An Information-Centric Framework for Designing Patient-Centered Medical Decision Aids and Risk Communication

Lyndsey Franklin[1], Catherine Plaisant, PhD[1], Ben Shneiderman, PhD[1]
[1]University of Maryland, College Park, MD

Abstract

Risk communication is a major challenge in productive patient-physician communication. Patient decision making responsibilities come with an implicit assumption that patients are sufficiently educated and confident in their abilities to make decisions about their care based on evidence based treatment recommendations. Attempts to improve health literacy in patients by way of graphical decision aids have met with success. Such decision aids typically have been designed for a general population and evaluated based on whether or not users of the decision aid can accurately report the data points in isolation. To classify decision aids, we present an information-centric framework for assessing the content delivered to patients. We provide examples of our framework from a literature survey and suggest ways improvements can be made by considering all dimensions of our framework.

Introduction

Risk communication is a major challenge in productive patient-physician communication. Patient decision making responsibilities come with an implicit assumption that patients are sufficiently educated and confident in their abilities to make decisions about their care based on the facts and figures of evidence based treatment recommendations. In actuality, many patients have low health literacy and numeracy which makes understanding treatment options and the risks associated with them problematic (1) (2) (3). Physicians may even underestimate patient information needs or unintentionally provide information better suited to their own knowledge base (4). This has been found even when patients are well-educated and come from higher-income and socio-economic conditions (5). Low numeracy and graphicacy have tempering effects (3) (6), however attempts to improve health literacy in patients by way of graphical decision aids have met with success. Decision aids are consistently shown to reduce patient anxiety, reduce passivity, promote realistic perceptions of treatment benefits and harm, reduce negative emotions, and increase patient knowledge about risks and treatment options (7) (8) (9) (10).

Other work has shown that more guidance from trained medical professionals such as physicians or nurse practitioners improves patient understanding of risks as well as patient satisfaction with treatment options (7) (11) (10) (12). Often, this guidance takes the form of jointly inputting patient health information into a standard system which then produces personalized decision aids that address the patient's unique circumstances. Patients are then walked through the decision aid before the consultation concludes (11). At this point, patients are left with one view of their circumstances which can only answer a limited, pre-determined set of questions. Some work suggests that patients are turning to additional, less formal and lower-level medical sources for additional information when their medical support team has been exhausted (4). In this case, an adaptive decision aid would be of even greater value.

Decision aids are typically designed for a general population, occasionally with some minor degree of customization, and evaluated based on whether or not users of the decision aid can accurately report the data points in isolation. Evaluations of gist knowledge determine whether or not patients understand a high-level view of the data (Drug A has a greater risk of side effects than Drug B) while verbatim knowledge describes whether or not patients can recall specific facts (12 of 100 people are at risk for Condition C). This is a narrow focus of the use of decision aids and the information they present. Other taxonomic systems for evaluating decision aids place them in a workflow and emphasize factors irrelevant to the content and design of a decision aid such as how it is updated or implicitly assume static content (13).

To expand the focus of decision aid classification, we present an information-centric framework for assessing the content delivered to patients. In the following sections, we define our framework, and then use it to organize examples and findings from a literature survey. We conclude with a discussion of significant research gaps.

An Information-Centric Framework for Decision Aids

Our framework is based on examining the content of decision aids with respect to the variety of information available and its presentation. This gives us several dimensions on which to classify a decision aid including (1)

decision type, (2) the timescale in which information is represented, (3) the number and variety of measurements, (4) information source, (5) personalization level, and (6) information format.

For the purposes of our survey, we consider a decision aid to be a standalone document which conveys at least one data point (measure) in some format. So, minimally, a decision aid will express a measure, say the risk of developing Type 2 Diabetes, in a particular format, say as a text paragraph describing the population the risk applies to. The advantages of our framework are that it is condition and severity agnostic: we can apply it to the design of a wide variety of decisions aids. It also allows for the design of complementary decision aids such that different aspects of the same data may be emphasized in the most efficient way and balanced across a collection of decision aids.

