Applying User-Centered Design in the Electronic Health Record (EHR) to Facilitate Patient-Centered Care in Oncology

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Abstract

Patient-centered care is an essential component of quality health care. To support patient-centered care initiatives at our institution, we created a feature in our EHR to centrally view information about the patient's values, goals and preferences. We applied user-centered design methods to ensure that the aggregate view was easy to use and would meet user needs. We created a six-week plan to iterate through increasingly detailed design mock-ups. We defined 7 user stories that later served as a basis for user testing scripts. We conducted user testing on our third design iteration; we reached theme saturation with 8 testing sessions. We incorporated findings into the fourth design (week 6) but continued to refine the design in parallel to development (through week 20+). The advance directives section required the most attention. We will use a pilot and additional user testing to validate the design and to inform future versions.

Introduction

Patient-centered care is a key component of quality health care. In 2001, the Institute of Medicine (IOM) called for care that aligns with and adapts to "individual patient preferences, needs and values"[1]. Patient-centered care also promotes meaningful conversations between patients and providers and improves relationships between the patient and care team[2]. Building communication and inter-personal skills among health care professionals is essential to patient-centered care initiatives; however, such initiatives can also leverage the electronic health record (EHR) to help support the delivery of patient-centered care[2, 3, 4].

After the IOM called for care where "patient values guide all clinical decisions,"[1] some organizations have described ways to support advance care planning for end-of-life care, including in oncology[5, 6, 7, 8]. A few have evaluated more general values as a pre-requisite to advance care planning[9, 10]. However, patient-centered care in oncology requires a wider focus, as the cancer care journey presents many opportunities to incorporate patient values into care before the end of life[11, 12]. For example, oncologists may consider the patient's upcoming family milestones or vacations when scheduling the next cancer-directed treatment. Similarly, treatments with a common side effect of dexterity-limiting neuropathy may be poorly suited for patients who are musicians or woodworkers.

To support patient-centered care initiatives at Memorial Sloan Kettering Cancer Center (MSK), Supportive Care leaders requested a feature in our EHR to centralize the display of information related to the patient's values, goals and preferences. Such information was available in the EHR, however, it was often in long notes or in parts of the EHR that users did not review frequently. Locating and reviewing the information was arduous and inefficient for users. Many users were not familiar with all potential data sources. The leaders envisioned that the feature would facilitate quick review of data stored in various EHR components (e.g. the registration system, clinic notes, scanned forms). While other organizations have described creating a central place in their EHR to support advance care planning in patients nearing the end of life[9, 13], to our knowledge, our project was the first to widen the scope to apply to all stages of the patient's illness trajectory. For our project, we applied user-centered design methods and an iterative process. User-centered design focuses on the user and user needs to ensure that design is intuitive, easy to use, and most of all--is useful. Our goal was to apply design-thinking to create an aggregate view of information based on user needs related to enhancing patient-centered care at MSK.

Methods

Setting

MSK is a dedicated cancer center with inpatient and outpatient services. The EHR at MSK, Allscripts Sunrise Clinical Manager, has "tabs" for users to navigate data and features. For this initiative, we chose to extend the "tab" metaphor for the display of the information about patients' personal values. We called the feature the "Values Tab".

MSK already had in place a variety of related notes and workflows to gather data pertinent to patient-centered care. A "Goals of Care Discussion Note" template, and various workflows to collect advance directives were in use. The Department of Nursing notes included discrete fields for data relevant to patient-centered care, such as preferred name, living situation and how the patient prefers to receive information (e.g., at a high level or with a lot of detail). Ongoing institutional initiatives additionally provided communication training for clinicians to enhance patient-centered care.

Multidisciplinary Project Team

The clinical leads on the initiative were three Supportive Care physicians (with co-appointments in Medical Oncology, Intensive Care, and Hospital Medicine, respectively). The team included representatives from an associated research project, Nursing, Nursing Informatics, Health Informatics, and Information Systems.

