

ASSOCIATION OF COMMUNITY
CANCER CENTERS

SHARED DECISION-MAKING:
PRACTICAL IMPLEMENTATION
FOR THE ONCOLOGY TEAM

Effective Practices for
Optimal Patient Engagement

Developed with financial support from and in collaboration with
Pfizer Oncology



Association of Community Cancer Centers

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INTRODUCTION

As new treatment options for cancer become available, patient involvement in decision-making is more important than ever. Research shows that patient engagement can make a difference in their health outcomes. Patients who are actively involved in making treatment decisions are more likely to be confident about their choices, satisfied with their treatment, and trust their providers.¹

To address the increased need for strong patient engagement, the Association of Community Cancer Centers (ACCC) launched an educational initiative to identify barriers to and effective practices for assessing current knowledge about shared decision-making and how it is practiced in community and academic settings. The project included a national quantitative survey as well as focus groups and interviews with multidisciplinary team members from four cancer programs. This enabled ACCC to gather information about the practices these programs have found to be effective in engaging patients in the treatment decision-making process.

This publication identifies a wide range of methods for building engagement with patients, with a special focus on shared decision-making in the context of metastatic disease, geriatric oncology, and limited health literacy.

Key terms that describe patient involvement in their care include:

Patient-Centered Care

In 2001, the Institute of Medicine (IOM)—now the National Academy of Medicine—defined patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The Institute of Medicine also noted that patient-centered care is a key recommendation for healthcare systems to integrate.² By practicing patient-centered care, a healthcare team creates an ideal environment for a patient to be engaged in their care decisions. A related term is “person-centered” or “person-focused” care, which addresses patient concerns and needs beyond the current health issue.³

Patient Engagement

Patient engagement refers to patients choosing to actively participate in their care as partners with their care team.⁴ Patients can be engaged in their care in a variety of ways. For example, they may contact a member of their care team to ask a question about a treatment approach; they may attend a learning session about an aspect of their cancer; or they may participate in an advisory committee at a cancer center and engage at a system level. There are many strategies that cancer centers can adopt to increase patient engagement in treatment decision-making.

Shared Decision-Making

Shared decision-making refers to the process by which patients, their chosen caregiver(s), and providers work together to make fully informed treatment decisions using the best available evidence and considering the patient’s values and preferences. This approach is most appropriate when there is more than one reasonable treatment option or when the scientific evidence is not available or is conflicting.⁵ When there are multiple reasonable options, the patient’s values and preferences become central to the decision-making process.

Some examples of these preference-sensitive decisions include whether to have surgery or radiation for early-stage prostate cancer, whether to have breast-conserving surgery or a mastectomy for early-stage breast cancer, and whether to have surgery or liver-directed therapy for hepatocellular carcinoma. In advanced cancers, there may be several therapeutic approaches with similar overall survival benefits. For many patients, the options in these scenarios may provide similar therapeutic benefits but cause different side effects or hold other uncertainties. As a result, different patients may make different choices based on what is important to them and their quality of life.



In Memory of Dana West (1969-2020): ACCC is grateful to Dana West of Southern Illinois Healthcare Cancer Institute for her instrumental support in this education project.

The process of shared decision-making involves the following steps:

1. Inviting the patient and any chosen caregiver(s) to participate in decision-making
2. Presenting and discussing options, risks, and benefits
3. Discussing the patient’s values and preferences
4. Helping the patient make a decision that is consistent with their goals and preferences

Patient Decision Aids

A patient decision aid is an evidence-based tool designed to help patients become involved in shared decision-making. Patient decision aids help guide provider/patient conversations, focus on the decision at hand, and elicit patient values and preferences regarding different treatments options.⁶ Many decision aids exist for different diseases and conditions. The Ottawa Personal Decision Guide is an example of a generic form that can be used to make decisions.

FIGURE 1: Example of a Patient Decision Aid

Ottawa Personal Decision Guide
For People Making Health or Social Decisions

1 Clarify your decision.

What decision do you face?
 What are your reasons for making this decision?
 When do you need to make a choice?
 How far along are you with making a choice? Not thought about it Close to choosing
 Thinking about it Made a choice

2 Explore your decision.

Knowledge List the options and benefits and risks you know.
Values Rate each benefit and risk using stars (★) to show how much each one matters to you.
Certainty Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1				

Download full guide here <https://decisionaid.ohri.ca/decguide.html>

To learn more about developing, selecting, and using decision aids, visit our expert-led on-demand Approaches to Shared Decision-Making webinar series at courses.accc-cancer.org/products/shared-decision-making-webinar-series.

