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IEmS: A collaborative Environment for Patient Empowerment

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Abstract— **Personalized medicine refers to the tailoring of treatment to the individual characteristics of a patient. Part of the personalized medicine is the patient profiling and the communicative relation between physician and patient. The ways of exchanging information, the nature of the information itself and the information assimilation capabilities of the patient can assist the physicians to have a better understanding. Taking advantage of these information sources, a smart environment could be implemented. This environment will be able to act as a decision support infrastructure to support the communication, interaction and information delivery process from the doctor to the patient. A prerequisite of personalized delivery of information and intelligent guidance of the patient into his/her treatment plans is our ability to develop an appropriate and accurate profile of the patient. In this paper we present a collaborative platform which will empower patient with knowledge about his/her health condition and at the same time it will assist the physician to have a better understanding about the patient's unique psychological profile. We also introduce the p-medicine project and its vision in the field of personalized medicine and show project's approach on patient empowerment.**

Keywords—Patient Empowerment, Personalized Medicine, Profiling

I. INTRODUCTION

Medicine is undergoing a revolution that is transforming the nature of healthcare from reactive to preventive. The changes are catalyzed by a new systems approach to disease which focuses on integrated diagnosis, treatment and prevention of disease in individuals. This will replace our current mode of medicine over the coming years with a personalized predictive treatment. While the goal is clear, the path is fraught with challenges.

The p-medicine EU project (http://www.p-medicine.eu/) aspires to create an infrastructure that will facilitate the translation from current medical practice to personalized medicine. Essential to the realization of personal medicine is the development of information systems capable of providing accurate and timely information about potentially complex relationships between individual patients, drugs, and tailored therapeutic options [1].

This paper focuses on current research activities related to the design and implementation of a collaborative environment for patient empowerment platform and its services. The entry point for the patients is the p-medicine portal. After registering to the portal the patients can access all patient empowerment services provided by the platform. The environment must not only represent data in a convenient format, but data must also be translated into language that is understandable to the patient. This is because the empowerment process implies that patients are able to understand medical statements, as well as legal and ethical considerations.

To achieve this translation, a collection of intelligent techniques is used to construct a patient profile. A profiling server collects information using different techniques and combines them to construct patient profiles. Central technique for collecting profiling information is the ALGA-C questionnaire which is used to collect psycho-cognitive information about patients.

The benefits of constructing patient profiles are:

- Optimize information delivery from doctors to patients: Doctors, having a graphical summary of the patient profile, can rapidly adjust the content and the level of verbal information to the patient's perceived needs and their level of understanding.
- Optimize information delivery to patients in the patient empowerment environment: Information delivery is optimized according to each specific profile. Predefined rules use patient profile to personalize the contents of the information presented and to customize ways by which users complete their tasks in the patient empowerment environment. This makes it easier for the patient to decide what interest to him/her is at the moment.
- Create Recommendation Services: Besides using profiling to adapt the information provided, the system can also be exploited to enable the automatic recommendation of actions or services to the patients. For example, possible clinical trials that the patient

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could be enrolled can be identified. Advanced matching algorithms will be used over semantically-enriched clinical repositories to achieve this goal.

Moreover, patients will be able to share their information with other patients, doctors, organizations. However, before any sharing of health information can take place, patients must give their consent. Our approach uses an adaptive user interface for

- the presentation of the e-consent
- an ontology and a semantic web rule language to formally describe patient choices
- a reasoning engine to handle the access and the management of the personal health information.

The rest of this paper is structured as follows: Section 2 highlights the challenges in the area and the approach we selected for the patient empowerment environment. Then, Section 3 presents the architecture and the design of our platform. Finally, Section 4 concludes this paper and discusses future directions.

II. CHALLENGES & OPPORTUNITIES

In an epoch where shared decision making is gaining importance, patient's commitment and knowledge about his/her health condition becomes more and more relevant. Nowadays patients spontaneously search for information on internet, as if they were thirsty of knowing what their future might prospect to them. Navigating around the web might provide valid information, but it can also make the patients get lost in the mess of websites, unknown sources, and inaccurate information. With this background of possible biased information, patients interact with physicians to choose the best plan of action in order to reach the best possible outcome. As Jan Geissler, Director of the European Cancer Patient Coalition and founder of Chronic Myeloid Leukemia Advocates Network, says "empowerment of patients is a pre-requisite for health, and access to high quality health information is fundamental to achieve this" [2].

