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BONVITA: Enabling Integrated Self-Care for Improving Chronic Patient's Wellbeing

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Abstract. In 2020, more than 20% of the population in the European Union (EU) was over 65 years of age, according to the statistical office of the EU (eurostat), while the percentage of older people in cities in the industrialized part of the world is expected to pass this level in the following years. This demographic challenge stresses healthcare systems and requires novel self-management solutions. Several apps in use for the management of chronic diseases have the potential, if used in a systematic manner, to provide the necessary means, not only for early prediction and prevention of health deterioration, but also to support evidence based medicine through the sharing of data for secondary use. This paper presents the BONVITA solution, designed specifically for enabling integrated self-care for improving chronic patient's wellbeing through the provision of a series of visualization options, coherent consent management, and cohort formulation and analysis over available datasets. Despite the fact that it focuses on three chronic conditions (i.e., cardiovascular diseases (CVD), diabetes and chronic obstructive pulmonary disease (COPD)) its modular design enables its deployment into other chronic conditions as well, towards building a scalable and sustainable solution for both healthcare and social care that can be transferable to larger city/ region/ country contexts.

Keywords: Consent management · Integrated care · Patient Empowerment · Wellbeing

1 Introduction

Integrated care is an organizational principle for care delivery, aimed at achieving improved patient care, through better coordination of the provided services [1, 2]. According to Contandriapoulos et al. [3] integrated health services are health services managed and delivered so that people receive a continuum of services relevant to health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care. These services are coordinated across the different levels and sites of care within and beyond the health sector, and according to people's needs throughout their life course.

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As the global population ages, the risk for developing a number of chronic diseases such as diabetes, hypertension, arthritis or other heart and/ or respiratory disorders increases [4]. Supportive physical and social environments enable people to do what is important to them, despite capacity losses [5].

What is considered to be important for the patient is to be in a position to plan her/ his care with people who work together to understand her/ him and her/his carer(s) [6]. Allowing control and bringing together services to achieve outcomes that are important to the patient is imperative.

Integrated care should not be solely regarded as a means to managing medical problems since the principles extend to the wider definition of promoting health and wellbeing [7]. It is important to note that according to [8] in 2021 the share of those aged 65 to 79 was higher in rural regions (16%) in the European Union (EU) than in urban regions (14%), in contrast to working age population (aged 20–64), where there is a higher share in urban regions (60%) than in rural regions (58%).

E-health promises to provide comprehensive treatment of chronic patients in rural areas, by means of innovative tools (such as Electronic Medical Records (EMRs), patient portals, telehealth and personal health records (PHRs)) and state of the art technologies (such as Artificial Intelligence (AI), cybersecurity, and High Performance Computing (HPC)) to support innovative integrated models for self-care from home, powered by a large diversity of personal data, and supported by an ecosystem for wellbeing to help motivate patients and engage a large community of support around the patient. Although several infrastructures and mobile apps have been developed so far for enabling integrated self-care for improving chronic patient's wellbeing, they usually focus on a single domain such as mental health [9], stress [10], frailty [11], COVID-19 [12], cancer [13, 14] etc. However, an open infrastructure is required in order to facilitate the common needs among all chronic diseases, enabling also the fine-grained service delivery per chronic disease.

Key considerations in this direction, have to do with compliance with relevant data protection regulations (such as the EU General Data Protection Regulation (GDPR)) and easy to manage consent management for accessing personal health data, link to nontraditional health data (such as exercise goals and eating habits), and proactive preventive care. All of this requires secure and timely access and/or sharing of data between organizations. Healthcare resources should be proactively ready to be used (only) when a chronic patient is in need, while a supportive environment and data-driven digital tools should create a supportive environment capable of preserving health and the self-management of citizens.