Data Elements

The clinical leads identified the data elements to include in the Values Tab. They grouped data elements into the following categories: (i) a "Values Summary" documenting patient values[11, 12], (ii) family/surrogate decision-makers, (iii) social history, (iv) spiritual and cultural history, (v) communication preferences, (vi) an "Illness and Treatment Understanding" patient-reported outcome[11], (vii) a "Goals of Care Discussions" section, (viii) advance directives and resuscitation preferences, and (ix) selected consult notes (i.e., Supportive Care, Psychiatry, and Ethics).
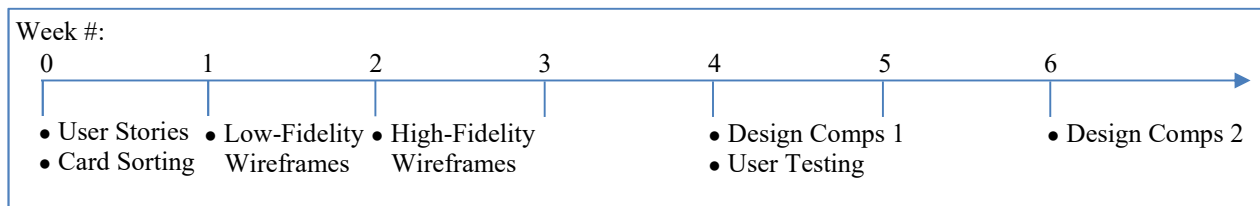
Design Plan

Figure 1. Timeline for design plan to apply design methodology and iterate on mock-up versions. Mock-up stages included 2 rounds each of wireframes and design comprehensives (design comps).

Once we identified the data elements to include in the Values Tab, we began the design process. Our general design timeline is shown in Figure 1. We iterated through design cycles with the following progression: (i) low-fidelity wireframes, (ii) high-fidelity wireframes, (iii) design comprehensives version 1 (design comps 1), (iv) design comps 2. For (i) low-fidelity wireframes, we created a high-level diagram of how to arrange and display information. For (ii) high-fidelity wireframes, we added more detail to the diagrams, such as some interactive features or how the tab may appear with varying amounts of information available (e.g., empty states for when data is not on file). For (iii) and (iv) design comps, we incorporated styling (e.g., format, color) and interactive features (e.g., drop-down sections, pop-up or modal windows); design comps 1 was an initial version and design comps 2 incorporated additional feedback from the project team and user testing. After design comps 2, we planned to hand-off to the development team and/or potentially conduct user testing 2 for validation and create design comps 3, if needed.

Each design cycle began with data collection (a feedback period of about 1 week on prior work and/or other data gathering). We held additional design sub-meetings (health informatics and the designer) and working sessions to review data, how to interpret data into design, or iterate on design, as needed. We created the next design version and then presented the resulting design to the clinical leads and project team. We used Invision.com to share interactive design and collected feedback on specific portions of the design. We also shared images of the design and received feedback via email.

User Stories and Card Sorting

For the first design cycle, we collected data through user stories and card sorting (see Figure 1). This cycle did not include a feedback period. To create user stories, the designer led a brainstorming activity with the project team to identify users, tasks and patient-values-related data needs for the tasks. The user stories grounded the design process in real use cases. The designer also conducted informal card sorting sessions with a convenience sample to understand how users may mentally group the identified concepts. In the sessions, the designer presented participants with cards marked with one concept each. The participants grouped the concepts, as well as named their groupings. Collectively, the sessions influenced how the designer grouped the concepts on the low-fidelity wireframe.

<u>User Testing</u>

We conducted user testing on the design comps 1, (week 4, see Figure 1). To prepare, we identified three stakeholder groups (i.e., Physicians, Nurses, Allied Health Professionals) and worked with the clinical leads to identify individuals and alternates for each group (weeks 1-2). We contacted the individuals and scheduled 1-hour (in-person or remote) testing sessions for interested users (week 3).

The designer led each user testing session and a coordinator took notes and assisted. We created test scripts based on the user stories and additional input from the clinical leads. The scripts included tasks for all user-types, as well as tasks specialized for user groups. The objectives of user testing were to gather general user feedback on the design and to confirm that the users could complete tasks with minimal instruction. We recorded voice and computer screens for each session. The designer reviewed all recordings to extract themes and the coordinator identified themes in notes. User testing results augmented team feedback in design sub-group meetings to create design comps 2.

