitted. In Fig. 3B, the clinical assessment software shows two distinct roles, i.e., the
348 researcher, which is a person who can manage the main functions of the clinical assessment
349 module and can apply a questionnaire, and the patient or caregiver role, that is the actor that can
350 respond the questionnaire.
351 In Fig. 3C, the data management module is represented, and the system user with
352 appropriated permissions can control the functionalities and upload the files resulting from the

353   session of data collection. Fig. 3D illustrates the module so-called idea collection and sharing,
354   which allows the system user to control new project proposals.
355
356   **Figure 3. Use case diagram of the main functionalities of SIDABI.** (A) represents the security
357   module, (B) the clinical assessment software, (C) the data management module, (D) the idea
358   collection and sharing functionalities, (E) the education and training module, (F) the
359   management of participants, and (G) the data query module.
360
361   Figure 3E represents the education and training module from which the user can manage the
362   information of the symptoms of PD and learn from a page that overviews the symptoms,
363   tutorials, and extra materials about the disease. Fig. 3F shows the patient or volunteer
364   management functions that are used to add and control the records of people in the system.
365   Finally, Fig. 3G illustrates the data query module with an actor accessing a menu with filters that
366   can help to narrow the results of research data. The software users can select the filters (e.g.,
367   study group, participant, equipment) to help them to get more accurate results, for instance, if it
368   was chosen a specific equipment, the query result brings all the files related to that equipment.
369   These functionalities mentioned above are detailed in Table 2. Additionally, the whole database
370   diagram of SIDABI is available in the supplemental information section.
371
372   **Table 2: Main functionalities of SIDABI.**
373
374   Figure 4 exemplifies some functionalities implemented in the system. In (A) represents the
375   screen for viewing and downloading data collection files, shared or not within research groups.
376   The filters (e.g., protocol, equipment, session date, researcher group) are used to narrow the
377   database's file search. Figure 4B illustrates the list of symptoms used to study and understand the
378   theory and practical issues by videos of Parkinson's disease and separated by categories. Fig. 4C
379   illustrates the volunteer registration screen with various specific information, and these data
380   remain in common with other modules.
381
382   **Figure 4. Examples of screens developed in SIDABI**. (A), (B), and (C) represent, respectively,
383   examples of the screens implemented for the Data Management, Education and Training, and
384   Clinical Assessment modules from the visualization in a PC, (D) illustrates the visualization of
385   the Idea Collection and Sharing module from a smartphone.
386
387   Finally, Fig. 4D illustrates the screen developed to view projects requested on the Idea
388   Collection and Sharing module. This screen exemplifies the behavior of the responsiveness in
389   using the system from a mobile device.
390   The SIDABI system presented so far has some characteristic similar to a clinical data
391   warehouse (CDW) in which it is possible to storage distinct file format, a complex type of data,
392   integration of a variety of applications, security, support decision making, support to researchers,
393   helps in querying and presenting information, and data management. However, CDW has a

394   complex infrastructure based on a variety of databases (raw data, meta data, summary data, data
395   marts), operational data sources, a layer to Extract, Transform and Load (ETL) information, and
396   many data access front end (e.g., analyzing, reporting, mining, medical information, business).
397   Besides that, CDWs also deal with policies of data backups, the workload in the system, capacity
398   of storage and no deletion of information [47].
399   SIDABI focuses on the integration of web applications to take care of people with
400   Parkinson's disease and help non-profit organizations. SIDABI is free and open-source, and in
401   any necessity, programmers can change the code and the database related to medical record
402   forms and functions that deal with information about Parkinson's disease and the system can
403   cover other disorders. The entire structure and source code of SIDABI can be found in the
404   supplemental information section.
405
406   **Usability and Agreement Results**
407
408   The questionnaire that evaluates SIDABI was designed to obtain the examiner experience and
409   the general characteristics of the system regarding the usability of the interface, error handling
410   and system feedback messages, ease of use, satisfaction, and whether the system meets the tasks
411   for which it was designed.
412   In this sense, from the 36 examiners, 83.33% had over five years of experience using
413   computers, 77.78% were between 18 and 25 years old, and 52.78% used the computer for more
414   than 10 hours a week. The dataset and codes to compute these statistics can be found in the
415   supplemental information section.
416   Figure 5 shows the answers obtained from the 36 examiners for each question of the SUS
417   questionnaire. Most of the even-numbered questions yielded scores around 1 to 2 points, which
418   characterizes a fair evaluation of negative purpose questions concerning the system's usability.
419   On the other hand, most of the odd questions scored between 4 and 5, a high score for questions
420   with a positive purpose, given the usability of the system.
421
422   **Figure 5. Response distribution in which the average is highlighted by the red dot and the**
423   **blue star represents the outliers.**
424
425   The SUS scores are given in Fig. 6. The red dashed line represents the mean score obtained
426   (82.99). The estimated standard deviation was 13.97, confirming the good usability of the system
427   as the obtained SUS score is above the blue dotted line (68 points), which represents the
428   acceptable value for a system evaluated with this scale.
429
430   **Figure 6. SUS scores by examiners**. The value 68.00 represents the minimum average
431   acceptable in the SUS score, and the value 82.99 was the mean score reached by the SIDABI
432

433   In addition, it is possible to observe, according to the scale proposed by Bangor, Kortum and
434 Miller [44], that the system is between good (71.4) and close to excellent (85.5 points). Most of
435 the examiners gave scores higher than 82.99 points, and 7 of them evaluated the system with
436 usability below 68 points.
437   The agreement between the examiners was verified using Kendall coefficient for the SUS
438 scale score. The SIDABI reached 70.2% of concordance with p = 5.9×10^{-44}, which suggests a
439 good agreement among the evaluators.
440

441 **Discussion**

442

443 The proposal of an integrated system for managing data from patients with PD was presented,
444 and the system could be installed in clinics that support people with PD, hospitals, and research
445 laboratories. The project aims to improve data management, avoiding loss of datasets,
446 fragmentation of information, decreasing research costs, and providing monitoring and clinical
447 assessment of PD patients. Furthermore, SIDABI unifies education, research, and the caring of
448 PD patients on the same system. All these functionalities in a free and open-source system can
449 facilitate data management and help institutions with low resources or those that maintain the
450 services through donations.
451   Additionally, the system improves the controlling of sensitive personal information, helping
452 in the privacy rights defended by California Consumer Privacy Act [26], Data Protection Law
453 Enforcement Directive of European Union [27], and General Personal Data Protection Act in
454 Brazil [28]. It is important to highlight that SIDABI assists with user authentication in data
455 management, controls data manipulation, and helps the system administrator lock and unlock
456 modules and permissions for functionality. In general, however, privacy rights [26–28] lay down
457 rules governing the collection, handling, storage and sharing of personal data managed by
458 organizations, prohibiting the sharing and use without consent of personal data. The system can
459 also be downloaded, changed, and anyone can adequate the functionalities under specific
460 necessities.
461   In the initial phase of the project, the system was installed on local servers of partners who
462 use the system in hospitals, clinics, and in our research laboratory (NIATS). The system is
463 currently installed on a dedicated local server in our laboratory. However, the ideal approach for
464 a multiplatform web system is hosting on cloud services.
465   Despite that, the system is promising since several benefits are provided by the solutions
466 developed. Diagnostic exams and assessments of specific PD symptoms, for instance, are easily
467 stored and organized in SIDABI. In this context, the research that assesses cognitive dysfunction
468 described by Klinger et al. [7] could have their data stored in our system per patient, facilitating
469 future analyzes, and allowing the comparison with other data. Likewise, the datasets resulting
470 from the work of Cunningham et al. [8] assessing hand dexterity, Pastorino et al. [9] which
471 record the patient's movement data to detect the ON/OFF medication condition, the evaluation
472 and monitoring of gait proposed by the authors Paredes et al. [11], Pepa et al. [16], e Patel et al.