This paper proposes a solution that includes services beneficial for both healthcare and social services to support rural areas moving beyond data silos of a single chronic disease and enabling citizens to open and trustworthy control their own data and the use of it. It focuses on improving self-management ability, as well as building a wider ecosystem for well-being including health and social care providers. It combines self-monitoring care in conjunction to the ecosystem of well-being towards the delivery of tailored advice, based not only on clinical findings, but also on genetic profiles, privately collected data, registry data, and other publicly available data relevant to the condition of the patient under consideration, in line with the key objectives of European Health Data Space (EHDS) [15]. The paper focuses on the design of this novel platform, encompassing current needs for integrated care for use, especially in rural areas, where the demographic challenge is higher, while at the same time is transferable and scalable to larger city contexts. To prove the scalability and the extensibility of the platform it will support disease-specific apps for cardiovascular diseases (CVD), Chronic obstructive pulmonary disease (COPD) and diabetes. The platform relies on already available modules implemented for stress (through the STARS-PCP project [9]) and frailty management (through the eCare PCP project [10]) repurposed for enabling integrated self-care for improving chronic patient's wellbeing.

The rest of this paper is structured as follows: In Sect. 2 we focus on use cases available and requirement analysis and Sect. 3 we present the designed architecture and the available modules. Finally, Sect. 4 concludes the paper.

2 Requirement Analysis and Use Cases

To enhance autonomy and support independent living, it is important to encourage citizens to take responsibility of their own health needs [16]. This is facilitated through technologies that provide digital services for accessing personal health data, gaining insights about health conditions and controlling access to data through notions of GDPR legislation and the new European data strategy [17, 18]. Health data ownership facilitates citizens to control their data and allow access to various actors based on their health needs but also as part of a volunteer offering to their data to the research communities [19]. Access to health data allows for a range of new possibilities to create systems that offer better control of health data and the ability to share data when appropriate. Data sharing can facilitate research towards personalized care approaches as well as for the creating of effective interventions to improve health and well-being [2].

Organizational structures for storing health data at healthcare and social care institutions are not focusing on how to facilitate the utilization of these data. Governed by legislation, health data remains in silos and cannot be shared for integrated care or to inform and guide research [20]. Moreover, health and social care systems have different structures and are rarely integrated. As a result, the actual technologies for self-monitoring do not allow for the sharing of data amongst healthcare and social service providers. New model designs that include sharing of data that has been generated by different actors, are imperative. Therefore, it is necessary to involve critical actors including citizens, eHealth and the welfare tech industry as well as healthcare and social service providers (private and public) [21].

Collected data needs to be collected and reused using cutting-edge innovation and technologies. A data lake can in a simple form serve as a safe harbour to store personal health data for citizens. An advance data lake can provide further benefits to different actors. It is applicable to different services as well as to different research, innovation and development activities [22, 23]. Transparent and open policies promote and build citizen trust. Feedback systems demonstrate gains for the individuals, both in the short and long run, and technological platforms that use the latest encryption technologies facilitate the development of a secure public-private data lake environment of data sharing [24].

The multidimensional needs of the individual would need more than just technology at home. Integrated care combined with self-management requires the interaction of health and social care services, in a flexible way to support individual needs and social context [25]. BONVITA as a technology platform will be tailored to improve control, safety, security, freedom and awareness of citizens' well-being.

Self-management of chronic diseases require citizens to have access to technologies that facilitate data management, provide tools to enhance health literacy about their condition as well as provide motivation based on their personal preferences [26]. Such technologies empower citizens to take responsibility for the design of their individual integrated care model and become self-responsible for their own health. This empowerment will improve patient's self-esteem making the system fully succeed [27].

Technology platforms need to be based on a value-based model revolving around the patient's needs to meet its main aim of improving patients' wellbeing [16]. For this reason, a health technology assessment (HTA) framework will be applied based on the early engagement of stakeholders, systematic literature reviews and scenario analysis to estimate the potential value of BONVITA, the digital platform which is under development [28, 29]. To establish the value and the impact of the technology, all involved stakeholders will be engaged during the evaluation phase including health and social care professionals, patients, informal carers, and administrative personel [30]. The framework evaluates stakeholder values on four domains (patient, economic, clinical and organisational) at defined stages with the purpose of:

- Identifying unmet user needs, elements adding value to the system and those to be modified.
- Generating evidence on results
- Evaluating the performance of suppliers and solutions.
- Identifying areas of opportunities
- Helping the innovators to complete a product that the health service wants

However, analysis of the details of the HTA framework that will be applied is beyond the scope of this paper. The following section focuses on the technical architecture of the proposed solution.

