Creating Patient Decision Aid Tools

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Abstract: This paper reports on the creation of a web application that facilitates the development and implementation of patient decision aid tools. We propose a software prototype model that allows medical personnel to easily and rapidly create digital prototypes of patient decision aid tools independently on the medical condition. Our application can be used as an online framework and is being tested by healthcare professionals.

1 INTRODUCTION

Several medical researchers and practitioners have been advocating for enabling patients to have a more active role in making decisions regarding the treatments to choose to deal with their medical condition. In order to achieve this, a shared decision making process needs to be pursued and implemented (Eason et al, 2012). Cross disciplinary studies have shown several benefits for patients who are involved in the decision process during their medical journey (Lee & Emanuel, 2013). Those patients, once empowered by providing them with a good understanding of their condition, the diagnosis, the possible set of treatments, and the pros and cons of each of these treatments, can then make more informed decisions about their treatment choice also by factoring in personal wishes and life situation. One of the main challenges in implementing this approach is the appropriate creation of tools that can help educating the patient, the healthcare professionals and the other stakeholders involved in the patient's journey.

Patient decision aid tools (Ottawa Framework, 2019) have emerged as clinical frameworks or guidelines in situations where there are alternative courses of treatment. They are meant to educate the patient and help him make a decision. Usually, these tools are developed by researchers or healthcare professionals in the form of small leaflets or paper cards. In recent years, multimedia tools have been emerging and a new development towards web-based patient decision aid tools has also caught up (Syrowatka et al., 2016). Developing patient aid tools is not an easy process. It requires following a standardized process that should include a carefully planned development, available research-based information, user testing, proper design, field testing and evaluation (Coulter et al., 2013).

We created a prototype model of a web application that makes it possible to create generic decision aid tools. With the term generic, we refer to a tool that is not tailored to a specific medical condition but can instead be easily adapted to accommodate to different conditions with only little effort.

Our web application is intended to be a ready-to-use software. It can be used as a sort of online content management system for the generation of patient decision aid tools that can be quickly prototyped and generalized over medical conditions.

2 PATIENT DECISION AIDS TOOLS

2.1 Related Work

The adoption of software programs by healthcare professionals has seen an ascending trend in the last decade. The joint work of software developers and healthcare professionals has made it possible to create tools that can help mediate the relation with the patient, minimize the errors in the care process, help doctors adhere to medical guidelines, streamline the process and last but not least, help the patients to have a better understanding of their illness, the treatment options and their role in making a decision (Wright et al., 2009).

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Over the course of the last decade, medical practitioners have documented better outcomes in patients who have been actively involved in the decision making (healio, 2016). The need to involve patients in the medical decision process has been also corroborated by scientific studies coming from the area of medical sciences and socio-psychology (Lee & Emanuel, 2013). The International Patient Decision Aid Standards Collaboration has developed quality criteria for the development of patients' decision aid tools (Elwyn et al., 2016). The actual development of such tools is then usually mainly focused on specific illnesses, such as prostate cancer, lung cancer, diabetes etc (AHRQ, 2019).

Like with most other areas, we have seen recently a switch from the paper-based decision aid tools to computer based ones. The benefits of digital decision aid tools as compared to the paper based ones have started to be investigated by both healthcare professionals and researchers. The importance for developing a computer-based decision aid tool was supported by a review conducted by Syrowatka et al (Syrowatka et al., 2016). The objective of this review was to identify if computer-based decision aid tools performed better than commonly used paper-based decision aid tools. Furthermore, the same study made a classification of the features that were integrated in existing computerized decision aid tools. The purpose of this classification was to identify whether specific features performed better than others and to figure out the degree of redundancy of incorporating certain features in an effort to maximize the quality of the decision making process. As with many other areas of our lives, the online environment has the capability of providing the user with a more interactive experience, allows for a mix of multimedia components, which in turns enables the user to have a better understanding of the subject or theme that is being presented. Furthermore, a digital decision aid tool can allow the user to interact with it, thus making the information presented and experience to be tailored to the specific characteristics, needs and wants of the user.

As it has also been outlined in other research studies (Hoffman et al., 2016), online platforms allow for media rich components to be integrated, making it possible for patients to benefit from a more interactive experience that ultimately facilitates the understanding of the information transmitted and goes beyond the limitations of the paper-based approaches. The media rich content can be presented in terms of instructional videos, inserted in the material send to the patient over the internet, or in terms of dynamic graphs and images that can help the patient better understand his individual case reported to the average condition or how certain probabilities related to the treatment would apply in his specific case. Animations, icons and graphs can be used to help bring the data from abstract to concrete. In (Flynn et al., 2015), a computerized decision aid for thrombolysis in acute stroke was developed. An assessment on when it is the best time to communicate to the patient certain medical related information to ensure a proper reception and understanding is also discussed.

