Piloting a Patient Resource Navigator System

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Patient satisfaction as a quality measure in cancer care is an increasingly important tool for healthcare organizations and providers to demonstrate patient-centered care, meet accreditation standards, and develop marketplace differentiation. Since 2013, the University of Kansas Cancer Center and Patient Resource, LLC (patientresource.com), have partnered to deliver a navigation and patient education system (Patient Resource Navigator) and recently evaluated this system to identify improvements in self-reported measures of patient satisfaction. As part of the pilot program, the University of Kansas Health System incorporated the system into its cancer center navigation workflow, coordinating oncology patient care and providing personalized education for individuals with a new or potential primary oncology diagnosis.

The Patient Resource Navigator System

Patient Resource Navigator is an advanced patient education, navigation, and reporting system that provides hospitals and cancer care teams with the tools to guide and track patients from their first appointment throughout cancer treatment and into survivorship and follow-up care. The system has multiple components, including a survivorship record of care, distress survey modules, and robust reporting features to help hospitals maintain accreditation standards, including the American College of Surgeons Commission on Cancer and the American Society of Clinical Oncology's Quality Oncology Practice Initiative. Personalized

> The guide outlines the patient's treatment plan and offers instructions on how to prepare for—and what to expect during and after—treatment; management tips for treatment-specific side effects; biographies and photos of the cancer care team; letters from survivors of a similar diagnosis; and an extensive list of local and national support services and resources.

patient education guides are developed for each patient, providing information to address a patient's specific diagnosis, stage, and treatment plan and survivorship care.

Upon referral to the University of Kansas Cancer Center, a patient was connected to a nurse navigator who completed an initial assessment of his or her needs and scheduled him or her to see a University of Kansas Cancer Center provider (first touch). Patients then received the customized appointment guide and, as

appropriate, the treatment guide and companion mobile and/or tablet app, followed by a survivorship guide. Each guide was mailed to the patient at the address provided upon new patient registration or hand-delivered by a clinical team member during a pretreatment teaching appointment (second touch). The Patient Resource Appointment, Treatment, and Survivorship guides are described in more detail below. The main components of each guide are shown in Table 1, below.

The Patient Resource Appointment Guide

This guide contains preregistration information to help new patients prepare for their initial appointments at the cancer center. Included are the following:

- Driving directions and maps
- Care team members name, credentials, and photos
- A photo and letter from the nurse navigator
- Tips to help prepare for appointments
- Information about what patients should bring to their appointment
- Billing and insurance options
- A detailed overview of clinical trials
- Cancer center-specific support services
- Local amenities for food, lodging, and transportation.

The appointment guide also includes patient registration forms and a printed schedule of appointments.

The Patient Resource Treatment Guide

This guide provides a comprehensive description of the patient's diagnosis and treatment. It includes diagnosis information specific to tumor type, site, and stage, along with results of biomarker testing. The guide outlines the patient's treatment plan and offers instructions on how to prepare for—and what to expect during and after—treatment; management tips for treatment-specific side effects; biographies and photos of the cancer care team; letters from survivors of a similar diagnosis; and an extensive list of local and national support services and resources. The patient's personalized app is introduced in the Treatment Guide. Whenever a treatment plan changes, new information is released to the app and condensed treatment updates are provided.

The Patient Resource Survivorship Guide

This guide includes a summary of a patient's diagnosis and treatment and serves as an ongoing roadmap along with the survivorship care plan. The Survivorship Guide provides evidence-based follow-up guidelines and specific information on any ongoing treatments. In addition, the guide educates cancer survivors on

Table 1. Key Components of Appointment, Treatment, and Survivorship Guides	Appointment Guide	Treatment Guide	Survivorship Guide
Registration Information	✓		
Cancer Center and/or Regional Wayfinding	✓	✓	
Clinical Trials	✓		
Care Team Credentials	✓	✓	✓
Diagnosis Summary		✓	✓
Treatment Details		✓	✓
Side Effect Management		✓	
Resource and Support Services	✓	✓	✓
Record of Care			✓
Late- and Long-Term Effects			✓