In order to have "high quality" health information it is not sufficient that its content is accurate. It is also necessary that accurate content is comprehensible to the person who has to use that information. Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make basic health decisions" [3]. The capability to obtain, process, and understand basic health information, facilitate the patients to look after themselves well or make good decisions on health [4]. Because health literacy is central to enhancing involvement of patients in their care, all strategies to strengthen patient's engagement should aim to improve it. In view of that, several factors other than the mere medical jargon can impair patient processing and understanding of health information. Psychological aspects and cognitive style, for example, are two more elements that affect the way patient approach, select and retain information.

Assessment of the patient profile in the clinical context can benefit patient care in several occasions:

- Increase physicians' and nurses' awareness of patients.
- Identify and prioritize problems such as physical or psychosocial problems that otherwise might have been overlooked and remain unrecognized.
- Identify patients' preferences among outcome goals (that often differ substantially from the physicians' preferences).
- Enable an anticipation of benefits regarding patients' adherence to treatment.
- Allow for the monitoring of disease progression and treatment that may not be revealed via clinical testing.

As a result of including patient profiling into the treatment process, the patient might feel better cared for which positively influence his/her emotional functioning and the communication between the physician and the patient is facilitated and improved.

As a result, shared decision-making will be promoted. It is essential for the patient to be actively involved and to participate in the decision making process concerning treatment in order to assure that decisions are consistent with the patient's values, preferences and general considerations. Shared decision making based on patient centered medicine involves a bi-directional information exchange between the physician and the patient [5]. For shared decision making to be effective, the content of communication in a medical consultation should include both factual data and patients' considerations. While the former is derived from clinical tools providing information about genetics and supposed treatments, the latter is provided by patient profiling techniques providing Health-Related Quality of Life (HRQL) information.

The uniqueness of every individual patient is not only determined by his/her unique genetic material but also by his/her unique personal psychological profile including psychological, psychosocial, cognitive and behavioral aspects. These dimensions mainly influence a patient's quality of life as well as patient satisfaction. Psychological aspects such as levels of anxiety, pain and depression as an example, substantially impact on a patient's quality of life and, in turn, influence the medical process and healing to a considerable degree.

Contemporary enhanced awareness of the strong correlation between quality of life aspects and the process of cure have led to recent attempts of finding reasonable and successful ways to include quality of life measures into the clinical process. The simplest way of obtaining information about users is through the data they submit via forms or other user interfaces provided for this purpose. Especially for patients, their profile information is commonly assessed by patient-reported outcome measures (PROMs) including HRQL information. PROMs can be defined as "reports coming directly from patients about how they function or feel in relation to a health condition and its therapy, without interpretation of the patients' responses by physician or anyone

else" [6]. Such measures can thus be described as instruments which provide patient-based information about health, illness and the effects of treatment. A large number of measures providing HRQL information are currently available. These instruments embrace a broad range of health dimensions such as physical, psychological and social functioning [7]. In addition to these aspects which are directly related to the quality of life of a patient, PROMs sometimes investigate broader constructs such as impairment, disability and handicap, also influencing quality of life to a substantial degree.

Barnato et al. [8] noted that "in an ideal world … patients would come to a cancer consultation armed with sufficient knowledge, clarity about their personal value, and the ability to engage in a thoughtful discussion about the pros and cons of treatment options. Providers, in turn, would be prepared to support their patients, armed with an understanding of the patient's knowledge gaps, personal values about possible outcomes and treatment preferences." (p.627).

However, clinical consultations take place under conditions of limited time where physician talk sometimes overwhelms patient's preferences and considerations. This gap between an optimal and many actual encounters could be reduced by implementing smart patient profiling techniques that raise awareness of patient considerations, facilitate the discussion of these aspects and thereby actively involve the patient into the medical decision process. This shared decision making process empowers the patient because it provides him/her with the chance of making his/her own, well-discussed and well-informed, choice concerning the treatment.

Some governmental and professional organizations have advised routine screening for the presence of heightened psychological distress in cancer patients (NICE, Rebalance Action Focus Group). However, there are several barriers preventing the routine use of screening or PROMs in clinical practice. These barriers can be classified in practical, attitudinal and methodological barriers [7]. The practical barriers include a lack of IT support concerning storing and retrieval of data, a lack of time and money needed to collect, analyze and appropriately use data as well as physicians' lack of familiarity and knowledge in the field of HRQL measures. Additionally, the format and length of most existing tools is a barrier to the adoption in clinical practice because a considerable amount of time is required for administering, scoring and interpreting the self-report measures [9]. Moreover, patients most of the times are not willing to fill in long forms providing information about them. Furthermore, users do not always write the truth when completing forms about themselves or they might not know how to express their interests or what they really want.