3 Architecture

The architecture of the proposed solution is shown in Fig. 1 and consists of four layers. The applications tier with mobile, disease-specific apps, the business logic tier with the various services provided the data management and finally the computational tier. In the sequel we will analyze each of those layers in detail.

3.1 Application Tier

The BONVITA infrastructure aims at enabling citizens to control their own health data, integrating data driven services for the self-management of three chronic diseases, i.e.,

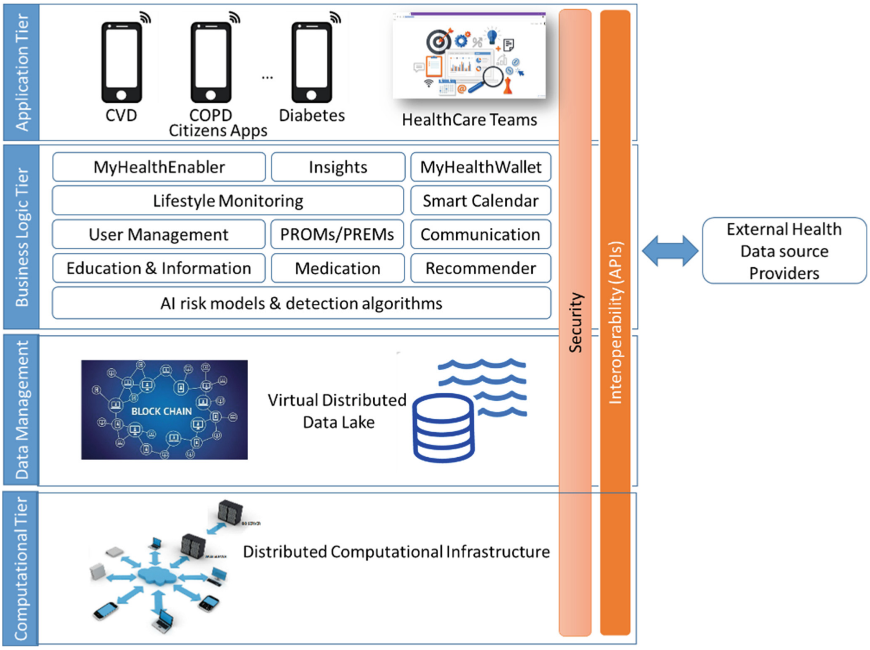

Fig. 1. The high-level architecture for the BONVITA solution for an integrated self-management model to improve chronic patient's wellbeing

COPD, Diabetes and CVD, in rural areas, selected due to their high prevalence and the fact that significant evidence exists for the positive results in self-management:

- **CVD:** A monitoring system for citizens at risk can prevent and/or predict adverse events, enabling better coordinate care. Further a CVD app can help citizens in adopting a healthier lifestyle and help them to adapt their changes to real outcomes.
- **Diabetes:** Diabetes is one of the most complex chronic conditions for patients to deal with, especially when it is in an advanced state or it is type 1, as it requires significant changes in the lifestyle.
- **COPD:** Mobile apps focusing on this disease can help educate citizens on how to live with their disease and how to rehabilitate themselves by reducing the visits to the hospitals.

Although those three diseases have been selected for proof-of-concept deployment of the BONVITA services, other disease-specific apps are also supported as well by the BONVITA ecosystem that helps motivate patients and engage them through a large community of support, enabling self-monitoring and self-care from home. All apps are able to capture citizen reported outcomes over time using secure, anonymous but identifiable data.

3.2 Business Logic Tier

Next, we present the key modules of the business logic tier. Those are the following:

MyHealthEnabler module provides a series of visualization options for individual health data. In essence it accesses the available health information and provides a pallete of graphical diagrams that can visualize the information at granular level, enabling zooming operations as well.

MyHealthWallet module provides consent management and sharing of the data between users of the various applications. Citizens are the owners of their data and can select to share their data with other users or healthcare providers. That consent can be easily withdrawn at will, whereas access to the information is recorded.

