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Nº 20 · November 2013

# From eHealth to mHealth Society Becomes the Driver of its Health Activities

#### Applying mHealth Solutions



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The European Journal of ePractice is a digital publication on eTransformation by ePractice.eu a portal created by the European Commission to promote the sharing of good practices in eGovernment, eHealth and eInclusion.

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# Editorial: Applying mHealth Solutions



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The on-going widespread uptake and use of mobile telecommunications and multimedia technologies, including such devices as smartphones and tablet computers, has opened up rich new avenues to exploit eHealth. Mobile health (mHealth) is now a rapidly developing trend within the field which employs these new technologies in healthcare delivery systems. Issue 20 of the *European Journal of ePractice* takes up the challenge of analysing mHealth as it is today, and offering some clues about how it should or could develop in the future.

Issue 20 is sub-titled 'Applying mHealth Solutions'. It features seven papers covering issues related to the development and implementation of mHealth solutions, and their effectiveness and impact. These papers examine some of the available mHealth tools and solutions that have been implemented. They include those in which the mobile devices are used by patients, and others where the devices are used by healthcare staff. They discuss tools which employ mobile devices in a patient-driven decision-support system, and other systems to increase the use of electronic health records and other institution-patient communications, such as remote bookings. They look at how mobile devices are used for specific physical and mental disorders, namely in the treatment of cardiological conditions and mood disorders. There is also discussion of the role that mHealth solutions can play in the organisation of healthcare, and of how mobile devices can be used by healthcare staff to improve the reliability of patient identification.

Issue 20 is populated by papers from authors from Belgium, Italy, Israel, Greece, Sweden, as well as Australia: hence, the lessons learned come from both within and outside the EU. A number of papers draw on the experiences of European Commission co-financed projects which, even if they were focused on specific clinical or geographical challenges, provide learning points for the design, introduction, and deployment of mobile health technologies. In several cases, they indicate the sensitivities of change management both in organisations and in societies working with vulnerable groups and individuals. Introducing mHealth in developing countries and emerging economies has generally received wide plaudits until now. However, many of these papers show that the journey towards widespread mHealth use may still face considerable organisational, social, societal, legal and regulatory challenges.

Issue 20 of the Journal begins with a paper by **Mor Peleg**, **Yuval Shahar** and **Silvana Quaglini**. The authors discuss MobiGuide, a decision-support system to provide patient-specific recommendations that is currently under development. A central feature of the system is that patients are become users through their use of smartphones, enabling their input to be personalised, and resulting. It results in patients with sharing the decision-making process being shared with their care providers. The MobiGuide system also enables patients to be monitored outside of the clinic, including at their workplaces and in their homes. Indeed, MobiGuide can deliver recommendations even without physical intervention from the care provider. The intended result is that the patients' safety will be increased and , their health quality will be improved, and healthcare costs will be reduced. The authors conclude with a discussion of some limitations of the MobiGuide system which should be addressed in future research.

The next two papers centre on applications of mHealth to support the provision of electronic health records.

In the first of these, **Isabella Scandurra**, **Jesper Holgersson**, **Thomas Lind** and **Gunilla Myreteg** present the development process of a Swedish eHealth service, that has taken place in the county of Uppsala, which provides patients with access to their electronic health records (EHRs) via mobile or fixed devices. Underpinning this system is the philosophy that it is very important to make the system citizen-driven rather than technology-driven. The idea is that involving patients in managing their own health will improve their quality of life as well as the authorities' control over healthcare expenditure. It is also anticipated that patients will take a more active role in the healthcare process. Providing patients with the information on their EHRs is anticipated to have two benefits, namely better opportunities for improved self-care, self-service and patient participation in the care process, and having information accessible to them wherever and whenever they desire. The paper concludes with a discussion of the potential implications and challenges of the system: it highlights in particular improved design methods from the domain of human-computer interaction, and appropriate evaluation methods for approaches to deployment.

The second paper covering the theme of electronic health records is by **Claudio Dario**, **Claudio Saccavini**, **Giorgia Centis**, **Federica Sandri** and **Lorenzo Gubian**. They discuss how text messaging can facilitate a higher engagement of users with the Personal Health Record (PHR) system in the Veneto region of Italy. Following several successful local experiences, through the use of text messaging, the scheme will begin to increase accessibility and visibility of the PHR, by delivering mobile booking and notification reminder services. Although various PHR solutions have already been implemented on regional and even national levels, their large-scale adoption still presents many challenges. The authors explain how text messaging can provide a way to bridge the gap between citizens and PHR services.

Aggelos Tsipis and Emmanouil Petrou provide the issue's fourth paper, a review of the state-of-play of telecardiology, the branch of telehealth covering the treatment of cardiological conditions. They aim to analyse the uses of telecardiology in the diagnosis and timely treatment of cardiac diseases, noting that telecardiology contributes to the close and constant monitoring of patients at high risk, thus increasing both their survival rate and quality of life. The authors also attempt to classify the uses of telecardiology. They conclude that telecardiology saves time and effectively reduces the distance between people in need of healthcare services and healthcare providers, increasing control over cardiological problems and reducing costs. mHealth solutions can also be used effectively for mental health treatments. Indeed, Lillian Seow, Adelln Sng and Andrew Page argue that mHealth is particularly suited to the domain of mental health. They describe their experience of an mHealth system implemented at a clinic in Australia, which mostly treats patients with mood and anxiety disorders. The mHealth system facilitates the real-time monitoring of patient progress, data management and prompt individualised feedback on a large scale. The data that the system provides can be used by therapists to adjust treatments to the needs of the patients, which is particularly important for patients who face poor outcomes. The authors conclude that the implementation of mHealth can create the opportunity for significantly improved collaboration between patients and healthcare staff, leading to better patient outcomes and cost savings.

The sixth paper in Issue 20, by **Paul De Raeve** and **Dorota Kilanska**, changes direction a little. It considers how mHealth can be most effectively employed from a health worker perspective. It discusses the role that mHealth solutions can play in the organisation of healthcare. More specifically, the authors argue that mHealth is well-suited to supporting a better kind of approach to healthcare which they envision for the future in the EU. They argue that mHealth can support sustainable healthcare systems by facilitating integrated care pathways which are cost-effective and patient-centred. The resultant integrated care system will also enable increased direct patient care by the nursing workforce, and transform the financial mechanisms underpinning healthcare provision.

A paper by **Tommaso Piazza** and **Sergio D'Angelo** brings Issue 20 to an end. The paper discusses how an mHealth solution can help healthcare staff to reduce patient misidentification, a leading cause of medical mistakes which can have severe, even fatal, consequences. Patient misidentification is almost always due to human error. So, the aim is to provide a system in which it is much harder to make such errors. The authors introduce the radio frequency identification (RFID) system which has been implemented in a transplant hospital in Palermo, Sicily. The system employs RFID tags and mobile handheld devices, networked via a Wi-Fi connection, to ensure accurate patient identification. The authors discuss the main features of RFID technology, and evaluate the benefits and costs of the system.

# Making Healthcare More Accessible, Better, Faster, and Cheaper: The MobiGuide Project

Decision-support systems provide patient-specific recommendations to care providers during clinical encounters. The MobiGuide project also addresses patients by making them users of the decision-support system through their Smartphone interface, by personalising guidance according to the patients' preferences in a manner sensitive to their personal context, and by involving patients in a shared decision-making together with their care providers. In addition, the MobiGuide system provides decision-support in non-clinically-controlled environments, such as the patient's workplace and home, and can deliver some of its recommendations even without a careprovider's intervention; hence, it is a Ubiquitous Guidance System. The clinical knowledge that constitutes the logic of the ubiquitous guidance system is based on evidence-based clinical guidelines. These properties make the MobiGuide system potentially highly accessible and fast. Moreover, patients' safety is increased. While keeping most monitored patients out of the clinic, the system leads to an increase in health quality and a decrease in healthcare costs.

#### Acknowledgments

This study was part of the MobiGuide project, which was partially funded by the European Commission 7th Framework Programme, grant #287811. The authors thank the team from the Polytechnical University of Madrid for provision of Figure 5, and thank all of the MobiGuide project members for their contribution to this project.



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#### Keywords

clinical guidelines, decisionsupport, patient guidance, personalisation, shared decisionmaking

In MobiGuide, decisionsupport is provided both to the patients and to their care providers.

"

#### 1. Introduction

Clinical practice guidelines are statements that include recommendations intended to optimise patient care for specific healthcare conditions, such as diabetes hypertension and atrial fibrillation. Their development is informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options (Institute of Medicine, 2013). Clinical practice guidelines can be formalised as computer-interpretable guidelines (CIGs) (Peleg, 2013). These include a clinical algorithm of clinical actions and decisions, as well as definitions of clinical abstractions and decision criteria. Formalisation of clinical practice guidelines as CIGs makes it possible to develop decision-support systems. Such a computer-interpretable guideline (CIG)-based decision-support systems match formalises guideline knowledge with patient data from an electronic medical record (referred to as Personal Health Record (PHR)) to provide patient-specific advice at the point of care. Thus, clinicians using a decision-support system can receive guideline-based recommendations that are specific to their patients' clinical data during patient encounters, increasing the chance of impacting clinician behaviour as compared to using only the narrative guidelines (Latoszek-Berendsen et al., 2010). Traditionally, clinical guideline-based decision-support systems provide patient-specific recommendations to care providers during clinical encounters with patients.

The MobiGuide project<sup>1</sup> goes beyond traditional decision-support systems by including patients in the scheme as users, and - so as to provide them with multiple benefits - gives them evidence-based clinical recommendations even when they are outside clinically controlled environments (at home, work, or leisure environment). The MobiGuide decision-support system is in fact a Ubiquitous Guidance System (Peleg et al., 2013). It delivers decision-support to care providers and patients any time and everywhere by initiating interactive sessions that provide patient-specific recommendations or by being notified in real-time when the system deduces from the data, through real-time or retrospective pattern detection, that the patient's situation requires attention (e.g., when a patient is at rest, more than three episodes of atrial fibrillation, with a heart rate above 110 beats per minute, are detected within a single hour).

By involving patients, the MobiGuide system grants several benefits to its users. These four benefits are described here. They include additional patient safety, motivation, adherence and a reduction in medical errors.

First, the system is equipped with wearable monitoring devices that measure the patients' biosignals such as heart rate, electrical activity of the heart, movement, and blood sugar level. Analysis of data from these monitoring devices can identify meaningful patterns in the data that require attention, such as an elevated heart rate that is considered too high for the intensity of the current physical activity, atrial fibrillation event or elevated blood sugar; thus, the system can issue context-sensitive alerts to the patients and guideline-based recommendations to their care providers when needed. This double-edged decision-support capability increases patient safety.

Second, by involving patients in their healthcare they become more motivated; motivated patients try to comply with healthcare recommendations more fully, resulting in better health outcomes.

Third, the systems personalises decision-support to the patient's personal preferences (e.g., delivering reminders to measure blood sugar before/after meal times, which are personalised according to the patients' preferences and life style) and their personal context (e.g., being on holiday, family members are temporarily unavailable to help with daily care). Thus, the MobiGuide system delivers recommendations that are more appropriate to each patient, and customises the treatment to the patient and further facilitating adherence to it.

1 <u>www.mobiguide-project.eu</u>

Fourth, health-care practitioners (such as nurses, physicians and physiotherapists) are provided with timely, evidence-based recommendations generated directly from the customised and personalised CIGs. This thus prevents all-too-frequent medical errors of omission and of commission.

This article explains how patients and physicians interact with the MobiGuide system, and how personalisation and shared decision-making are achieved.

# 2. A user's view of the MobiGuide ubiquitous guidance system

Traditional CIG-based decision-support systems include:

- CIG representation of clinical practice guidelines stored in a knowledge base serving as knowledge sources;
- A personal health record storing the patient's data; and
- A decision-support system that matches knowledge with data to provide patient-specific recommendations to care providers.

The MobiGuide ubiquitous guidance system includes the following extensions:

- Patients as users. In addition to care providers, patients are also users of the MobiGuide system. Care providers can access the back-end decision-support system using their work computers while patients access the mobile decision-support system through their smartphones.
- A Body Area Network (Jones et al., 2010). The body area network includes biosensors that patients can wear, a smartphone that includes the patient's user interface, and signal analysis algorithms and the mobile decision-support system that run on the processor of the smartphone.

The other components of the MobiGuide system are a black-box for the users. They include a personal health record, a knowledge base and a decision-support system that go beyond traditional systems. The decision-support system is distributed through a back-end decision-support system and the mobile decision-support system. The back-end decision-support system provides full decision-support based on all patient data available at the personal health record and on the full CIG representation, available in the knowledge base. This includes support for shared decision-making. The mobile decision-support system has access to a limited set of relevant CIG knowledge and to a limited set of data, arriving from the body area network.

The personal health record of the MobiGuide system integrates different data sources, including:

- Data from multiple hospital Electronic Medical Records (e.g. haemoglobin A1C values, current medication prescriptions);
- Signal data and patient input collected via the body area network;
- Decision-support recommendations (e.g. recommendation to decrease the number of blood glucose measurements to two days a week when a patient with gestational diabetes is in good glycaemic control and has been measuring her blood glucose regularly), temporal abstractions detected from personal health record data (e.g. perfect compliance to the measurement schedule during the past 3 days) and data entered by patients (e.g., level of palpitations that an atrial fibrillation patient is experiencing).

Figure 1 provides an overview of the vision of the MobiGuide system. A decision-support system (DSS) is at its centre. The Personal Health Record (PHR) serves to provide data storage, acquire data from the DSS, the hospitals' electronic medical records (EMRs) and the patient wearable Body Area Network (BAN) sensors and smartphone.



Figure 1: A high level overview of the MobiGuide Ubiquitous Guidance System

The knowledge base of the MobiGuide system extends the traditional CIG knowledge bases. In terms of the customised context-aware CIG knowledge base, it includes CIGs that contain definitions of potential personal contexts (e.g. the context of an irregular meal schedule). These are applicable for specific patient populations, and affect the medical plans that are recommended by the CIG. Personal events in the patient's life might activate these contexts in a manner unique to each patient (see further details in Section 4).

## 3. Personalisation in MobiGuide

A major goal of the MobiGuide project is to enable personalised treatment of patients, anytime, anywhere. Currently, personalisation of therapy is associated mostly with genetic factors; however, here the team is focusing on a broader view and on multiple additional aspects, in particular, adding the patients' preferences and the overall personal or technological context.

The personalisation of a clinical practice guideline is achieved in four phases: they are formalisation, customisation, personalisation, and application.

• Formalisation: This is a process in which the free-text source clinical practice guideline is represented as a formal CIG, using a language such as Asbru (Shahar et al., 1998) and a tool such as the GESHER knowledge-specification module (Hatsek et al., 2010), without any additions.

The output of this phase is a formal, executable CIG without any special customisation.

• **Customisation:** This is a process performed per CIG by a knowledge engineer together with a clinical expert. The customisation process expands the CIG to include all the different contexts that could affect the CIG that were not taken into consideration in the source version. These include how the CIG should change when the patient lives alone, or when the patient is in a high-exercise-level or a technological context, such as having no Internet access or experiencing a low mobile-device battery. We call these contexts CIG-Customised Contexts.

Each CIG-customised context (e.g., 'patient-alone') defines how the CIG changes for any patient that enters into this context. Note that the genotype of the patient is a special case of a universally occurring context that might lead to selection of a different option in a broad guideline. At this point, the CIG is customised for different universally occurring contexts, but is not personalised to any particular patient.

In addition, the CIG is prepared for the inclusion of two types of personal preferences: (a) for global clinical preferences, by adding the appropriate decision model that enables a choice of the CIG branch that best fits the patient's utility function; and (b) for local clinical preferences, by making explicit the options of e.g., choosing a sub-range of a medication dose, the preferred time to administer a medication, the option of using one of several similar medications.

The output of this phase is a context-sensitive, customised, but generic (universal) CIG.

- **Personalisation:** This is a process that usually takes place during one of the first encounters of a patient with his or her care provider (no knowledge engineer is involved at this stage). Together, the patient and the care provider define (a) which events or concepts (specific for the patient) might induce any pre-defined CIG-customised context and (b) the patients' preferences regarding their treatment. Both are described below.
- a. Mapping the patient's dynamically occurring events or data concepts to pre-defined CIG-customised contexts (which were defined in Phase 2). According to the patient's routine, the care-provider and patient specify the [external] events (e.g., patient actions) or concepts (derived from measurable patient data, such as 'high blood pressure'), which are specific to the patient, and which lead to one or more of the pre-defined CIG-customised contexts. In one patient's case, a 'training for a marathon' event might induce a 'high exercise level' context; in another patient's case, an 'attending a wedding' event might induce a 'high carbohydrate level' context. Note that the same event (e.g., wedding) could induce different contexts for different patients (e.g., 'high level of carbohydrates' for one and 'no availability' for another). The mapping between events or concepts and their induced contexts, which includes a specification of the temporal constraints including between the interval over which the inducing entity holds, and the interval over which the induced context '(DIRC). DIRCs are part of the dynamic temporal interpretation contexts theory (Shahar, 1998), which is one component of the knowledge-based temporal-abstraction methodology (Shahar, 1997).

The resulting patient CIG-specific DIRCs, that define the mapping between the inducing patient-specific events (or concepts), and their induced generic CIG-customised contexts (that are predefined in the customised CIG), are saved in the patient's personal health record.

Figure 2 shows a graphic example of the DIRC that describes the High-Carbohydrate Intake context that is induced by the patient's personal wedding event. When a personal wedding event occurs, the CIG's pre-defined High-Carbohydrate Intake context is induced with certain temporal constraints regarding the start and the end of the inducing event; thus, the appropriate knowledge for interpretation of blood glucose in this context is activated, and similarly, the context-specific recommendations by the decision-support system. The figure shows how the predefined, customised, High-Carbohydrate Intake context is induced dynamically by the personal, patient-specific event of a wedding. This DIRC is specific to a particular patient.



Figure 2: A dynamic induction relation of context (DIRC)

- b. Specification of two types of the patient preferences:
  - i. *Global preferences*: These preferences are used to choose between different paths leading from each decision point (a forking point) in the CIG. For example, one patient might prefer nutritional therapy to medication; alternatively, the choice might represent the result of a formal shared decision-making process, such as the determination that Warfarin is preferred over Aspirin for a particular patient (this example is elaborated further later in this article).
- ii. Local preferences: TThese preferences represent a personal customisation of an instance of a particular action in the CIG. It usually corresponds to a single CIG action step. As an example, a gestational diabetes patient might usually have breakfast around 7:00 a.m. on a regular week day, so the alert to measure blood glucose before eating should occur 30 minutes before that time.

Figure 3 shows a care provider's user interface for entering the patient's preferences about their default meal times. The figure shows the patient's preferred meal times as part of her preferred regular meal schedule - a set of (meal) events that induces the meal-time, preprandial (before meal), and post-prandial (after the meal) CIG-customised contexts. Together these compose the set of the 'Meals Schedule - Routine' predefined CIG-customised contexts. Also shown are the relative patient-specific preferred timing of measurements and alerts related to the meal-event times. The resulting patient-specific global and local preferences are saved in the patient's personal health record.

• Application: This is the process through which, during the CIG-application time, the MobiGuideUGS loads a series of data. These include the customised CIG (which is generic for all patients) from the MobiGuide knowledge base, and the patient-specific DIRCs (used to induce the patient's CIG-customised context) from the personal health record. In addition, the local preferences and global preferences are also loaded. The system applies a personalised treatment for each specific patient, within any of the predefined CIG-customised contexts, while considering the patient's personal preferences.

