

PROCare4Life: An integrated care platform to improve the quality of life of Parkinson's and Alzheimer's patients

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ABSTRACT

The incredible increase in smart sensing technologies has provided a very high range of new potential applications for healthcare systems. In this scope, several initiatives are taking the advantage of sensors technologies and the new capabilities to collect properly all the raw information. Thanks to the inclusion and combination of wearable and fixed sensors, image device sensors among others, the number of solutions for accurate health monitoring in different environments has grown exponentially. In this paper, we present a complete system called PROCare4Life divided into two main subsystems. The first, will use a combination of sensing technologies to collect the raw information and get prior knowledge with some detection algorithms to generate a final daily summary of the relevant data. The second, a cloud-based platform, that centralizes the entire ecosystem to perform a multimodal fusion using the collected data, medical information, and other relevant inputs from medical experts. Finally, the system tries to improve the quality of life by providing recommendations, alerts, events, and other relevant information to the users in different interfaces.

CCS CONCEPTS

• Applied computing \rightarrow Health care information systems.

KEYWORDS

Healthcare platform, Multimodal Fusion, Events detection, Sensors technologies, Cloud Platform, Parkinson and Alzheimer diseases.

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1 INTRODUCTION

There is an imperative need to increase the efficiency and sustainability of health and social care systems across Europe, as there is a growing tendency in the public expenditure on healthcare, being expected to reach 14% of GDP in 2030 [5]. The leading causes of this situation are represented by the aging of the population, accompanied by the rise in chronic diseases, including cardiovascular ones, diabetes, asthma, mental and physical disorders, and neurodegenerative conditions [14].

Comorbidities and the confluence of several chronic pathologies are becoming more frequent in senior citizens. These facts increase the need to develop models and tools that enhance integrated care health systems. Frailty and comorbidity are clinical manifestations of two distinct aging-related processes, namely diminished functional reserve and accumulation of pathological processes [13]. Nevertheless, frailty and comorbidity often overlap in senior citizens and impair quality of life and functional status. Studies report that, among community-dwelling seniors who are frail, 82% have comorbidities, 29% have a disability in at least one activity of daily living (ADL), and 93% have a disability in at least one instrumental activity of daily living (IADL) [24]. A similar overlap between frailty, comorbidity, and disability has been reported [19].

Dementia, Alzheimer's disease (AD), and Parkinson's disease (PD) are the most disabling in common chronic pathologies in older adults. These strongly impact the quality of life of affected people and their families, influencing the treatment of other chronic illnesses and overlapping with more conditions. Today, almost 10 million Europeans live with PD, AD, and other dementias. As a result of aging, the number of people affected by one of those conditions is forecasted to double by 2030, introducing significant challenges. In addition, recent studies have highlighted the potential connection between Diabetes Mellitus (DM) and PD [6], and research has shown that diabetes can increase the risk of developing both AD and vascular dementia.

All these challenges can benefit from an integrated care platform. This platform should be able to: establish correlations between comorbidities, investigate the use of polypharmacy, mitigate potential

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arising health risks, study social variables, and promote unified treatment procedures or social services needs. Such a solution could help patients, caregivers, and socio-health professionals manage several diseases, considering the social context. Furthermore, people suffering from the aforementioned chronic diseases experience difficulties in their daily lives and living alone and require specialized care services and treatments. This situation imposes high burdens on the public budget, requiring special attention to adequately address the sustainability of the socio-health system in Europe.

PROCare4Life platform recognizes that, fragmented approaches are being adopted today to address different cases and individuals. Therefore, an integrated care process should be adopted for enabling a smooth and optimized process, harmonizing from a holistic perspective, health models with social services. This platform is looking for an inter-disciplinary, integrated solution for the delivery of healthcare and social services, where each senior citizen mental and physical situation is treated in a personalized manner, taking into account his/her medical and social conditions. At the same time, the treatment model is efficiently deployed in a scalable way at both local, national and European levels.

Then, the organization of the paper is the following: Section 2 presents related works to the proposed system architecture, Section 3 provides a complete overview of the system architecture and its sub-modules, Section 4 explain real world pilots results and Section 5 collect some final conclusions.

2 RELATED WORK

Extensive research and market interest in this area have been conducted in the last decade, proven by many funded innovation projects. Furthermore, personalized recommendation systems have been developed and provide reminders: management of visits, calls, exchange of messages, documents, and access to proxy services (transportation, shopping, etc.). Platforms linked to wearable sensors and medical equipment to measure health parameters (weight, blood pressure, etc.) were developed, alerting carers in case of a problem. At the same time, personalized recommendations encouraged activities that promote social networking, nutrition, leisure, and mobility habits.