Decision Type

The type and complexity of a decision is very often tightly related to the nature of the condition and the treatment options available. We summarize our classification in Table 1.

Table 1 Types of Decisions Supported

Decision Type	Description	Example
Binary	A patient may either opt for a treatment option or take no action.	A patient may choose to have an abnormal growth biopsied or wait and observe it for changes first.
Multi-Option	A patient has more than one treatment option available, but some or all of them may be mutually exclusive.	A patient must decide how to best reduce the immediate risk of cardiovascular disease through diet, medication, or surgery.
Combination Options	A patient has more than one treatment option, several of which may increase the likelihood of others providing benefits.	A patient looking to reduce a high risk of lung cancer decides to stop smoking as well as improve dietary and exercise habits.
Continuous Management	A patient has made critical decisions about their care and now needs assistance in maintaining current treatment plans.	A diabetic patient must learn how to plan meals and improve food choices.

The severity of the condition a patient faces will impose emotional and social complexities and dramatically affect the time frame in which treatment decisions are made. However, in the context of this information-centric framework this does not impact the classification of the decision presented by a single given decision aid. That is, this framework is designed to be condition and stage-of-condition independent. The risks, implications, and consequences of treatment choices to deal with an aggressive cancer are severe, yet from an information perspective the types of decisions required share similarities with the decisions of a patient with a seasonal allergy: multiple treatment options may be available, some treatments will be more or less effective than others, and repeated attempts to manage the condition may be needed before ultimate success is found.

Decision aids for binary decisions are one of the most commonly studied as they are the least complex decision and often come down to a patient electing to undergo treatment or not (14) (15) (16) (6) (17). Studies indicate that framing effects of personalized risk and comparisons with the risk of an average population have a significant effect on whether or not participants opt for treatment (1). The order in which risks and benefits of a treatment is presented has been shown to influence whether or not participants felt positively about treatment though the presence of contextual information eliminated this bias (18). Edwards et al. (19) report on a randomized controlled trial where diabetes patients chose between a “treatment as usual” management plan and a “tight control” plan based on information presented in either text, graphical, or text and graphic formats. Their findings suggest that the format of the decision aid had no significant effects on the reduction of decision conflict, however participants preferred simple graphics which avoided anchoring information and induced information overload. Other work, however, suggests that intention to undertake recommended lifestyle changes was in fact influenced by graphical formats but only in participants also receiving high-threat communications (20) (21). Graphical decision aids have also been shown to impact the emotional response (22) of participants and decrease their passivity in counseling sessions (12).

Multi-option decision aids are often used when there are multiple treatments a patient can consider at once that for varying reasons are mutually exclusive of each other. For example, an early stage prostate cancer patient may be

given a decision aid to help decide between surgery, radiation, chemotherapy, or simply a watch-and-wait strategy (23). Or, a patient at high risk for breast cancer may need to choose the extent of preventative surgery (5). A key difference between multi-option decisions and binary decision is the emphasis of the decision aid: for a multi-option decision the information must support comparison between options through its format. This is different from a collection of binary decision aids which each individually tell a specific story about a single treatment. The collection may not provide the same information about each option nor will each aid necessarily provide measurements which can be compared across decision aids. Comparison is a difficult information process to support in some formats and studies have found that while participants prefer simple, familiar graphics, their knowledge as measured by question-answer accuracy is higher when more sophisticated graphics are used (23). When used as part of consultations, multi-option decision aids have been shown to improve knowledge and reduce decisional conflict (24). When choosing from amongst treatments, participants tend to prefer symbols to numbers to represent strength of the recommendation or evidence for the treatment and incremental risks are consistently perceived as lower in text-only decision aids (25). Other work has shown that both verbatim and gist knowledge are significantly associated with medically superior treatment choices (3).

