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Research and Applications

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Development of an electronic health record-integrated patient-reported outcome-based shared decision-making dashboard in oncology

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Abstract

Objectives: Patient-reported outcomes (PROs) describe a patient's unique experiences with disease or treatment, yet effective use of this information during clinical encounters remains challenging. This project sought to build a PRO based dashboard within the electronic health record (EHR), prioritizing interpretability and utility of PROs for clinical decision-making.

Materials and Methods: Codesign principles were used to define the goal, features, and visualization of the data elements on the dashboard. Codesign sessions occurred between February 2019 and May 2020 and involved a diverse group of stakeholders. Pilot evaluation of dashboard usability was performed with patients and clinicians not involved in the codesign process through qualitative interviews and the Systems Usability Scale.

Results: The dashboard was placed into a single tab in the EHR and included select PROM scores, clinical data elements, and goals of care questions. Real-time data analytics and enhanced visualization of data was necessary for the dashboard to provide meaningful feedback to clinicians and patients for decision-making during clinic visits. During soft launch, the dashboard demonstrated "good" usability in patients and clinicians at 3 and 6 months (mean total SUS score >70).

Discussion: The current dashboard had good usability and made PRO scores more clinically understandable to patients and clinicians. This paper highlights the development, necessary data elements, and workflow considerations to implement this dashboard at an academic cancer center.

Conclusion: As the use of PROs in clinical care is increasing, patient- and clinician-centered tools are needed to ensure that this information is used in meaningful ways.

Lay Summary

Decisions related to cancer care include multiple considerations, such as a patient's current clinical status and goals of care. Patient-reported outcomes (PROs) reflect the patient's unique experience of disease and treatment effects. However, there still exists considerable uncertainty regarding how to effectively use patient-reported information during clinical encounters. Here, we describe the development of a shared decision-making oncology dashboard, centered around the interpretability and use of PRO measures (PROMs) by both patients and clinicians in clinical decision-making. Codesign principles were utilized to define the goal, relevant features, and visualization of the data elements on the dashboard. Patients, care partners, clinicians, social workers, palliative care specialists, psychologists, and experts in health information systems were involved in the codesign process. One key feature of the dashboard is that real-time data analytics and visualization of data can be performed on PROMs and clinical inputs (labs, vitals, medications) and that these data elements can be trended over time to provide feedback to clinicians and patients about effectiveness of their shared-decisions, enabling a patient-centered learning health system. This paper describes the development process for the dashboard, results from early usability testing, and operational changes that were needed to launch this tool in oncology care.

Key words: patient-reported outcomes; cancer; shared decision-making.

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Key points

- **Key objective:** As patient-reported outcomes (PROs) are increasingly being implemented into clinical care, novel tools are needed to ensure that this information is used in a meaningful way by both patients and clinicians.
- **Knowledge generated:** With a diverse group of oncology stakeholders, we developed an oncology shared decision-making dashboard within the electronic health record that compiles relevant PRO and clinical data to enhance care decisions during point of care visits. PRO scores are converted into a color-coded system based on severity and can be trended over time. During usability testing, the dashboard demonstrated good usability by both patients and clinicians.
- **Relevance:** We provide an example of a tool codeveloped by oncology stakeholders centered around PROs relevant for shared decision-making. By presenting PROs in interpretable and meaningful ways in clinic appointments, the dashboard aims to align clinicians and patients with patient preferences and health status to facilitate coproduction of health care.

Introduction

Decision-making in oncology can be complex. Care decisions often involve unique patient factors, oncologist input, treatment toxicity, and contextual factors such as cost and family influence.[1] A number of studies have demonstrated that patient participation in oncology care decisions is lower than desired.[2] Thus, creation and implementation of tools that enhance shared decision-making (SDM) are still needed.[2–4]