473 [17]; the monitoring of bradykinesia proposed by Eskofier et al. [12], and the speech assessment
474 data described by the authors Dimauro et al. [13]. All of these data could be collected from the
475 same patient and stored in the same database and could be compared for a better understanding
476 of the disease, to monitor the evolution of the symptoms, and to search for ways to provide better
477 living conditions to patients in a much more effective way. In addition, any data can be shared by
478 configuring groups of researchers, which facilitates collaboration and analysis of the information
479 on the same platform.
480   Astakhov et al. [15] proposed a solution in integrating interinstitutional databases to facilitate
481 collaborative information between the projects. However, our research goes further, with data
482 stored in a structured way and with a secure organization to collect questionnaires, scales, exams,
483 and monitoring for each patient in an integrated manner and an easy-to-use interface.
484   The system architecture was designed to provide an easy-to-learn interface, with simplified
485 functionalities and good satisfaction for the user who works on the platform. These
486 characteristics can be observed in the usability evaluation applied to the system using the SUS
487 scale, which obtained a good score (82.99 points) in which the agreement of the examiners was
488 70.2% ($p < 0.001$).
489   Garzo et al. [18] applied SUS on its proposed system, and 37 people with PD evaluated the
490 system with an average of 78.6 points on the final score. Bank et al. [19] reached an average of
491 69.3 on SUS with 30 participants in the study (10 PD, 10 Stroke, 10 Healthy), and it was
492 identified the need to improve the interaction of the participant hand opening with the virtual
493 object. Meulen et al. [20] obtained an acceptable score on the SUS scale of 70.7 with 11 healthy
494 participants on the evaluation of a game for motor assessment of PD patients. The study could
495 identify problems within the wearable device used to reflect projected images and in the
496 controller. Kamdar and Wu [21] proposed a mobile application for monitoring mental health that
497 reached an average of 74 points on the SUS scale with 13 healthy participants that reported a
498 lack of desire to use the system frequently.
499   In addition, the authors Wijaya, Munandar, and Utaminingrum [22] obtained 51 points on the
500 SUS scale with 20 evaluators, and despite the regular result, the test revealed the difficulty that
501 users have in the system with the augmented reality marker. By contrast, Devy, Wibirama, and
502 Santosa [24] reached an acceptable proposal with a SUS score of 75.5 points in the multimedia
503 system for learning the English language, whose evaluation was carried out by 38 evaluators.
504 Finally, Indriana and Adzani [25] obtained a score on the SUS scale of 80.9 points, with 25
505 evaluators validating their e-commerce application. In this context, SIDABI obtained a good
506 score (82.99) from its 36 examiners when compared to the studies presented.
507   Furthermore, in Fig. 5, question 2 (relating to the system's high complexity) and question 6
508 (representing the system inconsistency) reached an average between 1 and 1.5. These low values
509 represent that the system is easy to use and has low inconsistency. Likewise, question 1 (reports
510 satisfaction with using the system) and question 5 (evaluates the system's well-integrated
511 functions) obtained an average between 3.7 and 4, a good score, but showing that these
512 functionalities could be improved.

513   Finally, a good score was achieved regarding the user experience, a characteristic that
514 influences quick learning when using the system. The user experience can be seen in question 7
515 (I think users will learn how to use the system quickly), which reached an average of 4.2,
516 question 8 (evaluates if the system is confusing) reached an average of 1.5, and question 10
517 (represents the need to learn many things to be able to use the system) that obtained an average
518 close to 1.5.
519   In the future, the module Data Query, which is illustrated in Fig. 2B, can be increased with
520 more functionalities such as opening files of datasets providing statistical analysis to support
521 general data understanding, some data mining tools, detection and classification of information.
522   The presented study had the intention to evaluate the usability of the system based on the
523 knowledge and experience of professionals from distinct areas (i.e., researcher's labs, hospital,
524 nonprofit organizations) aiming to understand whether the proposed system was adequate.
525 Further researches could be carried out specifically with PD health professionals to evaluate the
526 system usability, and also to the application of usability tests involving specialist programmers in
527 usability. Even though SIDABI was built using good practices in usability and a set of
528 responsive libraries to improve human-computer interaction, in future implementations, the
529 standard IEC 62366, used in medical devices, could be adopted to improve usability. Another
530 important study involving administrative gains in the use of SIDABI could be conducted. It will
531 be possible to compare scenarios before and after the use of the system after a considerable
532 number of institutions have adopted the system. The results of these studies could help to
533 understand the average cost of direct spending on software for people with PD [2].
534   The system described in this study has many segments that can be developed. The system is
535 modular and was designed for future expansions. For future implementations, it is possible to do
536 new implementations without a team interfering with each other's projects. Furthermore, the
537 system is open-source: the source code is available to the communities to improve and make the
538 functionalities grow up helping institutions that help people with PD.
539
540 **Conclusions**
541
542 SIDABI system is easy-to-use and has good potential in managing the biomedical data of people
543 with Parkinson's disease. SIDABI was analyzed by experienced evaluators regarding the time
544 spent using computer systems and obtained a good score (82.99 of 100 points) on the usability
545 test. In this sense, the system can bring satisfaction to the user in the solution of their tasks.
546   Researches previously reported in the literature did not return results similar to this study
547 until now. Therefore, the system is innovative in combining different solutions in this research
548 area, collecting innovation in projects, learning and training about the disease, evaluating and
549 monitoring patients with PD, and all of it on the same platform and with integrated functions.
550 With an organized and secure database, it is possible to envision a future of savings in research,
551 reducing time spent with recollect data, fragmentation of the information, and stimulating new
552 projects, innovations and facilitating sharing data between them. Moreover, objectively enhance

553 the decision-making of professionals regarding the symptoms of Parkinson's disease. The system
554 is free and open-source to help institutions with low resources.
555

Acknowledgements

557

558 We are thankful to the Parkinson Association of Triângulo (Associação de Parkinson do
559 Triângulo, Uberlândia, Brazil) for their participation in this study.

