

# Use of Patient Generated Data from Social Media and Collaborative Filtering for Preferences Elicitation in Shared Decision Making

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## Abstract

With the increasing demand for personalization in clinical decision support system, one of the most challenging tasks is effective patient preferences elicitation. In the context of the MobiGuide project, within a medical application related to atrial fibrillation, a decision support system has been developed for both doctors and patients. In particular, we support shared decision-making, by integrating decision tree models with a dedicated tool for utility coefficients elicitation. In this paper we focus on the decision problem regarding the choice of anticoagulant therapy for low risk non-valvular atrial fibrillation patients. In addition to the traditional methods, such as time trade-off and standard gamble, an alternative way for preferences elicitation is proposed, exploiting patients' self-reported data in health-related social media as the main source of information.

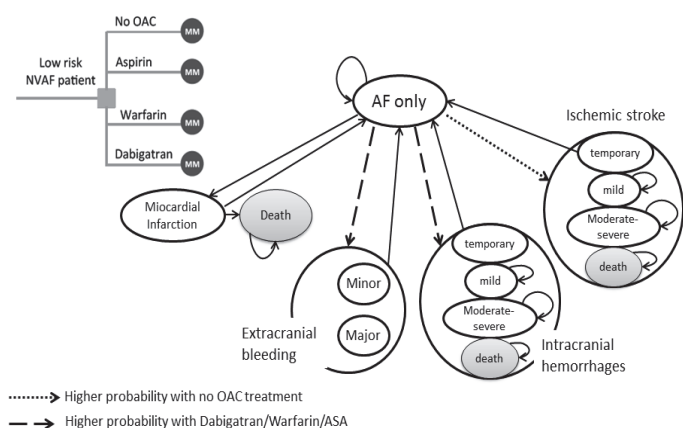
## Introduction

The role of patient preferences in modern clinical decision support systems (CDSS) is assuming a steadily increasing importance. Even in the context of CDSS based on computer-interpretable guidelines, derived from evidence-based medicine results, the decision process may ultimately depend on patient's preferences. In these cases finding a clear-cut optimal solution may depend on non-strictly-clinical variables (such as personal attitudes, lifestyle habits, economic situation of the patient, and different perceptions of the quality of life associated with different health states). Clearly, the ability of the CDSSs to support a process of care that is tailored to the specific patient's needs and characteristics may be a great added-value to most advanced CDSSs. For these reasons, formalizing, implementing and managing the process

where the doctor and patient collaborate to find the optimal clinical decision (shared-decision making) is becoming more and more relevant in CDSS solutions. One of the main challenges of those systems is being able to capture patients' preferences and effectively incorporate them into decision-theoretic models. Classic approaches with strong theoretical basis take advantage of utility theory (von Neumann and Morgenstern, 1947) to quantify the desirability of a health state and use utility coefficients as numerical parameters in decision models. Utility theory suggest that an individual whose preferences meet four basic axioms (completeness, transitivity, independence, continuity) facing a decision problem with uncertain outcomes will prefer actions that maximize the expected utility. However, the process of eliciting utility functions and corresponding utility coefficients for specific patients or populations has a number of challenges that are still unresolved and leave space for further research. In this paper we present some of the work that has been carried out to incorporate shared decision making into a CDSS in the context of the MobiGuide project along with some on-going work to further improve our approach to patient preferences elicitation.

## Background: the MobiGuide project

MobiGuide ([www.mobiguide-project.eu](http://www.mobiguide-project.eu)) is a Collaborative Large-scale integrated project, supported under the European Commission 7th Framework Program and carried out by a consortium of 13 partners from several countries in Europe. The project focuses on the development of a patient-centric CDSS based on computerized clinical guidelines for chronic illnesses. MobiGuide is a distributed system whose main components are (i) a Decision Support System (DSS),



**Figure 1 - Simplified representation of the Oral Anticoagulant Therapy DT and Markov model.**

devoted to the representation and execution of Computer-Interpretable Guidelines, (ii) a Body Area Network (BAN) including a network of sensors and a smartphone to support telemonitoring of the patient, and (iii) a Patient Health Record (PHR) for centralized storage of patients' data. Among the challenging objectives of the project, one involves the identification in the clinical guideline for the treatment of Atrial Fibrillation (AF) of those recommendations where a shared decision between care provider and patient is required. The implementation of these shared decision processes leads to two main action points: developing decision theoretic models to represent the decision tasks and collecting patients' preferences to run personalized models.

## Decision trees and direct elicitation of preferences

The core of the MobiGuide approach to shared decisions is to use decision trees (DTs) with embedded Markov models as a suitable probabilistic, graphical decision-theoretic formalism for representing and executing decision tasks (Quaglini et al., 2013). Although the long term decision making process can be represented as a Markov Decision Process the scenario we are addressing involves a single decision point, which can be modeled using a DT. In particular, we have developed a DT for the choice of anticoagulant therapy for low risk non-valvular AF patients (Rognoni et al., 2014). As shown in Figure 1, a list of possible decision options branch from the initial node of the DT. A Markov process starts at the end of each branch, representing the most relevant comorbidities and complications that the patient could experience in the future. The transition probabilities between pairs of health states depend on the therapeutic option.