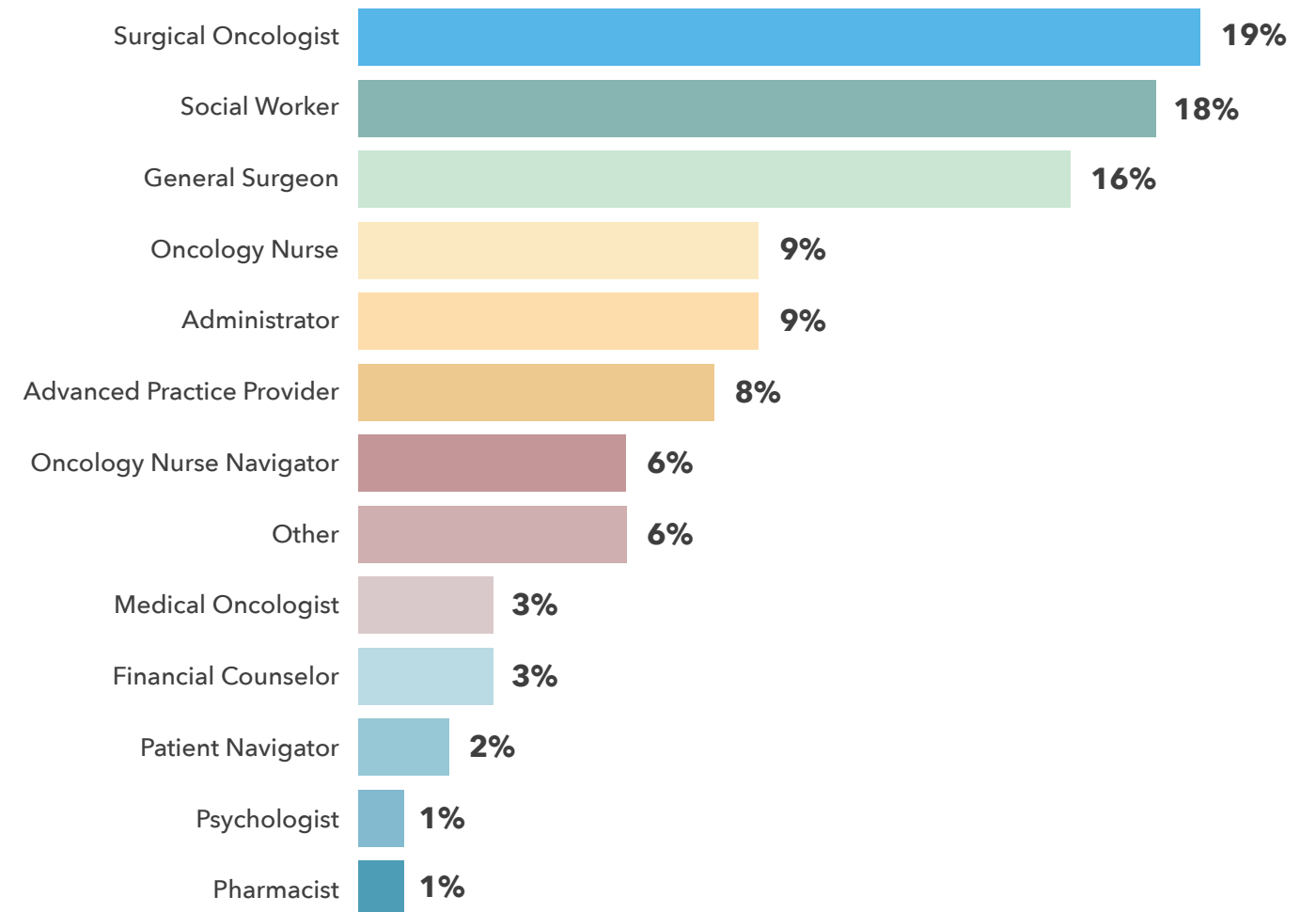
SURVEY RESULTS: WHAT WE LEARNED

ACCC convened a steering committee of multidisciplinary specialists, members of professional associations, and advocacy representatives to draft the 26 closed-ended, quantitative questions that made up the survey. Once finalized, the survey was distributed to members of ACCC, the Advanced Practitioner Society for Hematology and Oncology, the Academy of Oncology Nurse and Patient Navigators, the Association of Oncology Social Workers, and the American Society of Breast Surgeons.

private practices in 47 states and the District of Columbia. Respondents were recruited through each professional organization's membership lists, email blasts, and social media. Responses were collected via Qualtrics, and exploratory analysis was performed on the 443 responses. For the full list of professions represented, please refer below. Survey questions were designed to reveal the current landscape of general patient engagement, attitudes, and practices regarding shared decision-making across the care continuum; the use of decision aids; strategies used to address health literacy; and communication and documentation of shared decision-making conversations.

The survey received 443 responses from a wide range of healthcare professionals at academic cancer programs, community cancer programs, hospital systems, and

