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An integrated advanced communication and coaching platform for enabling personalized management of chronic cardiovascular diseases

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Abstract— **Chronic cardiovascular diseases directly account for millions of deaths, billions of Euros and a big number of disabilities affecting the world's population. Even though primary and secondary prevention factors are well known, the awareness and the concern of citizens and patients is not big enough to cause a significant change in lifestyle that modifies the increasing trends. Patients and families, professionals and healthcare systems are not prepared to fight against this burden in an effective and aligned way. Some disease management programmes based on ICT solutions have and are currently being tested around the world but their relative impaction has been very limited. This paper proposes a new turn into Personal Health Systems applied to chronic disease management by increasing the capabilities for personalization, providing the patients with motivation and coaching support and enabling the work of the professionals with intelligent tools for strategic and clinical decision making based on the newest medical evidence.**

I. INTRODUCTION

Cardiovascular disease (CVD) is caused by disorders of the heart and blood vessels, ranging from coronary heart disease, cerebrovascular disease, hypertension, peripheral artery disease, rheumatic heart disease, congenital heart disease and heart failure. They are the main cause of death globally and this trend increases each year and affects both developed and undeveloped countries. Each year, they are responsible for over 1.9 million deaths in the EU, causing direct health costs of €105 billion. Coronary Heart Disease (CHD) is, with half of all CVD deaths, the single largest cause of death in Europe. Heart Failure (HF) – a CHD being the most frequent cause of hospitalization for people over 65 – has over 10 million patients in the EU. The WHO strategy for reducing the burden of the disease includes a comprehensive action that requires combining approaches that seek to reduce the risks throughout the entire population with strategies that target individuals at high risk or with established disease [1].

The actions that are considered optimal for the management and prevention of CVDs include options like effective drug treatments, implantable active devices and lifestyle improvements. Nowadays, patients only receive feedback during visits to the doctor or on demand consultations, but they lack from a daily monitoring, closer follow up, and help on treatment routine. Non-adherence to the treatment regime is a major cause of suboptimal clinical benefit. Thus, there is still the need for more comprehensive and extended health programs that invest in improving how these actions are applied to the population, assuring the most effective treatment for the most appropriate patient, optimizing the use of resources and complying with the patient needs.

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II. OBJECTIVES

The main objective of the work described in this paper was to create an integrated advanced platform for the management of CVDs with a special stress in remote monitoring, clinical decision support and patient coaching. More specifically, the solution was designed in order to comply with the following secondary objectives:

- Significantly advance the level of personalization of the patient's treatment that can be provided, both in the side of the patient (actions to be done within the careplan) and in the professional (possibility to adjust the prescription).
- Enable the management of more patients with fewer resources, providing a high level of quality of care and spending the resources dynamically according to the evolution of the patients' needs and not to population based distributions.
- Incorporate specific motivation and persuasion technologies embedded in the patient services to really support and engage the patient in taking a leading role in the self-management of his health.
- Integrate the most advanced technologies in the fields of sensors measuring clinical parameters, algorithms anticipating the evolution of the disease and guiding the professional in the personalization of the treatment based on the latest evidence and the state-of-art methodologies for coaching patients with CVDs.

III. MATERIALS AND METHODS

The proposed platform addresses recent paradigm shifts in healthcare such as continuous home monitoring, personalized education and treatment, dynamic decision support systems for professionals and computerized clinical protocols for personalized disease management. In this line, the project develops a holistic approach for the management of the chronic conditions focusing in the following aspects:

- *For the* ***patient****:* the information about the disease and the treatment may be difficult to understand, absorb and be put in practice in the concrete moment and situation, and, the added-value of prevention is difficult to see. There is a clear need to improve motivation of patients and increase the personalization of the treatment.

- *For the* ***clinician****:* the excess of information is difficult to process in the current work-flows and the detection of trends and risks is many times not possible with enough anticipation. There is a need for better tools for filtering and clustering patients, enhanced indicators of patient evolution and mechanisms for incorporating a higher degree of personalization in the treatment with a reasonable usage of resources.