Table 2. Survey Questions and Percentage of Those Who Agree or Strongly Agree Across All Tumor Types

Survey Questions	All Tumor Types (N = 1,462)
The information was comprehensive and easy to read.	94%
The information helped me prepare for and navigate my appointments at the cancer center.	90%
The information in the guide(s) assisted me in following my provider's instructions.	78%
The guide(s) built trust and confidence in my treatment team and cancer center.	81%
The personalized guide(s) will influence me in my recommendation of my cancer center to friends and family.	79%
The mobile and/or tablet app was a helpful tool to me as I managed my cancer care.	65%

specific late- and long-term effects from their diagnosis and treatments, along with evidence-based options focused on improving quality of life post adjuvant treatment.

Results of the Pilot Program

From July 2015 to February 2017, the University of Kansas Cancer Center sent 14,084 surveys to patients who received one or more of the patient resource guides. These surveys were designed to determine the usability of and patient satisfaction with the guides. The surveys were emailed to patients approximately seven days after the patients received the information. One completed survey was counted per patient per primary oncology diagnosis.

The survey used a traditional Likert scale and included standard questions to assess respondent satisfaction with the usability and content. An additional question about the mobile and/or tablet app was given only to patients who received the Treatment Guide (provided when a patient receives access to the app). Survey questions can be found in Table 2, above.

Based on the data requirements of this analysis (survey included at least one quantitative response and the total represented in a disease group is $n > 40$) only 1,462 of the responses were included, representing 1,416 unique patients. (Note: Multiple patients presented with more than one primary cancer diagnosis throughout the course of this study, thus qualifying them for more than one survey.)

This adjusted survey number maintains a high enough response rate (10.4 percent) for meaningful conclusions, as is standard in similar electronic surveys.[1] The responses are described by primary tumor type in Table 3, page 54, excluding brain and non-melanoma skin cancers. Approximately two thirds of the respondents were women, and the median age was 62 (Figures 1 and 2, page 54).

Table 3, page 54, identifies the number and type of guides sent to the respondent patient population. Guides are grouped by primary tumor type, which is consistent with the most common tumor types represented at the University of Kansas Cancer Center.

Patient responses across all tumor types are reported in Table 2, above. Most respondents reported that the information in the guide(s) was easy to read and comprehensive (94 percent) and helped in preparing them for cancer center visits (90 percent). Most (81 percent) also agreed that the personalized guides were helpful in building confidence with the cancer care team and influenced recommending the University of Kansas Cancer Center to friends and family (79 percent).

Viewing the responses by tumor type shows response consistency across groups. Most notably, all groups agreed (more than 90 percent) that the educational information was comprehensive and easy to read. All responses by tumor type are reported in Table 4, page 55.

An open-ended question was included with the patient survey, and cancer center Patient Resource Navigation System users were asked for feedback to assess the user experience. Responses from the cancer center user perspective and the patient perspective were favorable. Table 5, page 56, highlights select qualitative responses and demonstrates the system's utility, including how users leveraged the system to help meet accreditation standards through reporting, prepare patients for their visits, and support patients and caregivers along their cancer journeys.

Table 6, page 56, shows select patient responses to this open-ended question. Patient comments indicate that the personalized guide(s) improved patient confidence by providing a reliable resource that could be referenced at any time, especially when patients could be experiencing information overload during a visit. The guide(s) reinforced the quality of the care team and the comprehensiveness of the care provided, which resulted in favorable impressions and future recommendations to the cancer center to others impacted by cancer.
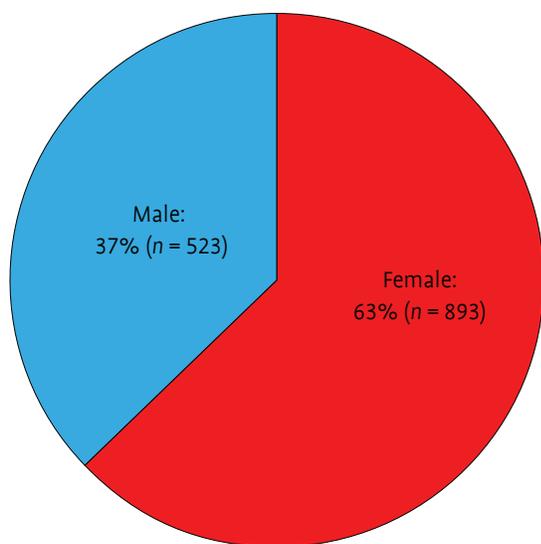
Figure 1. Gender of Survey Respondents