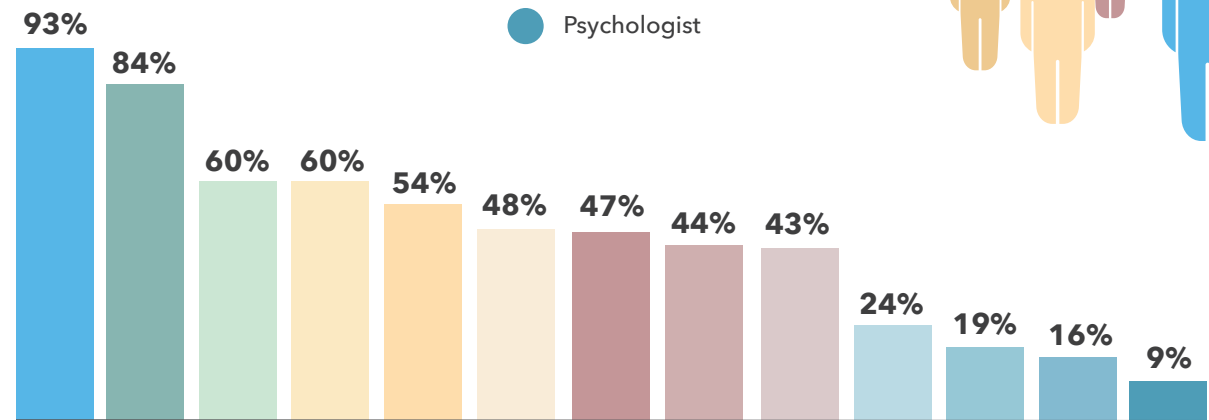
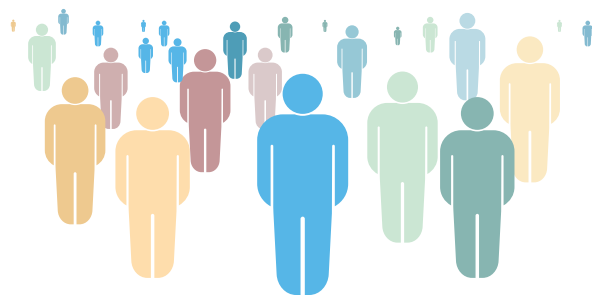
FIGURE 2: Who Took Our Survey



The difference in response numbers is due to survey logic and applicability of the question to the respondent’s role.

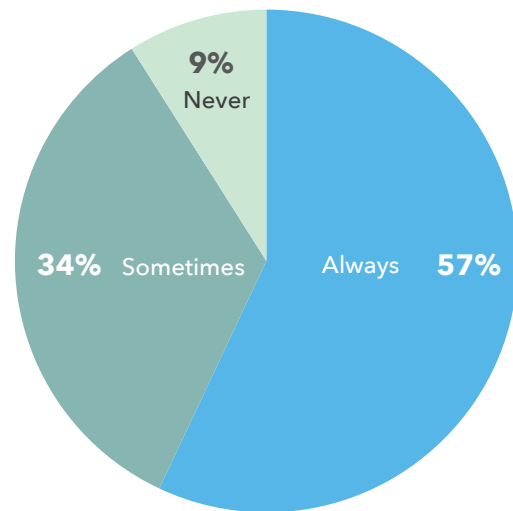
- Medical Oncologist
- Radiation Oncologist
- Surgical Oncologist
- Advanced Practice Provider
- Oncology Nurse Navigator
- Plastic and Reconstructive Surgeon
- General Surgeon
- Social Worker
- Oncology Nurse
- Financial Counselor
- Pharmacist
- Patient Navigator (not nurse or social worker)
- Psychologist

Who's involved in decision-making conversations with patients? (n=443)



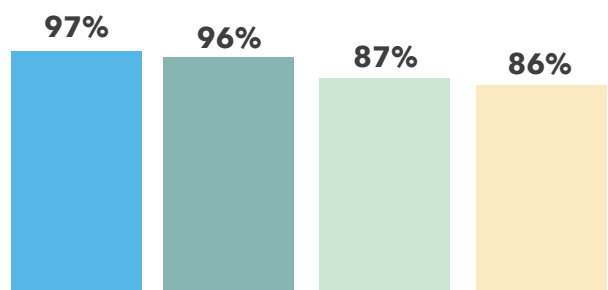
Frequency of respondent engagement with patients in conversations about treatment decision-making (n=443)

(n=443)

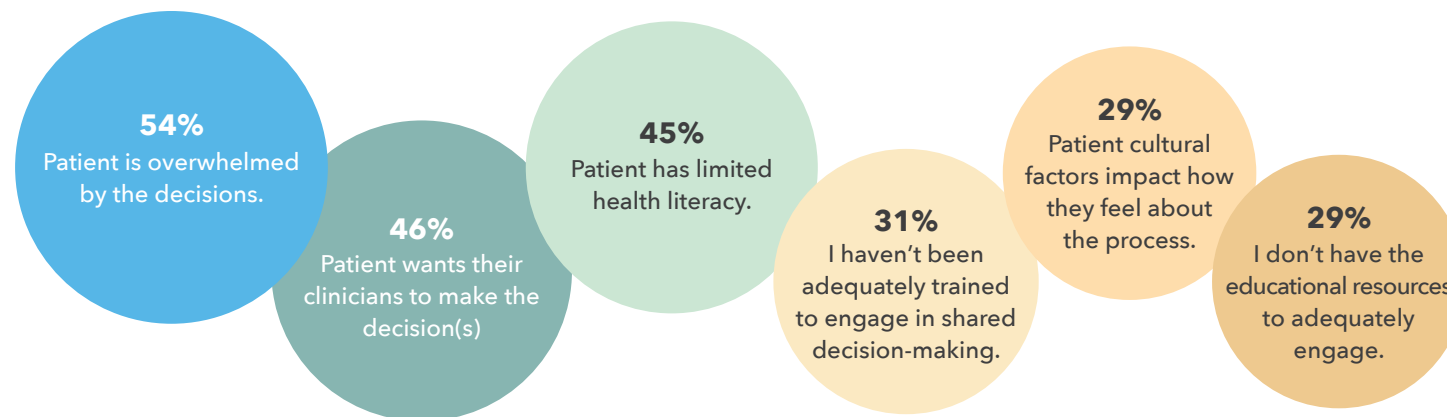


Common strategies to engage with patients during treatment planning (Responses indicate "Strongly or Somewhat Agree") (n=355)