			Home	Patient	Activation	Measurements
Home Patient Activation		MobiGuide Guiding patients anytime everywhere				
Mobi	iuide	•	🛕 Home			
/Guiding patient	s anytime everywhe	re	CIG Cust	mized Context	eals Schedule-Routine	
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Figure 3: A care provider's interface for entering a patient's preferences about a meals schedule and related measurements and alerts

# 4. Shared decision-making in MobiGuide

Shared Decision Making (SDM) in healthcare is a general term indicating situations in which patients (and/or their relatives) are not only informed of the various therapy options, or explicitly consent to one of these options, but are also involved in the treatment choice. While some clinical situations may be so well-codified in clinical practice guidelines that they do not require asking patients for their preferences, there are several situations in which there is not enough scientific evidence to produce sound recommendations, and in which patients are in principle able to participate in the decision process. However, not every situation is suitable for SDM: emergencies, cognitive impairments, and social status (e.g., the absence of family caregivers who could make a decision on behalf of a cognitively impaired patient), may cause the physicians to make the decisions themselves.

SDM is not a comprehensive, well-assessed discipline yet, and the literature reports on several different methods and techniques to apply it (Chewning et al., 2012; Steglitz et al., 2012) and also on challenges still to be faced (Katz& Hawley, 2013). Despite the variety of approaches, it is agreed (and any good practice suggests) that informing the patient is always the first step of any treatment decision. Thus, an SDM support system, first of all, must provide physicians with suitable means for communicating information to patients, for instance, through multimodal material. However, the patient usually plays a passive role in this step, while the process of SDM implies that he or she would play an active role in the decision. Therefore, additional steps need to be taken.

MobiGuide adopts a decision analysis framework, and in particular a decision tree formalism. At its first node, a decision tree shows as many branches as the number of possible decision options (treatment alternatives). From those branches, the tree continues by representing all of the relevant probabilistic events that may occur as consequences of the different options. At the end of each path, one or more payoff values are specified. Payoffs can be related to health outcomes (such as quality-adjusted life years or disease recurrence) or to economical outcomes (such as costs for the hospital or out-of-pocket expenses for the patient).

The qualitative structure of a decision tree branch (a path of a decision tree that depicts a series of health states) is a suitable tool for informing the patient about the consequences of different treatments. As a matter of fact, the graphical formalism of the tree facilitates the overall view of the problem, with an explicit description of the risks and benefits of every option.

To further facilitate support for the first step of informing patients, MobiGuide associates a set of descriptions to every health state. From this set, physicians can choose the description that they consider most suitable for the specific patient they are encountering. In particular, they can choose among text, images and movies, and, for each of them, between a 'soft' and a 'hard' version to illustrate a decision. The rationale is that one patient might prefer to know exactly which consequences a health state implies, while another patient might be scared by being offered too many details.

The second step in the shared decision-making process requires more intensive involvement of patients. Since different patients may perceive the same health states differently, it is crucial to introduce the concept of the quality of life. Every patient should be allowed to subjectively 'quantify' every health state with its desirability. These are the patient's utility coefficients or utility function (u). This utility function needs to be elicited from the patient.

MobiGuide implements the most common methods for utility elicitation: the rating scale, the time trade-off, and the standard gamble. A graphical interface is provided for each of them. As shown in Figure 4, in the rating scale method (Figure 4 (a)), patients indicate a value for the health state on a linear scale. In the time trade-off method (Figure 4 (b)), patients indicate how much [life] time they are willing to give up in return for living in perfect health. In the standard gamble method (Figure 4 (c)), a risk of death is graphically shown (using red dots) and the patients must say whether or not they are willing to take this risk (e.g., of a surgical intervention) in order to be cured. The physician may choose to interact with the patient using one or more of these methods according to the patient's attitude (for example, the standard gamble method is particularly difficult to use with highly risk-averse patients).

The third capability that MobiGuide provides for purposes of SDM is related to the economic aspect of the situation. There are interventions that may imply certain costs for the patient. Examples include home adaptation so as to host particular instruments or equipment, travelling from home to the hospital for follow-up visits, and the need for private therapists. To this end, the patients complete a questionnaire providing information about their home context, distance from their home and healthcare facilities, and so on. In this way, the system may calculate and present not only the expected health outcomes, but also the expected costs.

The figure (below) shows (a) the rating scale; (b) the time trade-off; and (c) the standard gamble.



Figure 4: The three methods implemented in the MobiGuide UGS to interact with a patient to elicit a utility coefficient for health states

As an example of the use of SDM in MobiGuide, Sacchiet al. (2013) report on a decision tree that is built on the following recommendation, which is part of a guideline for stroke management (American College of Cardiology, 2011):

'For primary prevention of thromboembolism in patients with non valvularatrial fibrillation who have just one of the validated risk factors (i.e. age greater than or equal to 75 years, especially in female patients, hypertension, heart failure, impaired left ventricular function, or diabetes mellitus), antithrombotic therapy with either aspirin or a vitamin K antagonist is reasonable, based upon an assessment of the risk of bleeding complications, ability to safely sustain adjusted chronic anticoagulation, and patient preferences'.

Note that two options exist for applying antithrombotic therapy i.e., therapy that helps prevent thrombosis. If the MobiGuide UGS, while inspecting the personal health record data during a patient visit to the doctor, detects that the patient is eligible for that recommendation, it informs the physician that a decision tree is available to handle this decision within an SDM framework. If the physician agrees, he or she starts by applying the decision tree, beginning the process by presenting it to the patient and explaining the three options which consist of 'Anticoagulant therapy', 'Antithrombotic therapy' and 'No drug therapy'. The patient is asked to collaborate in the decision-making process by using one or more of the three methods for utility elicitation. Eventually the decision tree is personalised by calculating a series of probabilities (the transitioning from one health state to another), according to the patient's age and gender. The mechanism also updates the default utility values using the personal values that have just been elicited from the specific patient. Then, the decision tree is applied to the patient's record, with the patient's personal elicited preferences instead of the generic utility function. The results are shown in terms of expected quality-adjusted life years and out-of-pocket expenses.

The calculation of these figures are not intended to directly provide a recommendation, but rather to be used as a basis for a more informed discussion with the patient.

#### 5. Experience with early prototypes of the MobiGuide system

The MobiGuide project started in November 2011. During the two years since its initiation, following an incremental development approach, the MobiGuide UGS has been developed. Two prototypes have been developed so far.

The first prototype was focused on the atrial fibrillation domain (a heart condition that causes an irregular or fast heart rate). It included over twenty components. The main components were the back-end decision-support system, CIG knowledge base, data analysis algorithm, personal health record, smartphone, together with a wearable electrocardiagram (ECG) and heart rate monitor and a physical activity detection monitor. The system supported the following functionality: (a) back-end decision-support system; (b) data integration and personal data storage and retrieval; (c) knowledge mapping, mediation, storage, and retrieval; (d) user interfaces for the knowledge engineers who are defining the CIGs and for patients and caregivers; and (e) a patient data acquisition system for acquiring user-input. Care givers could use the prototype to enrol patients into the MobiGuide system and receive support for shared decision-making regarding, for instance, a choice of anti-coagulants. Patients could receive a continuous display of their heart rate, physical activity intensity, and detect atrial fibrillation events. The system could alert patients when their heart rate was too high (given their level of activity intensity), and ask them for their level of palpitation when atrial fibrillation events were detected with high certainty over a period of ten minutes. If the patient indicates an unacceptable palpitation level, the system advises him/her to take appropriate medication (e.g., propafenone or flecainide).

The second prototype was focused on the domain of gestational diabetes mellitus (i.e., high blood glucose levels during pregnancy). The system included advanced versions of the components that have been previously described in the first prototype, and several important additional functionalities: (a) security features (authentication and authorisation); (b) the mobile local decision-support system, which receives projections of CIG knowledge from the back-end global (central) decision-support system, such as the number of measurements a day that patients need to measure their blood glucose values, and definitions of good compliance to the measurement schedule evaluated over a period of three days; and (c) retrieval and uniform storage of personal health data using generic methods and a standards-based patient information model. The system supported the customisation to patient-defined events such as regular days and holidays, as well as the definition of preferred meal times. The demonstration version of the system prototype simulates events occurring at different days over two months of pregnancy for gestational diabetes patients. The system sends patients

reminders to measure their blood glucose based on their preferences and context. The system assesses compliance to measurements over a period of three days, and patients receive feedback messages about their compliance level. Continued non-compliance is communicated to the physician who is advised to send a pre-prepared message to his/her patients via the system. If patients display good glycaemic control for over a month and are compliant to their measurement schedule, the system sends them a message communicating the instruction to lower the measurement frequency to four daily measurements twice a week, and computes compliance from that point onwards according to the new measurement plan.

Figure 5 presents screen shots from the two system prototypes. Illustration (a) indicates the atrial fibrillation prototype, showing measurement of heart rate, atrial fibrillation events, and (physical) activity intensity; whereas (b) displays the gestational diabetes prototype, showing a screen in which the user can input extra carbohydrate intake.



Figure 5: Screen shots of the patients' user interface of the MobiGuide system prototype.

Two years into the project, the MobiGuide system is still under development. Usage by patients and system evaluation is planned for the fourth year of the project. During the third year it is planned to complete the system with functionality that is still missing and then deploy it in two hospitals. The planned functionality includes (a) awareness services to enable patients to be informed of the usage made of their data; (b) interfaces for researchers who will use MobiGuide intelligent data analysis algorithms to analyse patient compliance, and (c) interfaces for administrators for the performance of system maintenance and support. In the final months of the project, it is planned to conduct an evaluation of the system with 10 to 20 patients in each of the two clinical domains. The evaluation will assess the system's functionality, usability, and sustainability; and measure its impact on the organisational workflow in the involved hospitals, on the patients' compliance, and possibly on certain clinical outcomes.

We already have some encouraging experience with the current shared decision-making module. A pilot evaluation was conducted with ten patients' representatives from a varied patient population: five males and five females of an average age of 66.6 years, within a range of between 49-77 years. The distribution of the atrial fibrillation types of patients was: 6 persistent, 2 paroxysmal, 2 post-operative. One out of ten patients had a cognitive impairment. The computer skills of the patients were as follows: 4 had never used a computer before, 2 had used computers occasionally, and 4 had used computers often. The main evaluation measure was the time in minutes that it took to complete the utility coefficients elicitation. The rating scale required the shortest time to complete (average: 1.5, range: 1 - 2) followed by the time trade-off (average: 3.2, range: 2 - 5) and standard gamble (average: 5.9, range: 2 - 15). Specific feedback regarding the user interface design of each elicitation method was received via qualitative comments. It is now being used to improve the user interface (Quaglini et al., 2013).

In addition, the back-end decision-support system was evaluated in the pre-eclampsia domain (Shalom et al., 2013) and the knowledge mediation component was evaluated in many domains, such as the domain of post-bone marrow transplantation (Martins et al., 2008).

# 6. Conclusions

Previous EU-funded projects have integrated a decision-support system with monitoring devices and electronic health records. Example projects are SAPHIRE: Intelligent healthcare monitoring based on a semantic interoperability platform<sup>2</sup>, Distance Information Technologies for Home Care<sup>3</sup>, HEARTFAID: A knowledge based platform of services for supporting medical-clinical management of heart failure within elderly population<sup>4</sup>, HEARTCYCLE<sup>5</sup>, CHRONIUS<sup>6</sup>, and ICARDEA<sup>7</sup>.

The decision-support system in most of these systems is interactive. Few cases include a proactive mode, mainly for alerting the patient or the doctor to initiate an encounter. In some cases the decision-support is not very sophisticated and is not always based on clinical guidelines, or it does not include advanced tools for medical knowledge engineering that enable clinicians and/or knowledge engineers to maintain the evolving clinical knowledge. The CHRONIUS project also addresses the social and environmental patient context.

MobiGuide goes beyond these five projects, as it not only integrates decision-support with monitoring devices and electronic health records, but it also provides the following six characteristics.

Mobiguide: (1) provides interactive and proactive guidance both to patients and care providers; (2) personalises guidance based on the patient's preferences and personal contexts; (3) supports a process of shared decision-making involving the patient and the care provider; (4) supports a distributed DSS, whose two-tiered architecture [central and local (mobile-device) decision-support] can function without an internet connection; (5) applies the system to two different clinical domains - atrial fibrillation and gestational diabetes mellitus - that represent both intensive and more sparse monitoring; and (6) integrates advanced medical knowledge engineering tools within the architecture, designed to enable both medical knowledge engineers and sophisticated clinical users to maintain the quickly evolving medical involving knowledge.

<sup>2 &</sup>lt;u>http://www.srdc.com.tr/metu-srdc/projects/saphire/</u>

<sup>3 &</sup>lt;u>http://cordis.europa.eu/projects/rcn/58097\_en.html</u>

<sup>4 &</sup>lt;u>http://lis.irb.hr/heartfaid/</u>

<sup>5 &</sup>lt;u>http://www.heartcycle.eu/</u>

<sup>6 &</sup>lt;u>http://www.chronious.eu/</u>

<sup>7 &</sup>lt;u>http://www.srdc.com.tr/projects/icardea/</u>

The MobiGuide UGS aims to make healthcare more accessible, better, faster, and cheaper. Accessibility is enhanced by providing decision-support not only to clinicians during patient encounters, but also to patients, any time, everywhere.

The increase in quality and safety of the delivered healthcare will be achieved by basing the decisionsupport on evidence-based guidelines and by coupling it with close monitoring. The monitoring can detect situations requiring a need to alert the patients and, when relevant, provide evidence-based recommendations to care providers; this dual notification process is expected to result in enhanced safety.

A central focus of the MobiGuide project is on patient empowerment, leading to patient involvement in their own healthcare which results in greater motivation. A key question that MobiGuide tackles is how to involve patients in a manner that ensures that they are not just passive users of a system that provides instructions based on the clinical practice guidelines, but that makes them active partners in medical decision-making and in goal setting. Setting their own goals would evidently increase the patients' willingness to comply with recommended treatment.

Obviously, patients lack the medical knowledge of clinicians; hence, they cannot suggest goals that are not in line with medical evidence. Therefore, opportunities in clinical practice guidelines are sought, in which patient involvement in shared decision-making is warranted and productive. Such opportunities include the selection of alternative decision options, where there is no single option that is preferred based on clinical evidence. In such situations, patient's utilities and preferences should be considered by the care provider making the decision. In addition, some local preferences such as meal times are obviously personal considerations of the patient that do not compromise medical care. They could easily be incorporated into the MobiGuide UGS as automated reminders for meal-related reminders for medications, measurement, diet, and exercise recommendations. Finally, the patients' personal context may influence their preferences as well as their ability to comply with recommendations. For instance, a personal context in which family members are available to help the patient in following medical recommendations, or non-routine schedules may occur during travel. These may place patients in temporary situations for which a less recommended treatment plans may imply a better balance of trade-offs between the effect of the recommended treatment on life-years and quality of life, and the ability of the patients to comply with treatment. MobiGuide's decision-support is context-sensitive, making recommendations that are more suitable for the patients' changing context.

The involvement of patients, together with the use of reminders and feedback services, is expected to empower the patients, increase their motivation, and enhance their compliance to the evidencebased recommendations, achieving even greater quality and safety. In MobiGuide, decision-support is provided both to the patients and to their care providers; furthermore, the patients are involved (a) in personalising the guidance according to their preferences, in a manner sensitive to their personal context; and (b) in a process of shared decision-making with their care providers.

Besides its significant impact on patient empowerment, monitoring patients at home implies a significant potential for several key economic and medical-quality benefits.

On the one hand, most patients can be monitored at home, without needing expensive, time-consuming visits to a clinic or even a medical centre. Typically, patients will not encounter emergencies that require remote handling. Obviously, this aspect of remote care carries major economic implications for an overburdened health-care system that increasingly treats elderly, chronic patients (who, although they comprise only approximately 25 % of the patient population, account for more than 70 % of health-care expenditures).

On the other hand, there may be patients who do require immediate attention [e.g., due to a recurrence or exacerbation of atrial fibrillation in spite of medication-based therapy, or due to experiencing a trend in increased severity in what was initially mild pre-eclampsia (toxemia of pregnancy) or mild gestational diabetes]. As a result of the system, they will not have to wait until the next weekly or monthly check-up. Their condition will be noticed immediately and handled through both channels - the patients and their care providers. This will even include the option of an urgent visit to the clinic or hospitalisation. This rapid monitoring and acting loop has significant potential to enhance the quality of evidence-based care.

# 7. MobiGuide's limitations and future research

Although the MobiGuide system is still under development, we can already note that it has some limitations which should be addressed in future research.

Naturally, the current main limitation of the system is the lack of clinical application, which will not happen for some time.

One of the major challenges encountered during the implementation of the MobiGuide system is the establishment and use of common standards for medical terminology and semantics. MobiGuide adopted a standards-based patient information model in which openEHR archetypes were combined that are designed to comply with the structure of classes from HL7's virtual medical record standard, which was specially designed for the goal of supporting clinical decision-support (González-Ferrer et al., 2013). The varied types of data stored in the personal health record of the MobiGuide system include recommendations made by the decision-support for specific patients and abstraction. The abstractions are derived, using context-sensitive medical knowledge from the patient's data, but these are not usually found in electronic medical records. Although we were able to map these new data types to our chosen information model, we found that the use of post-coordinated terms was necessary in order to capture detailed the semantics of concepts used (e.g., after lunch [postprandial] blood glucose measurement). In some cases, certain semantics could not be provided even by post-coordination (for instance, no standard way currently exists to specify the type of algorithm used to detect the atrial fibrillation episodes that are abstracted from the ECG data). Moreover, additional extensions to the virtual medical record information model were necessary in order to link the data stored (e.g., blood glucose measurements) to the specific CIG elements from which the recommendation and reminder originated. This information is necessary in order to assess patients' compliance to specific recommendations.

A third limitation stems from the large time and effort that knowledge engineers aided by clinical experts spend in analysing a clinical practice guideline, find opportunities for its customisation to patient's personal context and shared decision making, formalise it into a CIG language, and customise it. Hence, although the MobiGuide system could potentially provide decision-support in other clinical domains, substantial effort needs to be devoted to the definition of new CIGs, even when using the specialised tools that have been developed for medical knowledge acquisition (Hatsek et al., 2010).

A fourth limitation stems from the fact that many chronic patients experience several comorbidities. MobiGuide's knowledge base includes CIGs that are created based on clinical practice guidelines, each of which is usually focused on a single disease or clinical condition. This decision-support system does not have the capability of integrating recommendations and resolving conflicts between recommendations arriving from multiple CIGs. The development of such novel decision-support capabilities is an exciting topic for future research.

Fifthly, the current implementation of the tool for eliciting utility coefficients includes the three common methods: the 'rating scale', 'time trade-off' and 'standard gamble'. Some of the patients participating in the pilot study have found these issues somewhat difficult to understand. In particular, the time trade-off method showed a 'ceiling' effect towards the unity (i.e., many patients displayed a coefficient of 1 for atrial fibrillation). This means that their quality of life with atrial fibrillation was perfect. In this sense, they were not willing to trade off even a small percentage of their life in order to be cured of atrial fibrillation. Alternative ways of asking these questions, as well as different ways to elicit utility, such as questionnaires - the already validated EuroQoL tool as a standardised instrument for use as a measure of health outcome see www.euroqol.org - could be useful to allow more patients to express their preferences with regard to these various options.