Insight's module provides cohort formulation and analysis over the available datasets enabling analysts to gain useful insights on the store data. An overview of the data sets is provided, together with a data dictionary wherever applicable referring to relevant standard semantic definitions, clarifying intended meaning of data, including used algorithms in the case of computed data. Through the insights module data can be selected, anonymized, and extracted for research purposes.

Lifestyle Monitoring module collects user information about vital signs and biometric data, physical activity, food and nutrition, psychological state of mind, therapy adherence, and socialization. The implemented APIs enable the ingestion of various types of vital signs and can be pushed by mobile applications through their connected connected devices such as digital blood pressure monitors, digital glucose monitors, digital pulse oximeters, sleep and stress monitors, etc. In addition, the lifestyle monitoring module can collect user biometric data retrieved through smartwatch sensors (heart rate, sleep quality, and physical activity). Further vital sign can be recorded manually by the various mobile apps through the appropriate interfaces they implement as still the same API can be used for data recording. All vital signs available in the data layer can be interactively visualized through the MyHealthEnabler and the Insights modules for both the patients and the clinicians. A screenshot of the clinician view is shown in Fig. 2.

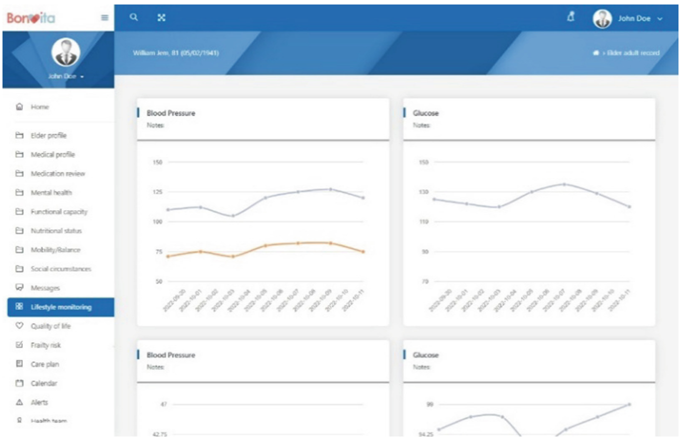

Fig. 2. Visualization of the vital signs stored in the data layer

Medication's module enables the management of the various medications that the citizens might use, enabling polypharmacy management, drug interaction detection and alert etc.

PROMs/PREMs are implemented **through the self-assessment** module. Patients use this module to report proms and prems in collaboration with their healthcare providers in order to collect relevant information from the citizens.

User Management module differentiates user types and can include new users in the system, including patients, their caregivers, formal caregivers, healthcare professionals, and social workers. An administration panel enables the creation of new healthcare professional and/or social worker profiles.

The Smart Calendar module enables patients, the caregivers, and care professionals to set up different events in the foreseeable future (e.g., planned goals and activities before the next meeting, which itself is planned and entered into the schedule). The patient can define personal reminders such as family birthdays and other socialization-related events as well. A screenshot of the smart calendar is shown in Fig. 3 and is connected with the various categories of information available for both the patient and the healthcare providers.