- I encourage patients to participate in the decision-making process.
- I ask questions to understand my patients' priorities/values.
- I explain the advantages and disadvantages of each treatment option.
- I explain each available option for treating their cancer.



Top barriers to shared decision-making (n=302)



82% indicated that they have experienced more than one shared decision-making barrier.

Are cancer programs prioritizing shared decision-making? (Responses indicate "Strongly agree" or "Somewhat agree") (n=308)

Shared decision-making is a top priority.

50%



Staff thinks that implementation of shared decision-making is important.

48%



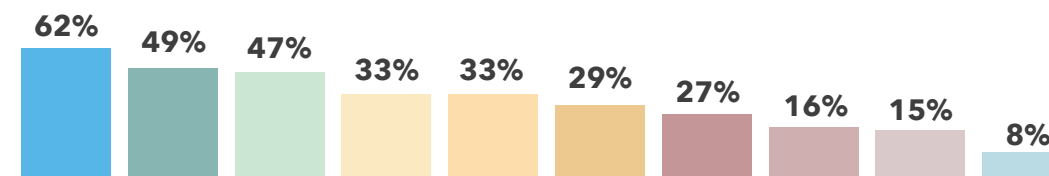
There have been efforts to formally integrate into clinical workflow/service lines.

33%



What training are cancer programs providing? (n=216)

- Cultural sensitivity training
- Having difficult conversations (e.g., discussing prognosis, bad news, and death and dying)
- Diversity training on gender identity and gender expression
- The role of families and caregivers in supporting treatment decision-making
- Eliciting patient values, goals, preferences, and priorities
- Incorporating what matters most to patients into treatment decisions
- Coaching on communicating treatment risks and benefits to patients
- Using patient decision aids
- Basic training about shared decision-making and how it is different from informed consent
- How to run a family meeting



EFFECTIVE PRACTICES IN SHARED DECISION-MAKING

To better understand how multidisciplinary cancer care teams approach patient engagement and shared decision-making, ACCC conducted a series of focus groups and interviews with four cancer programs. The resulting effective practices can be used by cancer programs to improve patient engagement in the decision-making process.

SOUTHERN ILLINOIS HEALTHCARE CANCER INSTITUTE CARTERVILLE, ILLINOIS



Southern Illinois Healthcare (SIH) is one of the largest healthcare systems in southern Illinois, with a service area radius of approximately 100 miles. With three hospitals located in Carbondale, Murphysboro, and Herrin, SIH serves a mostly rural and dispersed population of primarily low and medium socioeconomic status. The SIH Breast Center team, housed within the SIH Cancer Institute, has worked to build a program that engages with patients to help them take an active role in making decisions about their treatment.

Building a Relationship of Trust from the Start

Establishing trust from the start is critical to creating conditions in which patients feel safe and supported to engage in decisions about their care. At their very first appointment at the SIH Breast Center, all patients receive a binder with information about each member of their team, including background, contact information, and headshots. In this way, patients “meet” the members of their care team even before seeing them in person. Patients are encouraged to reach out to members of their team if they have any questions, which they frequently do.

Patients are also encouraged to contact their nurse navigators, who often serve as a sounding board and a communication pathway to their physicians. Nurse navigators know that getting to know their patients is important to helping them make care decisions, because those decisions are often influenced by non-medical factors. For example, does the patient have a job that makes it difficult to take time off for recovery after surgery? Is the patient a single parent with limited childcare options? Is it a burden for a patient to pay for the gas required to travel to radiation appointments five

days a week? Understanding what a patient is dealing with outside of their cancer contributes to informed conversations about individual treatments.

Consistent communication also minimizes patient confusion and increases satisfaction. The cases of all patients with breast cancer at SIH are discussed prospectively, and decisions are communicated across the team. Because tumor board meetings are attended by everyone on the care team, everyone knows about each patient, even if it isn't their patient. All members of the care team understand what is important to patients, and they are able to integrate those values and priorities into treatment decisions. **Overall, the most important part of trust-building is learning about the patient as a complete person—not just about their cancer.**

Addressing Logistical and Financial Barriers to Decision-Making

The SIH Cancer Institute's nurse navigator for patients with breast cancer, two financial navigators, and social worker collaborate with the clinical care team to find solutions to treatment barriers at the start of a patient's journey. Cost of treatment, basic needs like food and housing, and logistical costs associated with treatment (e.g., transportation and childcare) can all contribute to financial toxicity for patients. Identifying and understanding these challenges up front helps SIH proactively mitigate them as much as possible. Living in rural regions frequently means patients' transportation options are limited. Many rural patients without a car don't have the same access to taxis and public transportation that urban and suburban patients do. Even if patients have a car, they often are not permitted to drive themselves home after certain procedures or treatments. To help meet patient needs

for transportation, SIH has established partnerships with local public transit agencies to provide reduced-cost transportation options. SIH has also established a free emergency transportation fund to help patients travel to and from their treatments.