One novel approach to engaging patients in value-based healthcare is through "coproduction".[5] In healthcare, coproduction consists of the interdependent work of patients, families, and health professionals to design, create, develop, deliver, assess, and improve the relationships and actions that contribute most to an individual's health.[6–8] SDM is a key interpersonal process for coproducing healthcare. Coproduction aims to generate personalized solutions to address the burdens of illness and/or treatment.[5] Coproduction relies on a user-centered process or technology to leverage an end-user's motivation to add value, making a desired goal or outcome more convenient, efficient and cost-effective.[5,9] When coproduction is used in chronic disease management, patients can better manage their own condition and learn how to reduce the burden related to that illness. Patients with advanced cancer are ideal for healthcare coproduction, as they can experience a high degree of symptom burden related to their disease and therapies.[10,11] Side effects or symptoms can adversely affect physical, mental, and social functioning.[12] Despite the development of improved symptom-management interventions and guidelines for treatment, clinical teams often underestimate symptom burden in cancer patients and early, timely delivery of these interventions may be compromised.[13–15]

Incorporation of PROs into routine oncology care has demonstrated reduction in symptom burden and improvement in patient satisfaction, and even survival.[16–19] Further, integration of patient-reported outcomes (PROs) and clinical findings can support SDM.[20,21] Leading organizations now recommend integrating PROs into clinical practice to identify and respond to cancer patients' symptoms and psychological needs and inform oncology care decisions.[22–25] Northwestern Medicine (NM) has developed and implemented a PRO distress screening system at the cancer center, where data are captured through electronic methods and integrated into the electronic health record (EHR).[26] Despite the availability of this data, we have noted low to no use of the data by physicians during clinic visits. Reasons reflect those that have been reported in the literature: difficulty with interpretability and clinical application, competing clinical duties, and poor integration into current clinic workflows.[27–29]

Thus, we built an oncology-specific PRO tool based on the needs and preferences of our end-users (patients and clinicians), prioritizing interpretability and utility of PROs to support SDM. By presenting PROs in a meaningful way in clinic appointments, the aim of the dashboard was to better align clinicians and patients on patient preferences and health status using PROs during clinic visits. Creating the tool with clinicians and patients was felt necessary to support adoption, given that engagement of stakeholders are drivers of successful PRO implementation.[30] The objective of this paper is to describe the pertinent elements identified in the dashboard development process, results from usability testing, and the operational changes that were needed to launch this tool in oncology care in three clinics at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

Methods

Objective of dashboard

The oncology PRO dashboard was designed to meet the needs of patients with advanced lung and gastrointestinal (GI) cancers receiving palliative therapy. The desired dashboard functionality focused on the interpretability and use of PROs to measure symptoms and functional limitations that may facilitate SDM and promote healthcare coproduction. The premise for the dashboard was that patient-centered care should engage patients and family members in decisions that determine and define quality health care. The dashboard utilizes the digital Patient-Reported Outcomes Measurement Information System (PROMIS) and compiles relevant information into the EHR for use during clinic visits (Figure 1). This approach has been described in other settings, such as in patients receiving palliative care or management of chronic conditions such as rheumatoid arthritis, cystic fibrosis, and inflammatory bowel disease.[7,31,32] By using real-time data integration and analysis, the dashboard can also support a patient-level learning health system. For example, clinical teams and patients can assess effectiveness of interventions to address certain symptoms through longitudinal analysis of PRO scores related to that symptom.

Design and study population

The study was conducted in 3 phases—development of the dashboard, usability testing after creation of the dashboard (during "soft launch" of the tool), and evaluation of dashboard efficacy related to SDM and healthcare utilization. This paper highlights the findings of the first 2 phases. The dashboard project was approved by the Northwestern Medical Group Quality Oversight Committee in 2019 as a quality