Decision aids supporting the combination of treatment options are uncommon in the literature. This may be due to the fact that binary decision aids are much simpler to develop and when treatments can be combined to even greater benefit, it seems unnecessary to spend time explaining how their interaction will magnify their effects. But, they can be particularly effective in communicating the effects of lifestyle changes on long-term conditions and helping patients determine their priorities. Jones et al. (11) report on work where 90% of patients in a clinic environment were able to make lifestyle adjustments to address their risk of cardiovascular disease with the help of a model-based decision aid. Other systems have been successfully built to recommend lifestyle options to patients at risk of cardiovascular disease that are in agreement with clinical guidelines and practices (26).

Finally, decisions aids supporting continuous health management are often used in situations where patients have chronic conditions necessitating continuous management. Continuous management decisions differ from other types of decisions in that a single decision may have little immediate impact. However, over the long term of managing a patient's health, the cumulative effect of such continuous smaller decisions has a determining impact on the patient's condition. In some cases, a decision aid may provide supplemental information non-specific to a particular treatment to help a patient manage a care plan. For instance, an informative decision aid may provide resources for more information, counseling, or suggested lifestyle modifications. Critical decisions have been made and a patient has developed a care plan but must now incorporate those decisions into daily life. For example, Chaudry et al. (27) report on a graphics based aid designed to help low-literacy diabetic patients make healthier food choices. Others have assisted patients of cardiovascular conditions with learning the side effects of medication and understanding quality of life factors (28). Nurse practitioners assisted by decision aids for patients managing obesity-related health conditions increased their adherence to clinical guidelines (29). The intention of diabetic patients to adhere to their care plans increased while they interacted with game-like decision aids (30).

Timescale

Decision aids often include an explicit time frame in which the outcomes they communicate are expected to occur. Because the majority of decision aids are non-interactive, these timescales typically do not vary and provide a single snapshot of a patient's risk in an unchanging way. There are two classifications of time scales in our framework:

- Single Projected Point: A patient's risk is provided for a single point in time regardless of factors which may change during that duration. This is exemplified by a cancer risk calculator which provides a patient's risk of developing pancreatic cancer within the next 10 years.
- Multiple Projected Points: A patient's risk is provided at several distinct points in time, usually equidistant and changes to risk during the total timescale are evident through the repeated measures. An example is a table of a patient's risk of cardiovascular disease which has measurements for 5 years, 10 years, and 15 years from the current date.

The impact of timescales on decision aids is an understudied space in the literature. Single point measurements often range from the current moment in time to 30 or more years in the future when communicating risk. There is some evidence to suggest that short timeframes are best for achieving risk reduction through behavior change (31). Many decision aids or risk communications do not supply an explicit time frame for their data (32). For example, the National Center for Chronic Disease Prevention and Health Promotion reports that reducing blood pressure reduces the risk of major cardiovascular events by 50% (33). While useful to know, this gives a patient no

indication of the immediacy of the risk reduction. Most often, multiple projected points are used to communicate the changing of treatment effects or the evolution of a patients risk over time should no actions be taken (24) (7).

Measurement Types

A decision aid is designed to convey information to patients in order to help them chose their best treatment options. In order to do this, a variety of measurements may be provided so that patients may determine which factors are important for themselves. Measures are provided without priority and it is often the task of the patient to choose which are relevant based on personal preferences (see literature on patient preference elicitation). Examples of measures include the risk of experiencing side effects while taking medication, risk of needing additional treatments, risk of adverse events occurring after treatment completion, the numbers of patients opting for treatment, mortality rates, or quality of life measurements.

This list is intentionally not exhaustive. Evidence-based medical practice involves the consideration of a great many points of data and each is unique to a patient's personal condition. We include this dimension in our framework as an indication of the complexity of a decision to be made. With all other dimensions identical, a decision aid needing to reflect numerous salient measures will be more difficult to design than a decision aid detailing a single measurement, say the risk of experiencing headaches as a side effect of an oral medication.