To address these challenges and merge the two aspects of personalized medicine (genetic and psychological dimensions) in p-medicine, we will develop the Interactive Empowerment Services (IEmS)

III. P-MEDICINE INTERACTIVE EMPOWERMENT SERVICES

A. *Architecture*

Interactive empowerment services will be offered through an environment able to support the physicians' decision making process. Personal data will be merged with other data such as molecular information and imaging data to allow the integration of information provided to patients and doctors.

This environment will be an interactive environment. Thus, while the innovative aspect for the patient is the opportunity to have access to his/her own data, on the side of clinicians the ground-breaking element is the possibility to have access to data that is not just medical, but rather centered on values and needs of the specific patient, through the user's profile.

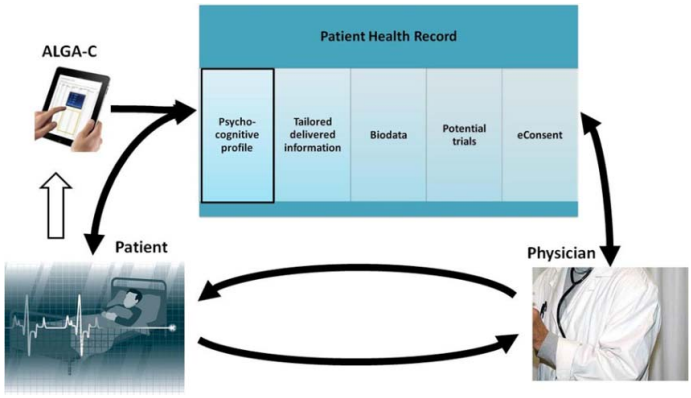

Figure 1. Patient Health Record (PHR) and the information cycle in the doctor-patient interaction.

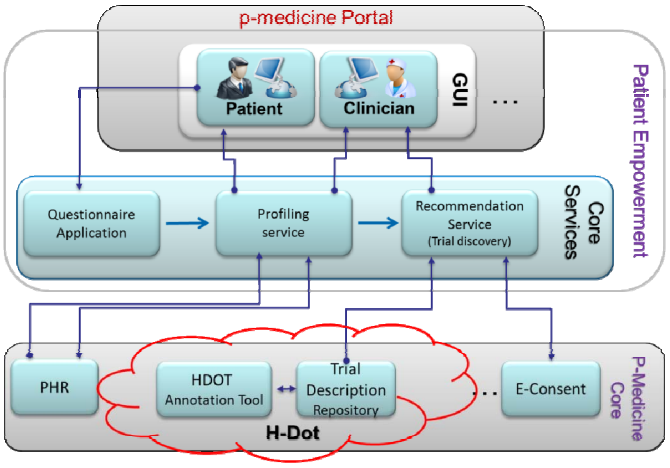

Figure 2. High-Level Architecture of the p-medicine smart recommendation service

Specifically, as shown in Figure 1, while waiting for the medical visit, the patient fills a questionnaire on an electronic device connected with the patient's personal health record. The outcome of the questionnaire is immediately stored in the PHR and re-coded in a patient's profile that is used by the physician to adjust content, level and modalities of verbal communication to the patient's needs. The combined clinical and psycho-cognitive information becomes patient's and doctor's common knowledge, around which they can build together long term efficient decision-making plans.

Furthermore, by having this information, the patient has the possibility to manage the consent for clinical trials and to track his bio-materials. Providing patients with „*consent management*" allows patients to control their own data and

enhances the interaction between patients and doctors when a request for a new consent is needed. This increases the efficiency again by involving the patient actively.

In the following we give a short description of the IEmS building blocks, as shown in Figure 2.

1) p-medicine Portal

The p-medicine portal is a web application providing comfortable access for the p-medicine users to the tools and services integrated into the p-medicine environment. The portal has been developed after the definition of the user groups, their roles and their requirements. After evaluation of several existing portal solutions the p-medicine portal is being built based on the Liferay portal (http://www.liferay.com/), a free and open source enterprise portal framework, which fulfills the complex user requirements needed in the project.

The portal can be accessed using a URL (http://pmedportal.ibmt.fraunhofer.de). The current version contains the initial functionality of the p-medicine security framework, tools for data mining as well as a trial management tool called ObTiMA (http://obtima.org/). Other tools and services will be integrated in the project when they become available.