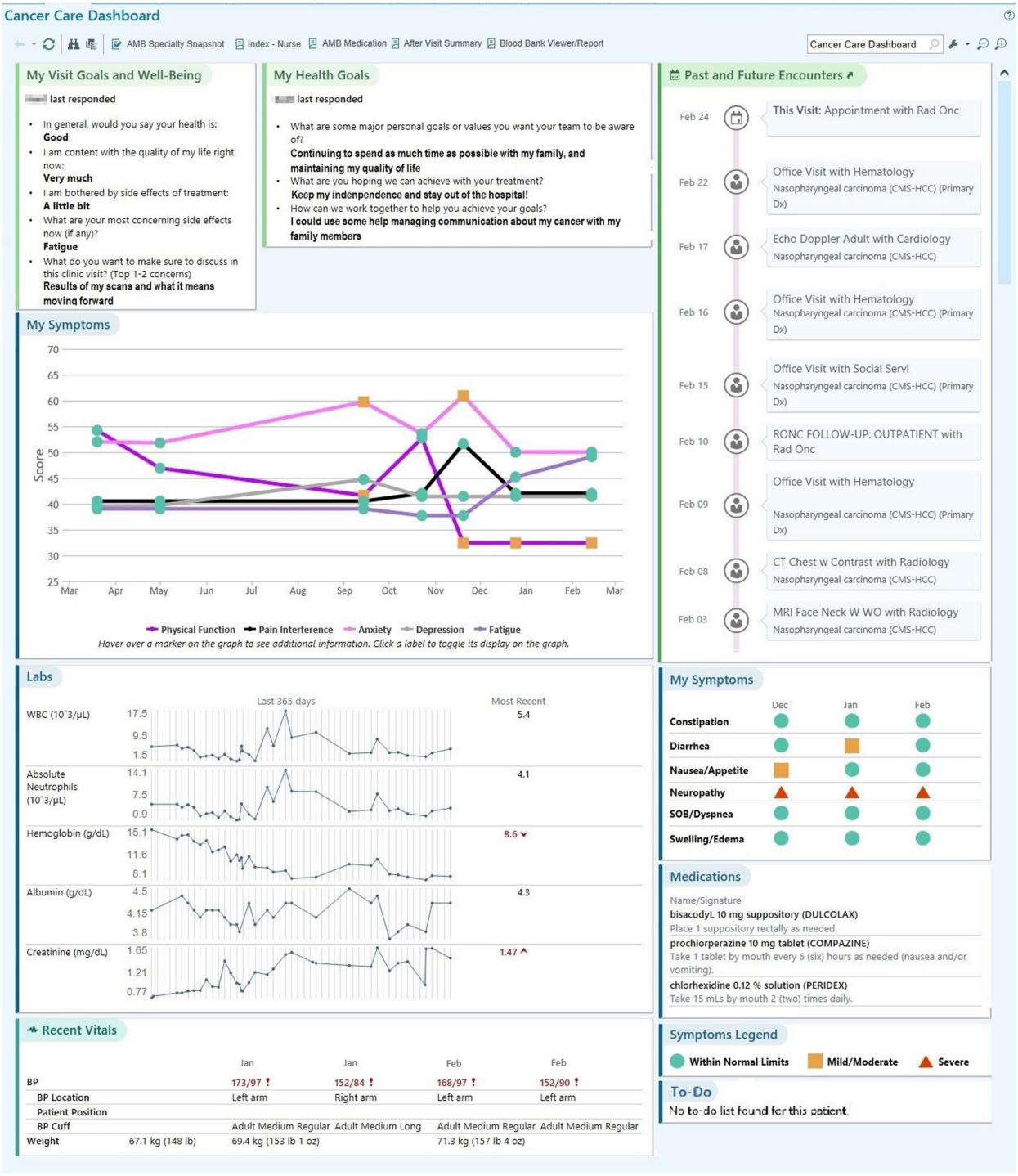

Figure 1. Dashboard integrated in the EHR (© 2022 Epic Systems Corporation, published with permission from EPIC, reproduced/adapted from Mohindra et al,[34] with permission from Wolters Kluwer Health).

improvement project within the health system. Components of the study such as usability testing, effects of the SDM and health care utilization were approved by the Northwestern University IRB (STU00211654/STU00212634). The entire codesign process spanned 16 sessions across 15 months occurring between February 2019 and May 2020.[33] The soft launch of the dashboard commenced in June 2020 and both in-clinic and telemedicine workflows were developed to facilitate the different types of clinical encounters.[34] A detailed description of participant recruitment for the codesign process has been published elsewhere.[33] Patients who completed usability testing were recruited via referrals from clinicians, other clinical research studies, and study flyers.

Dashboard development process

The dashboard development process focused on identifying (1) symptoms of highest relevance for lung and GI cancer patients; (2) desired display and interpretability of PRO

Table 1. Codesign stakeholder composition.

Codesign team ($n = 22$)	
Oncology physician champions	9.1% ($n = 2$)
Oncology advanced practicing practitioners	9.1% ($n = 2$)
Palliative care physicians	9.1% ($n = 2$)
Palliative advanced practicing practitioners	4.5% ($n = 1$)
Frontline clinicians (social worker)	4.5% ($n = 1$)
Patients	9.1% ($n = 2$)
Care partners	9.1% ($n = 2$)
Health IT analysts	9.1% ($n = 2$)
NM quality leaders	9.1% ($n = 2$)
Research investigator/facilitators	13.6% ($n = 3$)
Research staff	13.6% ($n = 3$)

scores by patients and clinicians; (3) goals of care questions that clinicians and patients felt would best facilitate SDM; and (4) relevant clinical data for SDM.