Male: 37% (n = 523)

Female: 63% (n = 893)

Figure 2. Age of Survey Respondents

<30 years, n=39 or 3%

31–50 years, n=279 or 19%

>70 years, n=313 or 22%
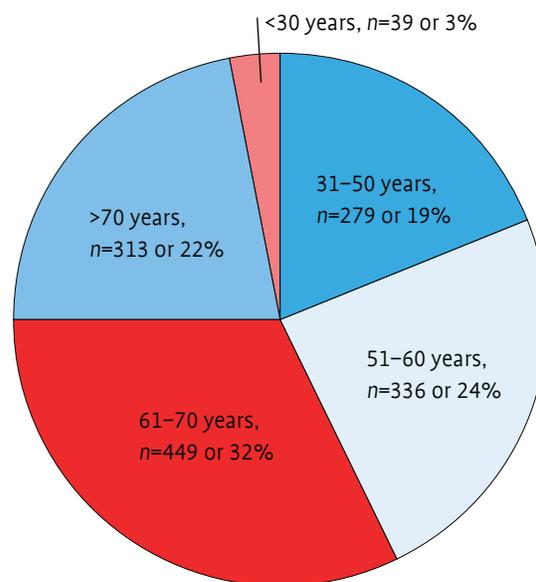
51–60 years, n=336 or 24%

61–70 years, n=449 or 32%

Table 3. Number of Responses by Primary Tumor Type and Guide(s) Received (n = 1,462)

Primary Tumor type[a]	Appointment guides only	Additional guides[b]
Breast	127	278
Gastrointestinal	75	93
Genitourinary	98	22
Gynecologic	60	55
Head and Neck	95	41
Hematologic	274	0
Lung	41	56
Melanoma	44	27
Sarcoma	76	0
Total	890	572

[a]Count reflects unique primary diagnoses, not unique patients
[b]Patients received Appointment Guide and Treatment Guide, Treatment Update, and/or Survivorship Guide.

Table 4. Survey Responses by Primary Tumor Type									
	BREAST	GASTRO-INTESTINAL	GENITO-URINARY	GYNECOLOGIC	HEAD AND NECK	HEMATOLOGY	LUNG	MELANOMA	SARCOMA
	n = 405	*n* = 168	*n* = 120	*n* = 115	*n* = 136	*n* = 274	*n* = 97	*n* = 71	*n* = 76
Question	Agree or Strongly Agree								
The information was comprehensive and easy to read.	94%	94%	93%	93%	92%	93%	96%	99%	92%
The information helped me prepare for and navigate my appointments at the cancer center.	91%	91%	87%	93%	88%	89%	94%	97%	97%
The information in the guide(s) assisted me in following my provider's instructions.	81%	80%	73%	77%	80%	73%	81%	86%	74%
The guide(s) built trust and confidence in my treatment team and cancer center.	84%	83%	78%	83%	82%	76%	85%	93%	75%
The personalized guide(s) will influence me in my recommendation of my cancer center to friends and family.	80%	80%	76%	79%	75%	78%	80%	92%	78%
The mobile and/or tablet app was a helpful tool to me as I managed my cancer care.	61%	57%	50%	100%	50%	n/a	75%	33%	n/a

Table 5. Qualitative User Feedback

"The books helped us achieve QOPI [Quality Oncology Practice Initiative] recertification back in May and, most recently, CoC [Commission on Cancer] recertification. From a productivity standpoint, we now have an accurate count of how many patients the navigators are following. As a result, we got approval for another navigator in breast and another navigator in head and neck surgery. The Leadership Team love[s] the reporting features, especially from a quality standpoint."