2) PHR

The advancements in the health care field create a continuing demand for electronic health systems (EHS) everywhere. In the field of EHS, electronic health records (EHRs) are considered critical for improving the delivery of healthcare services. EHR systems improve accessibility to health records, support continuing treatment as repositories of information during and after the treatment, and can be used as a knowledge base for further medical research.

In p-medicine we adopt the Tolven, a widely used EHR/PHR system. It is a free, open source, web based, robust platform that complies with many technical and operational standards and provides numerous extendable and configurable services. The Tolven software environment (http://home.tolven.org/) is composed of two basic UI components:

- an electronic Personal Health Record solution (ePHR)
- an electronic Clinician Health Record solution (eCHR).

The ePHR interface enables consumers to record and selectively share healthcare information about themselves and their loved ones in a secure manner and the eCHR interface enables physicians and other healthcare providers to securely access healthcare information (collated from any number of trusted sources) relating to an individual patient in a structured and easily accessible way. The healthcare data are stored in a healthcare informatics platform and are accessed via the ePHR and eCHR solutions.

From operational point of view Tolven complies with Meaningful Use criteria that have been established by the U.S. Office of the National Coordinator for Health IT (http://healthit.hhs.gov). "Meaningful Use criteria" define high level requirements for functionality, privacy and security. It's worth mentioning that security applies at many different layers and components in the system [10].

From technical point of view Tolven utilizes state of the art, industry-standard technologies such as Java, EJB3, Faces, Facelets, AJAX and relational database and supports various data formats such as CDD, CCR, and CDA documents and standardized Health Level 7 (http://www.hl7.org) (HL7) messages. Moreover, Tolven is built upon an architecture that is plugin-based down to the core module. This is an important advantage for maintenance, customizations and extensions that are often required from electronic health systems in order to meet specific healthcare environment needs.

3) Data Integration components

The p-medicine technological platform is a framework comprised by tools and services aimed at biomedical researchers and biostatisticians. The platform includes a federated Data Warehouse (DW) for storing heterogeneous data stemming from external repositories. These repositories range from private databases within hospitals and research institutions to public biomedical databases accessible through the Internet.

To achieve data transfer and semantic integration, a middle layer ontology, called *Health Data Ontology Trunk (*HDOT), will act as global schema of the integrated data sources. HDOT will also support tools for harmonizing various data sources. The semantic layer will support the annotation of existing heterogeneous data sources with HDOT as well as the HDOT-compliant set up of new data sources for clinical trials. The Ontology Annotator Tool will be provided, which is aimed at external users (mainly database administrators) who wish to include their databases in the project framework. Trial Description Repositories will be annotated using the HDOT annotation tool and their data will be extracted, transformed and loaded to the data ware house.

4) ALGA-C Questionnaire

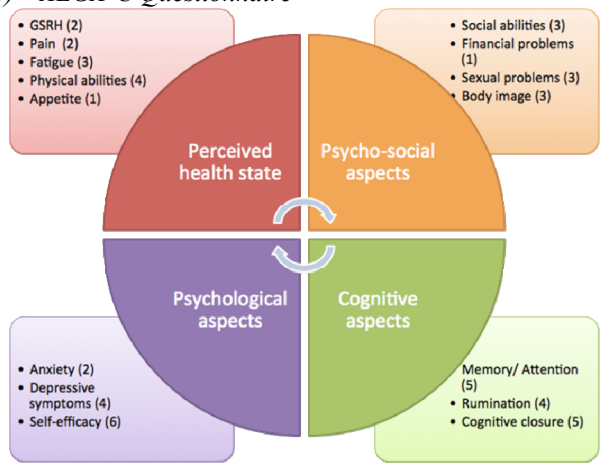

Figure 3. A schematic representation of ALGA-C. The circle represents the four main macro-areas, and the four boxes contain the different sub-dimensions with the relative number of questions in the brackets

According, to our knowledge, there is no single measure including cognitive aspects of the patient such as memory and attention, rumination, or self-efficacy. One of the biggest

problems in developing an instrument that measures all these broad areas is the fact that such an instrument needs to be very short and easy to fill out otherwise patients are not willing to comply. It is thus a major challenge to construct an instrument that measures all these areas and that is short and easy to fill out at the same time.