We used codesign principles to guide the development of the dashboard and promote likelihood of adoption of the tool. By involving end-users and other stakeholders (see Table 1) in the process we aimed to ensure their perspectives were included, paramount to creating value for the final product.[30,35,36] The codesign process for dashboard development was guided by the Coproduction Design and Implementation Flow Model (CDIFM) and mirrored principles noted in expert guides of implementation of PROs in the EHR.[7,37] This CDIFM model utilizes 4 interconnected steps: (1) end-user definition of the problem, (2) establishing context use, (3) building consensus on design elements and specifications, and (4) defining pilot testing of the product. Expert guidelines encourage stakeholder participation, a framework to aid in PRO selection, ways to support PRO interpretation by patients and clinicians, and patient access to PRO data.[37]

Codesign sessions progressed through the following stages: (1) establishing shared priorities, (2) dashboard specifications, (3) iterative redesign of dashboard prototypes based on continuous user testing feedback, and (4) implementation planning. The dashboard prototype was developed over 9 working sessions, where drafts advanced from low-tech design (hand-drawn by participants) to near final, programmed drafts within a test EHR environment. Facilitated discussions were used during working sessions to promote teamwork, ensure input from a variety of stakeholders, maintain adherence to dashboard goals, and promote concept advancement.

Results

Drafting and revision of dashboard mockups

Figure 2 displays the iterative drafting, revising, and stakeholder feedback that guided dashboard development during codesign sessions. In session 4, patients were asked to sketch the layout and key components of their ideal dashboard. Major elements and themes observed across individual sketches were compiled and used to develop a dashboard prototype. Drafts of the dashboard prototype were tested through fictional patient "personas" so end-users could interact with the dashboard in a clinical context. Feedback during these sessions highlighted: (1) the need for quick interpretation of symptom scores and (2) a way for patients to discuss their top concerns or changes to their goals of care. This resulted in color coding symptom results as green (mild), yellow (moderate), or red (severe). In addition, two areas of free text were added so patients could provide their answers to their goals for that visit and for their overall health. Session 7 focused on finalizing dashboard elements, such as what clinical data elements to include. Individuals created their own lists of prioritized elements, which were then reviewed and discussed by the larger team to come to a shared priority list. Team members voiced that the dashboard needed to provide "just enough" information to guide individualized care planning, but also not overwhelm users with too much information. Finalized dashboard elements included patients' health and treatment goals, PRO scores for symptoms and well-being, current medication list, and select labs. Clinical and patient-generated elements were displayed in a manner that would improve the overall effectiveness of the dashboard. For example, displaying symptom and lab results as graphical trends over time would highlight clinically important changes. Including a list of medications next to these results would help the care team identify whether changes may have resulted from medication side effects, or alternative explanations.

Dashboard components

"My goals and My symptoms"

The dashboard consists of patient-generated and clinical data (Figure 1). Patients respond to 2 types of questions through the electronic patient portal prior to their appointment: prompted questions ("my visit goals and well-being" and "my health goals") as well as PROs related to "disease-specific" and common symptoms of interest (Table 2). In the "my visit goals and well-being" section, patients can provide free text to questions related to their side effects of greatest concern and their top 2 concerns for their upcoming appointment. Patients are guided with "sample answers" to each question to help them generate ideas. In the "My Health Goals" section, patients are invited to respond to questions about overall personal goals, treatment goals, and how they would like to collaborate with the healthcare team. Specific questions were developed with user testing during the dashboard coproduction process.

