Proposal Full Title: Patient Guidance Support System for ubiquitous and secure Management of Personal Health Care Records through Patient-to-Doctor cooperation"

Proposal acronym: PGS@Home

Type of funding scheme: Small or medium scale focused research project (STREP)

Work programme topic addressed:
- **Call identifier:** FP7-ICT-2011-7;
- **Challenge 5:** ICT for Health, Ageing Well, Inclusion and Governance
- **Objective:** ICT 2011.5.3: Patient Guidance Services (PGS), safety and healthcare record information reuse
- **Target outcome:** (a) Patient guidance services (PGS) for personalized management of health data.
- **Deadline:** January 18, 2011.

Proposal submission date: January 17, 2011

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The emerging crucial point of healthcare organizations is to involve patients in autonomous monitoring and evaluation of their own health status by using personal ICT-based systems to manage data, and to ask for an effective cooperation of the doctor, if necessary. Two motivations urge this innovation: the growing costs of healthcare services, and the need to promote patient’s education. Therefore, objective of the proposed PGS@Home project is to design a Patient Guidance System (PGS) Architecture to allow the patient an ubiquitous and secure management of personal health data and, in case of not being able to recognize the health status, or of a critical health situation, to call the doctor for help. In this second case, the PGS Architecture will support an effective cooperation between the patient and the doctor in such a way to assure to the patient – either at home, or moving and/or monitored by wearable devices – a clear interaction with the doctor, in order to get an easily understandable healthcare service.

The main work areas of the PGS@Home project will therefore be the following:

- To enable the patient to contact his/her Personal Health Record (PHR), stored in a secure Digital Repository, by using a new “PHR Consultation Facilitator” and a new “Patient Consultation Support Base” of an as easy as possible use for unskilled persons;
- To enable the patient to call a doctor for help, by using a new “Patient-To-Doctor (P2D) Interaction Facilitator” which makes as cooperative as possible the communication between the two actors;
- To facilitate remote or moving patients in activating connection with either their family doctor or any other healthcare service centre through a Distributed Telemedicine Network (DTN).

The development of the proposed PGS@Home project will be based on the experience of three different and complementary Living Laboratories: an Italian Local Healthcare Agency, a French university clinics and the Nursing Faculty of a Bosnia University. The project ultimate result, i.e. the PGS Architecture, and its implementation and validation will be based on the research developed by two highly recognized universities, two research centers, a national telecommunication enterprise with wide experience in this sector, and a qualified software developer SME.
Concepts and objectives

The objective of the proposed PGS@Home project is to design a Patient Guidance System (PGS) Architecture to allow the patient an ubiquitous and secure management of his/her personal health data and, in case either of not being able to recognize the health status, or of a critical health situation, to call the doctor for help.

In this second case, the PGS Architecture will support an effective cooperation between the patient and the doctor (the two “actors” of the healthcare system) in such a way to assure to the patient – either at home, or moving and/or monitored by wearable devices – a clear interaction with the doctor, in order to get an easily understandable healthcare service.

The Patient Guidance System (PGS) Architecture will result from the functional integration of:

I. The PHR Intelligent Management System (PHR-IMS), composed by:
   I-1. a specific system and language to allow patient an easy monitoring of the personal PHR;
   I-2. a Digital Library of health status models and of rules to analyze the personal PHR, both specifically designed for unskilled persons;
   I-3. a Patient-To-Doctor communication system and language, to allow a cooperative interaction between the two actors in front of a call of the patient asking for help;

II. The IT network connecting patients whose health status is continuously monitored by portable devices with their PHR Digital Repository;

III. The Communication Support System between the PGS and the coordination centre (usually located at the regional level), to support all users of the PGS Architecture in front of unexpected events, either due to connection problems or due to exceptional situation of the patient’s health status.

The basic elements, essentially new, of the five components of the PGS Architecture will be:

a. The specific system and language to support the PHR consultation by the patient (named PHR Consultation Facilitator);

b. The Patient-To-Doctor communication system and language for an effective cooperation (named P2D Interaction Facilitator);

c. The ontology to organize the Digital Library, and the semantics on which the PHR Consultation Facilitator and the P2D Interaction Facilitator will be based, because the rules and languages will be designed with the specific scope of being tools to be effectively used by unskilled patients.

d. The PHR Digital Repository, managing information from multiple sources and of different type into a common PHR data base from which both patients and authorized doctors can get information on health status.

The basic scheme of the proposed PGS Architecture is the following Figure 1:
The basic functionalities of the above sketched PGS Architecture will be the following:

- To facilitate the patient in the consultation of his/her Personal Health Record (PHR), such to apply a personal monitoring of the health status as well as of safety alert parameters;
- To facilitate the patients mobility in three forms: Mobility of a patient inside the area managed by the Local Healthcare Agency where patient is residing, from his/her family doctor to other doctors, specialists and other health care centres; Mobility of a patient outside, i.e. towards sanitary centres of other Territorial Healthcare Agencies; Mobility of a patient to another country, with a different language.
- To facilitate the interaction between a patient and the doctor such that the former could receive help in understanding his/her own health status, and should be supported in giving an as clear as possible presentation of his/her symptoms;
- To support on one hand the request of new sanitary information by the doctor to the public (or private) Regional Agency managing healthcare services (also disseminating information on new products, new protocols, etc.), on the other, to help doctors in detecting potential patients mistakes in contacting them or wrong or unwilling choice made by non expert patients, using P2D.