Transportation isn't just a logistical issue; it can be a financial one as well. Some patients cannot afford gas, and SIH's financial navigation program can often help patients obtain prepaid gas cards through national and local programs. Eligibility for gas cards is assessed based on a variety of factors including diagnosis, treatment, insurance coverage, and income.

Of course, transportation is not the only financial challenge patients may face. To maximize the number of patients being evaluated for financial need, the financial navigators at the SIH Cancer Institute use a financial assistance platform and have worked with their IT team to build a feature into their electronic health record that flags patients who were not referred to financial navigation. Identifying treatment resources early can also help with clinical decision-making. For example, when there's an assistance program for a brand-name drug but not for its generic equivalent, assuming the clinician is comfortable prescribing the brand-name drug, the patient may be able to receive financial assistance to cover some or all of the cost. Because clinicians do not know about these opportunities, the financial navigators alert clinicians to them. From April to December 2019, SIH's two financial navigators secured nearly \$700,000 in co-pay or other financial assistance for 348 patients.

Helping Patients Make Sense of Information

Shared decision-making supports patients in understanding their treatment options and the risks and benefits of each. More than half (54 percent) of the respondents to ACCC's shared decision-making survey perceived “patient is overwhelmed by the decision” as a barrier to shared decision-making. When patients are overwhelmed, it can be difficult to have conversations with them about complex treatment options. By getting to know their patients and encouraging them to speak up if they feel overwhelmed, SIH care team members recognize when patients may be unable to absorb information during their initial consultation.

Taking cues from the patient, care team members can simplify the information, slow down, or may revisit some information later when the patient is better able to absorb it. Sometimes a tactic as simple as changing the subject and

asking patients non-medical questions such as where they live, what they do, or how old their children are, can help a patient reset and re-engage in the conversation. Breast cancer education handouts help visually explain to patients their diagnosis, staging, and the decisions to be discussed. Decision-making isn't a one-time conversation; it may need to happen over the course of several conversations in person, by phone, or email.



“After explaining the pathophysiology, I generally go into detail about the patient's diagnosis. Using an education tool that includes a diagram, I write the location of the tumor, the diagnosis, the phenotype, and size right next to the picture. This allows the patient to put

the diagnosis into context. I also have the TNM staging chart on the sheet and review their staging with them, which is very helpful. We then lead into a discussion regarding treatment.”

Arsalan Salamat, MD, Breast Surgeon, SIH Cancer Institute

Reframing the Conversation for Metastatic Patients

Patients with metastatic cancer not only need to process complex information to make an informed care decision, but they also have to cope with the feelings of loss that may accompany their diagnosis. They may not understand what it means to have stage IV disease, or what their goals of care should look like, given their high levels of anxiety and uncertainty. Keeping a strong focus on relationship-building and trust can help care team members better engage patients in productive conversations about treatments, possible side effects, and quality of life challenges along the care continuum.



“Remember, you are strangers to us in the beginning, and now you're having the most serious and important conversations of our lives that have intimate and far-ranging consequences. We might need a minute to get to

know and trust you first. What may appear as reluctance [to participate in decision-making] could simply be timing. Try again at the next visit and the one after that.”

Andrea Hutton, Breast Cancer Survivor; Patient Advocate, Metastatic Breast Cancer Alliance



Levine Cancer Institute (LCI) is a large cancer program with more than 25 locations throughout North Carolina and South Carolina with characteristics of both a community cancer center and an academic medical center. LCI has a strong culture of patient-centered care and promotes an environment that supports feedback across all levels of the organization—including patients—with the end goal of improving the patient experience. LCI is also the first ambulatory oncology care center to hold the Planetree certification in person-centered care, which not only focuses on caring for the whole patient, but also on caring for caregivers and the broader community.⁷

Using Technology to Support Treatment Decision-Making

Because so many of LCI's locations treat patients with cancer, LCI leverages its technology platforms to establish consistent treatment approaches across the healthcare system. This has been achieved through LCI's Electronically Accessible Pathways (EAPathways), standardized treatment platforms that allow all LCI clinicians to access the same evidence-based guidelines, treatment updates, and clinical trials, ensuring patients across facilities receive the most consistent, high-quality care possible.

When patients meet with their clinicians for an initial treatment consultation or when new treatment plans need to be

discussed, their clinician can quickly access the relevant pathway to discuss treatment options with the patient. From the pathway system, the provider can print out and distribute patient education on relevant topics, including side effects. Depending on the patient's needs, location, on-site resources, and availability of clinicians, additional care team members, such as social workers, navigators, or pharmacists, may also meet with patients to provide support or answer questions about treatment.