Results

The design process proceeded as planned, without major adjustments. However, we added design comps 3 and continued to refine the design for a total design period of 20+ weeks (see "Extended Timeline for Design Refinement" below).

<u>User Stories</u>

We started with 7 user stories, all of which involved facilitating communication and discussions with the patient and/or family. Four focused on care team members rapidly orienting themselves to the patient when they become part of the patient's care team: when the patient is admitted; when the patient requires a consult; when the patient requires a social work or chaplaincy referral; or when a clinician is covering for another who is part of the patient's regular care team. One use case focused on information needs during an acute crisis, another for the primary oncologist to quickly review patient data before a visit, and the final use case for sharing relationship-based care data (documented by nurses) with the entire care team.

<u>Card Sorting and Concept Groupings</u>

Data groupings and group names were relatively stable throughout the process. The card sorting activity, for the most part, validated data groupings as compiled. However, we re-organized some groups for the low-fidelity wireframes or at later points in the design process. We combined advance directives with important people to contact (i.e., emergency contact, health care agent and next of kin). We separated information preferences from other communication preferences for wireframes, but later re-combined them after user testing. We separated significant life events (originally part of social history data elements) to their own section, but then removed them in week 10 due to suboptimal data quality. Names for data groups also evolved through the design process, but mostly stayed the same or ultimately returned to original names. For example, we grouped some communication preferences with social history to make a "Basic Info" category, that we later divided into "Communication Preferences" and "Social Information." We re-named "Spiritual and Cultural History" to "Practices & Beliefs" for the low-fidelity wireframes, and then to "Cultural/Spiritual Practices and Beliefs" in the high-fidelity wireframes. We then changed it back to "Practices & Beliefs" in design comps 3.

<u>User Testing Preparation</u>

For user testing, we organized stakeholders into the three groups and aimed to test at least 3 users/group. We contacted 11 stakeholders. Of those, we scheduled 8 (3 physicians, 2 nurses and 3 allied health professionals) in week 4 (see Figure 1). One nurse was available in week 5; however, we felt that theme saturation was met in week 4 and did not schedule additional sessions. Each group combined users from different specialties—physicians were an oncologist, internist and intensivist; nurses were a chemotherapy infusion nurse and an intensive care unit nurse; allied health professionals included a chaplain, a social worker and patient representative/patient advocate. Two users were Ethics Committee leaders (the intensivist and social worker). All users were familiar with the tab project or related patient-centered care initiatives.

For the user testing script, we started with a general introduction to the tab and asked for high-level impressions. We then created tasks based on the user stories from earlier in the design process. We started with more general tasks to help the user become familiar with the tab, then moved to more targeted questions to confirm understanding of data representation and functionality in the tab, as well as to gather input on content and groupings. Some tasks required users to identify the proper section of the tab to complete a task, while others were more open-ended. We customized

the script for each user group. The nurse script was very similar to the physician script, except with different task focus (e.g., patient discussions about results for a physician and about medication management for the nurse). We excluded 2 tasks from the allied health professional script.

User Testing Findings

We included eight tasks (six general tasks for all 8 testers, and two for physicians and nurses only). All users successfully completed six tasks; however, for one task (to find the patient's preferred name in the banner at the top of the page), users first looked at another section ("Communication Preferences") before finding it. We therefore chose to insert the patient's preferred name into two sections. Responses varied for two more open-ended tasks, but a minority of users indicated less relevant sections.

Additional findings from user testing included: interest in additional source details (author, document, date), hover states were not intuitive (i.e., the original design displayed details when the user hovered the cursor over the data point text, but users did not realize this), need to highlight the most relevant advance directive documents (e.g., most recent version of specific documents), and need to clarify scope of sections (e.g., "Consult Notes" does not include all consult services). While the tab compiles data already on file, not all data types were familiar to all users (e.g., fields extracted from much longer nursing documents), which suggested the need for a "Frequently Asked Questions" (FAQ) section. Users questioned some data labels or if the design emphasized certain data elements more so than they felt to be appropriate. All of the preceding feedback influenced design comps 2. Users also requested data or functions that were out of scope (e.g., data that is not already available in the EHR); we tracked this feedback for future versions of the tab.