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# Development of Patient Access to Electronic Health Records as a Step towards Ubiquitous Public eHealth

A necessary activity towards moving healthcare services out of the physical premises of hospitals and into patients' daily lives is to supply citizens with various health services via the Internet, i.e. public eHealth services. However, developing public eHealth services for a large number of heterogeneous end-users is a complex task.

This case study investigated the development process of a novel eHealth service that provides patient access to electronic health records, which was developed and recently deployed within the scope of an EU project.

A conventional customer-vendor process was applied that resulted in a high degree of uncertainty regarding end-user needs of this novel service. The development team tried to compensate for this weakness by using agile methods. When developing public eHealth services for citizens, it is imperative to involve potential users, to evaluate the citizens' needs as a function of benefit, usability and security, and to handle those concepts responsibly throughout the process.

## Acknowledgements

The action research project 'DOME - Deployment of Online Medical Records and eHealth Services' is financed by VINNOVA (2012-02233) - Swedish Governmental Agency for Innovation Systems. The SUSTAINS implementation project is supported by the European Commission (No 297206). Special thanks go to the respondents at the Uppsala County Council and at the development company EVRY for inviting us to form a Triple Helix environment for future work.



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#### Keywords

electronic health record, electronic patient record, eServices, evaluation, patient-centric, public eHealth services, system development process, ubiquitous computing, usability

In this case study, the customer - vendor - enduser relationships in the development of public eHealth services was investigated in practice and led to a number of recommendations to bear in mind when designing ubiquitous public eHealth services.

### 1. Introduction

There is mounting pressure on EU healthcare systems due to the prospect of a lack of resources in the future caused by demographic changes in the population, as well as people's higher demands for improved treatment and care. As a result, healthcare authorities strive to streamline and standardise care processes through improved patient and information flows. There is a firm belief amongst many healthcare professionals and managers that one way to achieve improved quality of life for patients, while simultaneously improving control over healthcare expenditure, is to involve the patients in managing their own health (se2009.eu, 2009). A means to realise this is by implementing ICT systems that provide patients with access to their electronic health records (EHRs), and a number of other public eHealth services, reachable via e.g. mobile devices. These services aim at changing the role of patients, making them a more active partner in the healthcare process (Sustains, 2013) as well as improving efficiency and workflow across institutional and professional healthcare boundaries (CeHis, 2013).

In order to enable society to become the driver of its healthcare activities, appropriate tools need to be at the citizen's disposal: demands for ubiquitous computing are undisputed in this matter. Public eHealth services are intended to support patients, relatives and care professionals by being accessible ubiquitously, i.e. anytime, everywhere and anywhere (CeHis, 2013). In contrast to traditional healthcare services located at physical care premises, public eHealth services could be accessed using any device, in any location and in any format, either on stationary or on various mobile devices.

There are known informatics challenges when creating patient-centric health and social care services for ubiquitous access. One of them is how to transfer patient data from the health organisations' EHRs to the patient (se2009.eu). On a socio-technical level, the task for healthcare providers is e.g. to develop an ICT system that meets the needs and requirements of the patients, while at the same time being convenient and acceptable to healthcare professionals (for instance, physicians and nurses), and also economically sound from a societal perspective.

It is well known that the system development process creating health ICT is complex; it is difficult to plan (Samaras & Horst, 2005), and difficult to manage (Bradley et al., 2010). It has also long since been argued that ICT systems in healthcare must be designed with respect to the information requirements, cognitive capabilities and limitations of the end-users, as well as considerations of daily work in process-oriented organisations (Patel & Kushniruk, 1998).

Previous research highlights the need for a high degree of participatory activity from future users of a system in order to realise the expected end result (Olphert & Damodaran, 2007; Bødker et al., 2000). However, it must be noted that user participation in public eService development is challenging to put into practice (Axelsson et al., 2010). Public eService development most often has to deal with a heterogeneous target group if it takes on board all citizens (Henrikssen, 2004, Saha, 2008). Citizens cannot be obliged to participate; their participation is voluntary, and is performed in addition to their ordinary duties.

When developing eHealth services, the involvement of real users, i.e. patients, is desirable. However, the patients, in contrast to the clinical staff, are not members of the healthcare organisation, and accordingly are not easily reachable by the customer organisation (Scandurra et al., 2013). This consequently presents an even more complex situation when it comes to creating customer - vendor - end-user relationships in the development of public eHealth services.

In this case study, this situation was investigated in practice. It led to a number of recommendations to bear in mind when designing ubiquitous public eHealth services.

#### 1.1 Objectives

Innovations in technology are driving powerful changes in the way citizens engage in healthcare delivery (O'rourke K, Heckman J, Elwood D, 2012). An interesting question is how and where a process of moving healthcare services towards citizens in their daily life starts.

This case study investigated the development process of a novel eHealth service, developed and recently deployed in a Swedish county within the scope of an EU project (Sustains, 2013), as an example of a step towards ubiquitous public eHealth.

In this EU deployment project, a Swedish county council is working together with an IT development company to develop and deploy a public eHealth service that aims to enable patients' access to their own EHRs via the Internet. In the first phase, a regional service was deployed in November 2012, and made available to all patients in the county of Uppsala (Sustains, 2013). A second phase is currently in progress, where the aim is to scale this service to a national level and with the objective of providing this public eHealth service to all Swedish citizens (CeHis, 2013).

Following the recommendations of the European Commission in Horizon 2020 (2013) to strengthen public-private partnerships in research and innovation, a multi-disciplinary action research team is working alongside this EU project to study its effects and outcomes (DOME, 2013). In this study the action researchers focused on the development process through the analysis of interviews with the stakeholders involved.

The research objective was to highlight the activities performed in the development process that have a potential to increase patient empowerment. Furthermore, the aim was to point out potential implications and challenges that could impede a successful application, as well as to inform authorities, e.g. county councils, on successful methods for development and deployment before they initiate similar implementation processes.

## 2. Methods and materials

An explorative research approach was applied to undertake this constructive evaluation of an ongoing practice, namely how the development process was performed to create a novel eHealth service.

#### 2.1 Empirical setting

The county council of Uppsala, Sweden, was the initiator of the development and also the owner of the developed eHealth service. The county council is the coordinator of an on-going EU deployment project (SUSTAINS<sup>1</sup>) established in 2012 as a means to develop and deploy eHealth services providing patients with, amongst other services, online access to their electronic health record (EHR). There were two main actors involved in the development of the eHealth service: the customer and the vendor. The customer, i.e. the county council, has been an active participant and has been working in close collaboration with the vendor, i.e. the IT company's development team. This vendor-customer relationship was initiated several years ago and the customer and vendor have been working together with predecessors and prototypes of the current eHealth service since 1997 (Figure 1). The development team currently works according to Scrum<sup>2</sup> and was led by a Scrum master who has been

<sup>1</sup> SUSTAINS (Support USers To Access INformation and Services) is an EU project that aims to introduce services that provide citizens with online access to their EHRs (2012-2014).

<sup>2</sup> SCRUM in an agile software development framework for managing software development projects.

coordinating the development work as well as acting as the primary contact person to the customer. Besides the Scrum development team, usability experts were engaged in the development of the eHealth service addressing issues related to usability and user experience (Figure 2).



Figure 1: Part 1/2 of the timeline for the development process



Figure 2: Part 2/2 of the timeline for the development process

#### 2.2 Data collection - Interviews

To gather empirical data from the development of the eHealth service, semi-structured face-to-face interviews were carried out during on-site visits. The respondents had all been active participants in the development process and represented the customer and the vendor in equal numbers. The aim was to gain insight into as many different aspects of the development work as possible. Respondents from the customer were represented by the project manager, the project owner (who is also the coordinator of the EU SUSTAINS project) and the medical advisor for the project. In the case description, these three interviewees are referred to as Respondents 1-3. Respondents from the vendor were represented by the Scrum master and two usability experts who were engaged during different parts of the development process. In the case description, they are referred to as Respondents 4-6.

The interviewers, i.e. the authors, altogether formed a multi-disciplinary research perspective, as each author stems from a different but adjacent research area such as Health Informatics, eGovernment, and Organisational Change and Management Control. By combining all their expertise on the problem area, their aim was to create a deeper understanding of the difficulties as well as the possibilities that arise in practice in development projects.

Each interview was held by at least two of the authors in order to cover and follow up on multidisciplinary aspects. The length of the interviews varied between 60 (n=2), 90 (n=3) and 120 (n=1) minutes. Each interview was recorded and subsequently transcribed. In some instances where the collected material was judged incomplete, respondents were contacted again and further questions were asked of them in order to clarify and complete the earlier statements. These contacts were made face-to-face in some instances, and by email or phone in others.

#### 2.3 Data analysis

The analysis focused on identifying activities that have a potential to increase patient empowerment and to point out potential implications and challenges that could impede a successful application, as well as to inform on successful methods performed during this development process.

In a two-step process, this paper analysed the development process of the public eHealth service with content analysis (Hsieh & Shannon, 2005) to identify correspondences and misalignments of the respondents' answers.

The first step consisted of all four researchers reading the interview transcripts and discussing their implications amongst each other. Each transcript was summarised with respect to the objectives' keywords which made it possible to outline a basic understanding of the studied intervention. Two core concepts were identified: activities performed during the development process and the results of the activities and decisions made during development.

In the second step, two researchers performed an analysis of each concept, searching for and identifying keywords. Thereafter the keywords were compared and adjusted for purposes of increased reliability, stringency and clarity. Early in this process, the paper's authors collectively started to write their report by utilising an online collaborative word processing service and video conferencing meetings. This made it possible to make use of their different expertise, and to continuously develop and reconstruct their understanding of the case study. As a result, all four researchers have studied and processed the entire body of empirical material.

# 3. Results and discussion

This study of Uppsala County as a region in the EU project resulted in a description of how the process of moving healthcare services towards the patients' daily lives actually started and progressed. Furthermore, a discussion was held regarding the challenges and lessons learnt as perceived by the stakeholders in the development process and the researchers studying this process.

#### 3.1 Challenges when developing novel public eHealth services

The complexity of the system development process in eHealth is generally acknowledged in the literature as difficult to plan (Samaras & Horst, 2005), and difficult to manage (Bradley et al., 2010). Research also shows that ICT systems in healthcare must be designed by taking into consideration the end-users, as well as considering clinical work in the health organisations (Patel & Kushniruk, 1998). In the current case, when designing and developing a novel public eHealth service on behalf of the citizens or patients, but performed by the healthcare organisation and the IT development company, making room for such considerations was difficult. One of the problems stated by the development team was that of identifying the potential needs of a great number of more or less unique end-users from the medical treatment point of view. These end-users also have different experiences and understandings of IT. In this case, the customer emphasised that "the users have never seen a similar eHealth service, and they could therefore have difficulties imagining what it could be like and consequently find it difficult to pose demands for it" (Respondent 2).

Previous research has demanded a high degree of future users' participation in order to realise the expected end result (Olphert & Damodaran, 2007; Bødker et al., 2000). Experiences from other eService development processes in public administration show that this is challenging to put into practice (Axelsson et al., 2010), as future users are a heterogeneous target group; their participation is voluntary and performed in addition to their ordinary duties; and they are difficult to reach for the customer organisation (Henrikssen 2004, Saha 2008; Scandurra et al., 2013).

This situation is exemplified by an evaluation presented by the Swedish National Audit Office which concludes that increased internal efficiency was the main motive for the initiation of public eService development projects (Swedish National Audit Office, 2004). This has led to a problematic situation where many development projects have been driven by "a techno-centric approach with minimal citizen involvement" (Sæbø et al., 2011), i.e. new technology, rather than perceived needs, has guided what kind of services were developed.

This complex situation presents a number of challenges when it comes to creating customer-vendorend-user relationships for the development of novel public eHealth services. These are presented (below) as they also occurred in this project.

#### 3.2 Activities performed during the development process

As stated above, the county council of Uppsala is currently a part of the SUSTAINS EU deployment project (Sustains, 2013). However, work towards ubiquitous patient access to health information was initiated in the county council as early as 1997. This novel idea was put into practice in various projects until a political resolution was accepted in 2009. From that point on, discussions regarding patient access to EHRs could depart at the county council from a more theoretical level towards planning for a full-scale implementation. At the beginning of 2011, the development of the public eHealth service was initiated by the customer in terms of informal specifications concerning what basic functionality such a future eHealth service could include. These specifications were

accompanied by basic regulations for the information that the eHealth service should, and could, reveal to the patient: which information, when, and how. Later in 2011, the vendor was contracted and development of a first prototype of the eHealth service was initiated. When a new head of system development was hired, who was also a Scrum master, the need for a more agile and iterative development process was made clear. The prototype needed to be redesigned with respect to the user perspective, and usability experts from within the company were called to assist. They performed a heuristic evaluation (Nielsen 1994), created a conceptual model of the public eHealth service and three personas<sup>3</sup> in order to represent basic end-users' concerns for how to interact with the system. The personas represented potential users: an old woman experiencing dementia (and her relatives), a disabled child (and his parents), and a woman with multiple diagnoses.

This material inspired the developers. It was also used together with representatives of the customer in so-called sprint demos, initiated as part of the development process of the system. The vendor performed three week-long development phases between each demo for the customer. The customer representatives usually included the project manager from the county council, sometimes accompanied by other members of the project, staff from the university hospital's division of medical informatics and technology, and staff from the hospital's administrative branch responsible for the EHR system. No representative of the end-users was involved in this work: instead, the project owner from the customer organisation acted as a potential future user.

The development work started from the customer's initial list of informal specifications. This was however very broad, prompting the Scrum master to elaborate on the list to make it manageable. The finalised list consisted of seven modules and twelve functions, which the customer prioritised according to their perceived importance. The vendor was allowed to make changes in the priorities, e.g. if a certain function was not technically feasible, the developer could cross it out. At each sprint demo, the vendor showed the current state of the eHealth service and commented on what had been accomplished since the last demo. Reactions and feedback from all participants during these demos were collected by the Scrum master, and later analysed to decide if they should lead to corrections or changes.

In the early summer of 2012, as a mandatory stage in the EU-development project, the customer arranged a focus group meeting as an organised test day of the current prototype of the eHealth service. A problem perceived during the focus group day was that the guidelines for how to set up the test of the prototype were unclear. According to the development team, it was also not clear whether, or how, any feedback from this focus group day was used to improve the actual design of the system.

In late summer 2012, the customer carried out a first user test by enabling the county council's own employees to use a prototype of the eHealth service, thus allowing them to access their own health records as patients. This was a non-systematic test as all employees were free to test the eHealth service in the way they wanted and the only prepared way of collecting reactions or questions from the users was through an e-mail address provided as an option for users wanting to comment on any (high or low-level) problem they encountered using the service; it could relate to e.g. interaction flaws, bugs, usability aspects or just reactions on how it felt to gain this access. The feedback was read by the customer and, if it was considered important, it was batched into the development process during the sprint demos.

Another finding is that there were no goals or fixed targets for the eHealth service. The customer

<sup>3</sup> Personas describe basic characteristics of future users. The method is seen as an efficient tool for describing simple yet good enough models of users which can be used when designing system interactions, such as user dialogues or graphical user interfaces. See e.g. Gulliksen et al. (2003).

has deliberately refrained from specifying such issues as how the eHealth service is intended to contribute to the patients' wellbeing, how or how much the eService should ease the pressure on other different services provided by the healthcare system today, or what impact it should have on the workload of the clinical staff in general. According to the customer, the reason for not being more specific is that it was not meaningful or purposive to state goals and targets that were perhaps not valid: "It might seem careless, but we're the first out and we don't know. Somehow it's not meaningful to state a goal" (Respondent 2).

The logic was that "if a stated goal is invalid according to a future user, it will not matter if the system can fulfil the goal or not. In that case, the evaluation would be superfluous". The customer continued: "If you on the other hand failed to state a certain goal, you will not be aware of the mistake until an end-user points this out to you, which will happen when the eHealth service is implemented and in daily use" (Respondent 2).

It is evident that testing, evaluation and end-user activities are not in line with best practices for user participation and user-centred systems development (Scandurra et al., 2013). The customer is well aware of this. Rather, the customer was aiming at satisfying the future end users' needs and demands, and therefore claims that user participation at this stage would not be beneficial. Instead of making an inventory amongst patients today, the customer (and particularly the project owner) tried to take on the role as a future end-user. These arguments from the customer are easy to understand due to the novelty of the eHealth service being developed; future users, e.g. patients, have no baseline to refer to in terms either of missing functionality and possible improvements. This fact is also highlighted in research literature on user participation in systems development; user participation is not a guarantee for successful development projects, it just enhances the likelihood of it (Cavaye, 1995). Experiences from other ICT development projects could be summarised in the following way: it is not the invitation of users into the development process that ensures the design of a useful system. It is how well the users' presence is planned and how their contribution is handled that matters and that subsequently creates the benefit of the collaborative work.

In the Human-Computer Interaction literature, methods are also available for how to create novel ICT systems: these stretch from adopting a low degree of user participation to involving potential users in the actual design and evaluation of ICT systems. The authors of the present paper argue that, apart from the user-centred activities performed in current development process, a collaborative design process consisting of future workshops and an iterative prototyping process (as in Scandurra et al., 2008) would have been beneficial to establish gradually an understanding between users and developers, and that mediators with knowledge from both health informatics and user-centred design (Larsson, 2013) would have been valuable as methodological support.

#### 3.3 The results of the development process

A list of regulations formed a basis for the development of the eHealth service. This list was phrased by the customer (and formally decided on by the politicians of the county council). It regulates issues such as which information should be open to the patients, and when (whether in real-time or at a delayed time-period). The list of regulations was supplemented by a list of other basic requirements, which also emanated from the customer, that was developed as a result of the European collaboration in SUSTAINS.

#### 3.4 Confusion regarding usability aspects

One aspect that was somewhat neglected in the development process was the intended usability of the public eHealth service. The development project is best described as an interactive and flexible process, where people from the customer and vendor were involved in different parts of the project and at different times. In reality this means that some of the involved actors have only seen bits and pieces of the complete system, or they only examined the functionality of the eHealth service from a specific perspective. An example here is the usability experts, who worked for a few hours spread over a period of time and who evaluated usability aspects exclusively in terms of the graphical user interface. Also from the customer's side, some people were involved in other projects and switched their focus to this project during the actual process: "At that time I wasn't so involved, I know a list of requirements was made ... those steps [referring to the project owner, and coordinator of the EU project] knows more about" (Respondent 3). However the Scrum master at the vendor, along with the project leader from the customer, maintained an overall perspective of the eHealth service and its development.

The view of the eHealth service's usability is heterogeneous amongst the respondents. There are no clear definitions in the development regarding concepts such as the service's benefit, usability and security. The understandings of these dimensions tend to be blurred, and participants in the development have not, probably due to the lack of clear goals, discussed their understandings and/ or expectations regarding these matters.

From the customer's perspective the public, eHealth service is believed to be usable. As has been discussed previously, a number of various test activities have been performed during the development process, such as focus groups, sprint demos, and by having the employees in the county council use the eHealth service. However, the definition of the concept of usability was not discussed by the customer. When discussing this topic with the respondents, it is apparent that there is no unified view of it, and that several respondents do not differentiate between usability and utility, i.e. if the system is designed to fulfil specified goals by specified users (ISO 9241-11<sup>4</sup>), or if the system works as it is supposed to in terms of the more technical aspects of usage. A common belief among respondents from the customer is that this eHealth service is as usable as any other eService, such as Internet banking. Such types of eServices are considered to operate homogeneously, the customer representatives state: "Digital systems operate in a certain fashion....In comparison to these I perceive this system as highly usable" (Respondent 3), "It is like an Internet banking eService, and you don't get any manual in order to operate these" (Respondent 2). In other words, there are diverse opinions regarding how to define the usability aspects of the eHealth service, and also concerning who is responsible for taking these aspects into consideration. When talking to the usability experts involved at the vendor side, it is evident that there are several issues regarding usability which need to be refined. The usability experts' general opinion is that usability issues in many cases have been neglected by the systems owner: "As far as I remember there was no one responsible for usability aspects" (Respondent 5). According to the usability experts, additional time and resources would have been necessary in order to create a truly usable public eHealth service: "We have made no usability testing of the service" (Respondent 6). .