Identifying PROs of interest

Patients, care partners, and clinicians were asked to review a symptom inventory and determine which symptoms were considered "essential" to monitor. The final symptom inventory included common symptoms and functional status (anxiety, depression, pain interference, fatigue, and physical function) as well as select disease- or treatment-related symptoms (nausea, diarrhea, constipation, neuropathy, shortness of breath). Clinicians set "thresholds" for when symptom severity would prompt an alert to the clinical team. PROM symptom scores were classified as "mild," "moderate" or "severe" based on prior work.[38,39] Each symptom was reviewed for appropriateness by clinicians, who also set alert threshold levels and management strategies. For some symptoms, the clinical team desired alerts for any category change, such as dyspnea, where small symptom changes may have meaningful clinical significance. Other symptoms, such as fatigue, would not trigger an alert unless the symptom had changed to the "severe" category. Symptoms of interest and corresponding PROMIS surveys are summarized in Table 2. To reduce patient burden, each symptom was assessed with 1 or 2 items. Finally, a free-text area was added for a "to do" list of items needed prior to the next appointment, such as

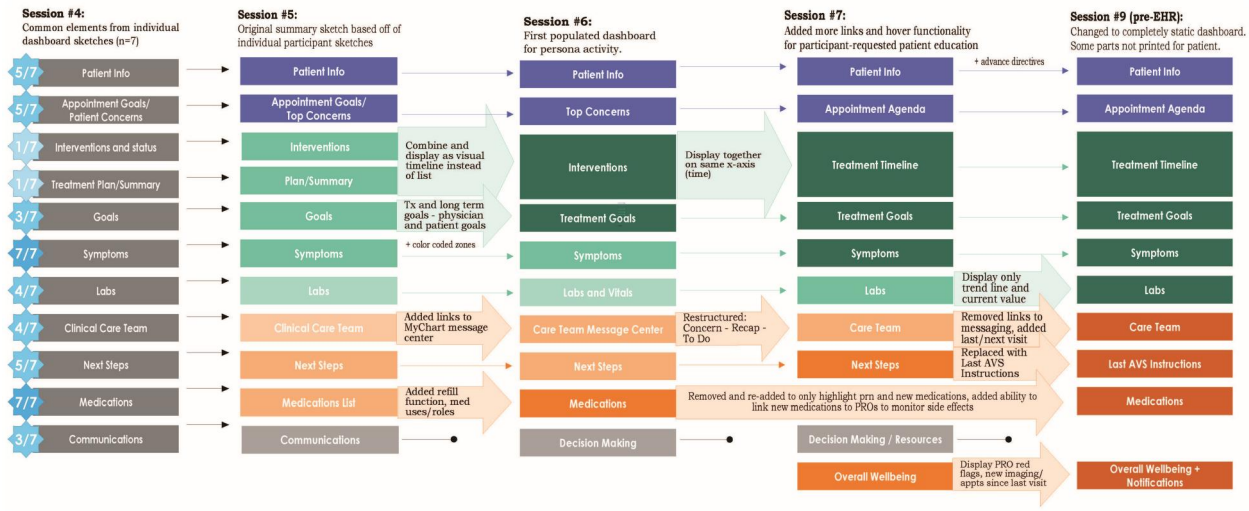

Figure 2. Dashboard Evolution through Iterative Co-design.

Table 2. Symptoms of interest and corresponding PROMs.

Symptom	Selected PROMs
QoL	FACT-G7 (Version 4), GF7
Health perception	Global01 from PROMIS Global Health v1.2
Fatigue	PROMIS Anxiety (Short Form)
Health perception	Global01 from PROMIS Global Health v1.2
Anxiety	PROMIS Fatigue (Short Form)
Pain	PROMIS Pain (Short Form)
Emotional distress	PROMIS Emotional Distress (Short Form)
Physical function	PROMIS Physical Function (Short Form)
Shortness of breath	PROMIS Item Bank v1.0—Dyspnea Severity (DYSSV014)
Edema	PRO-CTCAE22b- Severity
Nausea	PROMIS Scale v1.0—Gastrointestinal Nausea and Vomiting (GISX49)
Appetite	PROMIS Scale v1.0—Gastrointestinal Nausea and Vomiting (GISX55)
Neuropathy	FACT/GOG-NTX-4 (V4)
Constipation	PRO-CTCAE 15a-Severity
Diarrhea	PROMIS Scale v1.0 Gastrointestinal Diarrhea 6a (GISX38)
Side effect bother	FACT-GP5

medication changes or upcoming scans. Placement of this section on the dashboard was felt necessary to ensure that the patient's concerns and goals for the visit were being addressed. This information, as well as the PRO score reports as displayed on the dashboard, auto populated into the After-Visit summary.

