

# An Assessment of the Potential for Personalization in Patient Decision Aids

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**Abstract.** An increasing number of patient decision aids are being developed to assist patients in making personalized choices among health care options, but little is known about the current use of and potential for personalization of web-based decision aids. The purpose of this study is to estimate the potential for personalization of patient decision aids. We developed a coding scheme for personalization and analyzed web-based patient decision aids from all relevant developers according to the scheme. The most relevant subgroups of users and the current representation of the groups in the tools were identified. We then identified system behavior relevant to web personalization, and instances of adaptive system behaviors. The decision aids included in this study exhibit four out of five classes of system behavior eligible for personalization. With few exceptions, the tools do not contain automatic, adaptive behavior. Patient decision aids hold potential for web personalization. Relevant techniques are largely unexplored.

## 1 Background

Patient decision aids are evidence-based tools designed to help people participate in making specific, deliberated, personalized choices among health care options, in ways they prefer. According to a systematic review on the effectiveness on patient decision aids, the tools «differ from usual health education materials because of their detailed, specific, and personalized focus on options and outcomes for the purpose of preparing people for decision making»[1].

The term «personalized» is often included in the definitions and declared purposes of patient decision aids. Personalization can pertain to several aspects of a decision aid, such as the structure and content of the tool, the decision-making process, and the resulting choice. Within the domain of information and communication technology, personalization implies the use of technology to accommodate the differences between individuals. Technological personalization of patient decision aids could potentially tailor healthcare and healthcare communication by adjusting to the different biological, psychosocial and contextual idiosyncrasies of patients.

Web personalization is the employment of user features in web systems that adapt their behavior to the user. The overall aim is to meet the needs, goals and preferences of a variety of people. The adapted content can be variations regarding information, products,

people, services and activities. An exploration of the techniques in the domain of decision aids could hold potential for more informed, satisfactory, effective and personalized decisions. A large inventory of techniques for adaptively selecting, structuring and presenting content in web systems to user features (attributes and interaction data) have evolved during the last two decades [2].

Despite the fact that decision aids are intended to support the personalization of care, little is known about the current use of, and potential for web personalization inherent in the tools.

## 2 Design and Methods

The objective of this mixed-methods study is to estimate the potential for web personalization in web-based patient decision aids.

Based on a comprehensive anthology [2] we developed a coding scheme for current web personalization techniques. The scheme includes a checklist of possible user features and a catalog of adaptive system behaviors.

We identified developers of web-based decision aids by hand-searching the quality-assessed patient decision aids in the Ottawa Inventory[3]. Developers of decision aids only available in PDF format were excluded. One decision aid from each developer was included for further study. When a developer had produced more than one decision aid, we selected the decision aid that included the richest functionality present in the developer's portfolio of tools.

Applying the coding scheme, we identified explicit and implicit subgroups with comparable user features in the decision aids. Subgroups existent in the tools that were not present in the generic coding scheme, were added to the scheme. We identified and described the linguistic representation of subgroups in the decision aids.

We then mapped the system behavior in the decision aids to the classes and prerequisites of adaptable system behavior present in the coding scheme. Finally, we systematically identified user-adaptive behavior present in the decision aids.

## 3 Results

259 decision aids developed by 22 producers were found in the Ottawa Inventory. The 10 producers that met the inclusion criteria were responsible for 223 of the decision aids included in the inventory.

### 3.1 A Coding Scheme for Personalization of Patient Decision Aids

According to the coding scheme, the basic components of personalization are the media content, user features, user model construction and representation, and adaptive system behavior. We analyzed the decision aids according to the four classes. User features can broadly be classified into the user's knowledge level, interests, preferences, goals/tasks, background, individual traits and context. Adaptive system behaviors include adaptive

navigation support, adaptive selection, organization and presentation of content, adaptive search, adaptive collaboration and personalized recommendations. We adjusted and updated the coding scheme to the features identified in the decision aids. In example, we included somatic parameters as a subclass of individual traits.

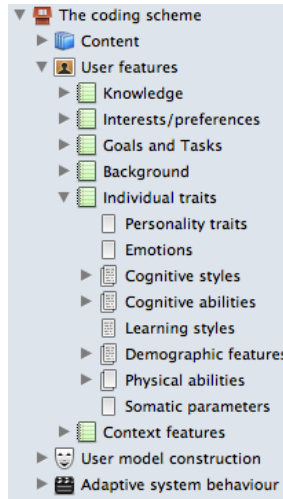


Fig. 1. Screenshot of the coding scheme. The subclass *individual traits* is expanded.

### 3.2 Content Types

8 out of 10 decision aids included at least two media types. 8 decision aids could be classified as hypermedia, by definition present when hyperlinks and at least 2 media types are integrated in a web system.

### 3.3 Explicit and Implicit Subgroups

The majority of the implicit and explicit subgroups targeted and represented in the decision aids could be classified in accordance with the user features subclasses in the coding scheme. The most frequently found subgroups were coping styles, emotional reactions, cognitive skills, user's beliefs, experiences of users, literacy level and somatic parameters.

Most of the content that could be differentiated according to subgroups pertained to the somatic parameters of individual patients. The most frequently used somatic parameters that defined subgroups of users were risk factors, factors relevant for the eligibility for treatment, incidences, prevalences, and probabilities, outcomes of decisions, etiology, lab test results and prediction of recovery.

One of the decision aids included an *evidence summary* that summarized the research underlying the decision aid. 53 % of the sentences in the evidence summary

contained information that described different subgroups. This information was, with few exceptions, not found in the decision aid.