The ALGA-C questionnaire aims to be a short and easy to fill out instrument to measure four broad areas: perceived health state, psychological aspects, psycho-social as well as cognitive aspects, all investigated by different sub-dimensions as shown on Figure 3. Data generated by the questionnaire can also be used to monitor the patient's quality of life, thereby facilitating the patients' involvement in the clinical decision process, finally leading to patient empowerment.

5) Profiling Server

Patient profiling server is the central point for the patient's data analysis. Profiling questionnaire, PHR and EHR systems are the main data sources of the profiling server. These sources with specific application programming interfaces (APIs) will communicate and export the data for further analysis.

The patient profiling server will also provide the necessary services for combining the different sources. Information collected from the sources will be exploited in conjunction with the provided knowledge discovery tools, in order to form a platform for the patient empowerment.

In essence, the aim of the server is to provide the necessary methods and algorithms to collect, merge and analyze the patient's data. The server will be able to develop a patient profile and to operate as an integrated analysis environment for patient data analysis and knowledge discovery tools.

A variety of knowledge discovery tools exists in the public-domain like Weka (http://www.cs.waikato.ac.nz/ml/weka/), R-package/Bioconductor (http://www.bioconductor.org/) and BioMoby (http://biomoby.org/). We focus on a specific domain of knowledge discovery algorithms in order to discover patterns using Data Mining, Information Retrieval or Machine Learning techniques. Bayesian network [11], association rules mining [12] and case-based reasoning [13] are three well known techniques for solving such problems. These techniques will be evaluated and the best or all of them will be implemented within the patient profiling server.

6) Recommendation Server

Having access to multidimensional, complementary data automatic recommendation services can be implemented for patients or doctors.

As an example, consider the registration of patients into clinical trials. Currently, registering patients into clinical trials and finding eligible trials for patients require manual search and clinicians may be overwhelmed by the number of clinical trials and the exclusion and eligibility criteria. However, having both PHR data and Trial Descriptions in the data warehouse p-medicine will allow the efficient recruitment of eligible patients for clinical trials. This service will be demonstrated in the context of concrete clinical trials, with realistic data set including longitudinal EHR and clinical trial data. Though automatic matching, we expect to reduce the search space with respect to the number of patients, CTs and exclusion/inclusion criteria that need to be manually reviewed to approximately 20% of the original search space.

Since the options are limitless, we will design the recommendation server modular and extensible in order to be able to add different functionalities employing different algorithms and mechanisms.

7) e-Consent

The patient's written informed consent is mandatory for research use of human biomaterial. "Multi-layered" consent, which requests from patients to make different choices on research that might or must not be performed on their samples, is increasingly recommended by ethics experts as a participative tool for patients. Management of multi-layered consent forms is to some extent already implemented in Biobank Information Systems. Hence, tools for aggregating and integrating this ethical-legal data into meta-biobanks and synchronizing patient's consent with scientific information will be developed in p-medicine.

A key feature of the service proposed is interactivity. With this term we refer to the possibility given to a patient to view data organized according to her/his perception of the domain, to retrieve patient-understandable information and, finally, to state decisions. IEmS will entail the tool developed in p-medicine to put people in control over the use of their data (such as type text, state decisions, upload and consult video materials). Providing patients with „consent management "offers a dual benefit: first of all there is the direct empowerment aspect of controlling one's own data; and secondly, it facilitates interaction with patients in order to ask for new consent (for new trials, secondary use of data) both increasing efficiency and again involving the patient actively. All these features need a scientific evaluation and validation before an effective use. To reach this goal, a series of experimental tests will be performed on individuals classified by age, computer skills and specific expertise through empirical user-based tests.

IV. CONCLUSION

In this paper we argue that the integration of psychological and personal variables into multi-scale data systems containing heterogeneous data from a patient will greatly improve the predictive power of decision support systems developed on the basis of these data systems. Besides this the patient might feel better cared for which positively influence his/her emotional functioning and the communication between the physician and the patient is facilitated and improved.

As a proof of concept we designed a modular patient empowerment environment where intelligent profiling techniques capture patient profile. Then the profiling information along with smart information technology resources are used to provide personalized information to the patient, and to support decision support and recommendation services.

The intelligent environment designed and presented in this paper, remains to be fully implemented and tested using real patients when all technology infrastructure will be ready to support it. Potential stakeholders will evaluate the environment

and developed tools will be validated to be compliant with evaluation criteria. Hopefully our platform will act as a decision support infrastructure, supporting the communication, interaction and information delivery process between doctors and patients.

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