LCI uses a care alignment tool (CAT) that documents clinician-patient discussions about their goals of care in the patient's chart for use in advanced care planning. In 2019, a quality improvement (QI) team of advanced practice providers began working with LCI's thoracic oncology clinic, using the CAT to better understand clinicians' goals-of-care discussions with patients and increase their use along the continuum of care. The CAT includes questions that probe a patient's biggest fear or concern for the future, most important goals, and preferences related to using sustaining measures at the end of life. The tool also includes open fields for additional notes regarding a patient's goals.

LCI's QI team has initiated two interventions within the thoracic clinic to increase the use of this tool and make it easier to use. A third effort to increase use started in August

2020 involves distributing an instructional toolkit to a broader set of clinicians in the LCI network. Year-to-date CAT completion as of July 2020 is 64 completed, compared to four in the same timeframe in 2019, a 1,600 percent increase. These conversations are time-intensive, which has been noted as a challenge to further adoption of CAT. Eventually, patients and providers will get more familiar with the language and concepts covered in these conversations, making them quicker in the future.

Informing Action Using Direct Patient Perspective

When asked about barriers to shared decision-making, respondents to the ACCC survey indicated that patients are overwhelmed by their decisions (54 percent) and have limited health literacy (45 percent). One strategy to overcome these barriers is to engage patients and caregivers in creating an environment more conducive to decision-making. LCI has a highly engaged Patient and Family Advisory Council (PFAC) composed of 12 patients and caregivers and 10 staff members from across the LCI network. The PFAC influences LCI's commitment to person-centeredness in a number of ways.

One PFAC member sits on LCI's patient education committee, which includes clinical staff and a health librarian. This committee discusses the development of new patient resources and revises existing resources. The health librarian seeks the input of PFAC members regarding patient- and caregiver-facing materials. PFAC members are a resource for the librarian, who can discuss with them a variety of topics, including making word and phrasing choices that are truly patient-friendly. LCI's operations staff have also included PFAC members in discussions about new construction, food offerings, and artwork. In addition, the PFAC contributes to creating LCI's oncology service line annual goals.

LCI staff involved with PFAC acknowledge that this type of program can be challenging to embrace. For a PFAC-like committee to help improve operations, members of the committee must be able to "see behind the curtains" of the hospital's operations to be able to make realistic suggestions. Leadership has to support and value PFAC's input, since they ask them to evaluate and endorse or reject the council's recommendations.

Contributing to the success of the PFAC is the presence of an enthusiastic champion/facilitator who helps maintain momentum for the group. Encouraging participants who represent the larger patient/caregiver population (including a diversity of socioeconomic and ethnic backgrounds) to join the council will make it more representative of the patients

served. Providing a more inclusive perspective will lead to increased patient engagement and LCI's PFAC will be better positioned to help keep a wide spectrum of patient needs at the center of treatment.

Engaging a Librarian to Improve Health Literacy

Improving patient health literacy can also play a role in increasing patient engagement in care decisions. When LCI embarked on an effort to standardize care and build a consistent set of patient education resources, PFAC identified the need for a health librarian. Librarians think about how people interact with information, their preferences for accessing it, their ability to access it digitally, and their preferred formats. A librarian's skills can be very valuable to patients and families facing complex clinical information and terminology. Because librarians specialize in information literacy, they are well-suited to help patients access and understand the information they need to make informed decisions about their treatment.

In 2016, LCI hired a health librarian to create a digital library for use across all of LCI's 25 locations, which is available to all LCI staff and includes patient education handouts and links to LCI-approved cancer information websites. The health librarian reviews all of LCI's patient-facing information—including marketing brochures, new visitor policies, and patient education—to ensure materials are written at an appropriate reading level. She also sits on PFAC, where members are often involved in the development of patient resources, and she chairs the oncology patient education committee, which also includes clinicians.

FIGURE 3: Example Questions from Care Alignment Tool, Levine Cancer Institute

CARE ALIGNMENT TOOL

What does the patient/decision maker understand about their medical condition and the natural course of their disease?

What is the patient/decision maker's biggest fear or concern for the future?

Pain and suffering Loss of mental function Other
 Becoming a burden to my family Death
 Loss of physical function No fears or concerns

Would you like to talk about your care goals? Yes No Discussion Time (Minutes)

What is the most important goal for this patient? Longevity Maintenance of function Care focused on comfort

Patient Desires No intubation No CPR No Dialysis No PEG No IV Fluids No antibiotics



Health Literacy

In the ACCC survey, 55 percent of respondents indicated that low health literacy is a factor that leads them to approach shared decision-making in a certain way. The most common adjustments mentioned were using translators or interpreters for non-native English speakers, providing more patient follow-up, and encouraging more involvement of caregivers who have higher health literacy.