560

References

562

563 1. Andrade AO, Pereira AA, Almeida MFS de, Cavalheiro GL, Paixão APS, Fenelon SB,
564 Dionisio VC. Human Tremor: Origins, Detection and Quantification. In: Practical
565 Applications in Biomedical Engineering [Internet]. InTech; 2013 [cited 2018 May 8].
566 Available from: http://www.intechopen.com/books/practical-applications-in-biomedical-
567 engineering/human-tremor-origins-detection-and-quantification
568 2. Bovolenta TM, Cesar De Azevedo Silva SM, Saba RA, Borges V, Ferraz HB, Felicio AC.
569 Average annual cost of Parkinson's disease in São Paulo, Brazil, with a focus on disease-
570 related motor symptoms. Clin Interv Aging [Internet]. 2017 Dec 14 [cited 2021 Jan
571 18];12:2095–108. Available from: https://www.dovepress.com/average-annual-cost-of-
572 parkinsons-disease-in-sao-paulo-brazil-with-a-f-peer-reviewed-article-CIA
573 3. Kassavetis P, Saifee TA, Roussos G, Drougkas L, Kojovic M, Rothwell JC, Edwards MJ,
574 Bhatia KP. Developing a Tool for Remote Digital Assessment of Parkinson's Disease.
575 Mov Disord Clin Pract [Internet]. 2016 Jan [cited 2017 May 6];3(1):59–64. Available
576 from: http://doi.wiley.com/10.1002/mdc3.12239
577 4. Dinov ID, Heavner B, Tang M, Glusman G, Chard K, Darcy M, Madduri R, Pa J, Spino
578 C, Kesselman C, Foster I, Deutsch EW, Price ND, Van Horn JD, Ames J, Clark K, Hood
579 L, Hampstead BM, Dauer W, Toga AW. Predictive big data analytics: A study of
580 Parkinson's disease using large, complex, heterogeneous, incongruent, multi-source and
581 incomplete observations. Draganski B, editor. PLoS One [Internet]. 2016 Aug
582 5;11(8):e0157077. Available from: http://dx.plos.org/10.1371/journal.pone.0157077
583 5. Roibu Crucianu PA. The Implications of Big Data in Healthcare. In: 2019 E-Health and
584 Bioengineering Conference (EHB) [Internet]. IEEE; 2019 [cited 2020 Jun 12]. p. 1–4.
585 Available from: https://ieeexplore.ieee.org/document/8970084/
586 6. Agrawal R, Prabakaran S. Big data in digital healthcare: lessons learnt and
587 recommendations for general practice. Heredity (Edinb) [Internet]. 2020 Apr 5 [cited 2020
588 May 30];124(4):525–34. Available from: http://www.nature.com/articles/s41437-020-
589 0303-2
590 7. Klinger E, Chemin I, Lebreton S, Marié R-M. Virtual Action Planning in Parkinson's
591 Disease: AControl Study. CyberPsychology Behav [Internet]. 2006 Jun [cited 2020 May
592 29];9(3):342–7. Available from: http://www.liebertpub.com/doi/10.1089/cpb.2006.9.342
593 8. Cunningham LM, Nugent C, Moore G, Finlay D, Craig D. Identifying fine movement
594 difficulties in Parkinson's disease using a computer assessment tool. In: Final Program
595 and Abstract Book - 9th International Conference on Information Technology and
596 Applications in Biomedicine, ITAB 2009 [Internet]. IEEE; 2009 [cited 2020 May 25]. p.

597   1–4. Available from: http://ieeexplore.ieee.org/document/5394307/

598   9.   Pastorino M, Cancela J, Arredondo MT, Pastor-Sanz L, Contardi S, Valzania F.
599   Preliminary results of ON/OFF detection using an integrated system for Parkinson's
600   disease monitoring. In: 2013 35th Annual International Conference of the IEEE
601   Engineering in Medicine and Biology Society (EMBC) [Internet]. IEEE; 2013 [cited 2020
602   May 28]. p. 941–4. Available from: http://ieeexplore.ieee.org/document/6609657/

603   10.   Caldara M, Comotti D, Galizzi M, Locatelli P, Re V, Alimonti D, Poloni M, Rizzetti MC.
604   A Novel Body Sensor Network for Parkinson's Disease Patients Rehabilitation
605   Assessment. In: 2014 11th International Conference on Wearable and Implantable Body
606   Sensor Networks [Internet]. IEEE; 2014 [cited 2020 May 27]. p. 81–6. Available from:
607   http://ieeexplore.ieee.org/document/6855621/

608   11.   Arango Paredes JD, Muñoz B, Agredo W, Ariza-Araújo Y, Orozco JL, Navarro A. A
609   reliability assessment software using Kinect to complement the clinical evaluation of
610   Parkinson's disease. In: Proceedings of the Annual International Conference of the IEEE
611   Engineering in Medicine and Biology Society, EMBS [Internet]. IEEE; 2015 [cited 2020
612   May 25]. p. 6860–3. Available from: http://ieeexplore.ieee.org/document/7319969/

613   12.   Eskofier BM, Lee SI, Daneault J-F, Golabchi FN, Ferreira-Carvalho G, Vergara-Diaz G,
614   Sapienza S, Costante G, Klucken J, Kautz T, Bonato P. Recent machine learning
615   advancements in sensor-based mobility analysis: Deep learning for Parkinson's disease
616   assessment. In: 2016 38th Annual International Conference of the IEEE Engineering in
617   Medicine and Biology Society (EMBC) [Internet]. IEEE; 2016 [cited 2020 May 27]. p.
618   655–8. Available from: http://ieeexplore.ieee.org/document/7590787/

619   13.   Dimauro G, Di Nicola V, Bevilacqua V, Caivano D, Girardi F. Assessment of Speech
620   Intelligibility in Parkinson's Disease Using a Speech-To-Text System. IEEE Access
621   [Internet]. 2017 Oct 16 [cited 2020 May 27];5:22199–208. Available from:
622   http://ieeexplore.ieee.org/document/8070308/

623   14.   Haddock A, Mitchell KT, Miller A, Ostrem JL, Chizeck HJ, Miocinovic S. Automated
624   Deep Brain Stimulation Programming for Tremor. IEEE Trans Neural Syst Rehabil Eng
625   [Internet]. 2018 Aug 1 [cited 2020 May 28];26(8):1618–25. Available from:
626   https://ieeexplore.ieee.org/document/8401333/

627   15.   Cancela J, Pastorino M, Arredondo MT, Hurtado O. A telehealth system for Parkinson's
628   disease remote monitoring. The PERFORM approach. In: 2013 35th Annual International
629   Conference of the IEEE Engineering in Medicine and Biology Society (EMBC) [Internet].
630   IEEE; 2013 [cited 2020 May 28]. p. 7492–5. Available from:
631   http://ieeexplore.ieee.org/document/6611291/

632   16.   Pepa L, Capecci M, Verdini F, Ceravolo MG, Spalazzi L. An architecture to manage
633   motor disorders in Parkinson's disease. In: 2015 IEEE 2nd World Forum on Internet of
634   Things (WF-IoT) [Internet]. IEEE; 2015 [cited 2018 Jan 8]. p. 615–20. Available from:
635   http://ieeexplore.ieee.org/document/7389124/

