



CANCERcare®

Decision Making at the Point of Care:
Voices of Oncology Providers
A Patient Values Initiative Issue Brief



2018



CANCER*care*®

About CancerCare®

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

CancerCare programs and services help 195,000 people each year. We distribute 793,000 publications and welcome 2.1 million website visits annually. In the past year, CancerCare provided nearly \$26.4 million in financial assistance. The size and scope of CancerCare has grown tremendously since 1944, but it has never wavered from its mission of providing help and hope to people affected by cancer.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

Our Mission

CancerCare is the leading national organization dedicated to providing free, professional support services including counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

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Executive Summary

Have the recent advances in precision oncology therapy neglected the “human” in favor of a single-minded focus on “being”? In oncology care, treatment options are increasingly personalized based on the genetic structure of patients’ cancers. As a result of dedicated attention to the very molecules and genes that drive cancer, the ‘quantity’ of life has improved. Little attention has been paid however, to ensuring that what patients value is actually incorporated or at least acknowledged in these extra weeks, months or years of survival gained. Importantly, for treatment to be truly personalized, patients’ values, preferences and quality of life concerns must be factored into treatment planning. Just as critical as understanding the genetic variations in an individual’s cancer is understanding how that patient wants to, or needs to, live her/his life.

In 2017, CancerCare established the Patient Values Initiative (PVI) with the overall goal of altering treatment planning and decision making so that patients’ preferences and priorities become key considerations in the process. As a first step, CancerCare conducted focus groups with oncology social workers and patients to better understand how patients participate in treatment decision making, and perceive their roles and relationships with their providers in this context.

The Patient Values Initiative aims to ensure that supporting patients and their genuine engagement in cancer treatment decision making becomes the standard of care, so that treatment plans reflect the priorities, goals and needs of each individual patient.

In the first PVI white paper, “The Many Voices of Value: A CancerCare Focus Group Assessment,” a key finding was that newly diagnosed patients felt unable to fully participate in treatment planning and decision making because they were overwhelmed by the emotional impact of their diagnosis and the amount and intensity of information that accompanied it. Patients reported relying on their oncologists’ recommendations, without much understanding of the impact the treatment would have on their lives. Information about their jobs, care partners, family and household responsibilities, access to transportation, and significant upcoming plans were not discussed before treatment plans were finalized. This feedback is consistent with the findings of the 2016 CancerCare Patient Access and Engagement Report, where patients reported having significant information gaps related to their treatment plan and its impact on their health and overall quality of life, despite having started treatment. Additionally, many patients admitted to not recognizing that their personal preferences and priorities *could* influence the choice of therapeutic options under consideration.

To expand on the qualitative research previously conducted, CancerCare conducted in-depth interviews with oncology providers, practice managers and electronic medical record (EMR) developers. The goal was to understand some provider perspectives on the importance and utility of learning about their patients’ lifestyles and priorities, and how and when this information is recorded and/or shared with the larger care team.

CancerCare interviewed a total of 15 people (see Appendix A): 6 oncology providers and 9 advanced practice nurses, practice managers, or health information technology (IT) experts. They represented perspectives from diverse settings of care, both academic medical centers and community clinics, rural and urban settings, as well as different geographic regions.



Key Takeaways

Table 1. Key Takeaways

1. Clinicians want to get to know their patients and this learning typically unfolds over multiple encounters along the care continuum.
2. Providers rarely collect information on patient preferences, priorities and lifestyles in a systematic way.
3. If patient-specific data on preferences, lifestyle, etc., are collected, there is wide variation in what specific information is being captured, when it is collected along the care continuum, and how it is used to inform care planning and decision making.
4. Electronic medical records (EMRs) are built for payment and process; they do not have fields for patients' lifestyle details or preferences.
5. Integration and interoperability of data remain major challenges to providers, especially as smaller and community practices are acquired and consolidated.
6. Financial concerns play a key role in patients' lifestyle choices and priorities; however, some physicians are hesitant to discuss financial concerns with patients because they typically do not know the full extent of out-of-pocket costs incurred by the patient.