<sup>4</sup> ISO 9241-11:1998, Guidance on usability <u>http://www.iso.org/iso/home/store/catalogue\_tc/catalogue\_detail.</u> <u>htm?csnumber=16883</u>.

The analysis highlights the endeavour to reach a goal that was not pre-stated. There was a lack of a visible, defined goal, which made it difficult to test the eHealth service to get end-user feedback. What questions should be asked in this case? Another effect of the lack of a fixed goal was the difficulty of designing clear-cut roles of responsibility. In the present case, the customer and the vendor express a degree of uncertainty concerning where responsibilities start and end. This was shown by the small extent of, and late use of, usability analysis along with difficulties concerning how to document and incorporate responses from the actual user tests made.

#### 3.5 Security issues

From a technical perspective, the eHealth service is considered to be secure and safe, both by the developer and the customer, with regard to privacy and confidentiality. This eHealth service uses the same authentication technology as other nationwide services, such as the health insurance office and the tax declaration office. However, on the one hand, there are some doubts regarding the availability of the eHealth service based on the fact that the service has not been tested thoroughly by end-users. As one respondent puts it: "Since we don't have all possible scenarios it is hard to say what might happen" (Respondent 1). On the other hand, the service is considered to be non-critical, since it only displays information from the EHR system, and no data can be altered.

However, security may also be viewed from a patient perspective, concerning privacy and information quality. An obvious utility put forward by the customer is that patients will have immediate access to information from a healthcare visit and, by doing so, potential errors made by physicians may be reduced: "I believe that the correctness will be improved now when things can be checked twice" (Respondent 2). Despite the fact that access to the eHealth service is considered to be secure, there are doubts and concerns from both the vendor and the customer regarding the actual usage of the service, mainly due to the variety of possible usage scenarios. "There is a risk that we haven't thought of everything, I believe we haven't thought of everything" (Respondent 2). Regarding issues of security and privacy, there is a national regulatory work in progress, covering issues such as: What if someone read information over someone else's shoulder? What if parents get access to sensitive information regarding their teenage children, which was not intended? These concerns, and others, will be addressed only after the public eHealth service has been made accessible.

The customer may also be criticised for not testing seriously enough various security aspects that are not connected to the national technical infrastructure. Perhaps security issues cannot be handled as easily as one respondent states: "If something unexpected happens we can always push the emergency button and shut it all down" (Respondent 2).

#### 3.6 Expected benefits from the two perspectives

Expected benefits from launching the public eHealth service can be viewed from two related perspectives: that of the customer and of the patient. By offering EHRs to its patients, the customer expects benefits such as increased efficiency and improved medical quality, since patients will have direct access to information which in turn could reduce the need for information provided by the health staff: "They [the patients] will ask less if they know more" (Respondent 2).

From a patient perspective, the possibility to obtain more information much more easily is expected to make patients better informed, both before and after healthcare visits, as well when they get information rapidly regarding various conditions, such as through test results. On the other hand, the expected benefits are so far only expectations: "We start without knowing 100% what the results will be." No evaluations were performed before the release of the service. Since this eHealth service is the first of its kind in Sweden, no conclusions can be drawn from previous or similar efforts.

## 4. Conclusions

A number of conclusions can be drawn from this study, that are related to activities performed in the development project. The developed public eHealth service itself has the potential to increase patient empowerment. However, the development process shows potential implications and challenges that could impede a successful application as well as successful methods that could be recommended to others before initiating a public eHealth service implementation process.

#### 4.1 Potential increase in patient empowerment

Given the demands and promise for larger changes in the healthcare sector, it is evident that the Given the demands and promises for larger changes in the healthcare sector, it is evident that the inherent characteristics of novel public eHealth services pose several challenges regarding how to manage and exploit these services and technologies efficiently. One of the major challenges is to involve the "third party", i.e. the citizen as the end-user, in the development process. This is unfortunately still not common in public administration (Axelsson et al., 2010). The public eHealth service development studied in this case provided no exception. Nevertheless, there are promising indications that this eHealth service, when widely used and studied using broader perspectives, will provide an increase in patient empowerment.

The history of this project's development dates back to 1997. At that time the focus was on the technological advancement rather than on a user-centred development process, which is the case for many public administrative services. The heritage that today's development team has to deal with is that decisions have often been technology-driven and not citizen-driven at all. However, the idea of this novelty has always been to increase patient empowerment by providing health information ubiquitously to the patient. The conviction was that the initiative would provide better opportunities for improved self-care, self-service and patient participation in the care process as well as raise the quality of the health information (Sustains, 2013). Another expected benefit is that the information is accessible wherever and whenever the patients desire, and is not connected to where the healthcare premises are located or when they are open (CeHis, 2013).

However, in the EU SUSTAINS deployment project, a central piece of future services providing ubiquitous health information is delivered to the citizen for the first time. Patient empowerment related to outcomes of the project and effects in broader perspectives need to be evaluated further (see the section of this article on Future Work). This should be done preferably by using key concepts such as benefit, usability, utility and security.

# 4.2 Potential implications, challenges and successful methods for recommendation

Initially, a conventional customer-vendor process was adopted. Results show that the development process was hard to plan and manage due to a high degree of uncertainty regarding end-user needs of this novel service. Previous research states the importance of end-user participation, which could have decreased the level of uncertainty.

The present study illustrates the difficulties in achieving this in practice. We consider that the recognised lack of end-user participation in this case, as in many other cases, is often based on a lack of previous experience and knowledge of methods that explain how to involve the users. In this case, it is evident that end-user and usability aspects were not involved in the planning of the development. The customer argued that it deliberately avoided involving patients as today's patients were not acquainted with such a future service.

Regardless, the development team was convinced that, if the customer would have been more knowledgeable about usability and end-user involvement, other activities could have been included in the whole process to specify requirements explaining what the customer and the users need and why. However, on the one hand, we do acknowledge that user participation is not always successful; usability skills, knowledge of user-centred methods and clear goals are needed, factors that were not always available in this case. On the other hand, the situation improved when the development team was given the mandate to move towards using methods for improving the potential usability of the eHealth service. By adopting some of the best-practice methods that the Human-Computer Interaction (HCI) domain advocates, the subsequent development began to use tools to improve the understanding of the future users' behaviour, needs and demands. Activities to recommend are the creation of a conceptual model of the entire eHealth service, the creation of personas, and the use of an agile development method where the customer also acted as a future user representative during system evaluations.

There are also activities that we consider could use improvement.

Some of the most critical parts of the development process are to specify project goals, specify requirements and to evaluate those against potential user needs. In public procurement, the regulations require that the customer receives what is asked for, but the requirements are often based on a high level of abstraction and are therefore not explicit or traceable enough (Larsson, 2013). The work by the developers is facilitated much more easily if the goals are traceable to a low-level specification and the requirements detailed. Best practice in HCI states that iterative refinements of the system specification as well as iterative evaluations of prototypes performed with potential user groups will secure a better outcome to the development process (Scandurra et al., 2013).

This study emphasises that public eHealth services should be evaluated with regard to the citizens' needs as a function of benefit, usability and security. It is also important that these concepts are continuously monitored in the development process. This can be reached by clear-cut roles of responsibility regarding the concepts within the project team, on both the customer and the vendor side. Clear goals and responsibilities would potentially have facilitated the focus group work, and the subsequent analysis of the work performed by patient organisations' representatives would have provided a direct benefit to the development process.

Another desired improvement concerns the testing before launching the eHealth service in public. Best practice indicates that a user test should be set up that is as close to reality as possible. Probably due to technical security constraints, the sample selection in this case was the healthcare staff. The problem is that healthcare staff members have extensive domain knowledge and are accustomed to the electronic health record used in the county council. A suggestion instead would be to involve the focus groups' participants, consisting of patient organisation representatives. They would have represented a potential future user better and the test results would probably have been more representative. Other recommendations are to carry through more thorough formative testing activities during the entire development process, and to carry through a summative user evaluation before the launch of the public eService. Such activities would follow HCI best practice.

Another conclusion is that the understanding of what is meant by the service's benefit, usability, utility and security is blurred amongst the participants. These concepts are multidimensional and should include both technical and social considerations. Participants in the present case seem to view e.g. usability either as a technological functionality (that the service "works" = utility) or as a measure based on subjective interpretation (which can lead to a usable product = usability), with different understandings of how these two concepts are related.

A recommendation is therefore to plan for a workshop where customer and vendor discuss their understandings and expectations regarding these kinds of concepts, to form the scope, agree on common goals, and understand how to share the responsibility involved.

Finally, there are other contextual aspects outside the scope of this study that will have an impact on this and similar public eHealth services. Some aspects are elaborated in the following section on future work.

## 5. Future work

The public eHealth service that was studied was released in late November 2012 to the citizens of the county council of Uppsala. Presently, many citizens are therefore accessing their health records for the first time ever. Aspects such as usability, benefits and security, discussed in this paper, are expectations of usage of the eHealth services from different perspectives and have so far only been tested on a very limited scale.

A number of studies remain to be performed around the possibility of obtaining ubiquitous access to health information. This research team considers the study of the mere usage of such information to be more important than studies about which technical platform is used or through which mobile device the information is accessed, although such technically-related research studies may be interesting as well.

In the county council of Uppsala, a central piece of ubiquitous health information is delivered to the citizen for the first time. Thorough evaluations based on real usage are needed, wherein both patient perspectives (of real end-users), as well as those of the healthcare organisation need to be considered:

- How will public eHealth services induce operational changes? Which role can users play in designing new functionality?
- What benefits can be identified when using the eHealth service? What is the general opinion regarding the usability of the eHealth service?
- Has the eService been found to suffer any security, safety or privacy problems?
- To what extent is the eHealth service effective, efficient and usable for the intended user groups?

These aspects need to be assessed in relation to the novelty of such an eHealth service. In this case, patients are all novel users with regard to this public eHealth service. Consequently, findings resulting in such assessments should be evaluated in comparison with other domains, e.g.:

- Internet banking services (that today have been running for a long time with experienced users),
- conventional ways of accessing health data, and
- other public ICT services where the citizen can access data from authorities other than health organisations.

Other interesting studies to be performed regarding ubiquitous health information are related to potential spin-offs from this eHealth service:

- Do citizens actually need full access to their health records or is it something else? In which cases and for which patients?
- How can data provided by the health organisations be used together with patients' personal health data inputs from existing or new applications?
- Which kinds of health information networks will be created when society becomes the real driver of healthcare activities? How will this change healthcare delivery and the way healthcare staff in different organisations work?

Finally, there are methodological questions related to how eHealth services should be studied, in which phase of development, and for how long.

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# Increasing the Engagement of Citizens in PHR Adoption by Using mHealth

This paper highlights how mobile health can be the key driver to increase the use of Personal Health Records (PHRs) through the higher engagement of users. Different Personal Health Record (PHR) solutions have been implemented so far on regional and even national dimensions, but their large-scale adoption is still a challenge, regardless of the technical or functional model considered. With an impressive penetration rate worldwide, mobile technology represents an easy and cheap channel to bring PHR-related services directly into the hands of citizens. This vision is in line with the strategy that the Veneto Region of Italy is considering adopting in order to guarantee widespread use of PHR services that will be tethered to the regional Electronic Health Record that is currently underway. Starting from several successful local experiences, an SMS textmessaging feature has been selected as the initial channel to increase accessibility to the PHR, by delivering mobile booking and notification reminder services.



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#### **Keywords**

Electronic Health Record, mHealth, Personal Health Record, mobile booking, notification services

66 Mobile health offers a wide range of features that can accelerate the adoption of the Personal Health Record by reinventing the way to provide its services directly into the hands of citizens.

## 1. Introduction

Personal Health Record (PHR) systems have been implemented based on different models depending on the source of medical data (Tang et al., 2006). In most cases healthcare providers have decided to open up their Electronic Health Record (EHR) systems to citizens by implementing web portals to access not just online clinical documentation but also a set of related services. These have as their overall goal to increase accessibility, save time both for citizens and healthcare operators, and improve communication between them.

Even though the benefits for the whole spectrum of stakeholders are clear, citizens' adoption of PHRs has not always matched the initial expectations. There are still several barriers to a widespread uptake among the population. This is mostly due to a lack of awareness and to cultural and change issues rather than to the technology itself (Cruickshank et al., 2012). Mobile technology has the potential to make healthcare more accessible by bringing eHealth services directly into the citizens' pockets.

This paper focuses on the contribution of mobile health to accelerate citizens' engagement with the use of PHRs and introduces the strategy that the Veneto Region<sup>1</sup> is supposed to adopt in order to bring PHR-related services closer to the citizens. Several local healthcare authorities (LHAs) in the region already provide the population with online access to their medical information and some other related services, such as online booking of diagnostic examinations and outpatient visits, online payment of services fees and reminders of appointments booked. By assessing these single local experiences, we acknowledge that the adoption rate of such services is still modest and it needs a higher level of citizen involvement to be effective on a large scale. Starting from data about mobile devices' penetration worldwide and in Italy in particular, it is assumed that mobile health (mHealth) could be the golden conduit to increase citizens' use of PHR services.

## 2. Traditional models of Personal Health Records

There is a broad conviction among healthcare professionals and managers that increasing the engagement of the citizen/patient in his/her own healthcare is essential to improve the quality of care and the sustainability of the healthcare system.

The European Digital Agenda dedicates one of its key actions (Action 75) to enhance citizens' participation in their self-care by 'promoting pilot actions to equip Europeans with secure online access to their medical health data by 2015 and to achieve by 2020 widespread deployment of telemedicine services', starting from the assumption that healthy and active lives are associated with well-informed, educated and pro-active patients and citizens (European Commission, 2010). According to this rationale, online access to personal medical information has become nowadays an opportunity for citizens in many countries all over the world.

As defined by the Markle Foundation's Connecting for Health collaborative, the PHR is conceived as 'an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorised, in a private, secure, and confidential environment' (Markle Foundation, 2003).

<sup>1</sup> Veneto is a region situated in the north-eastern part of Italy with a population of 4.9 million inhabitants. Taking into consideration the regional social and healthcare system, Veneto is divided into 21 local health authorities and two hospital trusts that provide assistance to the population covered, following national and regional guidelines.

This definition has always referred to the concept of a patient web portal translated into different technical solutions over the years according to how the implementation of PHR has been approached so far.

The first PHR systems were based on commercially products that citizens could populate by selfentering their data. In this sense, a PHR worked as a stand-alone application which lacks integration with any other system. This approach did not have the expected impact in terms of consumer engagement, as demonstrated by the Google Health experience, launched by Google in 2008 and discontinued in early 2012 because of the insufficient interest raised, which was limited to specific groups of users like 'tech-savvy' patients and fitness and wellness enthusiasts (Google, 2011).

The other most common family of PHRs includes tethered solutions conceived as patient portals but connected to a healthcare provider network. The citizen can log into the PHR and access directly his/her EHR that is populated by healthcare institutions with clinical data/documents. This model is limited when various neighbouring authorities adopt different EHR solutions that are not integrated and that need different logins for the patients to consult a range of clinicians. In the past few years PHRs are becoming regional and even national realities, based on Health Information Exchange (HIE) platforms: most times these conform to interoperability standards for the integration of data flows from different healthcare enterprises.

In Europe several countries and regions have already launched their PHR systems, linking them to shared healthcare records. The French Dossier Médical Personnel (DMP) is a meaningful example of a national healthcare tool for sharing and exchanging information about individual patients. The patient can use an Internet DMP portal called 'patient web access' to access a lot of different documents, from discharge summaries to test results and imaging.

In Italy a few pioneer regions have implemented a similar PHR system that is connected to the respective regional Healthcare Information Networks, although using a different technical infrastructure. Since 2008, in Lombardy, all citizens can access the SISS Lombardia (Sistema Informativo Socio-Sanitario) from a traditional web portal and choose the services that they require, e.g. EHR and eBooking, or they can input self-reported data about their own health status or family history. A comparable model of patient web portals has been implemented some years later by the Emilia Romagna Region as an access point to the regional EHR, named SOLE (Sanità OnLinE), and a range of similar online services.

Moreover, some local health authorities in the Veneto Region adopted such a paradigm when they decided to provide a web portal to access online services around their organisation-centric EHRs. However, even though several local surveys confirm the interest of citizens in such services, their large-scale use is still challenging. In all three local health authorities that implemented their own PHR a very low adoption rate with just a limited group of users that really accesses online clinical documentation over the course of a month has been observed. The histogram below shows the total number of monthly online accesses while the numbers in brackets refer to the average value for each account created.



Figure 1: Adoption rate of local PHRs in the Veneto Region

# 3. Can mobile health revolutionise the concept of Personal Health Records?

Today there is still much debate about how to raise citizens' awareness of the benefits of healthcare online services in order to increase their interest in them. Different drivers should be identified to bring these services to citizens, and mobile health may be going in the right direction. As devices are getting more and more sophisticated, with a large offer of applications easy to find and to be used, the mobile phone may serve as an alternative to computers in order to provide easier access to a PHR and the services associated with it.

According to the 2011 global observatory 'New horizons for health through mobile technologies' performed by the WHO, 83 % of Member States reported offering at least one type of mHealth service, ranging from health call centre/telephone help lines, emergency toll-free telephones to mobile telemedicine (WHO, 2011).

One of the preferred mobile application features is text messaging by SMS, which is a very common way of providing reminders for treatment compliance and appointments (WHO, 2011).

In 2012 about 3.2 billion people used mobile communications worldwide. With an estimated Compound Annual Growth Rate (CAGR) of 4.2 % during the period 2012-2017, mobile subscribers are growing four times faster than the global population. This rate was doubled by the growth of mobile connections to almost 7 billion in 2012, and an estimated CAGR of 7.6 % over the next 5 years, as many consumers possess several mobile devices or use multiple SIM cards (GSMA, 2013).



Figure 2: Compound Annual Growing Rate of mobile connections. Source: GSMA and A.T. Kearney (2013)

A 54 % mobile penetration in Sub-Saharan Africa (SSA), emerging from a CAGR of over 36 % over the last 12 years, provides a significant example of how developing countries are accelerating the process of mobile penetration (GSMA, 2012).



Figure 3: Mobile Connections, Population and Mobile penetration in SSA. Source: GSMA & Deloitte, Sub-Saharan Africa Mobile Observatory (2012) Data confirm that an effective channel for healthcare services delivery is already in place, without requiring users to be specially trained for this.

In Italy mobile use is even better established, and mobile penetration is close to its saturation point. More than 97 % of people over 16 years old use a mobile phone and in 62 % of the cases this is a smartphone. The preferred feature for users remains text messaging (SMS): it has been adopted by 89 % of mobile users (Nielsen, 2013).

The SMS can provide a suitable mechanism to bring a mobile PHR into people's daily lives and to get them more involved in their adoption. SMS services are becoming key applications used by many healthcare providers in Italy with the purpose of reaching patients' attention, especially in the area of appointment reminders (Politecnico di Milano, 2009).

Several different successful experiences of the use of SMS services addressed to citizens have been surveyed in the Veneto Region of Italy: six local health authorities send notifications by SMS or voice messaging to remind patients of their clinical appointments. In the local health authority of Asolo the service has demonstrated to be effective with about a 33 % reduction of no-show episodes two years after its introduction.

