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 care-provider’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.

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Keywords

clinical guidelines, decision-support, patient guidance, personalisation, shared decision-making

"In MobiGuide, decision-support 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\(^1\) 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 lifestyle) 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.

\(^1\) [www.mobiguide-project.eu](http://www.mobiguide-project.eu)
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.

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 holds, is called a ‘Dynamic Induction Relation of a 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).](image)

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:** These 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, pre-prandial (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.

![Figure 3: A care provider’s interface for entering a patient’s preferences about a meals schedule and related measurements and alerts](image-url)

### 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 valvular atrial 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 electrocardiogram (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 of two personal contexts: routine and semi-routine meal schedules and their personalisation 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.

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\(^2\), Distance Information Technologies for Home Care\(^3\), HEARTFAID: A knowledge based platform of services for supporting medical-clinical management of heart failure within elderly population\(^4\), HEARTCYCLE\(^5\), CHRONIUS\(^6\), and ICARDEA\(^7\).

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.

\(^2\) http://www.srdc.com.tr/metu-srdc/projects/saphire/
\(^3\) http://cordis.europa.eu/projects/rcn/58097_en.html
\(^4\) http://lis.irb.hr/heartfaid/
\(^5\) http://www.heartcycle.eu/
\(^6\) http://www.chronious.eu/
\(^7\) http://www.srdc.com.tr/projects/icardea/
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 decision-support 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 evidence-based 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 [post-prandial] 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.

8. References


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