Key Takeaway 1: Clinicians want to get to know their patients and this learning typically unfolds over multiple encounters along the care continuum.

- Physicians want to get to know their patients both personally and clinically, however, the first several meetings generally focus entirely on the diagnosis and treatment plan. During subsequent visits, after treatment is underway, conversations may become more personal and less clinical.
- Non-physician team members, such as advanced practitioners, nurses, patient navigators, social workers, or counselors, typically spend more time with patients than physicians.
 - Nurses, in particular, are often the main point of contact for patients during treatment and therefore, may have more in-depth conversations with them about their lifestyles, treatment side effects, job or family responsibilities, and other priorities or preferences.
- The content of these conversations is not systematically recorded or shared with other care team members. If a key personal issue is identified, it may be noted in the EMR and/or communicated verbally to the treating physician and other care providers.
- In some practices, patient navigators help collect patient preference data. For example, in one practice we interviewed, a social worker systematically meets with every new patient to probe lifestyle issues and priorities. Subsequently, the social worker writes a lengthy report that is added to the EMR. These visits do not always occur before treatment begins, however.

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‘Living with Cancer’ Defines Care Approach

The University of Arizona Cancer Center has streamlined the process it uses to learn about new cancer patients while simultaneously bringing their information into the EMR system in a way that covers all Oncology Care Model requirements. First, a nurse navigator conducts a phone or in-person intake interview with the new patient. After the first doctor meeting but before treatment begins, new patients receive a 'Living with Cancer' booklet that provides an overview of the services and a list of personnel that will be a part of their healthcare team. Next, the patient with her/his caregivers meet with a financial counselor to discuss anticipated out-of-pocket expenses based on the patient's specific insurance plan. They then meet with a social worker who is trained by their in-house psychiatrist to address issues such as identifying a power of attorney and healthcare proxy, and advanced care planning. Next, a nurse discusses her/his specific treatment plan, including anticipated adverse events, reportable signs and symptoms, and strategies for self-management. Discussions are tailored to the patient's specific circumstances and needs, and the information exchanged is entered into the patient's EMR.

All patient information collected from these visits informs treatment direction, and the process is built into the center workflow.

—Sandra Kurtin, PhDc, ANP-C, AOCN, Nurse Practitioner, University of Arizona Cancer Center

Key Takeaway 2: Providers rarely collect information on patient preferences, priorities and lifestyles in a systematic way.

- Providers and clinics use a broad range of intake forms, EMRs, and verbal/written data collection tools for demographic, medical and insurance information.
- The way providers collect patient information has evolved based on whether their practices are hospital or office based, community or academic centers, or specialty or general in clinical focus.
 - Hospitals and academic centers are more likely to follow well-defined protocols and formats that may not easily accommodate collecting and sharing what is considered by most to be “non-essential” information.
 - EMRs, which essentially function to record data for billing purposes, do not work as tools for patient-centric, relational medical care.

“I get satisfaction from knowing my patients, so I do ask questions around ‘what do you do in your free time?’ or ‘what do you do for exercise?’.”

—James Hamrick, MD, Community Oncologist, Kaiser Permanente Georgia, and Senior Medical Director, Flatiron Health

“I should not have to learn about my patients by reading their obituaries.”

—Oncologist, Academic Medical Center

“Patients may not always want or understand why we offer navigation or coordination of services. Some find it intrusive. We may have to talk to family members to get a full picture of what is happening with our patients.”