Extended Timeline for Design Refinement

At the end of the original timeline, the design was not ready for full handoff to the development team. We began discussions with development (week 6) and started a design requirements document for the developers (week 11); however, we also created design comps 3 (week 14). After comps 3, we continued to work on design for content sections (through week 16) and on ad hoc details as the development team requested clarification (on-going), but only updated the design requirements. After user testing, we also affirmed the need for FAQ and feedback sections but prioritized them behind sections containing relevant patient data. We designed the feedback section in weeks 16-19, including informal targeted testing with a convenience sample of 5 participants. The FAQ section work began in week 20 and is on-going. During the design iterations, we also received content change requests. We tracked content changes separately from design feedback and re-visited them in week 10. We made additional content changes in week 14. The project team planned to pilot the tab once developed, which would allow a later opportunity for user testing validation. Therefore, we did not conduct a validation on the final design comps.

Example Data

For the low-fidelity wireframes, we used completely synthetic data to rapidly start work (see example section in Figure 2A). For the high-fidelity wireframes, we aimed to represent more realistic examples of how the tab would appear in use and to introduce design for when data was not available (e.g., empty states). We identified 3 real patient charts with varied levels of relevant data available in the EHR. We then replaced all identifiers with synthetic data in a similar format. We used these data sets to produce 3 mock-ups in the same design representing patients with "low," "medium" and "high" (but not complete) amounts of relevant data available (Figure 2B-C). For design comps 1, we also included 3 variations (Figure 2D). For design comps 2 and 3, we filled in missing data to for the "high data" patient to become a "complete data" example (Figure 2E). The design requirements started with a complete data example followed by how the tab would look if a patient had no relevant data on file. In design comps 3, we also started to work through various display scenarios for more complex tab sections; this continued through week 16.

Special Challenges

The section for "Decision-Makers & Advance Directives" required the most attention (see Figure 2). The final design (Figure 2F) incorporated display logic to suppress the next of kin if a health care agent was documented. If a scanned "Proxy and Advance Directive" document was on file, but discrete data for the health care agent was not, the display logic prompted the user to review the scanned document. (Only limited users entered the discrete health care agent fields when they receive a health care proxy document.) We also identified the most important documents and included the most recent for each on the tab, compared to the original specification to include all documents in the "Advance Directive/DNR" folder (category) in the EHR. For the selected documents available on the tab, we also provided a drop-down (drawer) interactive feature to display past versions when needed.

Figure 2. Design Evolution of Advance Directives Section

2A. Low-Fidelity Wireframes

2B. High-Fidelity Wireframes (High Data)

2C. High-Fidelity Wireframes (Low Data)

2D. Design Comprehensives 1

2E. Design Comprehensives 2

2F. Final

Figure 2. Design iterations for the "Decision-Makers & Advance Directives" section. All identifiers are synthetic. Design started as a simple diagram of how to display and organize information (2A) and became more detailed. 2B-C show variations based on data available, and 2D-F incorporated additional features and styling. The final version (2F) displays the most recent and relevant data, with hover states (with icon cues) for data source information for discrete data fields, links to view documents, and drop-down (drawer) features for prior versions.

Discussion

We applied user-centered design methods to create a new feature in our EHR highlighting the patient as a person. We considered variation across users and patient data availability throughout the design process. User testing validated most of the design, but also raised a few areas of concern. We extended the design process timeline considerably to work through these concerns and various data scenarios. The advance directive section required the most iteration. Overall, while we could address some challenges through design, other challenges inherent to the EHR and related workflows remained.