From the EU projects focused on integrated care, we mention the 'Sustain' project [17], having the objectives to support and monitor improvements to established integrated care, and to contribute to the adoption of these improvements in different regions in Europe. Similarly, 'SCIROCCO' project (Scaling Integrated Care in Context) [20], aims to test models to facilitate the successful scaling up and transfer of good practices in integrated care across European regions. 'ICT4Life' project [11] aims at providing new ICT services to increase patients with PD, AD, and other dementias. One of the main objectives of this project is to develop a feedback-based decision-making engine able to integrate data from patients and multiple caregivers and historical data.

Research and development investments in integrated care systems generated a variety of qualitative as well as quantitative tools to support the health and social care needs of older citizens. The use of ICT contributes to providing daily health measurements integrated with medical information. In this perspective, the FrailSafe project [7] developed a wearable sensor device that could be worn under a t-shirt, and it measures individual medical parameters related to heart, respiration, and physical activity. The Bright Ageing project [1] involves testing a smart lighting system that is tailored to the user's personal needs and wishes. The aim is to reduce accidents resulting from poor lighting, improve sleep quality and raise the quality of life in general. Other off-the-shelf sensors used for smart monitoring are cameras [18], wireless presence sensors [15] as well as floor sensors [21].

Social care is also critical in an integrated care system. For instance, the Social Robots for Medicine Delivery project [8] develops a robot that can not only assist in medicine delivery at care institutions but also provide users with opportunities for social interaction. On the market, there exist several Electronic Health Record (EHR) apps. For example, AdvancedMD [12] allows users to review medication histories; review, add, edit and print patient charts, medications, problems. Drchrono [4], provides an environment in which charts can be created quickly with customizable medical forms supporting different clinical workflow. The users can also order labs and prescriptions through the mobile platform. Telecare [22] systems for the delivery of support services for people with or at risk for mental illness are another example of product.

The ambition of PROCare4Life goes beyond these initiatives by providing services for senior users suffering from neurodegenerative conditions using an integrated, flexible platform, medical knowledge base and communication channels in an efficient and cost-effective manner. The proposed integrated care platform aims to improve the satisfaction, time-management and learning curve of the involved actors in the care process. We accomplish this through user-friendly interfaces, improved access and means to update the health repositories, create appointment notes, and better track the health condition. Furthermore, by closely planning and monitoring the care pathway in different scenarios and for users with different needs, PROCare4Life is strengthening its market potential. PRO-Care4Life will validate the proposed integrated care platform, not only in the case of neurodegenerative diseases but also for other chronic diseases, including cardiovascular disorders, such as stroke, through large scale pilots deployed in five European countries. The feasibility and cost-effectiveness of the proposed solution will contribute to its wide adoption and exploitation as a commercial product.

3 SYSTEM OVERVIEW

PROCare4Life approach has been based on the quadruple aim suggested by Bodenheimer and Sinsky [3] and is widely accepted, as a basis, to monitor improvement in health and care provision. To the widely accepted Triple Aim to optimize health and care system performance (enhancing patient experience, improving population health, and reducing costs), these authors highlighted the importance of the health care professionals. This approach, now also widely accepted, recommends that the Triple Aim be expanded to a Quadruple Aim, adding the goal of improving the work-life of health care providers, including clinicians and staff, being PROCare4Life aligned with these goals. See below the graphical representation of the Quadruple Aim (Figure 1).

The care pathway redesign is a powerful tool to support the optimization of care and health service provision required when a new digital health dimension is added to the previous system. Thus, PROCare4Life can support the improvement and integration of how health and care services are provided from all of the four previously mentioned Quadruple Aim dimensions. Integrated care pathway (ICP) is defined as a person-centered and evidence-based framework. The intent is to inform multidisciplinary and multi-agency care providers, people using services, and their carers about what should be expected at any point along the journey of care [10]. According to the European Pathway Association (EPA), integration of the care pathway involves a complex intervention for the mutual decision making and organization of care processes for a well-defined group of people living with a condition during a well-defined period while placing the people living with a condition at the center of the health and care services provision.



Figure 1: Quadruple Aim which consist of reducing costs, improving population health, patient experience, and team well-being and productivity [9].