—Melanie K. Reed, MS, FNP-C, Skyline Urology



- Key care team members other than the physician often define the processes used to learn about and share personal patient information.
 - A social worker or nurse may become the de facto patient advocate, meeting with new patients, getting to know them, and communicating their priorities to the care team through staff meetings or informal conversations.
- Overall, it seems that conversations with patients about their preferences and priorities are happening on an ad hoc basis, are situational, and vary broadly in content. They may be recorded in a free field in the EMR, or in a notes section. There are rarely “rules” governing what specific information should be collected or when it would be helpful to communicate it to others on the care team.
 - While new tools and technologies exist to help providers learn about what is important to their patients, there is a need to increase overall awareness among providers that these tools exist, to recognize the value of the information gleaned, and to commit to factoring it into treatment considerations.
- Providers may narrow recommendations based on what they know (or assume) about the patient. Some providers feel that multiple options confuse patients, and that some patients want oncologists to be directive rather than share decision making.
- Providers noted the difference in treating a newly-diagnosed patient diagnosed versus one needing second- or third-line therapy. Discussing preferences and options may be more common when the initial treatment(s) has been unsuccessful and the patient’s prognosis is equivocal.
 - Even though some care team members may be aware of patients’ preferences and priorities, this information may not be reflected in treatment planning and decision making because there is not a systematic way to communicate it to the treating physician in time to affect recommendations.

“Never break bad news without a plan.”

–Michael Wong, MD, The University of Texas MD Anderson Cancer Center

Key Takeaway 3: If patient-specific data on preferences, lifestyle, etc., are collected, there is wide variation in what specific information is being captured, when it is collected along the care continuum, and how it is used to inform care planning and decision making.

- Clinicians may feel an urgency to approach patients with a plan and treatment directives to help calm them and communicate a sense of confidence and hope. They realize however, this approach has to be balanced with allowing patients space to understand how their cancer and its treatment will affect their lives. Ideally, treatment planning occurs in more than one meeting.

Key Takeaway 4: Electronic medical records (EMRs) are built for payment and process; they do not have fields for patients’ lifestyle details or preferences.

- In some clinics, information regarding a patient’s values and preferences is communicated as part of the initial consultation and is recorded as part of a present illness note, the social history, or in the context of a palliative care consult.
- IT experts report that even if the EMR is set up to solicit patient preferences, reporting this information to other team members presents a separate hurdle.
- For accountable care organizations, specific data points are built into the EMR since reimbursement

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models dictate elements of functionality. Currently, the focus in oncology EMRs has been to align information gathering with the Institute of Medicine's (now the National Academy of Medicine) 13 component care plan.

- Each EMR platform seems to focus on different aspects of patient care or reimbursement (i.e., quality, financial, etc.), but none is facilitating a patient-centric approach to care and treatment.

“The EMR will document whatever we tell it to do. The issue is the oncologist taking the time to do it. Oncologists should be practicing quality medicine, not clicking boxes in an EMR to prove they gave quality care.”

–Maureen Melody, MBA, Charleston Cancer Center

Key Takeaway 5: Integration and interoperability of data bases remain major challenges to providers, especially as smaller and community practices are acquired and consolidated.

- Given the significant issues that challenge EMR implementation and interoperability, obtaining data regarding patient preferences, lifestyle, etc., is not a priority for most practices.
- Community clinics that are acquired by larger centers are typically focused on integrating into and learning a new EMR system, and perceive they do not have direct control of or influence over the type of information collected.
- Providers at academic centers and health systems are typically using general EMRs, and even though they may want to expand data collection, they may not have access to a cancer-specific EMR platform.

- Designers of cancer-specific EMRs are only focused on patient-centric care to the extent that it is built into the payment models where certain metrics are required.

“When it comes to our electronic medical record, what you see is not necessarily what I see, even within the same organization.”

–Lee Schwartzberg, MD, West Cancer Clinic

Key Takeaway 6: Financial concerns play a key role in patients' lifestyle choices and priorities; however, some physicians are hesitant to discuss financial concerns with patients because they themselves typically do not know the full extent of out-of-pocket costs incurred by the patient.