The Hospital Trust of Padova gives citizens the possibility to book the time slot they prefer for a blood test (such a test usually cannot be booked in advance, which as a consequence forms a long queue). Citizens receive a notification by SMS confirming the exact time when they have to show up at the outpatient clinic: this appointment-setting has the double aim of saving time and minimising the length of the queue.

The service is accessed by mobile phone in 74 % of the cases, while in the remaining 26 % it is accessed through the hospital trust web portal.

Thanks to the regional project, Veneto ESCAPE, since 2012 all Veneto's five million citizens have been able to download their medical report from the Internet. During a medical visit or clinical examination the patient receives a paper reminder with the link and one-time credentials to access the medical report online once it is available on the local health authority's web portal. The service has proven to be well accepted by users, with 60 % of reports being downloaded (Arsenàl.IT, 2013).



Figure 4: Download rate of medical reports in the local health authorities of the Veneto Region

In the wake of this success, the local health authority of Treviso has designed a specific mobile app as an alternative to deliver this service. Six months after its introduction, 1.6 % of the medical reports produced are downloaded by mobile phone, confirming the growing trend to use this second option.

# 4. The Veneto Region approach to the personal Electronic Health Record

In the Veneto Region, all the local health authorities are joining their forces in order, in the year of 2015, to achieve the interoperability platform that will transform the already-existing, but fragmented, local EHRs in a regional Health Information Exchange network for clinical data-sharing on a regional basis.

This development is happening thanks to a bottom-up approach that is intended to make the future regional EHR a working tool capable of answering the health professionals' needs in the most efficient way. The system has been based on a pre-existing infrastructure connecting primary care physicians (general practitioners and paediatricians) with their local health authority. Starting from this platform, the first module in the implementation of the EHR is the complete dematerialisation of the prescribing cycle. There is a full automation of processes from the general practitioner or paediatrician prescription to the final drug delivery in the pharmacy - in case of medication - or to the appointment booking - in case of referral for a diagnostic test or outpatient visit. This initial phase will involve all prescribers (i.e., those who are involved in writing out medical prescriptions) in the Veneto Region for a total amount of 60 million prescriptions each year. 90 % of these prescriptions must be paperless by the end of 2015, according to the Ministerial Decree of 2 November 2011 (Ministero dell'economia e delle finanze, 2011).

Within the regional EHR program, strong attention is also paid to making the citizens part of the process, by giving them the possibility to access medical information and to interact directly with the healthcare system. There is, however, the evident matter of concern about PHR adoption, which has not met expectations in the other regions and countries that have already implemented it, regardless of the specific features and models considered.

The successful experience of the Veneto ESCAPE initiative, with its 60 % download rate of medical reports from the Internet, has shown that it is possible to catch citizens' attention once they are provided with easier access to the service. The aim is to develop a PHR solution that embeds a wide range of online services that not only address people's real needs, but are also well aligned with their skills and habits.

The ePrescription service is considered to be the first potential opportunity to engage citizens in the use of their PHR. The shift to the digital management of prescriptions allows the implementation of automatic notification services to remind patients of their scheduled appointments or drug consumption. Mobile technology can act as the catalyst to stimulate patients' interest without requiring any additional form of training, given that IT literacy and personal computer use can be considered significant barriers to PHR adoption (University College London, 2010), especially with elderly people. A recent regional survey within the Renewing Health project confirmed that 87 % of people over 65 years old are not confident about using a computer, while only 61 % are used to handling mobile phones<sup>2</sup>.

Data about mobile penetration along with the successful local experiences of mHealth applications in the Veneto Region have made mobile technology the preferred channel for the regional notification service for appointments booking and reminders sending.

<sup>2</sup> Elaboration from internal data collected within the context of the Renewing Health project.

European Journal of ePractice · <u>http://www.epractice.eu/en/journal/</u> N° 20 · November 2013 · ISSN: 1988-625X

## 5. mBooking and reminders for healthcare appointments

Today the most common way to book an appointment in the Veneto Region is still to have direct access to the booking office. 70 % of citizens still prefer to speak face-to-face to schedule an appointment. The second most frequent alternative is by phone. Some local health authorities provide a dedicated online service accessible through its own web portal. However, the proportion of appointments booked through this means is negligible: in most cases it does not exceed 2 % of the total bookings.

The adoption rate of online bookings in the Veneto Region is shown in the figure below. The percentage displayed (up to 5 %) is calculated on the total amount of operations performed.



Figure 5: Adoption rate of online booking in Veneto Region

In the context of the regional EHR project, an mBooking service will be implemented in the first semester of 2014. Its overall aim will be to reduce the workload of healthcare operators and save time for citizens by allowing them to book an appointment anywhere at anytime. The service will be fully integrated in the ePrescription workflow, and will be triggered by the prescribing doctor during the outpatient visit. The precise, several-stage, process is described here: the prescriber's electronic medical record (EMR) sends the eReferral request to a regional repository and workflow manager; this then forwards it to the local health authority booking system; it in turn notifies the patient by SMS of the first available appointment for that health service and a phone number to be called if the patient needs another appointment date. In the case of prescriptions with a low priority this process will be synchronous: it will allow the patient to receive the notification even before having left the general practice or the outpatient clinic. If the referral deals with a more complex and urgent service, a back-office intervention is usually needed. The SMS is thus sent after one day. The patient can either confirm the appointment within a given deadline just by answering the SMS or calling the booking number to reschedule another appointment. The same notification system will also send an

SMS to the patient to remind him/her about the appointment a few days before the scheduled date. After having used the healthcare service, the citizen will receive another SMS notification as soon as his/her medical report is published in the EHR, and is therefore available through the PHR. The SMS text will also include the link to the PHR to let the citizen access the clinical document directly through mobile phone.

Nevertheless, some diagnostic exams, such as lab tests, cannot be booked in advance. As a direct consequence, this leads to the creation of long queues in the waiting room. In this case, the citizen can use a different mBooking service to book the time slot during which he/she would like to have the lab test and subsequently receive an SMS confirmation about the exact time of his/her appointment. The successful solution developed in the Hospital Trust of Padova will be then deployed at a regional level and integrated into the PHR.

An SMS will be just the first channel to deliver such services, as it is still the mobile functionality most adopted by users. The implementation of the regional EHR will allow it to tether a rich assortment of cutting-edge mobile apps to the direct access of booking agendas and for the patient to choose the best date/time for the appointment or examine clinical documentation within the PHR autonomously.

## 6. Conclusions

Even if PHRs have an enormous potential to improve patients' healthcare access to data and lead to their empowerment, the adoption of these systems is still relatively slow. Nevertheless, there is a continuous evolution into more sophisticated models of healthcare data that integrate data flows from different sources. The reasons for this lag can range from a lack of awareness, concerns about data confidentiality and security, or simply the poor attraction power of these solutions.

Mobile services can contribute to changing consumers' behaviour. The technology is already in place. Almost half of the worldwide population owns a mobile phone and the percentage of smartphones is growing very rapidly. This phenomenon does not only involve advanced countries but also the developing world, where the mobile phone is bypassing traditional telephony systems and allowing people to communicate across vast geographical distances. A simple SMS can be a cost-effective means to capture the attention of a potential user, regardless of his or her age, level of education or place of residence.

In the Veneto Region of Italy, several local health authorities already provide mobile healthcare services to their population, especially as reminder notifications. They have proven to be well accepted by citizens and useful in reducing the health operators workload. If combined with the access to healthcare information included in an EHR, mHealth can bridge the gap between citizens and PHR services. This is the general approach that the Veneto Region is following with a view to implementing its regional health information exchange platform and opening it up to the citizens. The intention is not simply to repackage a web portal as a single all-in-one app that has the advantage of providing a portable solution, but also to optimise it to include all the powerful features that the desktop alternative has.

As text messaging (sending an SMS) is still the mobile feature that is most popular among citizens (and it does not require any particular IT literacy), the SMS has been chosen by the Veneto Region as the initial driver to start involving the user in eHealth, by making him/her part of the ePrescription workflow that will constitute one of the main processes to underpin the regional EHR platform.

mBooking is the first initial example of how a mobile phone can be more effective in gaining the citizens' attention (it can revolutionise the traditional pattern of usage of the user). It is the service

that manages to find the user, exactly when and where it is needed. There is not even need for an advertising campaign to promote the PHR services' adoption, its scalability is ensured only by the data that refer to mobile penetration. The SMS feature can be adapted to many other applications. It is the main channel to deliver notifications, and it can be the first point of contact that links to the medical reports viewer before consulting the practitioner.

The second step will be to follow the dynamic mHealth market that offers an extensive variety of user-friendly and targeted healthcare apps that can be adjusted and customised to reproduce each single PHR feature. This will give users more autonomy in interacting with the EHR system and managing their own health information.

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# The Clinical, Epidemiological and Financial Benefits of Telecardiology

Telecardiology is the use of information and communication tools to facilitate the practice of cardiology when the patient is separated from the healthcare provider by considerable geographical distance. This review of prehospital and posthospital applications aspires to analyse the uses of telecardiology in the diagnosis and timely treatment of cardiac diseases. Several studies have demonstrated that telecardiology, when applied to the diagnosis of acute coronary syndromes, significantly reduces the time to primary coronary angioplasty, thus increasing both the survival rate and patients' quality of life. Moreover, in patients with atrial fibrillation, a telecardiology application can lead either to the diagnosis of the first episode or to treatment modification for patients with the chronic form of the disease. Furthermore, in patients with heart failure, telecardiology monitoring may lead to a significant reduction in hospital admissions. Telecardiology contributes to the close and constant monitoring of patients at high risk of malignant arrhythmias and sudden death, such as cardiac arrest survivors, discharged patients with a myocardial infarction and patients with cardiomyopathies. In conclusion, telecardiology may play a significant role in reducing distance and time between people who are in need of healthcare services and their healthcare providers, with evident clinical, epidemiological and financial benefits.



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#### Keywords

acute coronary events, arrhythmias, heart failure, sudden cardiac death, telecardiology

<sup>66</sup>Telecardiology, a new era in the early diagnosis of heart disease.

Greece

## 1. Introduction

Telecardiology is the use of information and communication tools to facilitate practice of cardiology where doctor and patient are separated by a large geographical distance (Saxena et al., 2003; Kastania et al., 2008).

Since the first broadcast of an electrocardiogram in March 1905 by Wilhelm Einthoven (Hjelm & Julius, 2005) to date, patient monitoring has evolved and has lately progressed from a single local area network (LAN) connection to wireless systems, which use complex compression methods, signal processing and automatic diagnosis (Kastania et al., 2008; Skretting et al., 2005; Ziarani & Konrad 2002; Laguna et al., 1990). The evaluation of the need, the requirement for the application of a telecardiology approach and the implementation of a service of telecardiology, requires overall planning and development.

The reasons for using telecardiology for consultative providers include their need to develop access for patients through which it can:

- provide access to the local population;
- provide services through this access area in a cooperative manner;
- strengthen the involvement of patients by informing them about the services available and the quality of these services;
- reduce useless transfers to tertiary care providers;
- provide support to doctors;
- increase the use of local support services.

Telecardiology is best developed as a component of an integrated health system. The access area for patients should monitor control of referrals of patients and optimise the checks carried out in the area of access and other procedures offered locally.

Telecardiology applications can be divided into various types: a) prehospital, mainly aimed at early diagnosis of acute events such as acute myocardial infarction and life-threatening arrhythmias with the intention of transmitting this information to the experts prior to arrival of the patient at the hospital; b) hospital-acquired, aiming at synchronised action between small health units and a main hospital centre so as to provide specialised diagnostic and therapeutic approach for the patient, e.g. to perform an emergency tele-ultrasonography; c) post-hospital, including teleconferencing between general practitioners and cardiologists and ambulatory monitoring of chronic heart disease and arrhythmias (Scalvini & Glisenti 2005). Telecardiology is an important diagnostic tool because it offers real-time information on emergency treatment of acute cardiac events while helping to secure and continuously monitor chronic cardiovascular disease.

In this review we attempt to classify the uses of telecardiology. We also state that it remains necessary for the evaluation of telecardiology applications to study individual correlations with each cardiac disease.

## 2. Applications of telecardiology

This part of the review examines how telecardiology can assist in four separate types of cardiological events: acute coronary events, atrial fibrillation, heart failure and sudden cardiac death.

### 2.1 Telecardiology and acute coronary events

Coronary heart disease remains the leading cause of mortality and morbidity in developed countries. In European countries it constitutes the leading cause of death in men aged over 45 years old and women over 65 years old, while in the US it leads to 640 000 deaths per year. Worldwide, about 7.2 million people die each year from coronary heart disease, even more than those who die from cancer and infections (Tsipis et al., 2013). Emergency percutaneous coronary angioplasty in patients with myocardial infarction is the cornerstone for their survival. In addition it improves the quality of life of survivors because it minimises the extent of myocardial necrosis.

Telecardiology contributes to early diagnosis of acute coronary events by reducing the time of their treatment, thus contributing significantly to patient survival. Several studies on telecardiology and acute coronary events in both Europe and the US have been conducted during the early 2000s.

Schwaab et al. (2003) evaluated the diagnostic sensitivity and specificity of transmission over a telephone line of 12-lead electrocardiogram (ECG), a Tele-ECG, model CG-7100 and Card Guard in 130 patients with acute coronary syndrome. The transmission of the ECG was evaluated by two cardiologists and an internist and was compared with the conventional ECG held at the same time of the ischemic episode. In 98 % of the patients the quality of the ECG was appropriate for use, while the correlation between the two types of ECGs for the detection of old myocardial infarction elements and successful diagnosis of acute myocardial infarction were very high (Schwab et al.; 2003). In a similar study Mischke et al. (2005) investigated the diagnostic reliability of ECG transmission through a telephone line in 37 patients with myocardial infarction. The correlation between the two types of ECGs was 96 % in limb leads and 88 % in precordial leads, while there were no false positive diagnosis of acute myocardial diseases is primarily based on alterations in the morphology of specific waves and segments depicted on the surface ECG. Furthermore, an ECG is obtained by placing leads on the chest and limbs, literally recording the electrical activity of the heart as this is manifest on the skin's surface.

The TeleGuard study applied in Germany, recruited 11 hospitals and 1 500 patients with coronary heart disease, who were divided into two groups, one involving remote monitoring (752 patients) and a second one consisting the routine monitoring group (748 patients). Patients were able to record and transmit a 12-lead ECG and, at any time, in the presence of symptoms, call and consult the medical centre. During 12 months, 23 % of patients on telemonitoring contacted the medical centre, and the most commonly reported symptom was heartburn. 23 % of the calls were made within the first hour of the onset of symptoms, while 12 % were made in the subsequent period. About 24 % of ECGs broadcast to the centre showed pathological findings. A number of 157 patients (21 %) had a myocardial infarction and were driven into a reperfusion technique, while the rate was higher in all patients under telemonitoring versus those in routine monitoring (35 % versus 17 % respectively) (Katalinic et al., 2008).

The five-year ST SMART Study (Synthesised Twelve-lead ST Monitoring and Real-time Teleelectrocardiography) held in California in the USA, was designed to monitor the ST-segment of the ECG in patients with acute coronary syndrome and its transmission through electrocardiography from the ambulance to the hospital centre. The average time from the first recording and transmission of ST-segment elevation in the ambulance to angioplasty onset was 83 minutes, while for patients with no telemonitoring the corresponding time was 160 minutes. Furthermore, a greater percentage of patients with acute coronary syndrome initially presented arrhythmias (30.3 %) compared to patients who were tested with ECG after arrival at the hospital (26.5 %). Timely recording and broadcasting of changes in the ST-segment led to an immediate reduction of angioplasty in patients with acute myocardial infarction thus improving the patients' life expectancy (Drew et al., 2006).

The ECG transmission is a method of high diagnostic value, which accelerates decision-making by experts and contributes to the effective and rapid treatment of acute coronary events in patients. Telecardiology, consequently, reduces the effects of ischemic damage in myocardial tissue and improves cardiac function with the ultimate aim of increasing patient survival and improving quality of life for survivors.

## 2.2 Telecardiology and atrial fibrillation

Atrial fibrillation is one of the most common tachyarrhythmias and is often an incidental finding in patients without known cardiac disease. However, no accurate epidemiological data exist. The rate of developing atrial fibrillation in people aged less than 50 years old is estimated at around 1 % of the general population and it further increases in older people.

In 2001, 655 doctors participated for ten months in a large study conducted among the Italian population with the purpose of investigating atrial fibrillation. Atrial fibrillation was diagnosed in 719 patients (9%), 488 among them suffered from chronic atrial fibrillation, while 271 patients experienced their first episode of the condition. In the chronic cases of atrial fibrillation, teleconferencing among participating general practitioners (GPs) and specialised staff had the following results: 35 % of the patients needed no further treatment, 43.5 % modified their medication, 10.5 % needed additional diagnostic tests. In the cases of first episode of atrial fibrillation, 46.9 % of the patients were treated in the emergency department, 39.1 % modified their medication, and 7.5 % needed additional diagnostic tests (Scalvini et al., 2005).

In the EPI-DEMICS research (Rubel et al., 2005) conducted in France, Sweden and Italy, during the period between 2001-2004, a Personal ECG Monitor (PEM) was used with three leads (I, II, V2). The medical data were transmitted through mobile phones to a download and recording centre, with the purpose of providing an early diagnosis of arrhythmias. A part of the research took place in Lyon, France, where 50 patients were being monitored for arrhythmic episodes at their place of residence. The average recording was around  $12\pm6.1$  ECG for each patient: 97 % of the samples were suitable for evaluation. 20 % of the patients developed episodes of paroxysmal arrhythmia, such as supraventricular tachycardia, atrial fibrillation, atrial flutter, while for some patients, who were included in the research after having experienced a sense of palpitations, telemonitoring led to a first diagnosis of the arrhythmia episode.

Telecardiology can provide patients suffering from chronic atrial fibrillation with personalised monitoring and treatment. Furthermore, it helps significantly in the diagnosis and management of patients suffering an episode of arrhythmia for the first time.

## 2.3 Telecardiology and heart failure

In developed countries, heart failure percentages range from between 0.3-2 % in the general population and between 8-16 % in people aged 75 and older. According to the Framingham study, there is a clear exponential relationship between age and heart failure (McKee et al., 1971). Adding the high morbidity rate (45 hospital admissions annually per 100 patients with heart failure) and the high mortality rate (50 % in five years, almost the same rate as malignant tumours), it is understandable why heart failure is a major medico-socio-economic problem (Tsipis et al., 2013). The evaluation of the patients' quality of life is a relatively new scientific analysis, involving the efficacy of medical and nursing intervention, as well as the progress of the disease.

Scalvini et al. (2005) in the Boario Home Care study, which took place in Lombardy, Italy, investigated the efficacy of telecardiology in monitoring patients at their place of residence. The study involved 426 patients (230 patients in the remote monitoring group, 196 who received the usual healthcare monitoring). The remote monitoring group was equipped with an ECG recording device (1 lead) that had the capability of transmitting the data to a specialised medical centre through phone land lines. Furthermore, the remote monitoring also included frequent visits of the medical staff and patient counselling at the health centres. The results, after one year of monitoring, showed a reduction in the hospital admissions of the telemonitoring group (24 %) in comparison to the usual healthcare group (34 %). The telemonitoring group had an improved quality of life and their respective total healthcare costs were also reduced (Scalvini et al., 2005; Giordano et al., 2009).