An integrated care pathway aims to enhance the quality of care across the continuum of health and care service provision [2]. The care pathway representation in PROCare4Life includes the integration and optimization identified by the individual care pathways of the health and care professionals in the consortium, a multi-actor needs pathway and a project pilot specific pathway delineating assessments and time for the adequate integration of the digital technology being developed by PROCare4Life. The integrated care pathway has been framed through a person-centered lens, a lifecourse trajectory and the integrated care quadruple aim. Creating this care pathway leads to knowledge-based care planning, facilitates coordination and fosters multi-stakeholder involvement through referral to psycho-social support services and community links.

3.1 Target Population and User needs

In the PROCare4Life project, users were identified following profiles based on the clinical experience of the different members, but also on literature review as Patients, Caregivers, and Socio-health professionals. Patients are senior citizens who are older than 65 and affected by neurodegenerative diseases such as PD, AD, and other types of dementia, and may suffer from at least one chronic non-communicable disease (e.g., diabetes, arthritis, osteoporosis, cardiovascular disorders). The patient profiles allowed exploring into socio-demographic characteristics, medical profiles, frequent concerns, type of technological capabilities, interest in technology and other factors that could influence how PROCare4Life could fit into their lives. Caregivers accompany the patient in their comprehensive care journey and as such was considered a key player in the design of the PROCare4Life solution. And last but not least, professionals whose complementary perspective will help make PROCare4Life a solution not only for patients and their families but also to support professionals' decisions.

The needs assessment aims to identify the users' requirements, needs and expectations on the use of technology within the integrated health care system. The analysis was performed through conducting mixed qualitative and quantitative studies, online surveys, interviews and workshops, and how PROCare4Life platform approach will take account of them. The result of this analysis identified the following major needs: i) detecting and monitoring disease-related parameters such as motor symptoms, cognitive abilities, sleeping problems, and adherence to medication, ii) ensuring the security, privacy, and protection of data collected from the users, iii) providing the means of communication between patients, caregivers, and health and care professionals, and iv) generating personalized alerts, reminders, recommendations, interfaces for each user type.

3.2 Main architecture

PROCare4Life system aims to provide a set of solutions for senior citizens suffering from neurodegenerative diseases and also living with other chronic diseases, ensuring it is personalized, i.e., adapting the solution to the real needs and expectations of users. As neurodegenerative diseases affect not only the patient but also the people that are around them, the project has also the objective to improve the quality of life/services of all involved users in the care delivery system: patients, their caregivers, and health and care professionals. Thus, the ecosystem has applications and interfaces dedicated to the users' needs. PROCare4Life will support the senior users in improving their quality of life, through offering access to relevant information about their medical condition and the best actions for improving their well-being, through the PROCare4Life integrated platform. The platform is made up of three main components where most of the functionalities are cloud-based to ensure availability, scalability, computing capacity and storage, personalization, and security : low-level sensorial ecosystem, high-level subsystem, and user interfaces (Figure 2).

3.3 Low-level sensorial ecosystem

The Low-Level subsystem (Bottom part of Figure 2) is responsible for the data acquisition from different sensors the initial analysis of

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Figure 2: Procare4Life System Architecture where Low Level, High Level and Interfaces are presented.

the acquired data where disease-related symptoms and daily activities are detected. Furthermore, the activities and symptoms serve as input to the the Multimodal Fusion Engine (MF), which belongs to the high-level subsystem and performs long-term behavioural analysis and deviation analysis.

This subsystem was developed as a client-server architecture since this approach facilitates a flexible architecture and makes possible the independence and interoperability between different subsystems to allocate different types of processing's defining an application programming interface (API) to provide all the endpoints for all the events. The server is responsible for orchestrating the whole framework between retrieving and delivering the acquired data. For every selected sensor, a socket is opened from running at a different thread. Thus, the server is receiving data at the rate of each sensor. The data is pre-processed/stored depending on the type of sensor in a database. This approach is based on the Model-View-Controller paradigm which is highly used for this type of system. In PROCare4Life, *Model* is the server that will contain several forms with all the data related to all the involved operations

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Figure 3: Sensors selected for Procare4Life system. From Left to Right: Fitbit Versa 2, Xiaomi Aqara Door Sensor, Smartphone, Intel RealSense D435, MiniPC.

(i.e. start sensors recordings, stop sensors recordings, start data preprocessing), *View* is intended to provide all the code to show all the necessary data in the main sensors server interface, and *Controller* contains all the code related to processing, data gathering, and data extraction will be included here along the algorithms for events detection.