To achieve these capabilities, the platform incorporates evidence-based knowledge and computerized clinical guidelines on top of continuous monitoring, self-learning of patient follow-up trends and the presentation of data and results to enable the clustering and identification of risks, while being integrated within the care-cycle.

A. Personalization of the care

Clinical guidelines (or *Care Plans*) are a powerful method for standardization and uniform improvement of the quality of medical care. Clinical guidelines are a set of schematic plans, at varying levels of abstraction and detail, for management of patients who have a particular clinical condition (e.g., insulin-dependent diabetes). The application of clinical guidelines by care providers typically involves collecting and interpreting considerable amounts of data over time, applying standard therapeutic or diagnostic plans in an episodic fashion, and revising those plans when necessary[2]. Clinical Pathways differ from practice guidelines, protocols and algorithms as they are utilized by a multidisciplinary team and have a focus on the quality and coordination of care [3].

However, in both cases the intervention of the patient in the execution of the protocols is very limited, and the protocols themselves do not include all the variability that patient daily life presents, which, at the end of the day, is one of the main causes of the non-compliance with the treatments when put into practice. Theoretically, a personalized workflow doesn't differ from the former definitions, but tries to empower those two dimensions (the patient and his environment) as active actors of the care plan outside inpatient environments and the inclusion of the patient's daily activities and choices. A personalized workflow is, then, concerned on how the medical procedures are applied to meet the patient's particular needs within the patient's preferences context.

The use of careplans can reduce the variability in daily clinical practice produced by disagreements between professionals. However, the variability due to population reasons cannot be avoided, as the treatment used for each person may differ from others. Ideally, a well-designed careplan should reflect the treatment necessities for 60%-80% of the population [4], but current implementations in hospitals show that only 13'5% of the patients suffer serious variances from the original careplan [5]. In these cases, the patient is managed outside the careplan using traditional approaches. Processes followed by "out-of-careplan patients" can help in the correction of deficiencies detected in the careplan, but the storage of those deviations is needed in order to extract common patterns that can be added to a careplan.

This process can be improved by using computer aid systems based on pattern recognition techniques such as the "workflow mining" technology [6]. This technology is a research field that allows discovering new workflow models analyzing the data coming from past samples. These algorithms use the information available from past executions of workflows to infer a new model. Another technology that can be used to infer model using past samples is the "distance measuring between workflows instances". For example, this technique could help in finding a new model when a running workflow instance fails in achieving a goal, comparing it to the most similar one that did achieve it, and it can be applied to careplans [7].

In any case, any solution that focuses on supporting the patients in such environments must take into account the following elements:

- The patient must be considered the main actor in the care process, instead of the passive receiver of the actions performed by the caregivers;

- Motivational aspects and possible non compliance must be accounted for in the core of the model, instead of being considered just as undesirable deviations from the normal path;

- Recommendations and guidelines (actions) are usually less strict, and in some cases given even without direct mediation of a health professional;

B. Motivation of the patient

The behaviour of a person is the result of the interaction between physical, psychological and social processes. Behaviour affects health, from the way relevant information is treated to the way a medical treatment is adopted. In addition, a person acts in a context that often determines the options and resources for healthy behaviour. The most prevalent non-communicable diseases are all related to lifestyle, and this is a modifiable factor. Behavioural theories and behavioural frameworks provide a vast body of knowledge for understanding how behaviour is influenced by external factors. However, *there is no single theory that completely explains behaviour and the interventions needed to modify behaviour*. Instead, the theoretical models of behavioural determinants overlap and complement each other. [8]

In the development of interventions, the information in a personal profile is utilized to choose right methods and to tailor the intervention content and delivery so that it matches the needs and interests of the person in question. After suitable strategies have been identified, they should be tailored to personal motivators and resources in order to achieve personal relevance and maximize the impact of the care plan [8].