However, 41 percent of respondents never formally assess health literacy, and only 28 percent indicated that they always or frequently formally assess their patients. **To assess your program's ability to meet the health information needs of patients, please visit acc-cancer.org/health-literacy.**



Maine Medical Center (MMC) is the state's largest medical center and part of MaineHealth, an integrated health network with locations across Maine and eastern New Hampshire. Maine Medical Center Cancer Institute has a strong multidisciplinary approach to care, with eight disease-specific tumor boards and 11 disease-specific patient navigators. The prostate cancer multidisciplinary team has a particularly strong focus on patient engagement in shared decision-making, making use of a comprehensive set of tools for decision-making and a dedicated genitourinary patient navigator.

Integrating Decision-Making Tools Into the Clinical Workflow

Patient decision aids have been shown to improve communication between physicians and patients, increase patient satisfaction with their decisions, and decrease personal uncertainty about decisions.⁶ However, 59 percent of the respondents to ACCC's member survey indicated that they do not use patient decision aids.

A goal of the MMC is to promote communication among patients and their care teams with its comprehensive collection of publicly available web-based tools. In prostate cancer, these tools include patient decision aids, a tool called a "nomogram" that calculates the likelihood of an outcome, a prediction tool

called a Partin table, and institution-specific quality-of-life outcome statistics that collectively help patients make well-informed decisions. These resources help standardize information for patients across the system, since all patients have access to these tools.

When a cancer has multiple similarly effective treatment options but different possible side effects, such as in the case of early stage prostate cancer, it is particularly important for patients to engage fully in the decision-making process. When patients diagnosed with prostate cancer arrive for their first consultation, physicians use the same web-based tools that are available to the public to lead patients through the decision-making process to arrive at a treatment option. Urologists guide patients using all of these tools, taking time to ensure that patients are satisfied with the choices they make. If patients do not make a treatment decision with their physicians, they have ample time to go through the resources again with a nurse navigator before making a final choice. While it's valuable for patients to be able to access the same information on the cancer center website, the true benefit comes from having physicians and nurse navigators review the information alongside patients to ensure they understand their conditions and feel comfortable with their decisions.

FIGURE 4: Example of Patient Education About Decision Aids

Men diagnosed with prostate cancer have many options. Below are decision aids and calculators that can help estimate your risk for disease spread and recurrence. They will help you understand the potential benefits and harms of different treatments for prostate cancer. They will also prepare you to talk with your doctor about your options. Which tool you use depends on where you are in the stage of your disease and what treatment you have already had.

Pre-Treatment Prediction Tool	Partin Tables	The Agency for Healthcare Research and Quality
This nomogram predicts the extent of the cancer and long-term results following radical prostatectomy (surgery to remove the prostate gland and surrounding lymph nodes).	This tool predicts whether the prostate cancer extends beyond the prostate after surgery.	This decision aid is for you if you have been diagnosed with clinically localized prostate cancer. The information in this decision aid will prepare you to talk with your doctor about your options for treating or monitoring your cancer. The Maine Medical Center Prostate Cancer Program is piloting this tool to assess its usefulness and acceptance among patients.

Maine Medical Center's Prostate Cancer Treatment Decision Aids overview for patients, from <https://www.mainehealth.org/Cancer/Cancer-Conditions/Prostate-Cancer>

For older patients, seeing quality of life outcomes data broken down by age can provide even more textured information. In these circumstances, having discussions with patients about quality of life and personal preferences is important. Depending on a patient's age, there will be different risk statistics regarding erectile dysfunction and urinary function. Understanding this can have a big impact on the patient's chosen course of treatment.

Centering Patient Navigation

The MMC Cancer Institute patient navigation program is designed to be a decision-support program in which nurse navigators are neutral advocates for patients. When patients have a biopsy positive for prostate cancer, they are automatically referred to a nurse navigator. Patients first have consultations with their urologist and then their radiation oncologist, during which time they learn about their diagnosis and are educated about their options. The nurse navigator contacts the patient 24-48 hours after each consultation, giving patients some time to process their treatment options. Patient education is viewed by MMC Cancer Institute as an iterative process that continues until patients have all of the information needed to make a treatment decision.

The nurse navigator's role is multifaceted. In addition to coordinating patient appointments, nurse navigators assess

any barriers to treatment a patient may experience, including issues with insurance, transportation, support systems, food, or anything else that may inhibit a patient from moving forward with treatment. If patients are uninsured, nurse navigators connect them with social workers and/or financial counselors as necessary. Nurse navigators have flexible schedules to help meet the needs of overwhelmed patients who may need support making sense of their diagnosis and options. Calls with patients can last up to an hour. During these conversations, nurse navigators are trained to use the teach-back method, a technique to assess patients' understanding of their situation and their treatment options. Nurse navigators keep track of everyone who opts for ongoing monitoring rather than treatment through the active surveillance program and screen for potential clinical trials for specific patients.

Although the MMC Cancer Institute patient navigation model works well for this medical system, it may not be feasible for smaller hospitals where only one nurse navigator is employed. Being flexible helps. There are many models of patient navigation; what works for one institution may not work for another. Conducting a community assessment can help cancer programs better understand the needs of their specific communities and how to respond to them as necessary.