636   17.   Patel S, Bor-rong Chen, Buckley T, Rednic R, McClure D, Tarsy D, Shih L, Dy J, Welsh
637   M, Bonato P. Home monitoring of patients with Parkinson's disease via wearable
638   technology and a web-based application. In: 2010 Annual International Conference of the
639   IEEE Engineering in Medicine and Biology [Internet]. IEEE; 2010 [cited 2019 May 26].
640   p. 4411–4. Available from: https://www.researchgate.net/publication/49627657

641   18.   Garzo A, Silva PA, Garay-Vitoria N, Hernandez E, Cullen S, Cochen De Cock V,
642   Ihalainen P, Villing R. Design and development of a gait training system for Parkinson's

643   disease. Papa F, editor. PLoS One [Internet]. 2018 Nov 12 [cited 2020 Jun
644   29];13(11):e0207136. Available from: https://dx.plos.org/10.1371/journal.pone.0207136

645   19.   Bank PJM, Cidota MA, Ouwehand PW, Lukosch SG. Patient-Tailored Augmented Reality
646   Games for Assessing Upper Extremity Motor Impairments in Parkinson's Disease and
647   Stroke. J Med Syst [Internet]. 2018 Dec 30 [cited 2020 Dec 16];42(12):246. Available
648   from: https://doi.org/10.1007/s10916-018-1100-9

649   20.   van der Meulen E, Cidota MA, Lukosch SG, Bank PJM, van der Helm AJC, Visch VT. A
650   Haptic Serious Augmented Reality Game for Motor Assessment of Parkinson's Disease
651   Patients. In: 2016 IEEE International Symposium on Mixed and Augmented Reality
652   (ISMAR-Adjunct) [Internet]. IEEE; 2016 [cited 2020 Dec 16]. p. 102–4. Available from:
653   http://ieeexplore.ieee.org/document/7836471/

654   21.   KAMDAR MR, WU MJ. PRISM: A DATA-DRIVEN PLATFORM FOR MONITORING
655   MENTAL HEALTH. In: Biocomputing 2016 [Internet]. WORLD SCIENTIFIC; 2016
656   [cited 2020 Dec 17]. p. 333–44. Available from: www.worldscientific.com

657   22.   Wijaya AC, Munandar MWA, Utaminingrum F. Usability Testing of Augmented Reality
658   For Food Advertisement Based On Mobile Phone Using System Usability Scale. In: 2019
659   International Conference on Sustainable Information Engineering and Technology (SIET)
660   [Internet]. IEEE; 2019 [cited 2020 Jun 13]. p. 266–9. Available from:
661   https://ieeexplore.ieee.org/document/8986118/

662   23.   Katsanos C, Tselios N, Xenos M. Perceived Usability Evaluation of Learning
663   Management Systems: A First Step towards Standardization of the System Usability Scale
664   in Greek. In: 2012 16th Panhellenic Conference on Informatics [Internet]. IEEE; 2012
665   [cited 2020 Jun 14]. p. 302–7. Available from:
666   http://ieeexplore.ieee.org/document/6377409/

667   24.   Devy NPIR, Wibirama S, Santosa PI. Evaluating user experience of english learning
668   interface using User Experience Questionnaire and System Usability Scale. In:
669   Proceedings - 2017 1st International Conference on Informatics and Computational
670   Sciences, ICICoS 2017 [Internet]. IEEE; 2018 [cited 2019 Jun 17]. p. 101–5. Available
671   from: http://ieeexplore.ieee.org/document/8276345/

672   25.   Indriana M, Adzani ML. UI/UX analysis & design for mobile e-commerce
673   application prototype on Gramedia.com. In: 2017 4th International Conference on New
674   Media Studies (CONMEDIA) [Internet]. IEEE; 2017 [cited 2020 Jun 14]. p. 170–3.
675   Available from: http://ieeexplore.ieee.org/document/8266051/

676   26.   Goldman E. An Introduction to the California Consumer Privacy Act (CCPA). SSRN
677   Electron J [Internet]. 2018 Aug 1 [cited 2020 Oct 26]; Available from:
678   https://papers.ssrn.com/abstract=3211013

679   27.   Quintel T. European Union · Article 29 Data Protection Working Party Opinion on the
680   Law Enforcement Directive. Eur Data Prot Law Rev. 2018 Mar 20;4(1):104–9.

681   28.   Viana da Silva MV, Da Luz Scherf E, Da Silva JE. THE RIGHT TO DATA
682   PROTECTION VERSUS "SECURITY": CONTRADICTIONS OF THE RIGHTS-
683   DISCOURSE IN THE BRAZILIAN GENERAL PERSONAL DATA PROTECTION
684   ACT (LGPD). Rev Direitos Cult [Internet]. 2020 Apr 27 [cited 2020 Oct 26];15(36):209–
685   32. Available from: https://papers.ssrn.com/abstract=3569928

686   29.   Jailia M, Kumar A, Agarwal M, Sinha I. Behavior of MVC (Model View Controller)
687   based Web Application developed in PHP and .NET framework. In: 2016 International
688   Conference on ICT in Business Industry & Government (ICTBIG) [Internet]. IEEE; 2016

689   [cited 2017 Dec 15]. p. 1–5. Available from:
690   http://ieeexplore.ieee.org/document/7892651/

691 30. Sommerville I. Software Engineering [Internet]. 9th ed. USA: Addison-Wesley Publishing
692   Company; 2010. 792 p. Available from: http://www.softwareengineering-9.com

693 31. Qodim H, Busro, Rahim R. Islamic Calendar: Prototype of Hijri Calendar Application
694   using Rapid Application Development Method. In: 2019 7th International Conference on
695   Cyber and IT Service Management (CITSM) [Internet]. IEEE; 2019 [cited 2020 Dec 14].
696   p. 1–4. Available from: https://ieeexplore.ieee.org/document/8965410/

697 32. Fielding RT, Kaiser G. The Apache HTTP Server Project. IEEE Internet Comput
698   [Internet]. 1997 [cited 2021 Jan 18];1(4):88–90. Available from:
699   http://ieeexplore.ieee.org/document/612229/

700 33. Baş Seyyar M, Çatak FÖ, Gül E. Detection of attack-targeted scans from the Apache
701   HTTP Server access logs. Appl Comput Informatics [Internet]. 2018 Jan 1 [cited 2021 Jan
702   18];14(1):28–36. Available from: http://dx.doi.org/10.1016/j.aci.2017.04.002

703 34. Hellerstein JM. Looking back at Postgres. In: Making Databases Work: the Pragmatic
704   Wisdom of Michael Stonebraker [Internet]. Association for Computing Machinery; 2018
705   [cited 2021 Jan 18]. p. 205–24. Available from:
706   https://dl.acm.org/citation.cfm?id=3226614

707 35. Syromiatnikov A, Weyns D. A Journey through the Land of Model-View-Design Patterns.
708   In: 2014 IEEE/IFIP Conference on Software Architecture [Internet]. IEEE; 2014 [cited
709   2020 Dec 15]. p. 21–30. Available from: http://ieeexplore.ieee.org/document/6827095/