More specifically, the conclusion of the ten-year Boario Home Care study about the advantages of telemonitoring in heart failure were as follows: a) 35 % reduction of hospital admissions and 12 % hospital visits for cases not requiring hospital care, b) 99 % fewer patients visiting their GP due to the efficacy of telemonitoring, c) an 8 % increase in patients visiting their GP in order to start or modify their treatment, d) less time waiting for the beginning or the modification of the treatment (15 days less for 14 % of the patients), e) a decrease both in time and cost of transferring patients f) a stronger feeling of safety both for the patients and their family, and g) a better quality of life of patients and their family (Scalvini et al., 2006).

Louis et al. (2003) arrived at similar conclusions in an extended review of the international literature (covering the years from 1996-2002) concerning the advantages of telemedicine in heart failure management: a) a decrease in hospitalisation time, b) a decrease in the frequency and the possibility of admittance to hospital, c) reduction in total hospitalisation costs, d) a higher quality of life for patients, e) early diagnosis in cases of deterioration of heart function, and g) a mortality decrease by six months in patients whose vital signs and symptoms were under monitoring.

Telecardiology plays a significant role in the strategy of treating diseases and management of patients suffering from heart failure. The benefits have an impact both on the patient as well as on health care infrastructures. The patients' quality of life is improved, their functional ability in daily life activities is maximised while simultaneously addressing socio-economic issues effectively.

## 2.4 Telecardiology and sudden cardiac death

Sudden cardiac death is an unexpected condition. It happens either instantaneously or one hour after experiencing symptoms either by a seemingly healthy person or by a patient who is aware of his/her condition which was otherwise steady or improving. The most common cause of sudden cardiac death in people aged over 35 is coronary disease, while in people under 35 years of age the most common causes are cardiomyopathies and especially hypertrophic cardiomyopathy.

In Olmsted County, Minnesota, in the US, 3 296 cases of myocardial infarction were reported between 1979 and 2005 (2 997 patients survived). In a period of 4.7 years after hospital discharge, 1 160 deaths were reported and 282 (24 %) deaths were classified as sudden cardiac deaths, while 35 among them occurred 30 days after hospital discharge. After this period, the rate of sudden cardiac death was stable at a range of 1.2 % annually (Adabag et al., 2008). The use of an implantable defibrillator reduces the death rate caused by arrhythmias; however, a large number of deaths occurred due to heart failure.

Chadda et al. (1986) studied the role of telecardiology in detecting harmful arrhythmias in cardiac arrest survivors after hospital discharge. Nineteen patients were under remote monitoring through phone land lines and 28 patients were receiving the usual treatment. Ventricular arrhythmia was diagnosed in 78 % of the patients under remote monitoring. One death in 19 patients was reported under remote monitoring in 15 months, while 18 deaths were reported in 28 patients under the usual treatment (Chadda et al., 1986). The results were independent of the systolic function and ejection fraction, amiodarone treatment and the outcome of electrophysiological study.

Telecardiology contributes to the close and continuous monitoring of patients with a high risk of harmful arrhythmias and cardiac arrest, in this way it reducing greatly the mortality rate. In parallel, it contributes to early diagnosis in cases of cardiac function deterioration, and to managing patients with heart failure and a high risk of developing sudden cardiac death.

## 3. Conclusions

Telehealth is not just about technology, but is a means for the clinical treatment of patients.

In this sense, the most critical factor for a successful initiative in telehealth is the development of interpersonal relationships. Furthermore, maintaining the human factor, while 'visiting' patients through telehealth, is of vital importance both for the patient and the provider. Programming telehealth services is related to both the ethos and financial motives of health systems and providers, with the intention of reducing access barriers to healthcare of populations who live far away from healthcare facilities. It is self-evident that specialised staff members are important for an efficient, effective and accurate intervention by the provider through telehealth technologies. Functional programming should include an examination of current practice and the identification of the variables that have to be modified for the purposes of telehealth. Finally, the solutions offered by telehealth have to be easy to use and available in the clinical work area of the provider.

Telecardiology contributes to overcoming the obstacles of distance and time between those people who need healthcare providers and those who can provide healthcare services, with evident clinical, epidemiological and financial benefits.

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# Empowering Patients and Promoting Collaborative Practice through mHealth Applications in Psychiatric Care

The use of mobile health (mHealth), a field of technology that integrates mobile devices into patient care, has valuable implications for all areas of clinical practice. The rise in mHealth systems in mental health in particular is a promising development as it provides opportunities for patients to increase their engagement with their treatment, while also affording them greater power over their own treatment process. mHealth is valuable in all areas of medicine, but it is perhaps needed most in psychiatry, as the experience of a mental health disorder is so potentially disempowering. However, the effectiveness of mHealth systems in psychiatric care is dependent on factors such as the use of appropriate outcome measures, the willingness of staff and patients to incorporate such systems, and the technology itself.

The implementation of a mHealth system at Perth Clinic, a private psychiatric hospital in Western Australia, has allowed for real-time monitoring of patient progress, data management and the timely delivery of individualised feedback on a large scale. The real-time monitoring and provision of feedback on patient progress are especially important applications of mHealth in psychiatric care, as they are associated with a range of positive implications regarding treatment outcomes in patients. Therapists can use real-time data from mHealth systems to make treatment more responsive for individuals facing poor outcomes, instead of trusting particular treatment approaches to work. mHealth systems can be used to promote greater collaboration between patients and therapists.

Growth in mHealth is not only driven by advances in technology, but also by the people who use it. Flexibility is an integral aspect of any progress monitoring system that can be increasingly facilitated through the application of mHealth in a straightforward and cost-effective manner. The flexible nature of mHealth, which increases patient engagement and empowerment in the treatment process, confirms its key role in enhancing future interactions between patients, staff and management, while improving clinical practices and outcomes.



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#### Keywords

mental health, mobile technology, patient monitoring, patient feedback

<sup>66</sup> mHealth has the potential to improve empowerment among patients with mental health difficulties.

## 1. Introduction

mHealth is an emerging field of healthcare technology that incorporates mobile applications (e.g., mobile phones, iPads, and other wireless devices) into patient care. The rise of such mobile applications in mental health has created an opportunity to increase patient engagement with treatment, while affording patients greater power over the processes involved in their own treatment. mHealth is valuable in all areas of medicine, but it is perhaps needed most in psychiatry, as the experience of a mental health disorder is potentially disempowering for patients. The American Psychological Association (2006) identified the provision of 'real-time patient feedback' to benchmark progress in treatment and clinical support tools to adjust treatment as needed as a pressing need in psychology. mHealth also enables such a system to be implemented without requiring clinicians to become 'technicians'.

While the current paper outlines the application of mHealth in psychiatric care, mental disorders do not remain the sole domain of psychiatry, as they are also prevalent across general health services. Thus, mHealth has an extended capacity to reach many areas of health care related to mental health.

## 2. mHealth in an inpatient psychiatric facility

Arguably the greatest benefit of implementing mHealth in psychiatric care is its potential to enhance therapist-client interactions. In traditional clinical settings, patients consult clinicians at therapy sessions, during which clinicians obtain information about the patient's progress via the process of enquiring about the patient's current state. Such information gained from interactions with patients guide clinicians' decisions regarding treatment. As such, the locus of authority over treatment often tends to reside with the clinicians, as opposed to patients.

The application of mHealth however, facilitates a shift of power over treatment direction from clinicians to patients themselves. Patients can provide information about their progress in a self-dictated manner using a mobile format. Data obtained from such a mobile system can then be scored and presented back to patients and therapists in real time, enabling patients to collaborate with their therapists to make treatment decisions based on current information. The use of mHealth systems to monitor patient progress effectively encourages patient empowerment in psychiatric care by giving patients ownership over the information they choose to supply to therapists, while guiding and improving the treatment decisions made by therapists. Thus, the patient moves from being a passive recipient of healthcare to an active participant in the assessment of their own progress. Awareness of progress (or its lack) can encourage the patients to take a greater role in the decisions about their healthcare.

Perth Clinic is a psychiatric hospital in Western Australia. Operating as part of the non-government health sector, the facility treats inpatients and day-patients who present with a range of conditions, but predominantly mood and anxiety disorders. Various treatments (including pharmacotherapy and psychotherapy) are delivered by doctors, nurses, and other mental health professionals. In the context of treatment being delivered by a team of professionals, mHealth permits the monitoring of mental health patients' progress throughout therapy and the timely delivery of this information to all relevant staff.

In physical medicine, a thermometer functions as a quick way to assess health status. An abnormally high reading signals that something is amiss, prompts staff to identify what is wrong and consider if the treatment course needs to be reconsidered. At the heart of the Perth Clinic's mHealth system is an electronically delivered questionnaire that can be described as a 'mental health thermometer.'

## 3. Foundations for implementing mHealth for patient monitoring

The effectiveness of technological applications in clinical settings rests on the use of both appropriate measurements and accurate reference points for benchmarking patient status. This means that just as a thermometer needs both a method of measurement and an ability to distinguish abnormal from normal readings, so does also a 'mental health thermometer'.

The measure of psychological well-being utilised by the touchscreen technology in the Perth Clinic is the World Health Organization's Well-Being Index (WHO-5; Bech, Gudex, & Johansen, 1996), a fiveitem scale of psychological health comprised of positively worded statements relating to functioning over the past 24 hours. The WHO-5 is quick to administer, and is a reliable, valid, and repeatable measure of patients' functioning status (Newnham, Hooke, & Page, 2010). Each patient's WHO-5 scores are plotted against an expected treatment trajectory based on the patient's initial severity upon admission, which can then be used as a benchmark to gauge individual progress. A patient's progress can be classified as being either on-track or at risk of a poor treatment outcome depending on its position within the trajectory on a certain day. A companion symptom measure has recently been developed that complements the monitoring of well-being by tracking core symptoms (Dyer, Hooke, & Page, in press).

In addition to the selection of appropriate measurements of patient progress, valid methods of calculating the clinical significance (Jacobson & Truax, 1991) of a patient's treatment outcome are essential for the successful application of mHealth to monitoring in psychiatric care. Monitoring involves identifying when patients are either making expected progress (i.e., are on-track) or at risk of treatment failure (i.e., not-on-track). Distinctions between patient outcomes therefore need to be based on clinical significance if they are used to make clinical decisions (Ronk, Hooke, & Page, 2012). The concept of clinical significance allows the quantification of how reliable and how meaningful a patient's change is, producing four categories of status that can be listed as 'recovered', 'improved', 'no change', and 'deteriorated'. The use of clinically significant classifications in conjunction with appropriate outcome measures enables mobile patient monitoring systems to be implemented in a meaningful manner.

## 4. Delivery modes of the mHealth system

Within the inpatient programme, we have used three technological models to monitor patients. The questionnaire delivery is where mHealth has been most useful as the questionnaire is programmed in .NET and accessed via mobile technologies in one of the modes.

**Touch-screens:** The first delivery model, which served as a starting point from which externally accessible mobile monitoring systems have evolved, uses 15-inch Wyse thin client computers linked to touch-screens that are installed in each therapy room Patients access the touchscreen in a locked down kiosk mode. Patients log on to the system with a password-protected unique identifier, and questions are presented to them one per screen until the questionnaire is completed. The security of confidential patient data is assured because no information is stored on the thin client computer; instead, the responses are fed back to the hospital's database. The benefit of this delivery model is that the data collection can occur in the therapy room. Consequently, staff members can prompt the patients to complete the questionnaire and they are available to discuss the results immediately and incorporate the information into the treatment plan. The chief obstacle occurs with group therapy, as patients need to queue up to use the screen. It was these difficulties that encouraged the shift to implementation via mHealth.

Tablets: The second delivery model is where the patient can access the questionnaire via a mobile tablet device within the hospital grounds using a Wi-Fi network. Nurses can provide patients with the mobile tablet, which is loaded with software, thus enabling ready access to the questionnaire (alternatively, the software can be installed on patients' personal devices). The software installed on the tablet also has the capacity to allow the patients to access additional services (e.g., hospital information, menus and meal orders, timetables of therapeutic activities, and material relevant to the particular therapy the patient is participating in). The main benefit is that patients who may be too unwell to leave their rooms can still provide information to staff about their progress, but the drawback is that staff may not be immediately available to interpret and discuss the results.

**External Mobile Access:** The third delivery model involved a trial of people accessing the questionnaire from their own device outside the hospital. Using this model we have decided not to provide information back to these people about their progress until they return to the hospital for two reasons. First, it means that de-identified questionnaire scores are transmitted to the hospital. Since no information is sent back to the patient, it is impossible that any patient-identified information can be accessed by a third party. Second, it maximises the security of the hospital's database because patient information can be stored on a separate server. Hence the risk of a cyber-attack through the portal used to collect the data is minimised. The benefits of this delivery model are that day patients can complete the questionnaire from home. It would also be possible for inpatients, once discharged, to continue to provide information about their progress which could then be monitored by their treating doctor.

Each of these three technological solutions allow the questionnaires to be completed daily and the resulting scores to be scored, graphed, and communicated to therapy staff. In a large mental health clinic, many people are involved in the care of each individual and this ensures that the monitoring information can be provided in a timely manner to members of staff throughout the hospital and delivered in a manner that is suitable for each stakeholder. That is, different staff can receive information concerning just the patients they are treating, nurses and doctors on a ward can see the profiles of their patients, and hospital management can observe broader-level trends.

## 5. Impacts on treatment outcomes

The application of mHealth in psychiatric care increases the capacity for therapists to make more effective decisions based on the treatment responses of individual patients. mHealth systems allow for the real-time monitoring of patient progress, data management and the timely delivery of individualised feedback on a large scale. The monitoring and provision of feedback on patient progress are particularly important applications of mHealth in psychiatric care. Rather than relying on particular treatments to create improvement, therapists can instead use feedback from mHealth systems to make treatment more responsive for the benefit of an individual patient if the patient is at risk of facing a poor outcome.

Providing feedback has been found to be beneficial in reducing depressive symptoms in patients at risk of poor outcomes post-treatment (Newnham, Hooke, & Page, 2010). This beneficial effect is consistent with findings from other countries (Bickman et al., 2011; de Jong et al., 2012; Lambert et al., 2001; Miller et al., 2005;), but extends the effectiveness into inpatient and day-patient psychiatric care. Such outcomes indicate the value of monitoring and feedback interventions in enhancing treatment outcomes and preventing treatment failure.

Feedback also appears to have effects beyond the termination of treatment. Readmission can be considered as an indicator of negative outcome following psychiatric treatment. The costs of

readmission are high: patients face a significant disruption to their lives, while the health care system may incur otherwise avoidable and expensive financial costs. Feedback is associated with fewer readmissions following the completion of therapy for patients on track to make clinically significant improvement (Byrne, Hooke, Newnham, & Page, 2012). Thus monitoring and feedback programmes could result in greater cost-effectiveness, as well as clinically meaningful improvement for patients. A future direction for research may examine other aspects of the implementation of mHealth systems that reduce costs in psychiatric care.

mHealth facilitates large scale patient monitoring in psychiatric care, which has already been revealed to benefit treatment outcomes in a clinically meaningful and cost-effective manner. The implementation of mHealth in psychiatric care promotes greater collaboration between staff and patients in treatment. Feedback collected by mobile applications encourages dialogue about treatment progress between patients and staff, providing an opportunity for patients to engage in their own treatment, and empowering them in the process. This process of patient empowerment has been reflected by patient-reported satisfaction with the monitoring and feedback programme. In particular, patients felt that the monitoring and feedback gave them opportunities to discuss their progress with the therapist (with 82 % did not disagree) and identify what they can do to get better (with 88 % did not disagree).

## 6. Barriers to implementation and possibilities for future research

The clinical benefits observed thus far have helped to consolidate the practices of monitoring and feedback within the hospital. However, throughout the on-going administration of the system, several challenges associated with introducing new technologies into routine care have arisen. Given the focus of this paper on mHealth, these challenges to implementation, and their resolution, warrant addressing.

One of the biggest lessons learnt in regards to the implementation of the mHealth system is that the technology does not function independently. For the system to be a sustainable component of the treatment process, it needs to be patient- and staff-driven (Newnham et al., 2012). Correspondingly, maximising coverage of, and access to, the mHealth system has been a priority. Since the touch-screens are located in therapy rooms, patients who do not attend group therapy are not able to complete the questionnaire. These patients tend to be more unwell, have more severe symptoms, or are less engaged in treatment - intuitively, they would be precisely the group whom staff would want to know most about and who would be likely to benefit most from this kind of monitoring. Subsequently, the introduction of mobile tablet devices as a supplement has allowed patients to complete the questionnaire from any location within the hospital. This also provides future possibilities for monitoring patients more frequently throughout the day (e.g., for risk monitoring).

The use of touch-screens and other mobile devices for monitoring has also helped to circumvent therapists' common concerns that patients do not like to complete monitoring questionnaires and that it takes too much time (Pagoto et al., 2007). A survey of patients and staff showed 100 % endorsement of the touch-screen over paper-and-pencil questionnaires (Newnham et al., 2012). Therapists also encourage patients to complete the questionnaire at the start of the day, thus reducing the time that monitoring takes out of any therapy session.

With progress feedback now available to the therapy team, the next step for the hospital is to identify how best to use this information in treatment, and ways to increase the effectiveness and efficiency of feedback delivery within group therapy settings. This is an area of research where clinicians can make the greatest contributions given their clinical experience (Castonguay et al., 2013), and is a promising chapter for the future development of monitoring and feedback technology. At present, it is not clear whether mHealth systems can successfully be applied to monitor the progress of patients with mental illnesses other than those that have the greatest prevalence in the population (e.g., depression and anxiety). While mHealth systems have the potential to be extended in capacity to monitor most patients, there are some classes of patients whose conditions cannot be assessed via self-report. The measures of progress utilised by current mHealth systems do not target symptoms that are best assessed by clinicians. For example, patients who experience symptoms like delusional beliefs and a lack of insight may be more effectively rated by a clinician, rather than information from self-report measures. An additional concern is that some patients, such as those with illnesses that severely impact mental functioning such as schizophrenia, may be too unwell to complete questionnaires.

It is thus important that future research focuses on establishing the boundary between classes of patients that can be monitored using mHealth systems, as well as discovering methods to innovate in the use of mHealth systems in order to extend their capacity to reach a more diverse spectrum of patients as a whole.

Another topic for future research is the ways in which current technology can be expanded to include clinical support tools and aids for data interpretation.

The integration of mHealth systems into a mobile app is an exciting possibility that also warrants further investigation, as it could greatly extend the capabilities of current monitoring systems.

## 7. Conclusions

While mHealth is supported by advances in technology, its growth is primarily people-driven.

The application of mHealth technology in psychiatric care should be flexible in response to patient needs in order to involve and ultimately empower patients in the treatment process. The importance of flexibility in progress monitoring systems has been increasingly acknowledged by the psychological community in order to respond to the needs of each individual patient. Technology enables such flexibility to be attained. mHealth is versatile in its applications to psychiatric care, which are not limited to the psychiatric monitoring of treatment outcomes. Clinicians can also use information from real-time feedback collected by mobile monitoring systems to improve the management of suicide risk and predict patients' risk of self-harm (Doyle et al., 2012).

The implementation of mHealth creates an avenue for increased collaboration between patients, staff, and management. By increasing engagement and empowerment in the treatment process, mHealth has an important role to play in enhancing future interactions between patients, staff and management, while improving clinical practices and outcomes.

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## mHealth Redesigning Healthcare Budgets

Mobile health (mHealth) solutions enter the centre-stage of political agenda with the aim to redesign healthcare systems based on integrated care pathways related to an effective stakeholder engagement. When redesigning health and social care systems in the EU and their financial mechanisms to guarantee quality and safety, it is critical to foster health professionals- and patients-led mHealth solutions, which strengthen integrated care and workforce development.