One of the most prominent frameworks in the area of decision aid tools development is Ottawa Decision Support Framework (Ottawa Frameworks, 2019; Ottawa Decision Aid, 2019). This framework is based on identifying and resolving the decisional conflict and is supported by extensive research from psychology and sociology (Matlock and Spatz, 2014). It consists of three major components: decisional needs, decision quality, and decision support. The potential impediments for adopting patient decision aids on a large scale by clinicians is also discussed. The main impediments identified were: poor development, reluctance on the part of clinicians to use them, prohibitive workflow, maligned incentives, or inaccessibility at the time they are needed.

The web application we created facilitates the development of patient decision aids tools and incorporates several of the guidelines formulated in the Ottawa Decision Support Framework. Our applications is not a decision aid tool per se because it does not target any specific illness. Our software application focuses on the creation of web-based decision aid tools for virtually any medical condition. It provides a framework for the creation of a layout where physicians and medical personnel can easily enter research-based medical information and data to educate patients and make it possible for them to make choices when alternative treatments are possible. With our application it is easy to quickly prototype and standardize the creation of decision aid tools. The data entered can be text, video clips, audio clips, hypertext, and images.

2.2 Minimal Technical Requirements

While designing our application, and after an empirical analysis of informal discussions with medical personnel, we decided that it had to display a set of minimum features. These are:

- web-based: the system must be accessible in a web browser in order to avoid any additional software installation

- responsive: the user of the system will be able to access the application from different screen-size devices
- sharing and collaboration: this feature allows the medical personnel to collaborate when creating and defining the content of a given decision aid tool for a specific condition
- published API for data communications: this allows for a seamless integration of the application with other systems used by the medical organization
- print or export to PDF format: this caters for patients that prefer a paper version of the tool; digital features that are not available in paper format (e.g. video clips) are to be replaced with other supporting information and material (e.g. an image of a QR code to scan with a cell phone and play the video that could not be inserted in the PDF).

2.3 User Roles

The system is designed with multiple user roles, each role providing different levels of access and rights. Specifically, we have the following roles and levels of access:

- admin: it is the top-level user with access to the entire technical related functions and user administration functions; the typical person with admin role is a developer or one person from the medical institution
- designer: it is a specialist in creating patient decision aid tool layouts; s/he designs and creates new decision aid tools and usually has gone through some training with the content management system
- editor: it is person who provides the designer with the research-based information when a certain decision aid tool for a certain condition is being created; s/he is a subject-matter expert but does not need the technical expertise to create template layouts
- user: it is the end user of the system, typically the patient or a patient's relative, with no access to the system back-end; s/he is only able to view, read, provide personal input data entered via UI widgets and print a decision aid tool after this was shared with her/him in digital form by the medical personnel.

Usually, the designer and editor are expected to work in close collaboration when a new decision aid tool is created. The designer turns the information provided by the editor in graphical form and style them according to a few predefined layouts.

3 PROTOTYPING GENERIC PATIENT DECISION AID TOOL

3.1 Overall System Architecture

In this section, we present an overview of our system architecture. We split the architecture into 3 main components. Being a web application, we naturally mapped our system onto a three-tier architecture made up of a front-end, a middle tier, and a backend.

The front-end was created using standard web technologies such as HTML 5, CSS 3, and a mix of JavaScript and a set of JavaScript libraries. Figure 1 shows the different tasks allowed (indicated with file names), the different user roles, and relations between tasks and user roles.

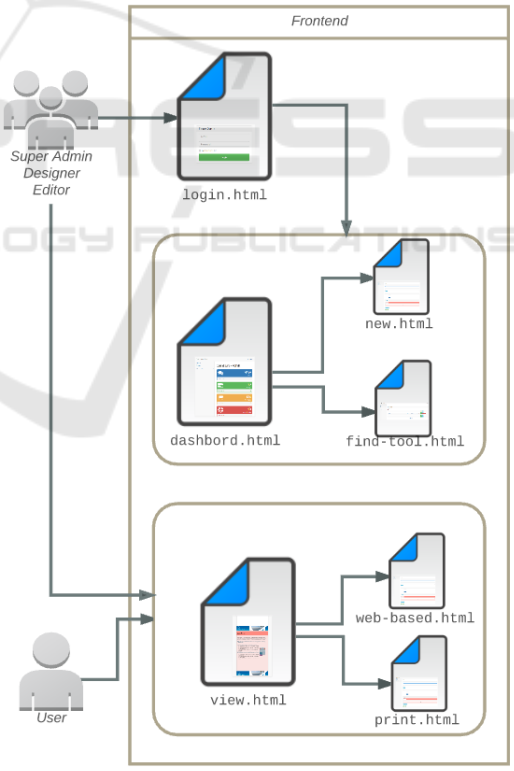

Figure 1: Overall system architecture: front-end.