The sensors selected for the project and the symptoms detected by each sensor are as follows (Figure 3):

- *Wristband*: Fitbit Versa 2. The heart rate, raw accelerometer measurement, and Fitbit API data (sleep, activities, steps...) are collected from this sensor. Real-time Fall Detection is detected by this sensors and support additional information for other movement related events.
- *Binary sensors*: Xiaomi Aqara Door Sensor. The data collected is an activation of open/close door. The sensors are used to detect number of visits to the bathroom or patient leaving the house.
- *Smartphone*: All models with at least accelerometer/gyroscope sensors, wifi and bluetooth. Freezing, bradykinesia, gait festination, walking patterns and loss of balance are the main symptoms detected by the data collected from the phone sensors.
- *Depth sensor*: Intel RealSense D435 + Skeleton Tracking SDK. This software along with the depth sensor is able to detect 3D skeleton joints on the body to track movements. Wandering is detected with this data.
- *Mini-PC*: It is the hub to connect all the sensors and the processing unit to analyze the data, create the summarization of all detected and identified events, symptoms, and daily activities every day for each patient, and send these summaries to the high-level subsystem using the provided channels from the main platform.

3.4 High-level subsystem

The high-level subsystem (Top part of Figure 2) is the Cloud-based component of the PROCare4Life solution, which centralizes handling the users and their clerical information and hosting the highlevel analysis engines, the Clerical & Clinical Data Repository (CCDR), and the back-end services necessary for operating other platform services such as the communications and authentication components, the identity management service, and the e-mail generator service.

- Multimodal Fusion Engine and The Recommendation Engine: The purpose is to utilize information gathered from the patients through several means considered, to detect clinically relevant deviations on the different modalities, and provide the outputs that can be used to support end-users in correcting these deviations.
- CCDR: The purpose of this component is to take information from different sources and provide a harmonized and combined structure to the different end-users. The information unification is based on the international standard for health care data exchange: Health Level Seven International Fast Healthcare Interoperability Resources (HL7-FHIR). The transformation of ProCare4Life data into HL7 resources is made by an API based on RESTFul services. This API also allows for the data to be retrieved from the CCDR to the rest of elements of the ProCare4Life platform in the particular structure they require.
- *Backend services*: The Data repository and Communication and social services are allocated in this module of the architecture.
- Identity Management: The purpose is to store user session and profile data, needed for the authentication and authorization mechanism.
- Communication and authentication/authorization layer: Represents the access point between the PROCare4life clients and PROCare4life high level cloud components, meaning that the external clients cannot access the internal high-level components without passing through this layer first. The PROCare4Life clients that access the high-level components are Mobile app, Web Platform, Game frontend and the low level Mini-PC.
- Notification services: E-mail generator, Notification and Social Communication components. The purpose of these components is to provide additional channels of interaction with the patients and users of the PROCare4Life solution, complementing those already defined in the smartphone application or the web-platform.

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Figure 4: Examples of the interfaces. Left: Web Interface, Mid: Gaming Tool, Right: Mobile Application.

In the multimodal fusion engine, the solution considers a longterm behavioural pattern analysis for generating scores that represent the high-level implications of the detected activities and symptoms, health-related data, and socio-demographic information. This analysis produces scores related to frequencies of motor symptoms, quality of sleep patterns, quality of physical activities, and adherence to medication intake using the activity data collected from the sensorial ecosystem, and high-level implications from cognitive states, electronic health records, personal profiles, and comorbidities. Consequently, the module generates seven scores: motor function score, cognitive states score, physical activity score, sleep score, medication intake score, patient profile score, and comorbidity index score. In the multimodal fusion subsystem of the engine these modalities are merged with a Bayesian approach to detect deviations from expected behaviours in terms of physical activities, cognitive abilities, sleep quality, and motor functionalities.

The recommendation engine assesses the outcomes of the multimodal fusion engine and the information collected at the low-level subsystem to identify triggers that could result in the production of patient-centered recommendations that aim to improve the daily life of the patients. Recommendations produced are in principle addressing the areas of physical activity, cognitive abilities, stress management and nutrition and are sent to the users of the system and presented in a proper and understandable way for each type of user (patients, caregivers, and health and care professionals).

3.5 User interfaces

The PROCare4Life solution provides three user interfaces: *Web Interface* to be used by the health and care professionals to manage and monitor their patients, *Mobile Application* to let patients access and manage their data in the PROCare4Life platform, and *Smart TV Cognitive Gaming Tool* to provide cognitive games and questions to create an experimental screening tool that will be used to assess the cognitive abilities of patients (Figure 4).