The advance directive documentation at MSK posed several challenges and the advance directive section was the most onerous to design. Due to multiple scanned forms and potential date abstraction errors, as well as overall context, we chose to make the most recent document readily viewable, but to also include prior versions, if on file. Similar EHR features at other institutions were comparable to our advance directives section[9, 13]. Our overall design attempted to allow the user to quickly collect the most recent data across sections without additional clicking or scrolling, when possible, whereas other approaches included a report view of all data with hyperlinks to jump to the relevant portion[13] or expandable tree structures to view more data about topics of interest[9]. Information in other organizations' features was similar to our advance directives section, but varied slightly (e.g., we did not include blood product preferences but did include emergency contact). Other institutions included data we displayed elsewhere on our tab (e.g., "Values Summary" and "Goals of Care Discussions") and have reported more focused templates and ways to quickly review them, such as using flow sheets[14]. Our "Goals of Care Discussions" section included a "view all" report, which emphasized the most recent conversation(s) rather than the ability to review changes by topic over time (e.g., the flow sheet). To our knowledge, others have not included relevant consult notes on their EHR modules or tabs.

We aimed to facilitate quick review of data about the patient as a person. We compiled data from multiple data sources, sometimes extracting note sections or single fields from much longer notes. The tab could also guide users to data they were not aware was available. For example, we highlighted a selected set of fields from nursing notes, which many other users did not always review. However, highlighting data the users were not aware existed posed additional educational challenges for the tab. Users' overall familiarity with and understanding of nursing documentation may still pose a challenge in use. Similarly, some data points were only collected on patients who initiated care at MSK in the past year or who were part of very limited pilot clinics. Creating a data view also did not improve data quality or workflows around data collection. For data only available on select patients or data with low quality, the tab could lead to more frustration. User testing revealed low familiarity with some data highlighted on the tab, as well as conflicting viewpoints about which data elements are relevant and when (e.g., when next of kin data are useful).

Future work includes piloting the tab, which will include user testing for design validation and additional evaluation. We plan to survey and interview selected users, as well as to collect feedback directly on the tab to further evaluate its content and design. We expect the pilot phases to engage clinicians performing a variety of roles in the outpatient and inpatient settings. We may also evaluate if the tab expedites data review and meets user needs. In parallel to our design and development process, one of the clinical leads analyzed stakeholder interviews for data needs, workflow integration preferences and overall culture related to the patient as a person. Interview themes or pilot evaluation may identify additional data needs. Future phases may incorporate user testing feedback that was out of scope for this phase or address data entry and editing, which was also out of scope for the tab's initial version.

We describe a pragmatic experience at an organization starting to apply design thinking to its EHR. As with many real-world projects, we had limited time and competing priorities. In an ideal setting, we would have had full stakeholder interview analysis and available data for all user needs before starting our design process. With more time and/or resources, we may have applied additional design methods or started design exercises earlier in our timeline. User needs and available data vary across organizations, and therefore our experience at a cancer center may not apply to all settings. Finally, the project is limited in the underlying data available and the quality of the data—success in the pilot will depend not only on an intuitive and easy-to-use design, but also the quality of data displayed.

Overall, we applied user-centered design methods to create a new "Values Tab" in our EHR. We used user stories, card sorting and user testing, as well as an iterative process with an interdisciplinary project team. Throughout the process, we re-organized and re-named sections, as well as eliminated some data concepts. At the end of our design timeline, the design was not ready for full hand-off to development. Instead, we continued to refine the requirements through the development stage. The section about advance directives and important people to contact required the most careful consideration and the most iterations. We plan to validate our design through additional user testing and a pilot of the developed product, as well as to add or refine content or features in the future.

Conclusion

We designed an EHR feature to support user needs for patient-centered care. While others have reported projects to capture data pertinent to patient-centered care or sections in their EHR to support advance care planning (a component of patient-centered care), to our knowledge, we are the first to apply design methodology to create an EHR section about patient values for all stages of cancer care. Patient values, goals and preferences play an important role in patient-centered care, which is a key component of quality health care. We hope that making such data easier to find and quickly review will promote and facilitate quality cancer care at MSK.