710 36. Django Web framework [Internet]. 2021 [cited 2021 Jan 17]. Available from:
711   https://www.djangoproject.com/

712 37. Hansson DH. Ruby on Rails Web-Application Framework [Internet]. 2021 [cited 2021 Jan
713   17]. Available from: https://rubyonrails.org/

714 38. Spring Framework [Internet]. 2021 [cited 2021 Jan 18]. Available from: https://spring.io/

715 39. Freeman E, Robson E, Bates B, Sierra K. Head First Design Patterns [Internet]. 1st ed.
716   O'Reilly Media, Inc. O'Reilly Media.; 2004. 638 p. Available from:
717   http://www.ncbi.nlm.nih.gov/pubmed/23386138

718 40. Majeed A, Rauf I. MVC Architecture: A Detailed Insight to the Modern Web
719   Applications Development. Vol. 1, Peer Review Journal of Solar & Photoenergy Systems.
720   Crimson Publishers; 2018 Sep.

721 41. Nielsen J. Usability engineering. Computer Science Handbook, Second Edition. San
722   Francisco, CA, USA: Morgan Kaufmann Publishers Inc.; 2004. 45-1-45–21 p.

723 42. Ganney PS, Pisharody S, Claridge E. Software Engineering. Clinical Engineering: A
724   Handbook for Clinical and Biomedical Engineers. 2013. 133–170 p.

725 43. Jordan PW, Thomas B, McClelland IL, Weerdmeester B, Thomas B, McClelland IL,
726   Weerdmeester B. Usability Evaluation In Industry [Internet]. Jordan PW, Thomas B,
727   McClelland IL, Weerdmeester B, editors. Usability Evaluation In Industry. CRC Press;
728   1996 [cited 2020 Jun 6]. 189–194 p. Available from:
729   https://www.taylorfrancis.com/books/9781498710411

730 44. Bangor A, Kortum P, Miller J. Determining What Individual SUS Scores Mean: Adding
731   an Adjective Rating Scale [Internet]. Vol. 4, Journal of Usability Studies. 2009 [cited
732   2019 Jun 20]. Available from:
733   http://66.39.39.113/upa_publications/jus/2009may/JUS_Bangor_May2009.pdf

734 45. Legendre P. Species associations: the Kendall coefficient of concordance revisited. J

735   Agric Biol Environ Stat [Internet]. 2005 Jun [cited 2019 Jun 17];10(2):226–45. Available
736   from: http://link.springer.com/10.1198/108571105X46642
737 46. R Core Team. R: A Language and Environment for Statistical Computing [Internet].
738   Vienna, Austria; 2019. Available from: https://www.r-project.org/
739 47. Khalaf Hamoud A, Salah Hashim A, Akeel Awadh W. CLINICAL DATA
740   WAREHOUSE A REVIEW. Iraqi J Comput Informatics [Internet]. 2018 Dec 31;44(2).
741   Available from: http://www.uoitc.edu.iq/ijci1/vol44issue2/4-
742   CLINICALDATAWAREHOUSEAREVIEW.pdf
743

Figure 1

Access, security, and system structure flowchart

The system requires user authentication (A) and user profile verification (B) to access the modules (C). The modules of the system are connected to a security module (D). The system architecture is based on the model-view-controller pattern (E). The system is hosted on the Apache webserver, and the data are stored in the PostgreSQL database (F).

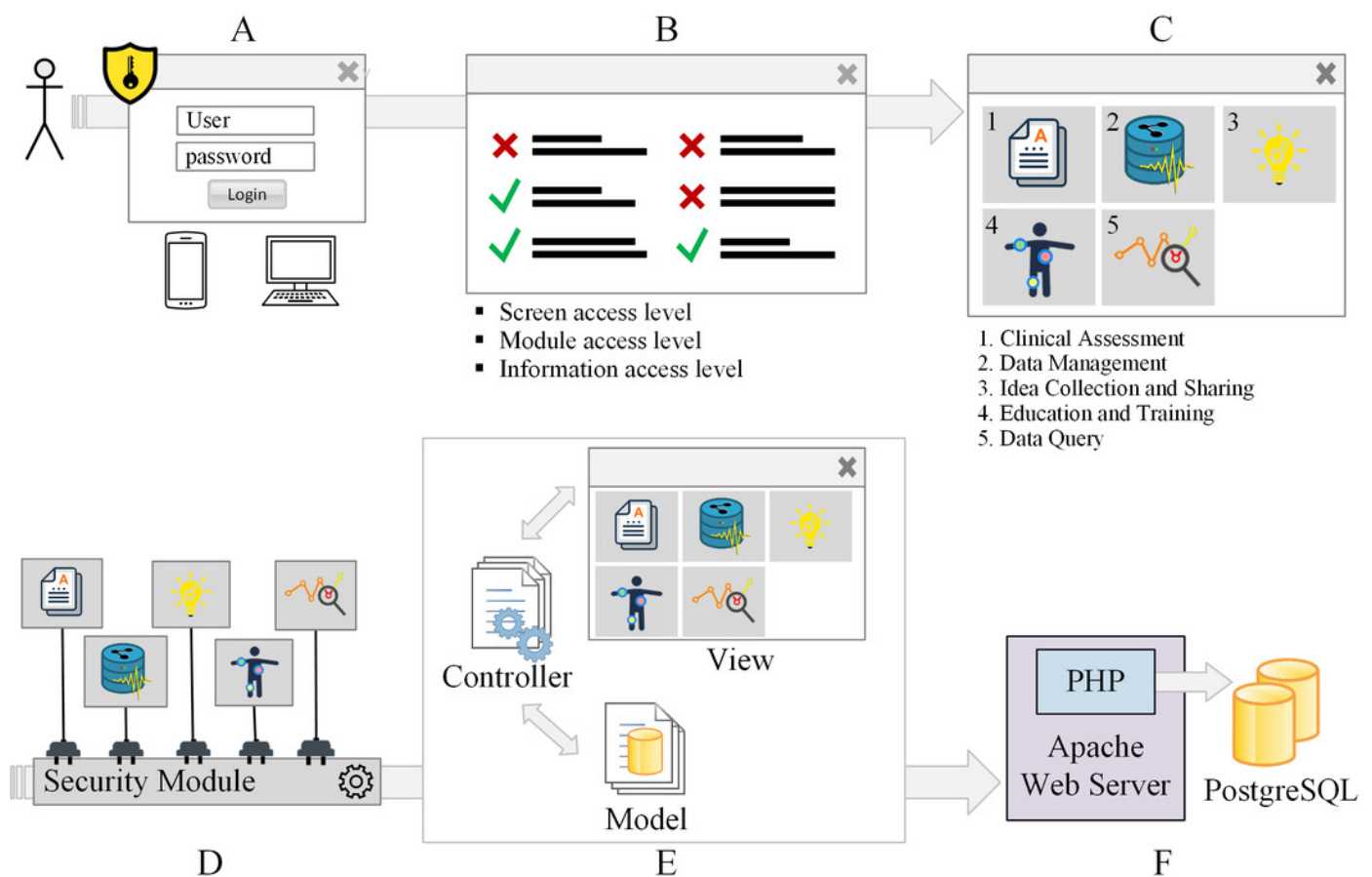



Figure 2

Main graphical interfaces of the system.