The web interface that consists of two roles that interact with the web platform: Administrator and Medical Professional is designed to be used by medical professionals and the technical staff at the medical facilities. The Administrator role was created to add and/or edit medical professionals' profiles. The Medical Professional role was created to provide a patient overview to the health and care personnel where they will be able to manage the patients list, their patients' profiles, add new patients, communicate with their patients, and check their health and activity measurements. All the data collected from each patient are presented in this overview for the health and care professionals to better monitor the detected symptoms and other analyzed data.

The mobile application was designed to be used by the patients, allowing passive and continuous monitoring of their daily activities, management of their medication, the filling out of questionnaires at the request of health/social professionals who assist them, the control of the sensorial ecosystem in the home environment, and the communication with their caregivers and health and care professionals through a chat interface.

The main idea of cognitive games tool is to provide games and questions for generating an experimental screening tool which can be used to assess the cognitive abilities of the patients. Using these interfaces that contain six games, a set of features will be extracted such as exhaustive information regarding the user interaction including execution times, button click tracking, information related to performance, transitions between games, time-spent on the games, difficulty level of the games, and user-ratings of the game. Subsequently, these features will be used to identify cognitive abilities related to concentration, mathematical calculations, object recognition, short-term memory, visual attention, and vocabulary recognition.

4 REAL-WORLD PILOTS AND PRELIMINARY RESULTS

In PROCare4Life, the main objective of the real-world pilots is to evaluate the feasibility of measuring disease progression and patient health status through the global functioning of the system. To accomplish this goal, the solution is tested and improved in an iterative manner in three phases. Pilot 1 involves the use of the adapted integrated care platform and the mobile application, having the goal to collect user needs and requirements and align them with the technological developments. Pilot 2 involves the modular use of the solution, consisting of deploying and testing various configurations, devices, and system set-ups. Finally, Pilot 3 corresponds to deploying the complete PROCare4Life solution, involving all the low-level and high-level components and updated according to the feedback received in the previous phases. The subjects of these pilots include patients, caregivers, and health and care professionals who are recruited by six different organizations from five countries (Germany, Italy, Portugal, Romania, and Spain) to be able to generalize the findings. The solution was tested in three scenarios: patient's home, daycare center, and rehabilitation center.

The pilot studies follow an iterative approach where the results of each pilot study feeds the next pilot and the corresponding technical developments. In order to execute the pilot study in each organization using a common procedure for each pilot phase a pilot study protocol was designed. The objectives of the pilot study protocol are to design i) the common clinical study for the evaluation of the solution's feasibility and usability and the patients' acceptance of the solution, ii) the validation analysis of the proposed integrated care solution, and iii) the assessment of the solution's impact. More details about the real world pilots in each country such as the size of the sample and study designs can be found here [16].

We completed the first pilot study and obtained the initial results from the second pilot study. System Usability Scale (SUS) [23] has a mean global score of 58.5±19.9 across all target users and the participants raised design concerns that need to be explored and rectified, which indicates low acceptability. Caregivers is the group that was most satisfied with the system (72.0±10.4) while patients' SUS mean score was 55.7±20.0. In order to further analyze the acceptance of users, a survey was administrated with questions referencing the user manuals. The acceptance rate was measured as 70% according to this survey. The technical solution and the user manuals are revised according to these survey results where comments of the participants to the open-ended questions are also taken into consideration.

The end of study survey included a 5-point Likert scale of satisfaction (1 - Very Satisfied, 3 = neutral and 5 - Very dissatisfied) and 3 open questions about the most/least valued aspects of the system and suggestions for improvement. The participants' mean satisfaction score was 2.6 ± 0.9 . Patients at the rehabilitation center and caregivers at home scenario were the most satisfied with the system (2.2 ± 0.8 , 2 - Satisfied). The health care professional in the home scenarios were the least satisfied (3.2 ± 0.9 , 3 - Neutral). Overall, the scores between scenarios did not differ significantly.

5 CONCLUSIONS

There is a pressing need for a rapid change in the way care and health systems are planned and developed to supply general population current and future demands. Thus, the rise for innovative solutions able to take full advantage of the most cutting-edge technical and medical advances is more important than ever before.

With its multi-faceted approach, PROCare4Life can make a difference in the healthcare ecosystem related to neurodegenerative disorders. Still, the wide scope of the solution has to be threaded carefully, as we have seen through the opinions of patients, caregivers and health professionals, making a balance between the scientific relevancy of the methodology provided and the final usability for end-users. In that aspect, ProCare4Life will continue its development taking careful consideration of patients, their caregivers and health professionals alike to truly become a useful tool that could go seamless in their daily life.

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