References

1. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.
2. Epstein RM, Street RL Jr. The values and value of patient-centered care. Ann Fam Med 2011 Mar-Apr;9(2):100-3. doi: 10.1370/afm.1239.
3. Nakagawa S, Clark EM, Cobbs EL, Livote E, Awan KS, Blackstone KA, Lindenberger EC. Promoting advance care planning documentation for veterans through an innovative electronic medical record template. J Am Geriatr Soc 2014 Sep;62(9):1811-3. doi: 10.1111/jgs.13008.
4. Lakin JR, Koritsanszky LA, Cunningham R, Maloney FL, Neal BJ, Paladino J, Palmor MC, Vogeli, Ferris TG, Block SD, Gawande AA, Bernacki RE. A systematic intervention to improve serious illness communication in primary care. Health Aff(Millwood). 2017 Jul 1;36(7):1258-64. doi: 10.1377/hlthaff.2017.0219.
5. Kamo N, Williams BL, Smith DL, Blackmore CC. Improving the electronic capture of advance care directives in a healthcare delivery system. J Am Geriatr Soc. 2017 May;65(5):973-979. doi: 10.1111/jgs.14695. Epub 2017 Feb 9.
6. Saiki C, Ferrell B, Longo-Schoeberlein D, Chung V, Smith TJ. Goals-of-care discussions. J Community Support Oncol. 2017 Jul-Aug;15(4):e190-e194. doi: 10.12788/jcso.0355.
7. Karim S, Harle I, O'Donnel J, Li S, Booth CM. Documenting goals of care among patients with advance cancer: results of a quality improvement initiative. J Oncol Pract. 2018 Sep;14(9):e557-e565. doi: 10.1200/JOP.18.00031. Epub 2018 Aug 16.
8. Huber MT, Highland JD, Krishnamoorthi VR, Tang JW. Utilizing the electronic health record to improve advance care planning: a systematic review. Am J Hosp Palliat Care. 2018 Mar;35(3):532-541. doi: 10.1177/1049909117715217. Epub 2017 Jun 19.
9. Bernacki R, Hutchings M, Vick J, Smith G, Paladino J, Lipsitz S, Gawande AA, Block SD. Development of the serious illness care program: a randomized controlled trial of a palliative care communication intervention. BMJ Open. 2015 Oct 6;5(10):e009032. doi: 10.1136/bmjopen-2015-009032.
10. Hoverman JR, Taniguchi C, Eagye K, Mikan S, Kalisiak A, Ash-Lee S, Henschel R. If we don't ask, our patients might never tell: the impact of the routine use of a patient values assessment. J Oncol Pract. 2017 Oct;13(10):e831-e837. doi: 10.1200/JOP.2017.022020. Epub 2017 Jun 30.
11. Desai AV, Klimek VM, Chow K, Epstein AS, Bernal C, Anderson K, Okpako M, Rawlins-Duell R, Kramer D, Romano D, Goldberg JI, Nelson JE. 1-2-3 project: a quality improvement initiative to normalize and systematize palliative care for all patients with cancer in the outpatient clinic setting. J Oncol Pract. 2018 Dec;14(12):e775-e785. doi: 10.1200/JOP.18.00346.
12. Epstein AS, Desai AV, Bernal C, Romano D, Wan PJ, Okpako M, Anderson K, Chow K, Kramer D, Calderon C, Klimek VV, Rawlins-Duell R, Reidy DL, Goldberg JI, Cruz E, Nelson JE. Giving Voice to Patient Values Throughout Cancer: A Novel Nurse-Led Intervention. J Pain Symptom Manage. 2019 Jul;58(1):72-79.e2. doi: 10.1016/j.jpainsymman.2019.04.028. Epub 2019 Apr 26.
13. Turley M, Wang S, Meng D, Kanter M, Garrido T. Impact of a Care Directives Activity Tab in the Electronic Health Record on Documentation of Advance Care Planning. Perm J. 2016 Spring;20(2):43-8. doi: 10.7812/TPP/15-103. Epub 2016 Apr 1.
14. Wilson E, Bernacki R, Lakin JR, Alexander C, Jackson V, Jacobsen J. Rapid adoption of a serious illness conversation electronic medical record template: lessons learned and future directions. J Palliat Med. 2020 Feb;23(2):159-161. doi: 10.1089/jpm.2019.0420.