The EU can turn the rhetoric of jobs-led growth into reality by supporting Member States and stakeholders in designing integrated care pathways and deploying mHealth solutions to facilitate the change of the financing methods currently underpinning the unsustainable healthcare systems in the EU. In order to get lead to the notion of an empowered patient within a patient-centred health and social care system, a new financing system will need to emerge to make healthcare systems accessible and sustainable.



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#### Keywords

health system reform, nurses and nursing, integrated care pathways, financing paradigm shift, integrated care pathways, mHealth, nurses and nursinghealth system reform

66 Mobile health solutions (mHealth) facilitate the data collection for the design of integrated care pathways, freeing up time to engage with patients and safeguarding quality and safety healthcare services by reforming the financing methods underpinning the traditional medical healthcare model."

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## 1. Introduction

Europe needs appropriate and sound investments in nursing care to make healthcare systems sustainable and keep healthcare services accessible and affordable for all citizens (European Commission, 2013). The redesign of the healthcare system is linked to the EU struggle to combat high unemployment levels, labour mismatches, poverty, and social exclusion (EU Employment and Social Situation Quarterly Review, October 2013). Therefore, good examples in of clinical practice pathways that provide evidence of the current opportunity to redesign healthcare systems (based on existing cost-effective integrated care models, and driven by quality and safety), need strengthening and up-scaling throughout the EU (Morlock et al., 2005; Lupari, 2011).

The European Federation of Nurses Associations argues that it is socially and economically unsustainable to maintain the traditional vision of healthcare delivery, which mainly focuses on curative and medical care approaches (EFN, 2012). Instead, the integrated care pathway (ICP) approach anticipates that care will be placed in an appropriate time-frame of an integrated process, and written and agreed by multidisciplinary teams based on the analysis of clinical data that shows evidence that the care is cost- effective, of high quality and safety. ICP approaches display agreed evidence-based standards to help a patient with a specific condition to move progressively through the clinical experience.

mHealth should therefore take up a more prominent role in documenting the care given to design cost effective integrated care pathways (ICPs) (National Leadership and Innovation Agency for Healthcare, 2005; Hauser et al., 2007, Nilsson et al., 2010). For example, implementation of an ICP for the care of patients with Chronic Obstructive Pulmonary Disease (COPD) can improve patient outcomes, despite the tendency of COPD to worsen over time (Dajczman et al., 2013).

By using mobile and wireless devices to improve health outcomes, the financial models underpinning EU healthcare systems require a shift from the current quantitative financing methods based on Diagnoses Related Groups towards a financing methodology incorporating indicators that capture integrated care and patient empowerment alongside quality, safety and cost effective patient outcomes.

The increasingly ageing population, chronic illnesses and comorbidity require the design of ICPs to ensure continuity of care in an un-fragmented health and social care system (Specchia et al., 2013). The coordination between the two current silos - hospital and community care - based on a holistic view of the 'social and health care lifecycle' needs to benefit from mHealth. Interventions that reduce attendance at hospitals and health centres, as well as readmission rates, can only happen with the coordination of social, community and institutional care teams (Venter et al., 2012). This coordination of integrated care needs to happen at the bedside, not remotely from the patient, carers and family. It needs to be provided in the community's delivery environments and not in dispatch centres, located away from the setting where care takes place. As such, mHealth solutions should become a support tool to develop a more generic and holistic financing method to design sustainable healthcare systems in the EU.

## 2. mHealth Creating New Financing Methods for Sustainable Healthcare Systems

The Diagnoses Related Groups, measuring only medical components of service delivery, drive healthcare systems to decrease hospital stays. This results in an inevitable moving of complex care to community and home care settings, which have difficulties in responding to this demand, while keeping a high quality and safety standard (Kahn et al., 1993; Braga et al., 1999; Harris, 2004; Forgione et al., 2004; da Nóbrega et al., 2009). Although the Diagnosis Related Group (DRG) system is widely implemented in benchmarking and financing healthcare systems in many EU Member States, the increased percentage of GDP shows that currently medical diagnoses and services mainly determine healthcare costs and ignore the cost-effective nursing and social care services in prevention and the existing cost-effective integrated care models (Entin, 1987; Sanford et al., 1987; Raso et al, 2000; Labrig et al, 2003; Schreyögg et al, 2006; Mayes, 2007; Stausberg et al, 2010; Lupari, 2011; AHCA, 2012; WHO, 2013).

In contrast to the DRG financing system, the International Classification for Nursing Practice (ICNP®) a common terminology for nursing care - is not recognised as a method to improve the sustainability of the healthcare systems in the EU. Although ICNP is a tool that allows documentation of the clinical practice of nursing and provides support for clinical reasoning and decision-making, nursing sensitive data are still invisible in health statistics and even in patient records (da Nobrega et al., 2011). Therefore, when redesigning healthcare systems in the EU, the financing methodology underpinning the sustainability of the healthcare system should deploy quality and safety nursing indicators as part of the designed integrated care pathways. Findings show that the use of evidencebased care pathways can turn the entire health and social care sector into a key driver of well-being, productivity and growth (Hindle & Yazbeck, 2004 and 2005).

## 3. A harmonised approach to design integrated care pathways

'Evidence-based integrated care pathways' is the ambitious term used for any care pathway designed by best practices that coordinate the care process and the patients' outcomes achieved. Although documentation, monitoring and evaluation of outcomes are central to the design of evidence-based pathways, the communication between the different sectors on the continuum of care is key to re-centre the focus on the patient's overall healthcare journey (Vanhaecht et al., 2007; Bandolier, 2013). Enhancing the quality and safety of care and improving the development of care partnerships, alongside the empowering of patients and carers, need more attention with the use of mHealth solutions. Areas of particular importance for nursing are: the enhancement of teamwork by means of digital technology, the common use of terms, semantics, concepts, frameworks and theories in nursing through ICNP, the support of clinical decision-making when employing mHealth nursing care pathways and the empowerment of patients and carers through the use of eHealth evidence-based services (Bakken et al., 2008).

The nursing care pathway becomes more than a guideline or a protocol. It also becomes a quality care indicator, which can support clinical judgments and actions to reach the best known patient outcome and allows understanding divergence from the pathway. The mHealth data gathered from the clinical decision-making processes for a sufficiently large number of patients are analysed to identify systematic features, which can be used to improve the further design of nursing care pathway, from a quality, safety and cost-effective perspective. Consequently, pathways become dynamic because they set out a clear expectation of the service for staff, managers, patients and carers, helping to increase quality and personalised care.

In order to allow eHealth services, mainly telehealth, telecare and mHealth services, to become fully efficient in all EU Member States, the development of standards, protocols and guidelines for the deployment of these services is urgently required. There is a strong need to work on a harmonised approach to be able to come up with common frameworks. This presupposes that information and decision-making support systems are employed so as to take account of individual needs, i.e. person-centred care (Roback et al., 2003; Swedish Society of Nursing, 2013). Studies have commonly shown that evidence-based clinical guidelines can be effective in improving the process and structure of care (Lugtenberg et al., 2009).

# 4. Advanced nurse practitioners designing cost effective integrated care pathways

Case management is a collaborative process through which Advanced Nurse Practitioners value, plan, implement, coordinate, monitor and evaluate the options and services required to: meet the health needs of a person and coordinate communication and available resources to achieve better patient outcomes (ICN 2008). Advanced Nursing Practice is a process to identify problems, design an intervention plan and coordinate activities with the patient, professionals and carers/families involved. In this integrated care process, the case manager, the advanced nurse practitioner (ANP), is committed to ensure that the targets set in the patient's care plan will be achieved. This will happen by mobilising the necessary resources and providing comprehensive and continuous care that meets the needs of the patient and the caregiver. Advanced Nursing Practice provides a unique clinical services), and thus utilising healthcare resources efficiently (Cohen & Cesta, 2005). Having access to vast amounts of information in a short period of time, at the clinical point of care, assures patient safety in the delivery of high quality care at the right time to the right individual (Ebell, 1999).

According to the ICN definition, the ANP is a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. What characterises ANP practice is knowledge and expertise, clinical judgment, skilled and self-initiated care, and research inquiry, not job descriptions, title or setting. Advanced nursing practice promotes the development of emphasis on all aspects of advanced practice not simply the promotion of advanced nursing tasks. To a large extent, this involves a shift of tasks from doctors to nurses, the main aims being to reduce demands on doctors' time, improve access to care, and possibly also reduce costs (Delamaire et al., 2010).

The available evaluations of established advanced nursing practices show that ANPs improve access to services and reduce waiting times for the set of services they provide. There is evidence showing that ANPs deliver the same quality of care as doctors for the range of services transferred to them (e.g., routine follow-up of patients with chronic conditions, first contact for people with minor illnesses), provided they have received proper education and training to become an ANP. Most evaluations of ANPs find a high patient satisfaction rate, even higher than the satisfaction rates for similar services provided by doctors. This seems to be mainly due to the fact that ANPs spend more time with each patient, providing patients and carers with more education and counselling (Delamaire et al., 2010).

In most countries, one of the main reasons for developing more advanced roles for nurses is to improve access to care in the context of a limited supply of doctors. Another reason for the development of APN roles is to promote higher quality of care, for instance by creating new posts to provide more personalised follow-up and counselling for patients with chronic illnesses in primary care or the creation of advanced nursing posts in hospitals to oversee quality improvement initiatives. In some countries, the development of APNs is seen as a way to contain cost. By delegating certain tasks from more expensive doctors to less expensive 'intermediate level' advanced nurses, it may be possible to deliver the same (or perhaps more) services at a lower cost. Also, by improving the quality of care, it may be possible to reduce health spending in the longer term by avoiding complications and unnecessary hospitalisations (Delamaire et al., 2010).

## 5. Patient empowerment

Patient engagement is central in the process of designing care pathways, as the main goal is to enhance patients' satisfaction during the care process. Within this context, it is important that nurses encourage patients and citizens to be more active, becoming responsible for their health management. Coaching is key to increase self-care (Wagner, 1998; Robinson, 2007; WHO, 2008; Bischoff et al., 2009; ICN, 2013).

This shift responds to the need felt by many individuals, including chronic disease patients and older people, who wish to be more informed and engaged in their own self-care (Epposi, 2013; EPHA, 2013). In order to acquire sufficient knowledge and be able to take advantage of individualised care, the patients require 'fit for practice' technologies.

In this regard, mHealth can offer customisable 'toolkits' for predictive, participatory and preventative care. Managing a particular health condition on a daily basis and throughout different stages of life can be very challenging. But, there is need to bring about the right balance between conventional and ICT-enabled healthcare supporting the work of health professionals, while expanding patients' knowledge and health literacy to enable them to be empowered even while experiencing a complex system of health and healthcare (EPHA, 2013).

## 6. Developing the healthcare workforce intelligence

Advanced nurse practitioners (ANPs) are becoming leaders in eNursing practice; they recognise the important policy issues to further advance the use of telecare, telehealth and mHealth by themselves and their fellow professionals. Key issues such as technology selection and implementation principles, interstate licensure, malpractice, and telehealth/mHealth reimbursement are important to further advance health system reform in the EU. In addition, evidence-based clinical pathways for demonstrating the cost-effectiveness of integrated care, using mHealth to support patient interactions, are key for the further reform of the healthcare system.

Given the reach of mobile networks and services that are becoming ever more intelligent, mHealth should play a more important role in supporting the development of the health workforce intelligence, primarily aiming at improving the efficiency and effectiveness of healthcare providers in delivering patient care (GSMA, 2013). mHealth has the ability to support the performance of nurses in clinical settings. Therefore, the electronic patient record system is central to the planning, provision and evaluation of care, while easily accessible and appropriate nursing information can facilitate decision-making and coordination of care interventions (La Mantia et al., 2010; Lyhne et al., 2012). In doing

so, mHealth innovation has to lower the workload of health professionals, facilitating knowledge acquisition, transfer, and exchange, which then directly impacts on many aspects related to the quality of health professionals' professional lives and their levels of work satisfaction (Watanabe et al., 1999; Fortin et al., 2006; Sargeant, 2004; Gagnon et al., 2011).

Freeing up time for service delivery is key for sustainable healthcare systems. Consequently, data collection should not become an administrative burden, pulling the nurses away from the bedside. Data that capture the main activities in nursing care - data on hygiene, feeding, mobility and several technical interventions - have been collected for many years in some EU Member States and have gradually been taken up by policy-makers to introduce nursing quality data into national and regional healthcare financing systems (Sermeus et al., 2005). However, the time nurses spent to collect these quantitative and qualitative data has resulted in pulling the nurses towards administrative tasks instead of closer to patients' bedside (Kalisch, 2006; Sansoni et al., 2006; Kalisch et al, 2009; Rotegaard, 2010). Freeing up working time by using mHealth solutions, can support nurses to focus on direct patient care and improve the quality and safety of care delivery. It is thus essential that nurses design integrated care pathways based on the already agreed international terminology (ICNP) for nursing with the use of mobile health solutions (mHealth), strengthening the nursing workforce intelligence and bringing nurses closer to patients. This will allow nursing care to become visible in patient records, national quality registers, guidelines and accreditation systems (Swedish Society of Nursing, 2013, Polish Nurses Association, 2009).

## 7. Conclusions

To conclude, mHealth can support sustainable healthcare systems by offering innovative costeffective and patient-centred care pathways within an integrated care system. By means of a strategic data collection, mHealth facilitates the nursing workforce to stay in the system of care and as such increase direct patient care. A high level of information and patient safety is vital in the further design of integrated care pathways. mHealth should promote a person-centred integrated care based on a cost-effective and patient empowering approach. When mHealth services are based on quality and safety indicators, a more pro-active leadership and knowledge position for nurses in advanced roles will facilitate the move from a traditional medical model of delivering medical services to a more integrated care system, with nursing and social care at the forefront of the design of evidence-based clinical pathways.

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# Implementation of RFID Systems for Positive Patient Identification: The ISMETT Experience

The use of information and communication technologies (ICT) in health care is continually increasing, and awareness that ICT is a fundamental tool for facing the major challenges in health care is now widespread. One of the fields that has seen rapid growth in recent years is mobile health, which offers a wide range of applications that can improve both the quality of the services provided to patients and the working conditions of the medical staff.

The focus of this paper is to evaluate the radio frequency identification (RFID) system implemented at the Istituto Mediterraneo per iTrapianti e Terapie ad Alta Specializzazione (ISMETT), a transplant hospital in Palermo, Italy. The system enables positive patient identification (PPID) through the use of RFID tags and mobile handheld devices, networked via a Wi-Fi connection with the computer system used in the hospital.

Patient misidentification is one of the leading causes of medical mistakes, and can lead to the administration of drugs or blood products to the wrong patient. These are events that in many situations can have severe consequences, and even lead to a patient's death. Misidentification is caused by human carelessness in almost all cases, so the implementation of technological systems to support patient identification and prevent adverse events contributes to improving the quality of care and patient safety. According to the literature, radio frequency identification (RFID) systems are among the best available technologies for avoiding medical mistakes. This paper presents the principal features of RFID technology and its possible applications in health care and, in particular, the way in which this technology has been used at ISMETT to support patient identification processes, laboratory activities, and transfusions.



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## Keywords

clinical risk reduction, health care, mobile health care, positive patient identification (PPID), patient misidentification, radio frequency identification (RFID)

<sup>66</sup> The implementation of technological systems to support patient identification and prevent adverse events contributes to improving quality of care and patient safety.

## 1. Introduction

Radio frequency identification (RFID) systems enable the automation of human and object identification processes (Derrico et al., 2011).

Identification implies the assignment of a unique identity to an object that allows it to be recognised unambiguously. Retrieving information concerning objects or people is the main scope of radio frequency technology (Sbrenni & Mattei, 2011). The system's components communicate with each other through radio frequency signals, thus obviating the need for physical contact between the devices.

RFID systems are increasingly used in a number of sectors, such as animal identification, the automotive industry, the pharmaceutical industry, retailing, transportation, tourism, and health care. Though this technology is complex, it is extremely easy to use.

In addition to the ease of use, RFID systems offer an excellent cost-benefit ratio, and their small size, wide operating distance and ability to identify even non-visible objects are some of the key features that make them superior to other systems. The adoption of RFID technology confers a number of tangible and intangible benefits, highlighted below.

# 2. System components

Typical RFID systems consist of three components (Sbrenni & Mattei, 2011; Yao, Chu, & Li, 2011):

- Tag: a small size radio frequency transponder, equipped with a memory, connected with an antenna, and usually inserted into a wristband, a label, a smart card or electronic devices (e.g., clocks, mobile phones). The transponder enables the transmission of information, with no need for physical contact between the devices.
- **RFID reader:** a transceiver controlled by a microprocessor. It is equipped with an antenna and is able to detect the presence of several tags situated in a certain area (the width of which depends on the frequency of communication), make queries and receive information from the tags.
- **Management system:** an information system that is networked with readers. This allows extraction of all available information associated with the tags, which are usually identified by means of a unique identification code.

Through the electromagnetic interaction among the devices, all the objects in which a tag is inserted can be located, identified and tracked in a simple and immediate way.

# 3. RFID and health care

Hospitals have much to benefit from the adoption of innovative solutions based on RFID technology. The implementation of technological systems to support patient identification and prevent adverse events contributes to improving quality of care and patient safety.

In health care, a simple error, such as patient misidentification can be fatal. One of the main goals of every hospital is to reduce patient exposure to risk. Traceability of patients and of their clinical data is one of the major challenges hospitals face. Currently, there are several initiatives, both in Italy and Europe, aimed at reducing clinical risk by means of RFID systems. For example, some hospitals have adopted RFID systems to improve the quality of some critical care processes, such as the administration of drugs or blood components, the application of medical devices, and the tracking of specimens.

Moreover, RFID applications in hospitals ensure compliance with Joint Commission International (JCI) regulations, and guarantee a high quality of care. JCI standards require observation of the five 'rights' of medication management: right patient, right medication, right dosage, right route, and right time.

According to the literature (Catarinucci, Mainetti & Tarricone, 2011), two of the principal areas of application of RFID technology in hospitals to guarantee patient safety reduction of risk are identification and validation, and support for operational processes.

Patient misidentification is a common health care error. Recent studies have shown that an increasing number of medical errors are caused by the administration of wrong drugs, usually a direct consequence of patient misidentification. Hence, it is very important for a hospital to try to prevent these mistakes by adopting structured procedures that help to correctly identify patients.

RFID systems have several applications in the health area, including:

- **Patient identification:** a wristband containing a RFID tag that is assigned to the patient when he or she is admitted to the hospital. The tag contains the patient's demographic and clinical information. Using RFID readers it is possible to check, at any moment, the patient's identity and quickly and safely retrieve all the needed information, even if the patient is unconscious, disoriented, or unable to communicate.
- Identification and mother-child association: through RFID technology, the association between mother, new-born and related medical records can be managed by using bracelets worn by the mother before entering the delivery room and by the baby at birth (Eprojetech srl, 2008). The identification code of the hospital and a progressive identification number are stored in the wristbands. This makes it is possible to track and control all contact between mother and new-born, and ensures proper association with the relevant medical records.
- Identification and patient-sample association: the incorrect labelling of biological samples is one of the risks of the diagnostic process. It is clear that any exchange of samples can lead to misdiagnosis and, as a consequence, administration of ineffective or harmful drugs. Thanks to RFID technology, a labelling system that connects the patient and all the samples associated with him through a unique identification code, can be implemented, thus reducing the risk of errors.
- Identification of blood bags: several studies have shown that transfusion errors (i.e., administration of blood of a wrong blood group or transfusion in the wrong patient) are unacceptably frequent and have, in almost all cases, serious consequences (Dzik, 2003). A study by Aller, in 2002, states that the majority of transfusion errors that lead to death are caused by misidentification (Aller, 2002).