Framing effects have been consistently found when equivalent measures are studied. Patient treatment preferences have been shown to vary based on whether patients were presented with survival rates or median survival times (23). Supplying comparative measures such as the risk of an average population has been shown to increase the likelihood that a patient opts for treatment if the patient's risk is above average (1). Some common measurements such as numbers-needed-to-treat are found to be easily misinterpreted by patient and physician alike (9). Verbal expressions of risk and other measurements are known to have a wide degree of interpretation between physicians and patients (17). Caution and clarity are needed in presenting measurements as even familiar formats such as bar charts have been shown to be misinterpreted by patients in some studies (20).

Data Source

The information presented in a decision aid should come from credible and verifiable sources. With that assumption, there are three common sources of data presented in decision aids:

- Model Based Data: a scientifically developed model accounts for one or more condition-specific parameters and classifies a particular patient's risks based on the patient's personal expression of model parameters.
- EHR Data: a patient's personal records are compared against the records of other patients and measures reported in a decision aid are a reflection of the outcomes of other patients with similar health records as the given patient.
- Summary from Literature: Clinical trials and other forms of scientific study have been summarized and the findings relevant to a particular patient are distilled into the content of a decision aid.

Summaries from literature may be the easiest data sources to obtain and redistribute making them a popular choice for data for any decision aid. Scientific studies have the advantage of publications which make providing reference information to patients simple. Model based data is also present in decision aid research though not as frequently as literature summaries. Breast cancer decision aids frequently make use of the Gail Model for patient-specific risk estimates (25) (34) (18). Similarly, cardiovascular disease can be modeled by several systems including expert systems using ARIC data (26), the UKPDS risk engine (35) (31), and the Framingham Risk model (35) (11) (31). An advantage of model-backed decision aids is that small changes can provide feedback to patients using interactive decision aids as demonstrated by Jones et al. (11) and others (21) (22). Not all interactive decision aids invoke models, however. Ancker, Weber, and Kukafka (36) report on the use of interactive graphics for communicating a static value of risk to low-numeracy participants. A smaller number of decision aids draw their data from electronic health records now that they are becoming more common and standardized. For example, the Hughes riskApp uses EHR data to identify high risk hereditary breast and ovarian cancer patients and model their risk of developing cancer across their lifetime (Figure 1) (37). Kharrazi (30) reports on the development of an interactive system for children with diabetes which uses parent-input reports of compliance as records to drive an in-game reward system.

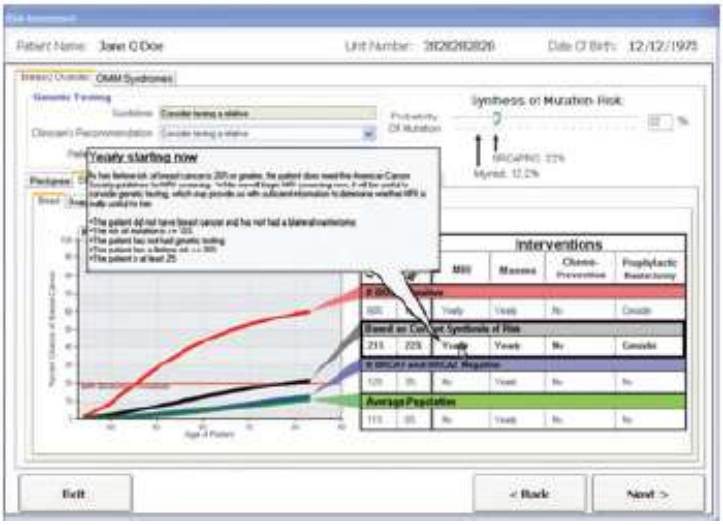

Figure 1 An EHR and Model based system for identification of high risk cancer patients. From **(37)**.

Personalization Level

A decision aid's relevance and the information it contains is often directly related to its ability to capture a patient's unique circumstances. The level of personalization supported by a decision aid can range from a series of predetermined options a patient may select from to the capacity to include a patient's entire medical history. We include this dimension as an indication of the personal relevance of the presented information in a decision aid. With all other dimensions identical, a decision aid personalized with a detailed medical history of a particular patient will be more relevant to the patient than a decision aid customized on a subset of that patient's history. Such increased relevancy has been shown to make health communications more effective (39).