(A) The viewing on mobile device of the authentication system screen. (B) The viewing on PC
of the screen showing the modules of the system (1 – 5).

Figure 3

Use case diagram of the main functionalities of SIDABI.

(A) represents the security module, (B) the clinical assessment software, (C) the data management module, (D) the idea collection and sharing functionalities, (E) the education and training module, (F) the management of participants, and (G) the data query module.

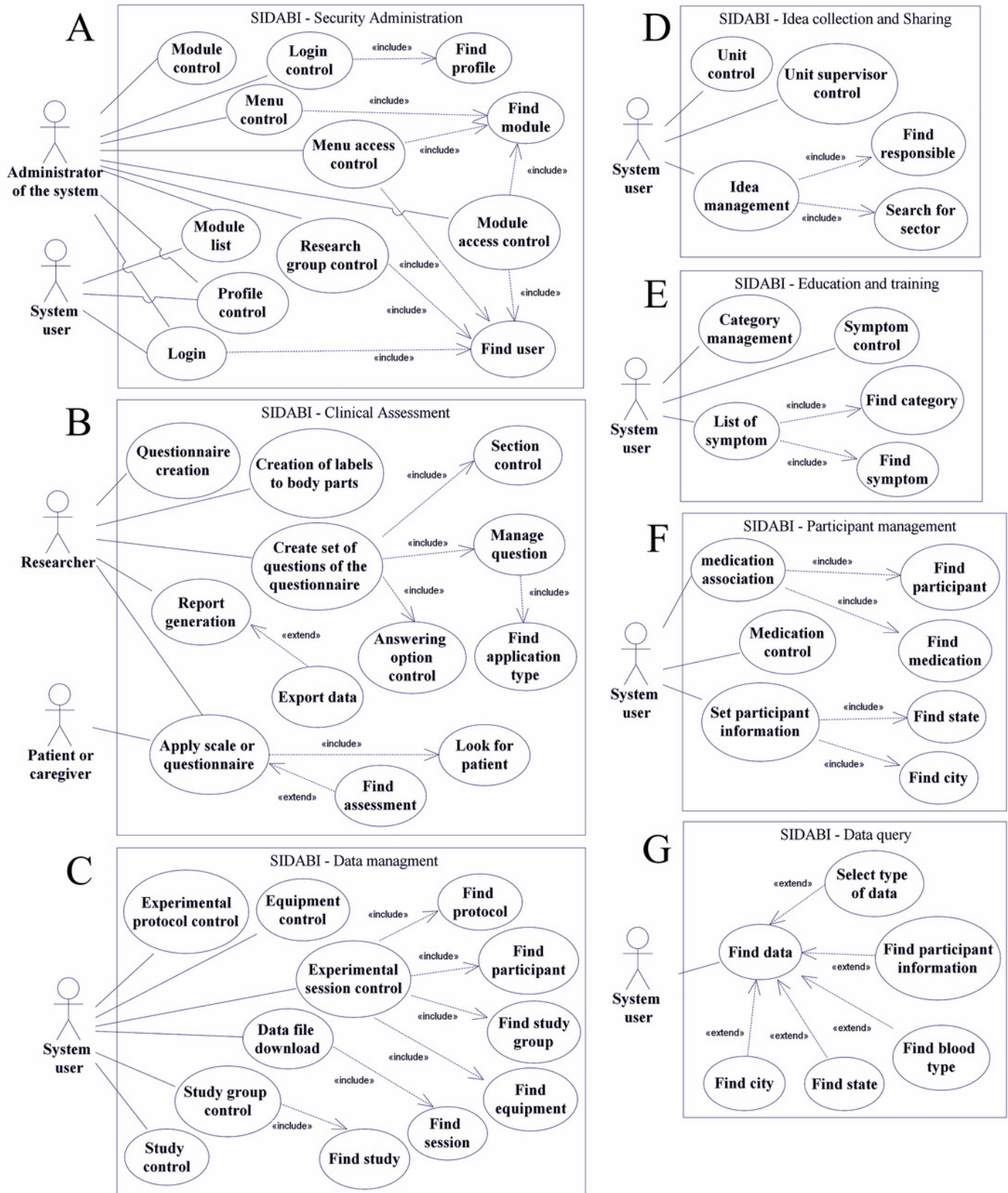



Figure 4

Examples of screens developed in SIDABI.

(A), (B), and (C) represent, respectively, examples of the screens implemented for the Data Management, Education and Training, and Clinical Assessment modules from the visualization in a PC, (D) illustrates the visualization of the Idea Collection and Sharing module from a smartphone.