- Practices reported that Medicare's Oncology Care Model has increased their awareness of costs of care, since they are required to report an episodic view of costs every six months. However, discussing financial costs as part of treatment planning is not typical in academic practices as most physicians have not been trained in this kind of communication and the tools are not available to help them estimate patients' expenses.
- Community physicians said they feel compelled to discuss cost with their patients in order to ensure an understanding of the patients' financial status before starting treatment.
 - Many practices try to get financial assistance for patients. Since that is not always available, providers, especially those taking on some of the financial risk, are more likely to discuss the costs each patient will incur.



Summary and Next Steps

The findings from our prior research underscored that patients need resources and opportunities to help them recognize and articulate their preferences before treatment plans are finalized and treatment begins. Care team members can have a key role in helping patients identify the critical aspects of their lives that should be discussed during care planning. The in-depth interviews with providers, care team members, and health IT experts reported herein illuminate some of the issues and barriers that they confront in trying to become familiar with their patients before treatment is initiated.

“There is an assumption that there is a care team, when it is really more of a relay team.”

–Susan M. Love, MD, MBA, Chief Visionary Officer, Dr. Susan Love Research Foundation

Patients’ preferences and priorities are important to cancer care providers, who recognize that individual patient’s needs are key elements of patient-centric care planning, shared decision making and adherence to the treatment plan. Unfortunately, clinicians and the care team do not have easy and efficient access to this information; they instead rely on ad hoc collection and EMR recording methods that are not typically timely or effective in informing personalized treatment decisions.

Clinics and practices are unlikely to change their work flows to incorporate data collection that is not required by a pathway or reimbursement. Since work flows differ among care settings, new data collection and reporting processes will need to be structured within these environments, making “plug-and-play” or “one-size-fits-all” modules impractical solutions.

CancerCare is building on the qualitative research among social workers, patients, care providers and administrators

Addressing Financial Concerns Before Treatment Begins

One private practice physician said his patients understand that discussions around financial cost are a growing part of the U.S. healthcare system. As a physician who runs his own business, he is confronted each day with the realities of treating cancer patients in need and the costs associated with their care: “I always have had to help patients understand their out-of-pocket costs before we go too far down the road with a specific treatment. There may be a medicine that has a slight advantage over another, but it is much, more costly. For some patients, it is worth the cost, for others it is not, but burying this conversation is not an option.”

– David Oubre, MD, Pontchartrain Cancer Center

conducted in the first two phases of the PVI, with additional research. The next steps include a quantitative survey among oncology clinicians and administrators to inform if and how they think patient preference data should be collected, who on the care team is best positioned to collect it, what resources are needed, and how collection of these data can be incorporated into existing practice work flows.

Over the next several months, CancerCare will field this quantitative provider survey, and then develop and test prototype tools that providers can easily and efficiently implement to capture information about patients’ preferences and priorities. The findings of this work will inform advocacy materials for providers, patients and policymakers in support of cancer care that is truly

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customized to the needs and values of each patient. The ultimate goal of the Patient Values Initiative is to ensure that supporting patients and their genuine engagement in cancer treatment decision making becomes the standard of care, so that treatment plans reflect the priorities, goals and needs of each individual patient.

“Most oncology providers adhere to evidence-based guidelines and clinical pathways when planning cancer management. However, it has only recently been recognized that early involvement with patients about their goals, preferences and values is an essential component of high-value cancer care.”

– Maureen Killackey, MD, FACOG, FACS, Clinical Director, New York-Presbyterian/Lawrence Cancer Services, Herbert Irving Comprehensive Cancer Center, Columbia University

Appendix A: Participants in In-Depth Interviews

Role	Type of Organization
Clinician, Administrator	Community hospital owned by urban academic comprehensive cancer center
Clinician, Manager	Leading EMR developer/supplier
Clinician, Manager	Community hospital owned by urban academic comprehensive cancer center
Clinician, Administrator	Urban academic cancer center
Breast Surgeon	Cancer research foundation
Administrator	Urban cancer center
Clinician	Rural cancer private practice
Administrator	Urban urology practice
Clinician, IT Expert	Urban cancer clinic affiliated with academic medical center
Clinician	Urban academic comprehensive cancer center

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