The system middle-tier is shown in Figure 2. We created a model-view-controller architecture based on PHP and hosted on a free cloud service. We developed our own model-view-controller

architecture instead of using an existing framework. Frameworks can prove very efficient in terms of development time and security. Frameworks that are used on a large scale have high security implementations and the pre-built functions can speed the process of development from hours to minutes. However, frameworks have also limitations (Manger et al., 2015). One of the major limitations is that the developer is constrained to work within its specifications and limits. In our context, we wanted to be sure to be browser independent and to not decrease our application performance due to large overhead of additional framework code. Moreover, it can prove difficult to introduce multiple frameworks in the same project and due to the library limitations, for the development of our application multiple frameworks would have been required.

Frontend and middle-tier communicate with each other through an RESTful API that, while emphasizing the separation of concerns principle among component, also acts as the system gateway to data. With the API it is also possible to integrate our architecture into other systems that the medical institution might use.

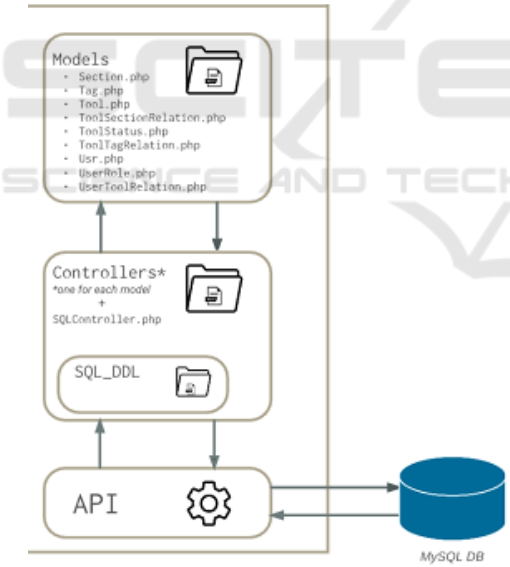

Figure 2: Overall Architecture: Middle-Tier and Back-End.

Eventually, a MySQL database is used to persist the data related to the information and meta-data stored in each patient decision aid tool.

3.2 Creating a Decision Tool

In the section, we report on the process and steps necessary to the creation of a patient decision aid tool.

The designer is the person in charge of going though this process. Whenever a new decision aid needs to be generated, basic information about it is required for laying out a first simple structure of the digital document (see Figure 3). This includes for instance the title to assign to the decision aid tool, a set of semantic tags, an image, and a variable number of sections. The title is used on the cover page as well as to identify the decision aid. The semantic tags are keywords used to describe the decision aid tool being build. These tags are used for search and classification purposes when more aid tools are available on the system backend. An image is provided to ensure the visual identity of a decision aid tool. While collecting system requirements, we were made clear by the management of the hospital we started this project on, that it was important to have a uniquely identifiable message or text on whatever decision aids implemented both on paper aids and digital aids. At this stage, the image is typically the logo of the institution. This is be placed as a footer on each section/page of the decision aid tool being created. An additional image can be uploaded to act as background image throughout the pages of the final product. Sections are the core components of a decision aid tool, notably where the subject-matter information is actually structured. This information must be provided by subject-matter expert.

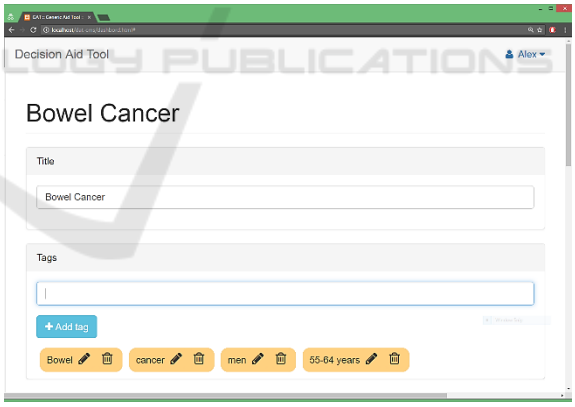

Figure 3: Initial steps in creating a new decision aid tool.

Each section has three main components: a title, a color and the content of the section. At the moment, we have a set of predefined sections including: introduction, condition description, treatments, pros and cons, user preferences, decision, conclusion, and glossary. More sections can be created, and sections can be deleted as well.

In the introduction section, text can be added to introduce who is this tool targeted to or any other information the expert believes should be conveyed

at the very begin of the decision aid tool. The condition description section provides an overview of the medical condition. The section ‘treatment’ describes the available treatments along with the pros and cons for each of them. The section ‘user preferences’ is essentially supposed to be a short questionnaire that the patient is asked to filled in.