Incorrect transfusions are usually the result of mistakes made during the monitoring of the patient at the bedside, immediately prior to the transfusion (Sun Microsystems Healthcare Division, 2005). It is therefore essential to put structured procedures into place to ensure that the right blood is transfused into the right patient. Once again, RFID technology seems to be the most adequate for supporting these operations, because it allows the exact identification of blood bags and patients, even if the patient is unconscious. Each bag that arrives at the hospital should be tagged with an RFID tag that uniquely identifies the bag and shows a variety of information, such as blood group, origin of the blood, and the intended recipient. Immediately prior to transfusion RFID readers can match the patient and the blood bag, thus minimising the risk of adverse events (Fuhrer & Guinard, 2006).

# 4. The ISMETT experience

The Istituto Mediterraneo per iTrapianti e Terapie ad Alta Specializzazione (ISMETT) is a joint publicprivate partnership between the Region of Sicily, through the ARNAS Civico hospital in Palermo, and UPMC, an integrated global health enterprise headquartered in Pittsburgh, USA (one of the leading non-profit health systems in the United States (US)). The partnership has brought together resources, intellectual capital, and advanced technologies to offer state-of-the-art treatment.

Over the past decade, ISMETT has become one of the leading organ transplant centres in Europe and a major referral centre for other Mediterranean countries. More than 1 000 transplant procedures have been performed at ISMETT. At ISMETT, transplant is not the only solution to end-stage organ failure and associated complex diseases. Specialised procedures include surgical, radiologic, and endoscopic techniques, and medical therapies to treat severe diseases and avoid transplant. ISMETT's specialists work closely with UPMC's transplant teams, and are supported by advanced diagnostic services, offering patients the most sophisticated therapies available.

ISMETT collaborates with major research centres in Italy and abroad, including the University of Palermo, the Italian National Research Council (Consiglio Nazionale delle Ricerche (CNR)), the Zootechnological and Zooprophylaxis Experimental Institutes of Sicily, the University of Miami's Diabetes Research Institute, the McGowan Institute for Regenerative Medicine, the University of Florence, HIMSS and the European Institute of Oncology. ISMETT is also associated with Sicily's Micro- and Nano-Systems Technological Innovation Research Consortium. The Consortium promotes, implements, and manages research and training projects, and encourages cooperation programmes between Italian and international research organisations. The institute follows the guidelines of the American health care model, which identifies the technologies as the enabling tools for increasing the efficiency and the effectiveness of care.

In order to reduce patient risk and improve the quality of care administered to patients, ISMETT has implemented projects involving RFID and mobile technology within the clinical environment. The project's goals are to ensure the correct identification of patients, guarantee the right association between the patient and the laboratory samples, as well as that between the patient and the blood products to be transfused.

In the project implementation, ISMETT decided to use passive RFID tags. This type of tag is activated only when it receives stimulation of the electromagnetic field produced by the reading system, operating on the frequency of 13.56 MHz and conforming to ISO standards/IEC 15693 - parts 1, 2, and 3, and to ISO/IEC 14443 - parts 1, 2, 3, and 4.

The tags are based on the Philips Icode SLI chipset, which is equipped with a unique and unchangeable 64-bit serial number inserted by the manufacturer, and with a rewritable 1k bit memory organised in 32 blocks of 4 bytes each.

The tags are placed in a disposable wristband assigned to the patient on admission and, if necessary, replaced. The patient's surname, first name, gender and date of birth are printed on the wristband in order to facilitate immediate identification, in case the computer system is unavailable. The patient's ID number is printed on the wristband, as well, both in letters and in barcode. After the wristband has been verified by reading of the data in the RFID tag, it is immediately worn by the patient. The tag contains the patient's demographic information and a code that identifies the reason for hospitalisation.

# 5. The reading devices

In order to allow patient identification in different areas and directly at the bedside, a Wi-Fi palm device has been adopted as reading device.

The hand-held devices are equipped with a barcode reader, a radio frequency front-end, and readout electronics. The radio frequency front-end is a resonant antenna on the specific wavelength of the tag as well as a radio frequency transceiver, and is connected to the readout electronics.

The readout electronics are designed to activate, read, and write one or more tags, even simultaneously. They are controlled by a programmable device, and convert the analogical signals of the RF front-end into digital information and vice versa.

The hand-held devices used in the hospital have the following main features:

- Portability;
- Barcode reader;
- RFID reader;
- Resistance to bumps and drops;
- Outmost sterilisation capacity;
- Wi-Fi connectivity.

In order to minimise the impact of the introduction of the new system on the activities of health workers, a careful analysis of the processes and of the way these processes would be changed due to the introduction of new systems was conducted. The project's design took into account both the information systems in use at the institute as well as the procedures in place.

# 6. Patient identification and checking of the match between patient's identity and the vials

In November 2011, ISMETT launched a project concerning the application of RFID technology through the use of a mobile device to ensure the correct identification of the patient at the bedside and at the time of collection of blood samples as well as to verify the correspondence between the patient's identity, the samples to be analysed in the laboratory, and the associated results. The system was subsequently extended and also applied to the activities of microbiology and pathological anatomy labs.

Being able to identify the patients and verify that their identity matches the one connected to the vials at the bedside, facilitates quality patient care by decreasing the risk of error.

At present all the blood samples at ISMETT are verified using this RFID-supported process and following the workflow described in the next section of this paper.

# 7. Description of workflow

The workflows that have been studied and implemented for patient-sample matching are described below and illustrated in the following diagrams, which show the workflows related to day hospital and inpatients (Figure 1) and to outpatients, respectively (Figure 2). The workflows are almost identical, except for the second step.

The difference between the two workflows is that when an outpatient arrives at the hospital, the test to be done has already been ordered by the physician. For inpatients, only the admission orders are already placed on admission. All the other orders during the patient's stay are inserted by physicians through the electronic medical record (EMR).



Figure 1: Workflow of the process related to day hospital and inpatients



Figure 2: Workflow of the process related to outpatients

**Step 1 - Patient admission**: The process starts when the patient arrives at the reception. ISMETT does not have an emergency room, it is therefore assumed that there has already been initial contact between the patient and the institute, directly or mediated by the patient's primary care physician. As a result, the patient's demographics are already in the Admission Discharge and Transfer (ADT) system, which assigns a unique nosological or visit ID that identifies the reason for hospitalisation.

A wristband is given to the patient after verification of identity found on the patient's national health system card, a personal card carried by every Italian citizen entitled to receive the benefits of Italy's National Health Service. The wristband contains a RFID tag, and is associated with the printed information on the wristband.

**Step 2** - **Orders and label printing (day hospital and inpatient):** Through the electronic medical record, the physician orders the test(s) to be done. The clinical secretary searches for and identifies the patient in the laboratory information system (LIS). The patient demographics are already in the system, and shared in real time by the ADT system using an HL7 interface. Subsequently, the secretary books the test(s) requested by the physician and prints the labels to be placed on the vials.

**Step 3 - Orders and label printing (outpatient):** The nurse searches for and identifies the patient in the LIS. Subsequently, the nurse books the test(s) requested by the physician and prints the labels to be affixed to the vials.

**Step 4 - Sample taking:** The nurse goes to the patient's bed with vials and checks the correct match between the patient, the vials and the tests to be done, through the use of a handheld device with a dual-head capable of reading both the barcodes of the laboratory samples and the RFID tag inserted in the wristband assigned to the patient. The handheld device signals the correct match for each of the exams booked. After verification, the nurse can take the sample and send it to the laboratory. If the verification fails, the system will alert the nurse. In this case it is possible that the failure derives

either from an error by the nurse or from a technical problem. The nurse is then required to make an additional, manual check of the patient's identity and, if such verification is successful, paper documentation certifying the identification of the patient and the technical problem must be added to the samples. The samples can then be sent to the laboratory.

If the nurse ignores the failure in verification and sends the sample to the lab, the check-in of the samples will be stopped.

**Step 5 - Check-in of the samples:** In the laboratory, the lab technician performs the check-in of the sample. Using the LIS functions s/he reads the sample's bar code labels. The system checks whether the association between the sample and the patient has been verified at the time of sampling. If the verification is successful, the lab technician performs the requested analyses. If a sample has not been validated by the nurse, the laboratory staff will check for any paper documentation to justify the missing validation. If such documentation is present (e.g., missing validation is due to a technical problem), the check-in can be enforced and analysis of the sample carried out by inserting a compulsory note. If, instead, there is no paper documentation, check-in is stopped and the process ends.

# 8. PPID in transfusion processes

Safety of transfusion therapy is the result of a complex process, including activities ranging from donor selection to the infusion of blood components in the patient, and subsequent follow-up (transfusion chain) (Assessorato Regionale alla Sanità, 2010). Any non-compliance or mistake, at any level, can lead to adverse effects on the patient.

Total transfusion safety is determined by the sum of the processes carried out by the transfusion centre to ensure blood quality and safety (*blood safety*), and of the processes carried out by the operating units requiring blood components to be transfused (*transfusion safety*).

While intrinsic blood safety is nearly 100 %, transfusion safety is still surprisingly lacking: the rate of error in the transfusion process is approximately 70 % of all adverse transfusion events (an error every 2 000-30 000 transfused units, according to the published case studies) and, among these, more than 75 % occur in the identification phase (Luppi, 2006).

The literature shows a surprising uniformity in the incidence of errors and a substantial invariance of the phenomenon over time. This is due to the human factor inherent in the blood transfusion chain and results in the assumption that the level of attention of the operators is never constant, but is inevitably subject to fluctuations especially when performing simple and repetitive processes.

It thus becomes imperative to implement security systems that are no longer centered on the person but on the system. They should be bolstered by the use of ICT that allows automation and standardisation of the processes, thus limiting operator errors and the variability of the human factor.

ISMETT receives blood and blood products from the Blood Bank located at the ARNAS Civico Di Cristina Benfratelli Hospital, in Palermo.

The workflow applied before the implementation of the new RFID system was entirely manual, and exposed patients to various risks associated with the chances of errors in patient identification, blood typing, the possibility of incorrect transfusion due to homonymy, and the chance of incorrect transcription of the blood group in the medical record.

In order to make the entire process safer, ISMETT introduced a computer system that allows:

- A shared record between ISMETT and the Blood Bank;
- Printing of labels for the vials that will then be read by the Blood Bank's equipment without need for any re-labelling of the vials;
- Request for typing, blood bags, and blood products;
- Compliance with the obligation of sending data on adverse reactions to the Blood Bank;
- Management of the register of transfusions, and blood products present at ISMETT;
- Verification of patient-sample correspondence and patient-blood bag matching;
- Greater control over expenditures related to the use of blood products;
- Transmission of the results of typing blood from the Blood Bank to the EMR used by the institute without need for any data transcription.

The workflow shown in the chart below represents the scheme of operation of the system.

# 9. PPID in blood-gas analysis

Arterial blood-gas analysis, also known simply as blood gas analysis, is a test used to measure the partial pressures of arterial blood gas and pH of the blood. In order to do the test, a blood sample must be taken at the level of the radial or femoral arteries, or, in children, in the brachial artery.

The blood is collected via a heparinised syringe that must not contain air bubbles in order not to alter the biochemical values of the gaseous sample. The syringe must be kept on ice and analysed quickly (within 20 minutes) to avoid blood clots.

Arterial blood gas analysis is used especially when it is necessary to do an exam, the results of which must be obtained very quickly, rendering it impossible to wait until the samples are processed in the laboratory.

ISMETT also uses RFID technology for the validation of blood samples on which the blood gas analysis should be done. Figure 4 illustrates the workflow.



Figure 4: Workflow of blood gas analysis

**Step 1 - Order of blood gas analysis:** The process begins when the physician, logging on to the EMR and, orders a blood gas analysis for a patient.

**Step 2 - Printing of label:** On the EMR, the clinical secretary visualises the requested transfusion, logs on to Emonet, and searches for the patient's demographics and prints the request for the transfusion and the labels to be affixed to the blood samples.

**Step 3 - Sample taking and execution of blood gas analysis:** The nurse verifies the patient/syringe/ exam matching at the bedside with the RFID device. If the verification is successful, the nurse takes the sample and does the test. Otherwise, a check could be done in order to understand the reasons for the missing a verification. Once the test has been performed, the system both prints the results and sends it to the EMR via an HL7 message.

# 10. Cost-benefit analysis

Although there are many publications on the use of RFID in hospitals, very few have reported analyses of the costs and benefits arising from the application of RFID technology. This is probably due to the difficulty in quantifying and/or monetising the benefits offered by RFID systems. The reduction of human error that can be so harmful to a patient is difficult to monetise, because of both the difficulty in identifying the number of accidents avoided through the use of technology, and the problem of assigning a monetary value to a possible accident. For the sake of simplicity, this paper chose to adopt an easier, although certainly more limited methodology, by undertaking a quantitative analysis only on the costs of the PPID project and not on the benefits obtained.

## 10.1 Cost analysis

ISMETT has implemented RFID technology for PPID to support verification of laboratory tests, verification of blood bags and blood components, and blood gas analysis. Some of the costs are attributable to single processes, and are easy to calculate, while other costs are shared among the various processes. These costs have been split among the processes through activity-based costing (ABC) methodology, based on suitably chosen cost drivers.

The analysis only considered the incremental costs, which means that all those items that refer to costs already incurred by ISMETT for resources before the implementation of the system but used by the system itself, were not considered.

The total investment in equipment, software and hardware, training, and redesign of processes, supported by ISMETT over a period of five years will amount to  $\notin$  203, 635.,00, most of which ( $\notin$  156 074,00) is attributable to laboratory analysis, and the rest divided between the blood transfusion services ( $\notin$  29 955,00) and the blood gas analysis system ( $\notin$  17, 606.,00). This is because the systems share much of the purchased equipment, though the average annual number of laboratory tests performed (767 455), is significantly higher than the number of transfusions (2, 733) and blood gas analyses (76 489).

Moreover, the annual expenditure for the non-durable goods (wristbands and tags) and extraordinary maintenance must be added. The estimate of such expenses amounts to  $\leq$  38 260,00 per year.

Considering the time horizon of the investment, amortisations of equipment and variable costs, the annual equivalent cost amounts to  $\notin$  89 100,33. Dividing this for the average number of hospital admissions and visits, (38 000 per year) an additional cost per hospital access of approximately  $\notin$  2,34 arises. This cost is extremely low if the reduction in clinical risk, the increase in the quality of care, and all the benefits arising from the implementation of RFID systems is taken into account. These benefits are described below.

## 10.2 Benefits analysis

There is a number of benefits that derive from the implementation of an RFID system for PPID, and some of them are intangible. The benefit analysis performed by for this project was exclusively qualitative.

The benefits have been divided into categories: for patients, for professionals, and for the organisation.

## 10.3 Benefits for the patients

Several studies have shown that RFID technology applied to PPID brings unquestionable benefits to patients:

- **Reduction in misidentification events:** RFID technology can reduce mistakes in identification processes, and facilitates early recognition of error by requiring medical staff to follow structured procedures;
- Reduction in errors of administration and/or blood transfusions: the direct consequence of the reduction in identification errors is a reduction in errors of an administration for drugs and blood bags. The system is designed to increase patient's safety and ensure compliance with the five 'rights' of medication management;

- **Reduction of waiting-time:** the automation of processes and the reduction in mistakes result in greater efficiency and lower need to put corrective actions in place. Consequently, there is a greater availability of medical personnel and, therefore, a reduction in waiting times for the patients;
- Increased security, trust and reassurance of patients: patients' psychological condition is something that can affect the way they react to the treatments they receive. Being able to generate a feeling of being in a safe environment, being followed by skilled and trained personnel, and not running the risk of being a victim of medical malpractice, generates a greater reassurance in patients and increases their trust in the hospital staff;
- Increased patient comfort: the RFID tag inserted into the wristbands does not require a line of sight to be read, so it is not necessary to move and trouble the patients to access the information contained in the tag;
- Increased customer satisfaction: all the benefits described so far reflect an increase in the quality of the activities carried out at the hospital, with a consequent increase in the perceived quality and in patient satisfaction.

## 10.4 Benefits for the workers

- Improved access to patient information: demographic and clinical information on the patients is easily accessible through RFID devices;
- Faster access to patient information: in the hospitals characterised by paper-based reporting systems it is common practice to collect all the data about patients in paper folders. With computerisation, it is possible to find the needed information quickly since there is no need to seek among a multitude of papers;
- Accurate information on the display: as opposed to what may happen when using paper records, with the use of technological devices there is no risk of misinterpreting what has been reported, e.g., unclear handwriting;
- Improved diagnostic processes and decision-making: the ability to have information quickly, clearly and accurately speeds up the diagnostic process and allows for better decision-making;
- Efficient workflow organisation: automation and standardisation of processes, as well as ensuring the correct identification of patients and the association between patient samples, exams, and blood bags, in turn ensures that the procedures put in place are actually the most efficient ones. Moreover, thanks to the reduction in errors, the workload associated with corrective actions is minimised;
- Reduction of work-related stress: several studies have shown that the risk of work-related stress has negative effects on both human health, and the quality and effectiveness of the work results (Karasek & Theorell, 1990; Cavicchioli & Ieri, 2007). The implementation of RFID systems to ensure the correct identification of patients may have a positive impact on work-related stress. An alert system that is activated when an error occurs can help reduce anxiety, which may arise in workers engaged in delicate and risky activities. In addition, the increased efficiency in workflow and error reduction can decrease the workload, for example by avoiding the need to repeat sampling and laboratory tests. Finally, the prevention of mistakes results in fewer emergencies and deaths, events that are clearly a source of stress for workers who have to face them.

## 10.5 Benefits for the organisation

- **Increased effectiveness:** the system developed and the highly standardised and structured procedures ensure that patients are uniquely identified;
- Increased efficiency: the tangible benefits related to efficiency are attributable to an increase in the quality of the processes and, consequently, to a reduction of resources used to solve the problems introduced by potential or actual non-compliance. Moreover, thanks to the automation of certain processes, such as the collection and sharing of information, the use of resources in activities with higher added value can be maximised;
- **Compliance with standards and legal obligations:** the application of structured procedures, and the presence of a monitoring and control system ensure total adherence to quality standards required by hospitals, both in terms of the quality of care and privacy issues;
- Image enhancement: increasing the effectiveness and efficiency of processes results in a higher quality of care and, consequently, in an increase in patient satisfaction, and enhancement of the image and prestige of the institute.
- **Reduction in legal and insurance costs:** lowering errors and accidents leads to a decrease in the risk for the hospital of being sued, and to a reduction in insurance premiums.

# **11.** Conclusions

This paper is focused on the implementation of an RFID system, which ensures positive patient identification thanks to the combined use of passive tags and mobile handheld readers. The system enables hospital workers to check the correspondence among the patient's identity, the laboratory sample and the blood products directly at the bedside, minimising the risk of making human mistakes, such as erroneous labelling or medication administration.

The main features of RFID technology and its possible applications concerning identification processes in health care have been presented with a particular focus on the way in which the technology is used at ISMETT, a medical institute and joint public-private partnership based in Palermo, Sicily. The costs and benefits of the system have been highlighted, and it has been demonstrated how, thanks to a relatively low additional cost per hospital access, it is possible to achieve a wide range of benefits both for the patients and the care providers.

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