C. Interactive Design Methodology

To achieve the final system, an iterative process has been carried out with both patients and professionals, extracting their main needs and requirements and validating and refining the platform within the design and development phases. Additionally, experts from the different medical and clinical disciplines related to the patient target groups (from psychological and behavioral sciences and from healthcare planning), have been included as active part of the design team, working closely with the technical teams to achieve a technically advanced, clinically innovative but sustainable and manageable platform of disease management services.

IV. RESULTS

The outcomes of this work have resulted in the creation of an open service oriented platform for the management of Heart Failure (HF) and Coronary Artery Disease (CAD). The platform incorporates: innovative sensors that measure both traditional and new parameters related to these diseases; a clinical decision support system integrated with different components of the platform (calculations of parameters, personalized care-plans, detection of trends, etc.); and a usable and practical user interfaces for patients and professionals specially adapted to increase the effectiveness of the management.

A. Professional Services

The platform integrates a set of professional tools aiming to facilitate the management of a large number of patients, with different degrees of the disease, and optimize the use of resources accordingly to their health needs. These services also enable the definition of different levels of alerts, alarms and notifications, which are based and computed from actual measured values and personalized trends. Services also allow the filtering and ranking of such alerts, alarms and notifications according to the professional's preferences. Finally, professional services give access to the information and recommendations provided by the clinical decision support system and allow the personalization of the treatment given to patients without deviating from clinical guidelines.

B. Interoperability and data modeling

The communication between services and components in a service oriented architecture requires the use of a data model that is able to fulfill the information exchange needs. Moreover, the interoperability with a broader range of systems also requires of a data model that is widely accepted by the community and, more important, by the healthcare industry. However, the existence of a model that fully covers the requirements from newly designed services is not possible in the practice, leaving to the system architects the task of defining new models or extending existing ones.

This is the case for a platform like the one mentioned in this article, which incorporates on its own information model research data that is not currently used in the healthcare domain (e.g., new measurements obtained from sensors not included in domain models yet). The model that best fits the healthcare domain is Health Level 7 (HL7), which defines a reference information model (RIM) flexible enough to be used in the modeling of any information exchange. However, HL7 is such an abstract model that still requires the definition of agreed vocabularies that further constrain the information and enable the standardization of the communication capabilities.

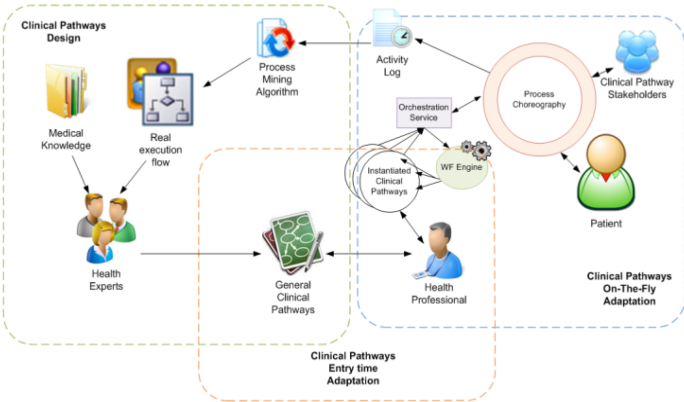
The last few years, the Continua Healthcare Alliance has adopted this methodology, creating a general purpose architecture and defining and standardizing the interfaces between each component. And probably the most important thing of all, it has brought consensus to the healthcare industry. The system designed matches the three lower levels (WAN device, Application Hosting Device and PAN/LAN device) in the architecture defined by Continua. More specifically, the WAN-interface (based on HL7) has been adopted and implemented, extending the model to the specific needs of our system.

C. Care-Plan Management

When a new care-plan is created, it may contain incorrectness that make difficult the use of the system in first stages and must be debugged at runtime. The correction of such incorrectness needs to be applied as soon as possible to prevent rejection from professional users. The process of modification of a care-plan is a manual procedure that requires a lot of time and effort, as the amount of information to be revised in order to produce the correct changes can be considerable large. In addition, while the information is being revised, similar cases might occur. If no information about past decisions is available, bad decisions can be repeated and information on successful modifications may not be available.