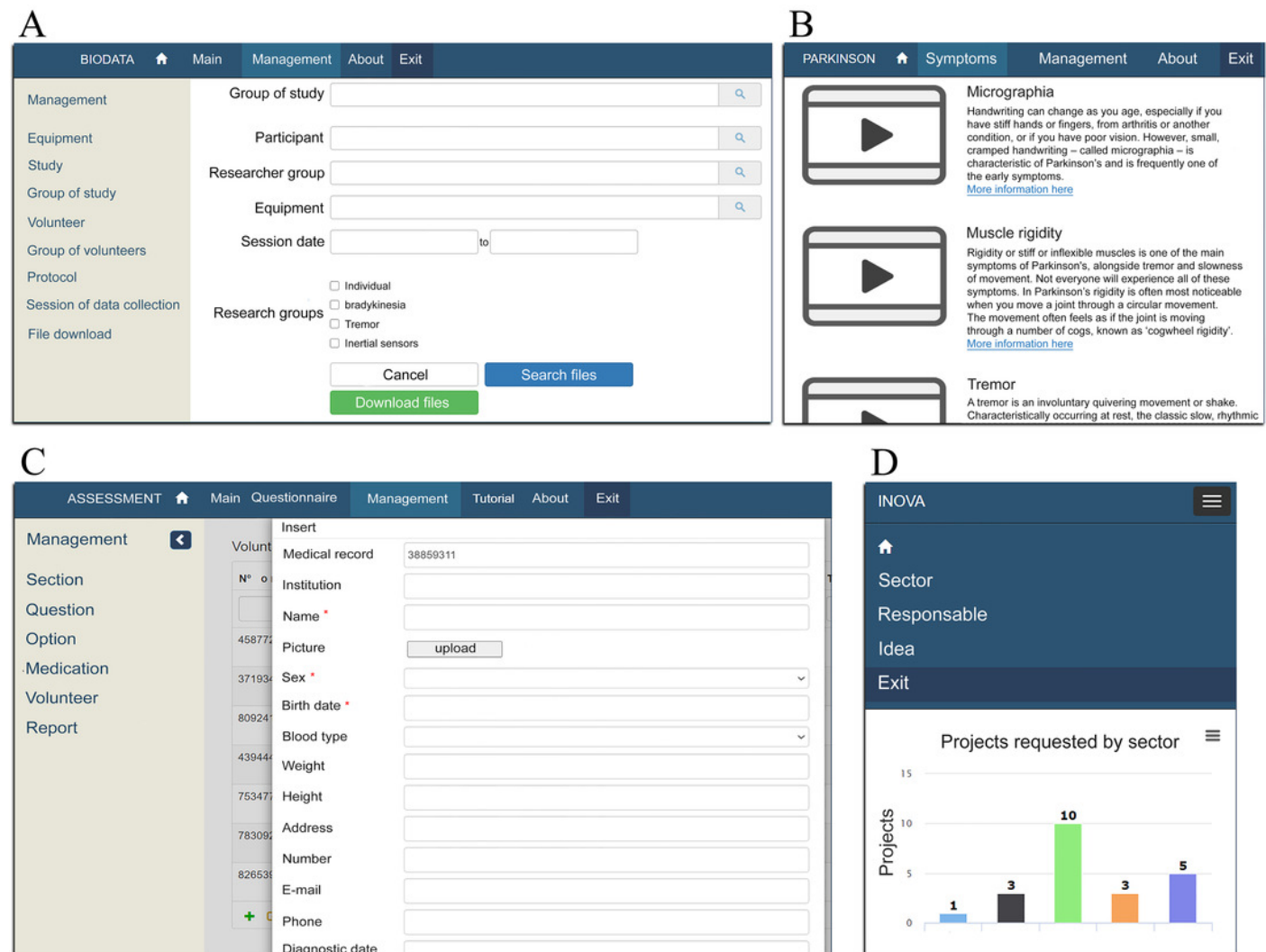



Figure 5

Response distribution in which the average is highlighted by the red dot and the blue star represents the outliers.

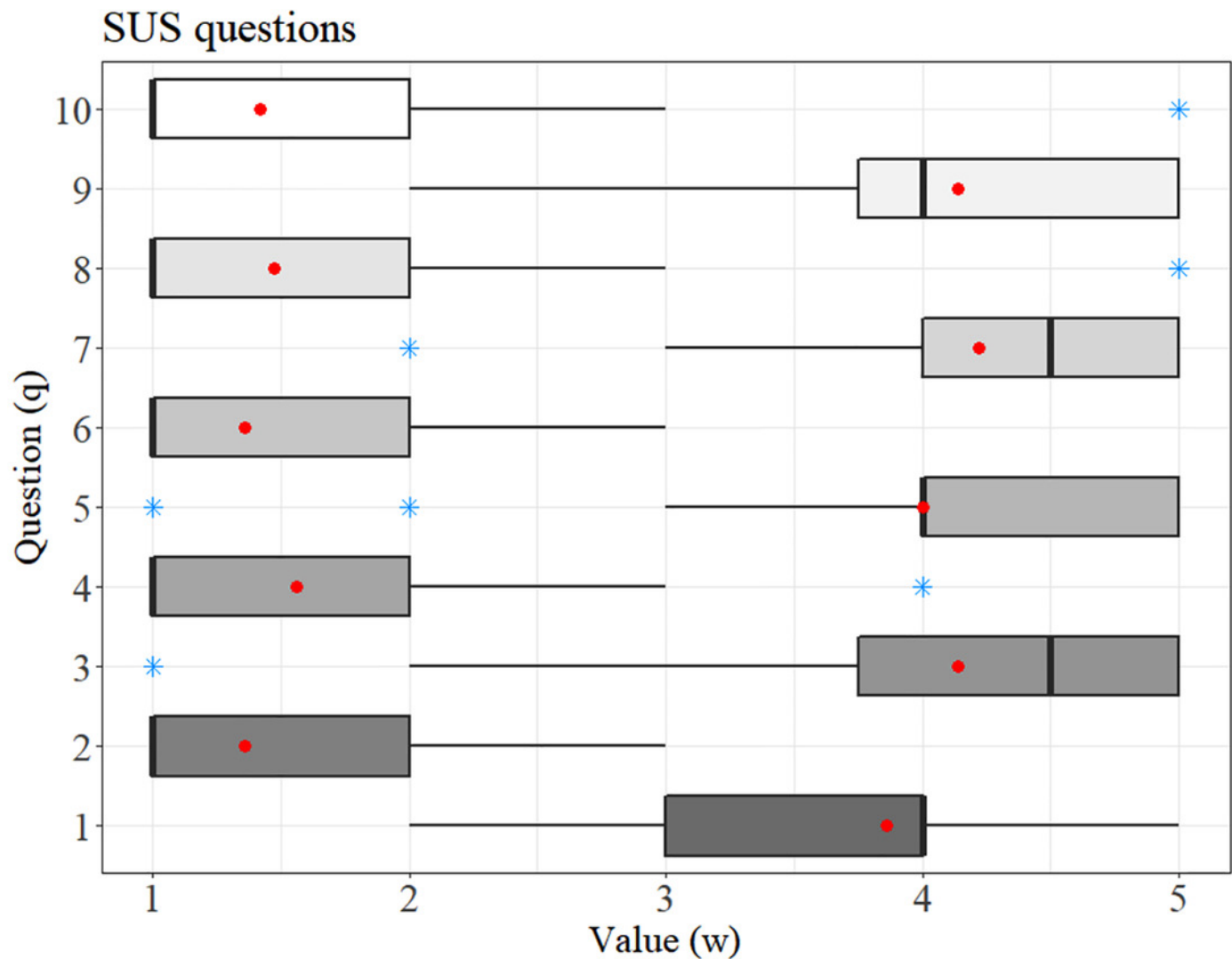
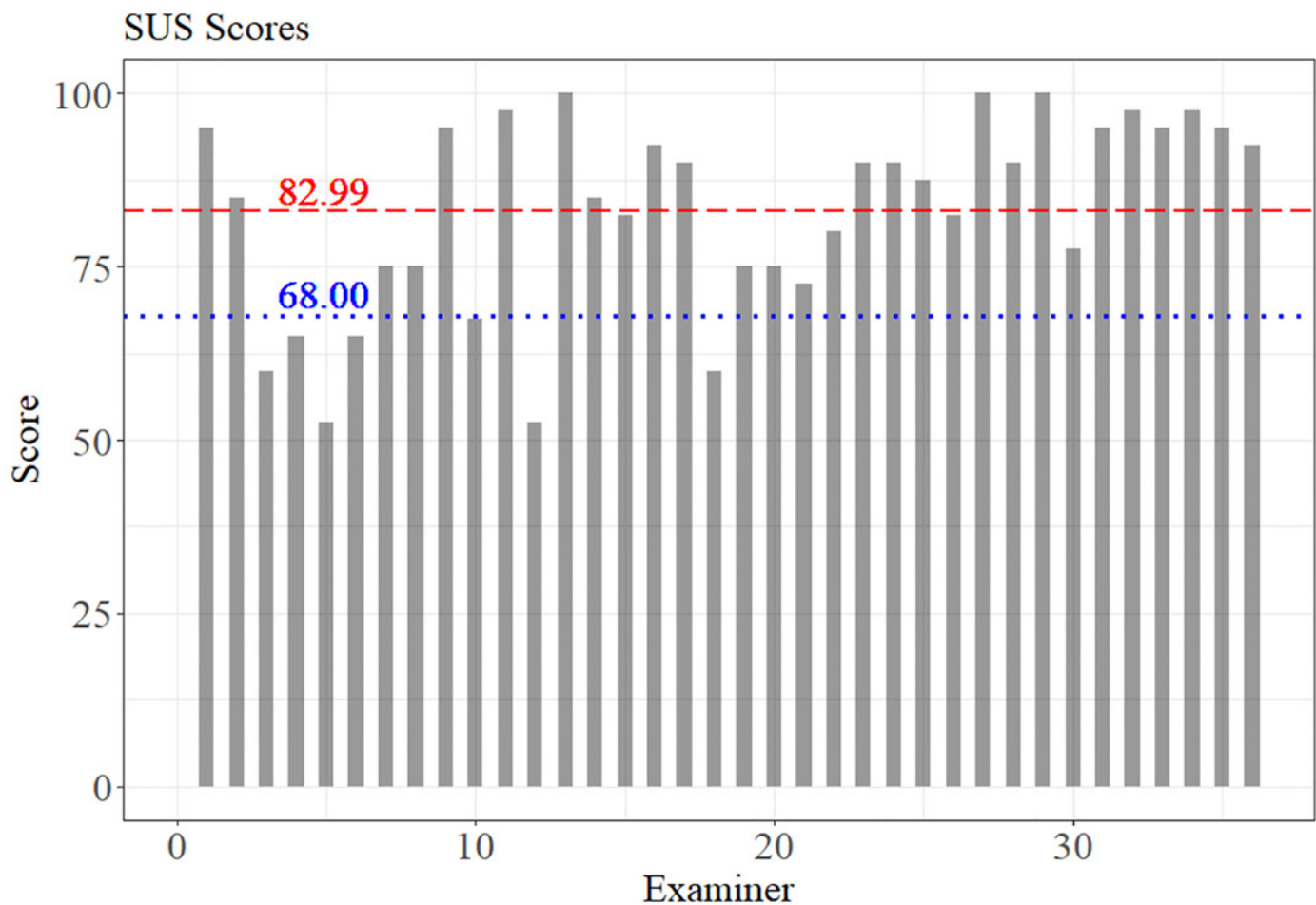