Running the decision model results in the calculation, for each of the decision options, of the expected amount of

life years of the patient. However the length of expected life is not the only relevant outcome to consider, as quality of life (QoL) has also to be taken into account. Quality Adjusted Life Years (QALYs) incorporate mortality and morbidity in a single quantity by combining a patient's expected life years with the quality of those life years. More precisely, the number of years spent in a certain health state is "weighted" by a multiplicative utility coefficient (UC), which values the quality of that health state. UCs range from 0 (death) to 1 (perfect health), and they are, in principle, very subjective values, since they reflect a patient's feeling about a health state. For this reasons the use of proper and highly personalized UCs can be an effective way to incorporate patient preferences into a medical decision problem. Authors of many publications involving the use of DTs and QALYs (e.g. cost/utility analyses) often use UCs available in the literature to quantify their models, disregarding that they could have been derived from a different population. However, it is nowadays acknowledged that environmental data play an important role in quality of life assessment (Ryder et al., 2009). An alternative approach consists in obtaining UCs for each specific patient directly to guarantee the best degree of personalization of the decision problem. For this purpose we developed a web-based software tool named UceWeb. Our tool supports three of the main elicitation methods described in the literature, namely Standard Gamble (SG), Time Trade-off (TTO), and Rating Scale (RS).

SG has its theoretical basis directly in the axioms of Von Neumann-Morgenstern utility theory (Gafni, 1994). The patient is asked to choose, within a hypothetical scenario, between living the rest of his life in the health state that is being evaluated or accepting a gamble whose outcomes are complete healing or sudden, painless death with probability  $p$ . The more a patient is experiencing a poor QoL, the higher risk he would accept to have a chance of healing. The probability  $p$  is then varied until the patient is indifferent between the two choices. Then UC is calculated as  $(1-p)$ .

In TTO (Torrance et al., 1972) the patient is asked to choose between living his entire remaining life ( $t1$ ) in the specific health state being evaluated or to live shorter ( $t2 < t1$ ) but in a perfect health state. If the patient is experiencing really poor QoL he will be willing to trade some of his remaining expected life (i.e. to live shorter) for a better QoL. Similarly to  $p$  in SG, the amount of time a patient is proposed to give up to heal completely is varied until the patient is indifferent between the two choices. The UC is then calculated as  $t2/t1$ .

Finally, in RS, an analogue scale is presented to the patient, ranging from 0, associated to the worst health state imaginable (usually death), to 100, corresponding to perfect health. The patient is asked to place a marker on the

scale according to the degree of desirability of the health state being evaluated. RS is usually quickly understood by patients and it is often used to order health states from the less to the most desirable, as multiple states can be placed along the scale in one go. However the value produced by RS is not a true UC (Torrance et al., 2001) but rather what is called a “value”, calculated as  $x/100$  where  $x$  is the marker position on the scale.

## Using social media and collaborative filtering for preferences elicitation

### Motivation

A significant effort has been devoted to carefully design the UceWeb tool to optimize the process of UC elicitation and achieve the double goal of interface usability and accuracy/reliability of the resulting UCs. However some limitations of the current direct elicitation approach are still hard to overcome. UC elicitation methods like SG or TTO, albeit theoretically sound, are often difficult to understand for patients. SG asks the patient to evaluate a hypothetical risk of death, which some patients with severe conditions might not be willing to reason upon. Similarly, many different variants of TTO have been developed to try to overcome some of its limitations (Buckingham et al., 1996). On the other hand, ability to correctly understand the questions is essential to guarantee the quality of the elicitation results. This is one of the reasons why elicitation is usually assisted by a trained professional (physician or a psychologist). However the presence of a human interviewer can add some significant bias and anchoring effects. For example the value chosen for the initial question (“...would you take a 5% risk of death?...”) in the SG method can indeed lead responses to cluster around that value (anchoring), and it could be influenced by the physician’s knowledge on the actual surgical risk of an intervention the patient could undergo (bias). Another factor that can impact the effectiveness of direct elicitation is the need for the patients to evaluate unfamiliar health states. As a matter of fact, in a shared decision-making framework, often there is the need to represent in formal decision models possible future health states that can occur as consequences of the different treatments being evaluated. Patients can have a hard time in answering the UC elicitation questions for health states they are not experiencing at the moment or have never experienced in their lives. Finally all the issues that affect direct elicitation can be even more evident in particular groups of patients like the elderly or those having cognitive impairment. In extreme albeit not so rare cases, direct elicitation might also result impossible to perform.