EHR integration and real-time data and analytics

The dashboard allows for visualization of patient data, including PROs with translated score (mild, moderate, severe), results, vitals, labs, and medications in real-time in a single tab in the EHR. We created the dashboard in the EHR (EPIC Systems Corporation) reporting framework as a Snapshot report. The dashboard components, that is print groups, were a mix of standard EPIC functionality and custom-developed solutions. Custom development for multiple components was required because either standard print groups did not exist for certain types of data, standard print groups existed but did not present all desired data, or the display of data was not concise or did not allow for correlation. Custom print groups were developed using M code and the EPIC code library.

In terms of PRO trend and visualization, consensus from codesign sessions was to use a single graph displaying results from multiple symptoms over time. Although EPIC had a standard print group to graph PRO scores over time, each symptom score appears on its own graph. To achieve a single graph with multiple PROs, we had to create a custom print group using a third-party JavaScript graphing library. This library allowed the print group to be interactive—clinicians could hover over the graph's data markers to see additional information, and they could click on the graph's labels to toggle the display of individual symptoms. We also defined custom data markers that had different shapes and colors for scores that were within normal limits, abnormal, or critical. PROs were grouped into "common symptoms" and "disease specific" symptoms and displayed in different places for quick visualization.

Clinicians can access the dashboard through the EHR at any time and will view the patient's most recent data. Patients can review the dashboard with their clinician at their clinic visit and have access to their PRO score reports in their After-Visit Summary on the online portal.

Operationalization and setting

The oncology dashboard was launched in 3 oncology clinics: Thoracic and GI oncology clinics deliver both standard of care treatments in addition to clinical trials; the early phase clinic focuses largely on phase 1 trials. Patient identification was created with logic programming in the EHR to identify patients with a diagnosis of Stage IIIB/C/IV lung or GI cancers (esophageal, colorectal, gastric) in their problem list and/or with a "palliative intent" chemotherapy or immunotherapy treatment plan. Previsit surveys, consisting of both the PROMIS symptom surveys as well as the visit and treatment goals survey, were administered to patients 3 days prior to their appointment through the online MyChart portal (MyNM.org). Surveys were administered every 30 days. An additional MyChart message and/or a phone call from a health outreach coordinator was completed 1-2 days prior to the appointment if surveys were still incomplete at this time.

Patients who needed assistance completing the surveys received in-clinic, in-person help or at home over the phone.

Usability testing

Qualitative assessment

Prior to launch, to assess usability and acceptability, we performed 2 focus groups with patients and clinicians not involved in the dashboard codesign process or pilot testing. The focus groups used the final paper mockup of the dashboard for feedback. The transcripts from these groups were analyzed using rapid qualitative analysis.[40] Participant feedback was sorted into a coding template that was organized by general topics corresponding with the focus group guides and comments from participants on each respective domain. Overall, most patients found that the dashboard layout and symptom-severity color coding were easy to navigate and interpret. Some patients asked about whether they could personalize which symptoms were tracked (this functionality was not included in the current version of the dashboard). Most patients liked viewing their data over time but noted that they did not always recall timing of when their cancer therapies changed relative to symptom scores. Patients appreciated the ability to include their goals in clinic visits and encouraged that clinicians use this information when deciding how to approach the visit. Including relevant portions of the dashboard into the After Visit Summary was valuable for recall later, including the "to do" list. Overall, patients felt that the content of the dashboard could help inform shared decisions. Similarly, clinicians agreed that tracking symptoms would be beneficial for patient care and that understanding patient goals throughout their treatment course is important. Some clinicians were concerned the information on the dashboard could increase patient anxiety.

Usability—quantitative assessment

As early development phases occurred with paper mock ups, additional usability was done during the "soft launch" of the dashboard in oncology clinics. Across 2 time points, a sample of 19 patients provided a total of 24 responses to a usability measure (3-month: $n = 14$ responses; 6-month: $n = 10$ responses). While 5 of these patients provided responses at both time points, the majority ($n = 14$) responded to only 1 of the 2 time points (Table S1). Across items, the number of missing responses ranged from 0 to 3 (Table 3). Overall, patients tended to be female (68.4% of total sample), White (78.9% of total sample), non-LatinX (89.5% of total sample), and have a college degree or higher (84.2% of total sample).