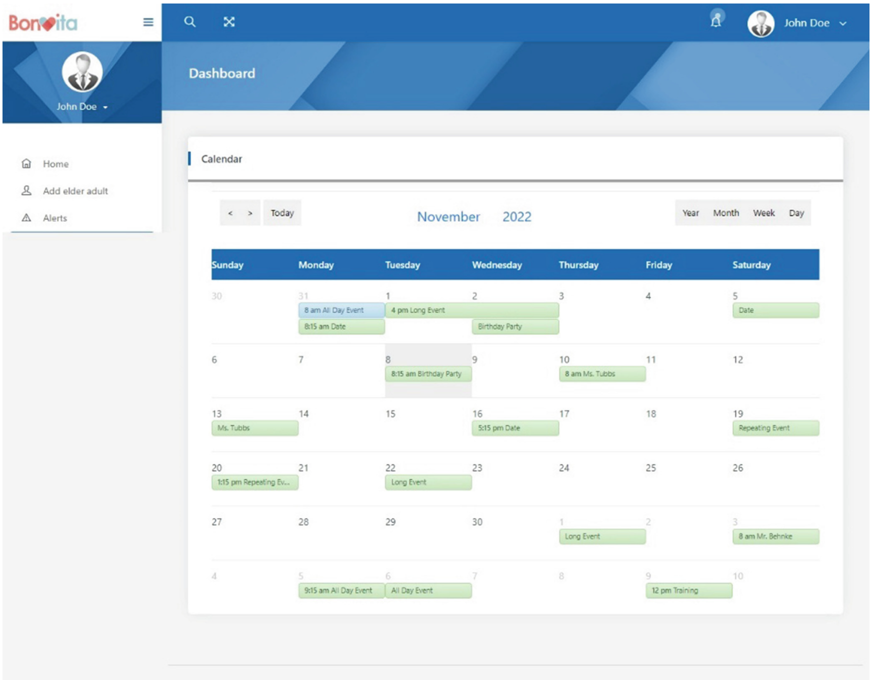

Fig. 3. Smart Calendar visualization

Communication module supports synchronous and asynchronous communication between patients and their care team, as well as between citizens for social purposes, by exploiting a messaging system. Predefined messages can be configured to be sent to users at specific time points based on the shared care plan. Further the communication module facilitates access to existing peer networks by grouping accounts in forum like places, enabling to exchange opinions, and experiences.

Recommender module sends personalized pieces of advice about how to reach the level of health behaviors that each user requires. This module is directly linked with the vital signs and activity monitoring module, whereas it is possible to recommend also activities based on user profiles (e.g., guided walks). Currently using the recommender module the healthcare professionals can set recommendation rules based on the available data, specifying which actions should be performed with given conditions [31]. The module is also used for specifying alerts that should notify the patients or the healthcare providers with a critical flag as well. A screenshot of the alerts shown in the healthcare provider view is shown in Fig. 4.

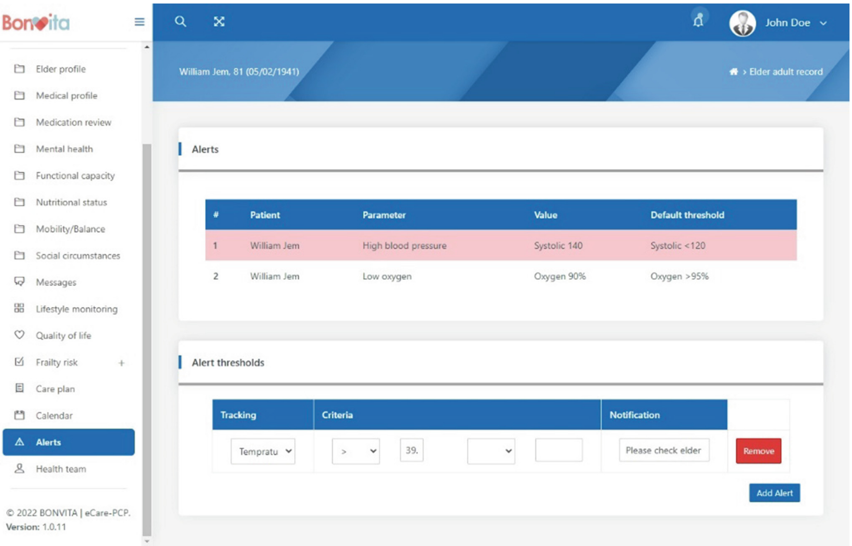

Fig. 4. Alerts from the clinician view

Education & Information module provides information material, educational resources, and training to support emotional, psychological, and physical well-being and empowerment. Training materials are provided in order to increase the skills of citizens as well as their caregivers and care professionals. The training content is selected from a list of available modules divided in three main topics: (i) soft skills for training emotion regulation strategies, effective communication and active listening, empathy, negotiation, and conflict resolution, resilience and self-motivation, loss and grief, etc.; (ii) IT usage training on new technologies in order to leverage the potential of the system itself as well as to empower patients and care professionals; and (iii) training in acts of care such as self-care, health promotion, care techniques, adoption of healthier lifestyles etc. The training modules will include multi-media content (tutorials, videos, interviews, etc.) with special attention on demonstrations (e.g., how to use medical devices). The presented content is dynamic, i.e., content is suggested depending on the user's knowledge and capabilities as well as their accomplishments during training.