The questionnaire can contain multi-choice questions as well as open questions. Right after that section, a typically one-page section follows where the patient summarizes his/her decision, based on the information process until that point. A possible decision is not to decide any treatment at that point but rather defer the choice, that is, delay the decision to a later point in time or avoid the decision altogether. A conclusion section is used to inform the patient of the expected next steps. Eventually a glossary section is used to list and describe all the technical terms used in the decision aid tool. Sections are color-coded i,e, are associated with different colors to allow for a better navigation of the tool by the intended final user.

One of the most powerful functionalities of the system is the way through which the content of a section is created or edited. Once the designer presses on the content of a section, an HTM editor is enabled. The editor makes it possible for the user to enter and edit the content of the section in any way s/he wants. Figure 4 shows a screenshot of the editor in action, more precisely in a case where the designer was attempting at inserting an image into a section. Once the designer finishes editing the content of a section, s/he can save it and preview it.

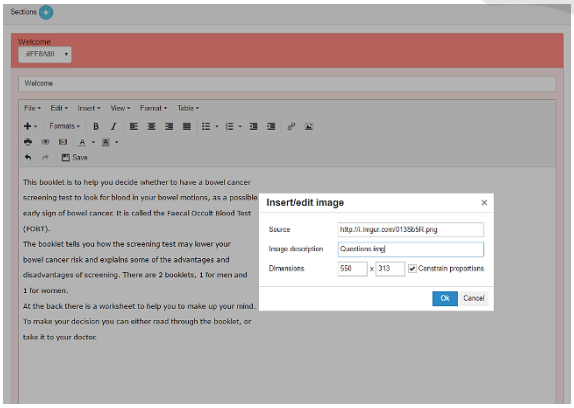

Figure 4: Inserting an image in a section with text.

Figure 5 and Figure 6 show how a new decision aid tool may look like in print mode (i.e. after selecting the option to print the digital patient decision aid tool) and the digital version after some content has been added, respectively.

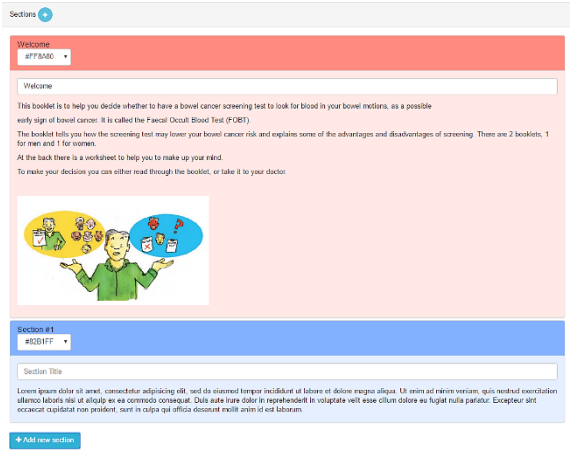

Figure 5: Patient decision aid tool as it looks in preview mode after some data has been entered.

Another functionality of the tool is the collaboration and sharing mechanism for the tools. Here is the place where a designer can request access to a tool if s/he does not have access to this tool yet. Another functionality under development is the automatic addition of terms into the glossary. The rationale here is that, once the designer enter text into a section, s/he can highlight a (sequence of) term(s) and provide a description for it. By doing so, the term will automatically be added in the glossary section along with the description of its meaning.

Figure 6: The first three pages of a patient decision aid tool formatted in print mode (preview).

4 CONCLUSION AND OUTLOOK

We developed a web-based application that helps create generic patient decision aid tools. Our system was developed based on requirements collected with healthcare professional working at a Danish hospital.

At the moment, the system exists in its prototype for it still requires further work and development even after it has been released to the users for testing. Primary usability testing with a few beta testers resulted in positive feedback. The usability of the

system needs be thoroughly tested in the field, as the purpose of this software is to become a tool that professionals are willing to use and comfortable with. The system usability also has to target a set of quality criteria (Syrowatka et al., 2016; Elwyn et al., 2006) Specifically, user testing needs to figure out if the tool we have developed

- provides information in sufficient detail,
- presents data in an unbiased manner,
- includes methods to clarify values and preferences,
- provides structured guidance for deliberation and communication,
- presents information in a balanced manner,
- presents up-to-date research-based medical evidence,
- discloses conflicts of interest,
- uses an appropriate plain language, and
- ensures that the decision is informed and value-based

The API that we implemented allows for future integrations of the software into the systems that the healthcare professionals are already using on a daily basis. The integration can be done based on both a push or pull model.

As the next development step, we plan to integrate the system with Merriam-Webster's Medical Dictionary (Merriam-Webster, 2019) and Google Custom Search (Google, 2019). This integration will allow the users to be able to access additional resources in creating decision aid tools and the patients will be able to find definitions of any terms in a tool, if in doubt about the meaning.

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