Figure 6

SUS scores by examiners.

The value 68.00 represents the minimum average acceptable in the SUS score, and the value
82.99 was the mean score reached by the SIDABI

SUS questions.

1   **Table 1**. **SUS questions**

Question	Description
1	I think that I would like to use this system frequently
2	I found the system unnecessarily complex
3	I thought the system was easy to use
4	I think that I would need the support of a technical person to be able to use this system
5	I found the various functions in this system were well-integrated
6	I thought there was too much inconsistency in this system
7	I would imagine that most people would learn to use this system very quickly
8	I found the system very cumbersome to use
9	I felt very confident using the system
10	I needed to learn a lot of things before I could get going with this system

Main functionalities of SIDABI.

1   **Table 2. Main functionalities of SIDABI**

Module	Functionality	Description
Security Administration (settings)	Login control	This functionality allows registering a new user in the system. Specific information, such as name, username, password, e-mail, profile, and user credentials (i.e., administrator or common user) are required.
	Profile control	This sets the category of the user (e.g., student, professor, guest).
	Module control	This functionality controls the creation and exclusion of modules in the system. The user has to inform an acronym, title and image that represents the purpose of the module.
	Module access control	It is used to control the access of users to specific modules.
	Menu control	It allows the assignment of specific menus to the modules of the system.
	Menu access control	This functionality restricts the access of specific menus to specific users.
	Research group control	It is used to create research groups.
	Researcher association	This functionality allows associating a user and a research group.
Clinical Assessment	Questionnaire creation	It is used to create a customized questionnaire that may be a clinical scale.
	Creation of labels to body parts	In Parkinson's disease, it is very common to assess body parts through specific questions. The creation of identification labels for body parts (e.g., jaw, upper left limb, and right hand) allows for the recording of specific clinical evaluations.
	Create set of questions of the questionnaire	The user can create the whole questionnaire or scale with this functionality. It is possible to create question sections, questions, answering options. Each question can be linked to a label of a body part.
	Apply scale or questionnaire	It is used to apply the scale or questionnaire to a patient. The user can select any available questionnaire (e.g., UPDRS, PDQ-39, a personalized scale).
	Report generation	The user can visualize the scale or questionnaire scores obtained by a participant and by date of evaluation.
Data Management	Equipment control	This allows registering the type of equipment used in data collection. The user has to inform the name and detailed description of the equipment.
	Study control	This functionality is used to register information about the study of the research (e.g., description, start date, ethics approval information, number of sessions of data collection)
	Study group control	It is used to create a group of study, and it is necessary to inform the study, name, description, inclusion criteria, and exclusion criteria. This functionality is used to group participants of the study.
	Experimental protocol control	This allows for the creation and specification of experimental protocols.
	Experimental session control	This allows the user to store data resulting from an experimental session. Information such as study group, participant

		identification, equipment specification, protocol description, general observations, date and hour of the session, medication, file format (e.g., edf, csv, txt), and sharing permission are included.
	Data file download	This functionality allows the use of filters (e.g., participant, equipment, research group) to find and download files.
Idea collection and sharing	Unit supervisor control	The supervisor is responsible for the unit. This functionality allows recording basic information such as name, occupation, and contact.
	Unit control	It is used to register a sector of work in a hospital, clinic, or institution. The user has to inform the name, phone, and responsible for the sector.
	Idea management	This functionality allows adding an idea that can be converted into a project. It is essential to inform a description, keywords, a sector, and the identification of the person responsible for the idea.
Education and training	Category management	It is used to create categories to organize the symptom list in sections such as motor and non-motor symptoms, tutorials.
	Symptom control	The allows creating a record specifying a symptom, which includes title, detailed description, a link to a video sample, a link to extra information, and the category.
	List of Symptom	This lists symptoms or other kinds of information available in the system.
Participant management	Set participant information	It controls the records of participants and patients. To insert a new volunteer is essential to fill in several fields such as medical record, institution, name, sex, birth date, weight, type of diagnosis, date of diagnosis, etc.
	Medication control	It is used to control different types of medication. It is essential to inform name, detailed description, dosage, unit.
	Medication association	This page is used to associate a participant with medication. To create an association, the user has to select the participant and the medication and fill in the dosage field.
Data query	Find data	This functionality finds records and files in the system. The user can choose some filters (e.g., type of data, age, sex, diagnosis, research group) to narrow the query, and the results show the files of data collection sessions, questionnaires, and scales presented in the entire system.