A patient's specific risk of a condition is the most common level of personalization. This patient-specific risk can be derived from a wide range of factors such as height and weight (29) (26), medications (28) (35), diet plans (28), exercise regimens (28) (21), treatment preferences (23) (24) (38) (26), and other lifestyle factors (26) (35) (11) (34). In some cases, these personalizing data are gathered automatically from a patient's electronic health record (11) (30).

Information Format

Finally, the most widely studied dimension within our framework is the information format of a decision aid. With the utilization of the internet, a broad range of media has become available for the communication of patient treatment options. Rather than attempting to capture all the possible media now used for the production of decision aids, we focus this dimension on broad categories of presentation. Decision aids may belong to one of several categories summarized in Table 2. The same data may be presented in a variety of ways and a number of decision aids may be designed to support patients making the same decision. A patient may be given multiple decision aids of differing formats in order to make the information as clear as possible or to leverage the advantages of some formats over others. The classifications within our framework refer to the format of a single decision aid as a stand-alone product.

Text-only decision aids are commonly found in research literature where they are very often used as a control condition in a randomized trial. There is evidence to suggest that patients prefer other formats, particularly those that provide immediate feedback on questions (38). This may be due to a difficulty in interpreting statistics which has been shown to hinder both patient and physician alike (9). Some work has even found that numeric text alone produces low knowledge in comparison to pictographs (2). Other studies have suggested that the believability of data was perceived as greater in decision aids which contained graphics instead of just text (21) and that risk presented as text-only data is often overestimated (25).

Table 2 Information formats in decision aids

Format	Description	Example
Text	Treatments, risks and outcomes are expressed in written formats without graphics or augmentation.	A patient is given a report to use in determining whether or not to undergo a medical procedure.
Graphics	Treatments, risks, and outcomes are expressed in a graphical format such as bar charts, pie charts, pictographs, etc.	A patient is given a booklet of infographics which portray the risks of experiencing side effects of a possible medication as a series of bar charts. Each chart represents a side effect and each bar of each chart represents a year of treatment.
Text + Graphics	A decision aid contains both text (as described above) and graphics (as described above)	A patient is given a report with particularly salient study results called out in a table and risks communicated through pictographs.
Animation	A decision aid uses graphics which are animated to reflect changing measures or guide patients in understanding one graph's relation to another.	A patient is given a video which narrates a smoker's cumulative risk of acquiring lung cancer as a series of pictographs. Each step in the animation alters the data in the pictograph by one year at a time.
Interactive	A combination of text, graphics, or animation is available which patients may manipulate through a series of controls and observe the effects on relevant data.	A patient's risk of cardiovascular disease is assessed based on current lifestyle factors and then the patient selects a number of lifestyle adjustments to observe how those adjustments affect projected risks.

The study of graphics as decision aids has provided evidence that features which support the accurate or correct interpretation of data are different from those that prompt behavior modifications (15). Numeracy and graphicacy have been repeatedly shown to affect the accuracy of patient understanding (5). Pictographs such as Figure 2 have been shown to help patients attain higher risk comprehension, particularly those with low-numeracy (3). Factors such as horizontal layout and shading have been investigated for their impact of graphic understanding (6). Familiar graphics are often preferred based on qualitative reports but can also lead to less accurate knowledge (19). There is danger in applying unfamiliar graphics such as funnel plots which allow patients to apply their own, possibly incorrect, interpretation to data (20).

The combination of text and graphics in a decision aid has some mixed results. Participants have reported information overload when risk communicated through graphics is augmented with additional information as text (19). Other work has suggested that tables, which combine text with graphical layouts, are associated with higher verbatim knowledge in patients but at the cost of lower gist knowledge (3).