The use of workflow technology eases the follow-up of the path followed by a patient inside a care-plan. In addition, the modification of processes using graphical tools allows correcting in an easy way deviations from the original care-plan by just adding new nodes or removing incorrect ones. Nevertheless, implementation of those features in workflow engines is a challenge by itself, as current engines introduce strong limitations in the modification of running workflow instances: some engines allow changing a small set of features while others directly forbid this functionality. Figure 1 depicts the technical design of the care-plan manager including the authoring by means of the experts, the personalization of the plan and the process mining applied to evaluate the accuracy and applicability of the design.

Figure 1: Workflow architecture of the platform



D. *Patient Coaching Services*

The platform's motivation and coaching strategies focus on education, goal setting, feedback, rewards, and system help. These are functions that the system will provide to support the patient in long-term disease management. After studying the educational content, a "passport test" is organized by the system. The test can be implemented as a questionnaire into the Patient Loop system. The goal of the test is to ensure the patient has understood the educational content and can do proper self-management.

In addition to the traditional educational content, the system will incorporate a prediction tool that predicts the patient vital sign values given his/her current and past vital sign data and, e.g., full compliance to medication. The idea of the tool is to show the patient the importance of active disease management. By showing the effect of, e.g., 100% compliance and 0% compliance, the system can simulate the future values based on previous, general patient data. Such predictions are not exact, as they use an "average patient model" (thus patient data from a large population though personalized with the patient history), but they can indicate the importance of active disease management by showing the average effect.The goals for patient vital signs (e.g., HR, BP and weight) and lifestyle changes are defined by professional together with the patient. The goals are updated at each encounter and the physician enters the new, agreed targets into the system. Small incremental steps motivate and give the feeling of control. However, the targets should always be measurable and time-based. In such a way, the SMART (specific, measurable, achievable, realistic, time-based) criteria have been taken into account for the design of the coaching services.

For the patient, the system shows a goal overview: 1) the ideal value, 2) next agreed target (with target date), 3) last measured value and 4) comments the user has added to the measured value for each factor (e.g., weight, blood pressure, exercise, smoking, etc.). The purpose of goal overview is to give the patient the possibility to check the agreed goals and ideal values with current status. In addition to the overview, the goals can be visualized also graphically, showing the past trend, the latest values and the agreed target. Educational content related to each factor can be offered in the overview screen.

The system checks progress after each measurement by analyzing the trend of each variable. The feedback is shown as messages and graphical visualizations with past measured values and the next agreed target. Immediate feedback is shown after each measurement is processed.

V. DISCUSSION

Personalization is one of the core issues that need to be included in any disease management programme that wants to achieve a high level of effectiveness. However, this is a challenge both for patients and for professionals, as the variability on the preferences, the casuistic and the changes in life situations makes very difficult the process of describing and considering all these possibilities in advance. ICT technologies can play a major role in achieving the desired level of personalization without boosting the resource expenditure. However, much research needs still to be done in better embedding this personalization along all the cycle, including self-learning capabilities based on the system's usage and validate these enhanced functionalities in large trials in real scenarios.The second key factor is the need to include behavior change and psychological aspects in the design and provision of services to the patients. Each time more, systems rely in the patient's self-management and responsibility and they need to be empowered and motivated to continue and maintain a healthy lifestyle and comply with the medical treatment.

VI. CONCLUSION

All these results will be validated in different system configurations along the years 2011 and 2012, in real settings and with patients and professionals. Future lines of research will be focused in extending disease management platforms to support risk management with lighter patient services but enabling the integrated coordination from the healthcare systems. Additionally, more connection between these solutions and advanced tools for healthcare planning and healthcare assessment could be explored. This will increase the role of ICT in supporting the changes that current healthcare systems are experimenting.

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