    Melisa Wojteczko, BSN, RN-BC, practice operations manager, Head and Neck, Thoracic Specialty Sections, UF Health Cancer Center Orlando Health.

"The Appointment Guide makes a wonderful first impression of our cancer center and provides a face to the navigator who has already connected with that patient. We have had many patients comment that they knew they were coming to the right place as soon as the guide arrived on their doorstep. As an administrator, the reporting functionality in the portal is extremely helpful to monitor workload for each of the navigators. It also provides access information, such as the number of business days from initial referral to first consult, which helps us ensure that we have the right number of providers available at each location to meet our patient demand."

    Teri Banman, BSN, RN, OCN, nurse manager, Navigation, University of Kansas Cancer Center.

"I have personally found the program beneficial from a continuity of care standpoint. I can pull up patient profiles and get a quick understanding of what treatment they have had or are going to have without having to spend any time in their medical records. I am able to look at their Patient Resource profile and see their treatment timeline from start to finish."

    Megan Lockwood, RN, BSN, thoracic specialty nurse navigator, UF Health Cancer Center–Orlando Health.

Table 6. Qualitative Patient Feedback

"Based on this guide alone, if I had a friend with cancer, I'd recommend they come here."

"This book right here...this means something to me. This has my name on it."

"The reality of what was happening to me really sank in. The guides motivated me to begin learning more and to take an active role [in my treatment]."

"The guides built confidence and reinforced my decision to change doctors and my hospital."

"The guide was very welcoming and full of helpful information. It helped settle my nerves. Most importantly, it showed that the providers and staff do care about their patients, which is sometimes hard to find in the medical field."

"Because there was so much information being given before, during, and after the treatment, it was very helpful to have the guides to reference once we were on our own. I still look at them to see if there is something I forgot or missed. I appreciated the information received before our very first appointment right through the information received at discharge."

Reporting and Metrics

Cancer center users (providers) reported that the navigation system and corresponding guides streamlined the initial intake process and appointment planning process. Additionally, access to real-time data and reporting has helped providers improve the accreditation process and more easily track process outcomes (such as business days out from referral to first appointment). The navigation system's data and reporting can be exported and feature pie charts and graphs. Reports include the following data sets:

1. *Referrals.* Review external and internal referrals according to who made the referral (self or provider), type of cancer, date of appointment and provider, and the average time from initial referral to first appointment (which was, at last reporting, 8.33 days).

2. *Treatment, Diagnosis, and Clinic Details.* Evaluate data sets by number of patients with a specific tumor type, stage, treatment plan, clinic, physician, and treatment location.

3. *Geography.* Sort patient populations by gender, cancer type, and stage in a specific geographic region.

4. *Guides.* Search by clinic location, cancer type, and type of guide provided to patient.

5. *App User.* Identify demographics of patients using the app and sort by treatment location, tumor type, and physician.

Closing Thoughts

The cancer patient experience has become more complicated in the era of personalized medicine and fragmented delivery systems. Therefore, we are constantly striving to improve the patient experience through better outcomes and national benchmarking. In addition, having access to real-time data and reporting supports many of the national accreditation requirements for cancer programs and hospitals. This pilot has demonstrated that incorporating a navigation system into clinical cancer care delivery can help educate patients, improve patient satisfaction, and aid cancer programs in collection and monitoring of key data thresholds, such as business days out and other metrics that can impact the patient experience.

Going forward, we will be working toward achieving better patient compliance with the mobile app, as well as reviewing data regarding how guide touchpoints affect patient adherence and satisfaction. ◨

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Reference

1. PeoplePulse. Survey response rates: tips on how to increase your survey response rates. Available online at: peoplepulse.com/resources/useful-articles/survey-response-rates. Last accessed November 1, 2017.