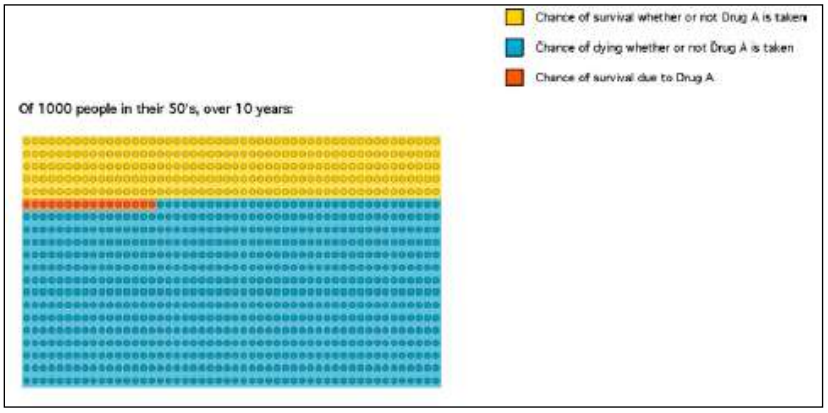

Figure 2 Example Pictograph from Price, Cameron, Butow **(6)**

Interactive decision aids and animated decision aids are less prevalent in research literature but their effect has been encouraging. Low-numeracy participants have been found to report higher risk-feelings than high-numeracy patients except when using interactive graphics (36). Uncertainty of cancer risk was effectively communicated through a dynamic visual format by Han et al. in (40). Interactive decision aids have also consistently led to more expressed emotional responses including relief about small risks, concern over large risks, and feelings of empowerment (22). Participants not making use of interactive features report lower intentions to make lifestyle changes or adhere to care guidelines when compared with participants in interactive conditions (30) (11). One barrier to the adoption of interactive decision aids is studied by Xie, Watkins, and Huang (14) who indicate that the controls used by interactive decision aids are frequently non-intuitive to target populations such as older adults. Some evidence has also suggested that interactivity can distract patients from understanding relevant information (41).

Discussion

In our survey of risk communication and decision aids we found many decision aids which effectively communicated the risk of certain conditions and/or treatment side effects and reduced the anxiety patients feel when presented with a great deal of information they must come to understand. We note, however, that there is a dearth of research investigating the role of interaction and interactive decision aids, particularly when used as a means for making combined treatment decisions or for greater personalization. We see several ways in which an interactive system could overcome shortcomings of static graphics or text in displaying complex information:

- The effects of multiple variables on a single risk factor can be isolated and demonstrated individually and together on the same data.
- Multiple presentations of the same data decrease the reliance patients must have on any single graphic, particularly when views are coordinated.
- Patients can decide which treatment options to explore and change their minds many times.
- Patients can obtain high-level understanding of data and then explore personally interesting facts in greater detail.
- Patients can return to the decision aid multiple times during the course of their decision making and investigate new facets of their treatment options.

Pictographs are a popular choice for communicating the probability of an event happening but as static graphics they can only reflect a single point of data for a single point of time. Ancker, Chan, and Kukafka (22) and Ancker, Weber, and Kukafka (36) make use of interactive pictographs to first conceal the graphic representation of risk and then reveal it through game-like clicking interactions (Figure 3). Additional controls might allow patients to investigate the effects of time by revealing how the number of individuals who experience an event increases or decreases over time or how those rates increase or decrease compared to a second population of individuals. Alternatively, patients might have the option of changing which model drives their risk estimation in order to understand the variability or uncertainty of their health risks.