Usability was assessed with the Systems Usability Scale (SUS), a 10-item question bank rating 0 (*strongly disagree*) to 4 (*strongly agree*) how easy or difficult a new system or device was to use (Table 3).[41] Sample items included "I thought the dashboard was easy to use" and "I found the dashboard very cumbersome to use." Negatively worded items are reverse-scored, and then a total score is calculated ranging from 0 to 100. Total scores were calculated for all cases, except for one case in the 3-month assessment that only included the first 3 items of the scale. For all other cases, a missing response was imputed with a "neutral" response (score of 2) before calculating the total score, in accordance with the scale guidelines.[41] A mean score of 70 has been established as a benchmark of an acceptable user experience, with higher scores classified as "acceptable to good" (70-84) or "excellent" (>85).[42,43] The dashboard demonstrated "good" usability in both patients (mean total score at 3 months = 75.57; mean total score at 6 months = 75.25) and clinicians (mean total score at 6 months = 71.25).

Discussion

The goal of the PRO oncology dashboard was to enhance SDM, as a point-of-care mechanism for patients and clinicians to discuss and manage emerging and chronic symptoms and make shared treatment decisions reflecting the patient's goals of care. Through a codesign process, we were able to identify priority symptoms for monitoring and assessment of functional status, as well as identify key questions to understand a patient's visit goals and overall goals of care for patients on palliative therapy. All data elements were able to be compiled into a single tab within the EHR and the tool was noted to have good usability by patients and clinicians early into launch of the tool.

Based on usability testing, the current dashboard had good usability and made PRO scores more clinically understandable to multiple end-users, that is, patients and clinicians. Among patients, SUS scores remained good (>70) at both 3 and 6 months, which was a favorable finding given that we were limited to using the current EHR for the build. More research needs to be done to understand how usability may change over time. Despite being able to identify "pertinent symptoms" and reduced survey burden to 2 item assessments per domain, feedback from usability testing highlighted the need to determine the "appropriate amount" of information. The "right" amount of information may change through the course of care, as patient's illness or symptom burden may worsen over time or stage of disease. Other studies have also noted that patients on chemotherapy may be less likely to complete PROs however these patients often see the most benefit from PRO assessments during care.[17,44] Further, different components of the dashboard may have differential value based on current clinical status, such as evolving goals of care.

Usability was also noted to be good among clinicians, but SUS scores were lower among clinicians than patients. The dashboard was meant to be used during clinic visits, as opposed to remote monitoring, to enhance SDM during clinic visits through use of PROs. The launch of the dashboard occurred during the COVID-19 pandemic (June 2020) and there were challenges to implementing a novel tool into clinical care during that time. Clinical teams received training on how to use the dashboard while also adjusting clinical care to ensure social distancing and adopting telemedicine. Attention to the dashboard competed with these other changes in clinical care. Changes in workflow and clinical staffing were heightened during launch of this dashboard, and these factors may have contributed to lower SUS scores from the clinical team.

One important aspect of the dashboard was direct integration into the EHR and use of information systems already present within the healthcare system as this was a quality

Table 3. Cancer care dashboard usability evaluations.

Item	Patients 3-Month			6-Month			Clinicians (6-Month)		
	N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*
I think that I would like to use the dashboard frequently	14	3.21	0.70	10	2.50	0.97	4	2.50	0.58
I thought the dashboard was easy to use	14	3.14	0.86	10	2.90	0.57	4	2.75	0.50
I felt very confident using the dashboard	14	2.71	1.20	9	3.22	0.66	4	2.50	0.58
I found the various functions of the dashboard were well integrated	11	2.82	0.75	10	2.90	0.74	4	2.50	0.58
I would imagine that most people would learn to use the dashboard very quickly	13	2.62	0.77	10	3.00	0.82	4	2.75	0.50
I found the dashboard unnecessarily complex (*R*)	13	3.23	0.60	10	3.40	0.70	4	2.25	1.50
I found the dashboard very cumbersome to use (*R*)	13	3.16	0.69	10	3.00	1.25	4	2.75	1.50
I thought there was too much inconsistency in the dashboard (*R*)	12	3.25	0.62	10	2.90	1.29	4	3.25	1.50
I needed to learn a lot of things before I could get going using the dashboard (*R*)	12	2.75	0.97	10	3.20	1.14	4	3.75	0.50
I think that I would need the support of a technical person to be able to use the dashboard (*R*)	13	3.46	0.52	10	3.20	1.32	4	3.50	1.00
Total score	13	75.57	11.37	10	75.25	14.16	4	71.25	15.07