The following Figure 2 gives a sketch of the Intelligent Management System to be made at disposal of the patient in order to make a consultation of the personal PHR and, in case of critical situations, to ask the doctor for help.

1. Data generated from the patient monitoring system (portable device, wearable computing, etc.)
2. Data & information from a contact call by the patient (patient’s inputting data using a Web form, phone call with a health care centre operator, etc.)

3. Ontology with patient medical and social models as well as rules concerning healthcare services that could be obtained (e.g. administrative norms established for the considered region, country, etc.), generated by formalizing existing and newly defined models, as well as by integrating/extending existing standards, taxonomies, etc.

4. Semantic rules to guide the calling patient to analyze his/her own PHR and making a personal “diagnosis” of the proper health status such as to recognize if a call to doctor is necessary, owing to unclear vision of the health status or to physical problems;

5. Facilitator of the patient interaction with the system (input), exploiting medical and social models to tailor the PHR monitoring process to the patient’s characteristics, attitudes, etc. (“interact to understand”), and Generator of a snapshot of patient health status to be stored (by descriptive model based on measured parameters, historical data, models & thresholds), by verifying each time the patient’s clinical parameters and adjusting their thresholds to the current conditions of the calling/monitored patient;

6. Patient instance (PHR) in the Digital Repository;

7. Patient profiling (models, thresholds, history, etc., mining literature and analogies), doctor profiling, Patient-To-Doctor matchmaking and guide to read of patient history (e.g. augmented reading, variation in patient health status), description of the rules for diagnosis to the calling patient (reasoning, procedures and prescriptions), update of the Digital Repository with the outcomes of the Patient-To-Doctor cooperation process.
Application in Living Laboratories

**PHR personal management and P2D cooperation in the Local Healthcare Agency (ASL-Asti)**

The Local Healthcare Agency (Agenzia Sanitaria Locale) ASL of the Province of Asti, Piemonte Region in North-West Italy, is a typical public institution to manage, control and financing the healthcare service units located in the province territory and the hospitals located in the towns of Asti and Nizza Monferrato (see the partner’s descriptive format in Section 2.2). The ASL operations consist in the organization of all territorial services, and a special attention is dedicated to the dissemination of healthcare service opportunities over the territory, directly to patients at their home, to avoid spare of time and costs for patients and sanitary operators in the healthcare centres. To perform such operations and to monitor the services supplying to patients, the ASL collects detailed information on the patients’ calls as well as on the doctors’ contacts.

**PHR management by monitored patients (Nice Clinical Centre)**

Into the PGS@Home project, the development and validation of the PHR Intelligent Management System (PHR-IMS) is also based on the experience of a Living Laboratory in the following actions: high-level healthcare servicing (diagnosis, prevention, education), patients and doctors education (medical and paramedical training) and research and innovation (contributing in medical science and pharmaceuticals advances). This significant tasks can be performed by the clinical partner (Centre Hospitalier Universitaire de Nice – CHU Nice), which provides specific missions of public health care and the management of serious or complicated diseases that no other national institution can support.

**PHR remote management in Bosnia: implementation criteria (Apeiron University)**

A specific scope of the PGS@Home project is to verify the potential application of the PGS Architecture in a country where the healthcare system should be innovated. This is the case of the new European country Bosnia i Herzegovina (EU Associated Country). Then, the third Living Laboratory (the Pan-European Apeiron University with its Faculty of Nursing and its important contacts with the Government of the Serbian Republic of Bosnia) will play the role of “verifier” of how the PGS Architecture could be implemented and applied in its own country. The scope of this “over-the-territory” validation is to recognize how easy it will be the design of a PGS Architecture in a region where this system could be used as core of the innovated healthcare territorial organization.

**Measurable Objectives**

**OM-1.** Data registered at the first aid stations (Pronto Soccorso) of the Local Healthcare Agency of Asti (ASL-AT) suggest that the PGS@Home system implementation will give rise to the following reduction of improper services of about 20% (the white color registered patients, i.e. patients with no real disease), thus having a corresponding reduction of time spent by operators.

**OM-2.** This saving of resources and time at all first aid stations correspond to a reduction of the first aid service cost of about 12% (costs due to improper calls to the internal doctors and operators).

**OM-3.** Moreover, taking into account the average time spent by a patient in the waiting room of the doctor’s surgery, to have a face-to-face medical examination, estimated at about 40 minutes as average (data evaluated at the ASL-AT for a average number of 85 contacts per year between patients and doctors, referred to 103.000 patients, that is the 48% of persons living in the Asti province and having registered contacts with doctors of the public healthcare agency), for a rate of un-necessary contacts of the same value as the one
measured at the first aid stations, the global time spent by a patient waiting for service at the doctor’s place can be estimated about 2 and \( \frac{1}{3} \) days per patient per year.