Decision Support System module will implement AI risk models and detection algorithms for calculating the various clinically validated risk scores available in the BONVITA platform based on clinically validated models (e.g., Seattle risk model for CVD). Besides these risk scores, machine learning algorithms will continuously monitor all data that are collected trying to identify dominant features and the most influential factors for risks, including also the various scores calculated and the healthcare professionals' evaluations. We foresee that as the multidimensional data collected through the BONVITA solution grow, we will be able to build models with better accuracy with respect to existing risk scores, tailored specifically to the citizens using each health app.

3.3 Data Management Tier

All data available within the BONVITA solution will be stored centrally in a virtual data lake, exploiting the OMOP-CDM and the FHIR data model for storage. In addition, relevant terminologies such as SNOMED-CT, LOINC, MEDRA, ICD-10 etc. will enable the unambiguous storage of the various data. As such the data will be already FAIRified, I.e., findable, interoperable, reusable and accessible through APIs that will provide the necessary data to the various modules. The virtual data lake will allow applications to blend data from various sources, local or remote, and it is connected or disconnected from data sources when required by the apps that use it. It is a directory of citizens' data sources (with accurate and updated data descriptions) so that applications can search for data as if it were a single data set and retrieve the needed data from its location. It guarantees control access based on user consent (managed by Smart Contracts). The users of applications/analysts/insights may only see and/or access the data they are entitled to.

3.4 Computational Power Tier

The bottom layer is the actual computing nodes running the different components of the entire system. The computational layer is distributed enabling scalability and elasticity upon request, whereas each node is intended to be operated by independent organizations, and each node consists of both a public and a private layer.

3.5 Security and Interoperability

Security spans across all layers whereas interoperability services are offered by both the data management & AI tier and the business logic tier as well.

Regarding security, **blockchain is** used for storing all relevant information in the data lake. Smart contracting is used for making changes in the data enabling effective logging of. Further **encryption** is used for pseudonymization, data integrity, confidentiality and accountability.

In ensuring successful **interoperability** the BONVITA solution, key technical syntactic & semantic standards are supported. For the healthcare domain, ICD10–11

CM, LOINC, SNOMED CT, DICOM, HL7/FHIR and IEEE-073 PHD/ITU H.813 are adopted. For the data exchange of these health-related data sets, it should be using HL7/FHIR is adopted for data exchange of health-related datasets between the internal and external systems.

4 Discussion and First Results

One of the main novelties of the designed infrastructure is that it breaks the silos of disease specific mobile apps and enables the harmonic management of all health information of the citizens. Further, it allows the sharing of data through smart contracts and consent, enabling healthcare providers to have regulated access to the available information. The infrastructure has already been validated in scenarios for the management of stress [10], where healthcare professionals evaluated BONVITA in terms of functionality, design, clearness of the instructions of use, and general usability. In detail, about functionality and design, healthcare professionals positively evaluated BONVITA as useful, pleasant, easy to use and clear. Similar positive evaluations have also been reported on the clearness of the instructions of use and BONVITA solution has been evaluated as recommend to other patients and healthcare professionals. Nevertheless, these positive results, mixed evaluations have been reported regarding the BONVITA ability to communicate with patients and as added value. Currently the BONVITA solution is being evaluated for the management of frailty and through the following months it will be tested first by healthcare providers and then by elder adults.

5 Conclusions

This paper presents the design of a novel platform for enabling integrated self-care for improving chronic patients' wellbeing. The platform capitalizes modules already implemented for stress and frailty management, repurposed through a modular infrastructure able to accommodate management for multiple chronic diseases. We anticipate that in the following months the platform will be linked with other external apps for managing COPD, CVD and diabetes exploiting the rich infrastructure already available. Key challenges that we expect to be successfully addressed by its use, under different settings, concern the degree of openness of the platform for the incorporation of personal data spaces, the effectiveness of leveraging access to real-world data, the effective coordination of caregivers, and the empowerment of citizens in a trustworthy environment.

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