R: Reverse-scored. Item scores range from 0 (*strongly disagree*) to 4 (*strongly agree*), with higher scores indicating better user experience. Total scores are computed by summing all items, and then rescaling scores to range from 0 to 100. Total scores ≥70 indicate acceptable user experience with the dashboard, and scores ≥85 indicate excellent user experience.

improvement project. Several studies that have evaluated PRO reporting in different populations, settings, and health care systems have noted prioritizing ease of interpretation/use and minimizing burden to end-users.[44–46] While using our existing technology allowed for potential cost savings, reliance on the EHR meant that some aspects of dashboard functionality and display had to be adjusted when upgrades to the EHR were made and full optimization for the patient experience were not accounted for. Long-term sustainability will need to evaluate whether health systems choose custom-built PRO tools or those from external platforms in the context of cost, including local information systems resources, end-user preferences, and meaningful use of this data.[44–46]

As using PROs during clinic visits was not the standard of care at the time of the project launch, and the need to limit personnel within clinical areas, we created a part-time virtual health outreach coordinator role to support PRO education and completion, which was most critical for telemedicine encounters.[34] Other studies of EHR-based PRO data have utilized multiple methods to engage patients, including use of portal messaging or in person support via medical assistants or personnel dedicated to capture of PROs. The health outreach coordinators have been integral to the implementation of the dashboard. Identification of effective patient outreach and implementation strategies, success of implementation, and an understanding of effect on SDM and healthcare utilization will be the subject of phase 3 of this study and results are forthcoming.

Given the narrow population of interest for the current dashboard, future work will focus on how to expand the dashboard to other disease sites, stages of disease, and a more diverse patient population. There is also interest in providing patients with PRO score reports prior to their appointment to enhance use of their data during the visit, rather than in the after-visit summary. Further, the dashboard was available to all clinical team members caring for this cohort of oncology patients, which includes nurses, social workers, and clinicians from palliative care and oncology. This allowed the same patient-generated information to be utilized by all clinical team members to understand patient goals and address symptoms consistently. It will be important to understand how different clinical team members utilize this information.

Beyond contextual factors, there are limitations to the applicability of this work. This dashboard was developed based on stakeholder input from a single academic institution, in an urban setting, for patients with advanced GI and thoracic malignancies. Other stages of disease, malignancy types, and practice settings may have different preferences on display or data elements for inclusion.[47] The usability testing had a small sample size with limited patient responses for both time points. Examining this tool with a larger and more diverse patient population and how SUS scores may change over time will be important to determine drivers of success. Health outreach coordinators are among the first people to introduce the dashboard to patients; however, they were not included in the codesign process which focused on dashboard content rather than implementation. Future work should include these professionals in the formative stages of novel healthcare tools to better design for implementation and optimize the workflow integration process. Lastly, user-centered design principles and experts were not involved in creation of this tool and the current prototype may be suboptimal given lack of this perspective and evaluation.[48,49] Nonetheless, we have identified core principles, such as having a place for the patient's voice (visit goals, goals of care), defining symptoms of mutual interest with minimal assessments, and maintaining easily interpretable score reports and trends, that will guide future iterations of the dashboard and can be used by other institutions to meet the needs of their patient populations.

Conclusion

As the use of PROs in clinical care is gaining momentum and becoming a core element of value-based care models, patient- and clinician-centered tools may be needed to ensure that this information is used in a meaningful way for clinical care. Here, we provide an example of a tool codeveloped by oncology stakeholders centered around PROs relevant to for SDM and creation of a learning health system, meant for point-of-care use.

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Author contributions

Conception and design: David Cella, Lisa R. Hirschhorn; Data collection: Ava Coughlin, Victoria Morken; Analysis and interpretation of results: Nisha A. Mohindra, Laura M. Perry, Madison Lyleroehr; Draft manuscript preparation: Nisha A. Mohindra, Laura M. Perry. All authors reviewed the results and approved the final version of the manuscript.

Supplementary material

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Conflicts of interest

None declared.

Data availability

The data in this article will be shared on reasonable request to the senior author.

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