### 3.4 Representation of Subgroups

The decision aids embedded a number of different strategies to address user groups with different features. The most frequently applied representations of subgroups identified in the decision aids are the following:

- Listing several subgroups and making specific statements true for each subgroup one by one
- Making statements that are untrue or irrelevant to at least one subgroup
- Alluding to subgroups without specifying the attributes of the subgroups
- Giving an average for all subgroups combined
- Suggesting that a patient belongs to one, particular subgroup
- Listing only some subgroups
- Not acknowledging the existence of relevant subgroups
- Asking user to determine the relevant subgroup her-/himself
- Helping the patient determine the relevant subgroup e.g. through an interactive tool
- Describing how health personnel should determine the relevant subgroup
- Giving general information but acknowledging that subgroups do exist
- All decision aids in the study included information that was true and/or relevant only to subsets of users with particular user features.

### 3.5 User Model Construction and Representation

Direct or indirect evidence of the application of user models was not found.

### 3.6 System Behavior and Adaptation

All decision aids presented selected and organized content. 6 of the decision aids included a search field, but only 1 included a search field that searched specifically for content included in the tool only. The search fields in the remaining 5 decision aids searched the content in all of the website. 1 developer included a tailored search field to selected websites. With 2 exceptions, the decision aids exhibited static navigation. None of the producers enabled user collaboration. 1 included a user forum directly related to the tool. 1 decision aid included automatic recommendation of content based on implicit interaction data. Users could manually enter personal data in 9 of the 10 decision aids, the most frequent feature being the possibility to adjust text size.

**Table 1.** Decision aids included in the study

<b>Clinical condition</b>	<b>Developer</b>	<b>Hyper media</b>	<b>Adaptive behavior</b>	<b>Corpus</b>
Treatment options for early breast cancer	Cardiff University and others, UK	Yes	Basic	Closed
Stroke prevention in atrial fibrillation	Healthwise Inc, US	Yes	Basic	Closed
Statins for prevention of cardiovascular disease	Mayo Clinic, US	No	Basic	Closed
H1N1 vaccination	CHEO, Canada	Yes	Basic	Closed
Treatment options for early breast cancer	Baylor College of Medicine, US	Yes	Medium	Closed
PSA testing	Health Dialog Inc, US	Yes	Basic	Closed
Long term feeding tube placement in elderly patients	Ottawa Patient Decision Aid Research Group, Canada	Yes	Basic	Closed
Mammography screening	Public Health Agency of Canada	No	Basic	Closed
Premixed insulin for type 2 diabetes	AHRQ, US	Yes	Basic	Closed
Treatment options for early prostate cancer	National Cancer Institute, US	Yes	Basic	Closed

## 4 Discussion

Whereas paper-based and linear media can be personalized to a very limited degree, web-based hypermedia systems can adapt their content and presentation to individual users employing an array of techniques. The web-based decision aids included in this study display 4 out of 5 classes of system behavior eligible for personalization. None of the systems contain advanced adaptive behavior. All the selected decision aids are closed corpus systems.

The web-based decision aids analyzed in this study target and address several subgroups within what is mainly a one-size-fits-all format. A number of strategies are applied to relate the content to different subgroups, of which some are potentially misleading, inappropriate, and might entail increased cognitive burden and unnecessary uncertainty. A relatively large amount of content could have been differentiated according to different patient's somatic parameters.

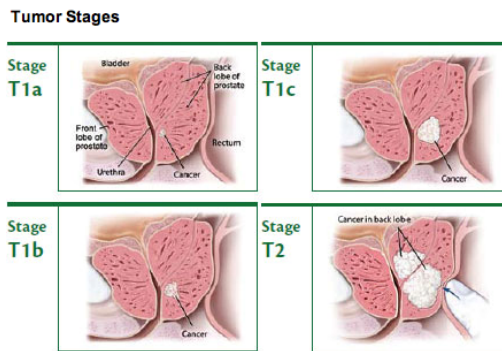
In the case where the evidence supporting the decision aid was provided, our analysis indicates that most of the information could be differentiated to individual patients. This information was only to a limited degree reflected in the decision aid.

As decision aids are developed to support patient's personalized choices, the general absence of personalization in current decision aids is a paradox. According to our findings, a significant amount of content in both the decision aids and their underlying

evidence base could be tailored to the somatic parameters or other features of individual subgroups.

In addition to personalized *selection* and *organization* of content, system behavior could adapt to users in a variety of ways. To give an idea of the potential, personalization techniques could include:

- *Presentation* of the content most relevant to the user by priority-on-context techniques such as coloring or scaling
- Supported *navigation* by augmenting links with annotations that give visual cues, for instance of progress
- *Recommendation* of peers with similar features that is treated at the same hospital, to the patient
- Personalized web *search* adapted to the health literacy of the user
- Personalized *collaboration* where users e.g. build a shared list of questions to ask their caregiver or physician



**Fig. 2.** In the patient decision aid *Treatment choices for men with early prostate cancer*, information about different tumor stages is presented identically to all users. The presentation could be personalized utilizing techniques that highlight the tumor stage relevant to the individual patient. Content fragments could be dimmed, colored, scaled or sorted. Reprinted with permission from the National Cancer Institute.

## 5 Conclusion

Existing web personalization techniques constitute a rich resource of developmental possibilities for various aspects of decision aids that is largely unexplored. By adapting system behavior already present in current web-based decision aids, the content and functionality could potentially be tailored to a range of user groups. The time and effort in using the techniques must be weighted against the possible benefits.

Advanced personalization techniques require the representation of user features in user models, which is unlikely to be worth the cost when decision aids are stand-alone applications. User models could potentially be built utilizing input from the electronic patient journal. Embedding decision aids in patient portals holds promise of enabling

adaptive behavior of decision aids. The advance of semantic web technologies such as RDF and OWL, and the use of an open corpus knowledgebase, could bring added possibilities.

## References

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