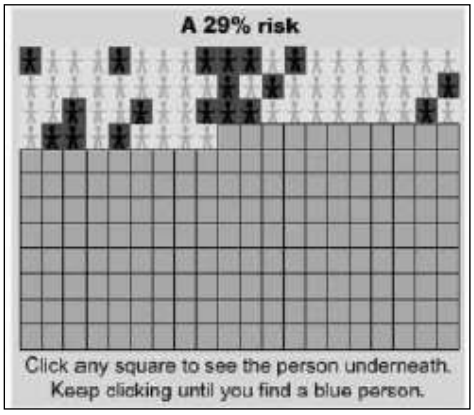

Figure 3 An Interactive Search Pictograph from Ancker, Weber, and Kukafka **(36)**

Jones et al. (11) test an interactive system for communicating a patient's cardiovascular risk as part of their study on the feasibility of clinic-based decision aids (Figure 4). Their prototype makes use of a model for generating a patient's Framingham Risk Score based on the patient's current health condition and several patient selected lifestyle options. A reactive set of bar charts displays the patient's current risk score, an idealized risk score possible should the patient opt for every possible healthy lifestyle choice, and the patient's currently selected risk score based on what lifestyle modifications the patient has actually selected. This simple interaction has the ability to demonstrate to patients in a visual way the progress they could make in reducing their risk score as well as providing them a chance to discover which of their preferred risk reduction lifestyle changes have the largest impact to their health. One limitation, however, is that the visualization presents a single projected data point for a patient's risk (a 10-year risk of cardiovascular disease). An alternative visualization might make use of electronic health records of similar patients to show what cardiovascular-related events other patients encounter and when over the course of their management of their condition those events occurred. A patient may find it useful to know that while smoking cessation alone dramatically cuts their risk, diet changes and exercise reduce risks as well and also result in the need for fewer medications over a lifetime.

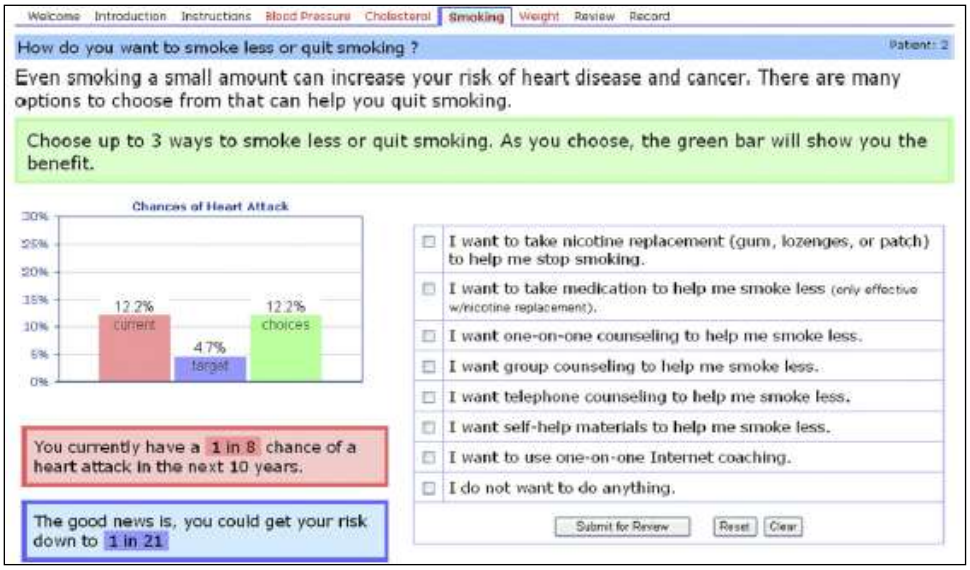

Figure 4 An interactive interface for prompting lifestyle changes in high risk cardiovascular patients. From Jones et al. **(11)**

Conclusion

We have presented an information-centric framework which provides a mechanism for describing the content of a decision aid and how that content is presented. It can be used as a means to compare the roles of decision aids and what data can be represented with it. Our framework overcomes limitations of other frameworks by shifting the emphasis of evaluation from strictly accuracy and by allowing design factors such as interaction, format, and decision type to be represented. In future work, we will use our framework to design an interactive decision aid to help patients choose between different treatment options (a multi-option decision) based on electronic health records and the outcomes of similar patients over the course of their treatment. We are also in the process of evaluating our framework with other decision aid designers and experts knowledgeable in the varying roles decision aids play in patient-centered risk communication.

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