On the other hand, the availability and relevance of raw data about patients’ preferences, QoL and other health-related information is growing. More and more often patients report their status, share their experiences and discuss their health in discussion boards and other social platforms. This kind of user-generated data has been widely used in the industry to get valuable knowledge about people’s preferences. The application of collaborative filtering and recommender systems (Su and Khoshgoftaar, 2009) is nowadays very popular in the marketing and sales departments of major companies. However the potential of these techniques have not been so widely explored in the field of health-informatics until now.

### The envisioned novel approach

We are currently investigating the possible benefits of using text mining and artificial intelligence methodologies in the process of eliciting parameters related to QoL and patients’ preferences. Our chosen reference use-case is the elicitation of utility coefficients of the health states represented in the previously described DT model developed for MobiGuide. An outline of the envisioned logical architecture of the system is shown in Figure 2.

The growing amount of data self-generated by patients can be a valuable resource to get insights about patients’ experiences, opinions and preferences. An initial corpus is being built from medical discussion boards using the medpie framework (A. Benton et al., 2012), which includes a de-identification module to comply with ethical and privacy requirements. Data coming from health focused discussion boards as well as from more generic social platforms mainly consist in unstructured information. However text mining and sentiment analysis techniques (Pang and Lee, 2008) can help to extract valuable and quantifiable information from them. In our reference use-

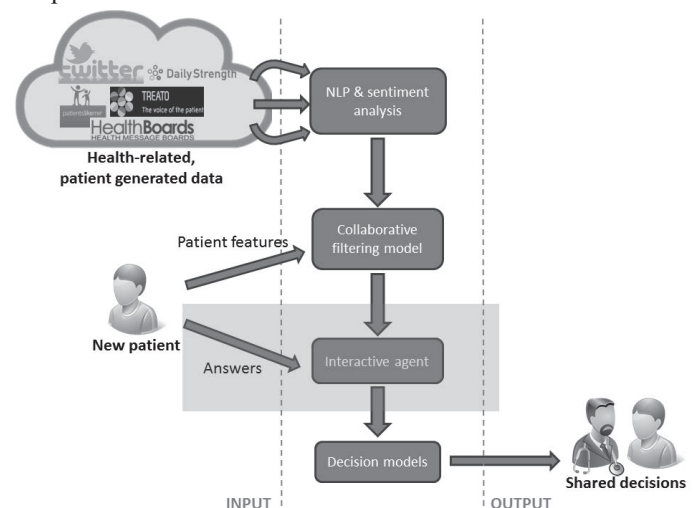


Figure 2 - envisioned logical architecture of the system

case, the measures we are interested in are the UCs associated to a set of health states. Data collected from health-related social media will undergo a first elaboration step (Figure 2) that will help extracting patients' opinion and converting it to a more exploitable value (see the following section for more details). The obtained values will then be used to train a collaborative filtering model so that, when UCs need to be elicited for a new patient, the model can be used to predict, or bound, these values based on the preferences of similar individuals (patients' profiles should also be mined). This first prediction can then be refined by posing some direct questions to the patient before actual use of the UCs in the decision model. However this refinement step might not be required (Figure 2 marks it as optional with a grey box) and its actual inclusion in the system will be evaluated once the first preliminary results on system performance will be available.

### Valuing patients' opinions

Apart from the direct elicitation methods previously discussed, another popular way of assessing QoL and utilities is by means of questionnaires. EuroQoL ([www.euroqol.org](http://www.euroqol.org)) is one of the most widely adopted, and it gives the possibility to directly convert the scores of the questionnaire into UCs. EuroQoL evaluates the impact of five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) on the QoL experienced by the patient. We are investigating the possibility of using sentiment analysis to derive the degree of negativity that patients associate to each of these dimensions using discussion board threads. In this way we would be able to virtually score the corresponding EuroQoL questionnaire sections and finally perform the conversion to a proper UC using the standard EuroQoL index value calculation algorithm (Rabin and Charro, 2001).

### Discussion

One of the main challenges of the proposed approach consists in being able to convert the information gathered by social media to a summary numeric value and use it as a source of information about health utility.

It is of course very unlikely that we will be able to score all the dimensions of the EuroQoL questionnaire for each single patient only looking at what he reported on social media. However, scoring the questionnaire even partially will allow us to derive the boundaries of a range of values the actual UC will fall in. These observations, although less precise than UCs directly elicited by a patient, will still be a valuable resource for training the collaborative filtering model to predict utilities for new patients.

### Conclusions

The presented methodology for UCs elicitation based on collaborative filtering model and patients' social media self-reported data is still work-in-progress. The proposed approach aims at overcoming some limitations that affect direct elicitation methods providing an alternative way to assess patients' preferences and QoL. Interesting collateral results consist in exploring secondary use of health-related social media as a source of information for QoL studies.

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