FIGURE 5: MMC Quality of Life Outcomes Data for Prostate Cancer

RADIATION THERAPY					
Age Group	Average Age	Normal Urinary Function 2 Years After Treatment		Normal Erectile Function 2 Years After Treatment	
		Normal Urinary Function Before Treatment	Abnormal Urinary Function Before Treatment	*RT Alone	*RT with Hormone
<60	56	78% (14/18)	75% (6/8)	67% (8/12)	20% (1/5)
60-69	64	85% (47/55)	63% (25/40)	76% (29/38)	21% (4/19)
70+	73	89% (50/56)	67% (29/43)	61% (14/23)	8% (1/12)

*Includes patients treated with High Dose Rate (HDR) brachytherapy, or Intensity-Modulated Radiation Therapy (IMRT) external beam, or both.

ROBOTIC ASSISTED RADICAL PROSTATECTOMY					
Age Group	Average Age	Normal Urinary Function 2 Years After Treatment	Normal Erectile Function 2 Years After Treatment		
			Bilateral Nerve Sparing	Unilateral Nerve Sparing	No Nerve Sparing
<60	55	86% (249/293)	78% (141/180)	59% (55/94)	25% (1/4)
60-69	64	79% (299/380)	64% (116/180)	45% (50/112)	22% (6/27)
70+	71	65% (48/77)	67% (14/24)	61% (11/25)	0% (0/7)

<https://mainehealth.org/cancer/cancer-conditions/prostate-cancer>

The Role of Nurse and Patient Navigators in Supporting Decision-Making

Nurse and patient navigators play a central role in helping patients with the decision-making process. The Academy of Oncology Nurse and Patient Navigators (AONN+), which partnered with ACCC on this project, invited ACCC to lead two focus groups at their Annual Navigation and Survivorship Conference held from November 7-10, 2019 in Nashville, TN.

Nurse and patient navigators, social workers, and financial navigators comprised 29 percent of survey respondents, and 88 percent indicated that they always or sometimes play an active role in decision-making conversations.

The conversations covered a broad range of topics related to patient engagement in decision-making, the challenges of working with patients, and effective practices in helping patients arrive at fully informed decisions. The focus groups elicited the following insights into how to support patients in the decision-making process:

- Priming patients with small pieces of information early and often can help them become familiar with clinical terms as they arise, which may help them feel less overwhelmed.
"So, you're planting the seeds of what's coming...you are very upfront: 'Not all of this may apply to you, but we may need to be waiting for these markers...before the next step can be made.'"

- Patient education resources are useful, but they should be reviewed with the patient as necessary—not all at once.
"You never give them [patients] a bag of multiple things. You pick out the valuable ones for that one encounter and then you personalize it with the patient."
- Director, Cancer Care Delivery Research (also a nurse)
- When there is only one good treatment option and it needs to start immediately, engaging the patient in other small decisions can help them feel more in control.
"Advocate to let them know they have choices. Empower them to have the choice and let them know you're on their side, even if they want to go to the clinic down the street."
- Oncology patient navigator
- Patients can be fearful of making the wrong choice, which makes thorough and informed shared decision-making even more critical to decreasing decisional regret.
"They're worried they're going to make the wrong decision. 'This is all on me.' It's a burden on them."
- Director, Cancer Care Delivery Research (also a nurse)



Lorna Espinal, MSN, RN, Oncology Patient Navigator, Levine Cancer Institute

UNIVERSITY OF ARIZONA CANCER CENTER TUCSON, AZ



The University of Arizona Cancer Center (UACC) is an NCI-designated Comprehensive Cancer Center and part of the Banner Health System. To better support patient engagement, the UACC Cancer Committee created a streamlined intake process for new patients called the "Living with Cancer" program. New patients meet with intake staff, financial coordinators, nurse navigators, and social workers, who assess patients for any potential barriers to care. Patients also meet with social workers and attend tailored treatment meetings to talk about the potential adverse events of different treatment options. Staff connects patients to the people and resources relevant to the conditions of their specific diagnosis.

Engaging Patients with Metastatic Cancer in Treatment Decisions

Shared decision-making is most relevant when there is more than one medically appropriate treatment to choose from. But in cases of metastatic cancer, there may be only one clearly beneficial treatment option. Nevertheless, patients can be engaged in their care decisions. Having conversations with patients to ensure they understand their diagnosis and help them articulate goals of care is important across all stages of cancer treatment. However, goals of care may change more frequently in metastatic disease compared to early-stage disease. With early-stage cancer, the goal is often a cure. With metastatic cancer, goals may shift depending on the treatment burden and disease progression over time.

There are several strategies that have helped UACC support their patients with metastatic disease. Like all patients, metastatic patients are supported by a team assembled to address their multiple needs. Not only is the physician involved, but the advanced practitioner, nurse navigator, social worker, psychologist, nutritionist, and other clinicians may also be engaged in the process. Hearing the same information from multiple people reinforces consistency of messaging so patients are able to better absorb information and learn to trust their care team.

The UACC team has identified several strategies for promoting effective goals-of-care conversations. Providers should be trained in communication skills, tailor the message to the patient, and allow the patient time to process the information. Having multiple conversations using consistent messaging and helping patients prioritize what is most important to them are key to navigating a patient through a difficult choice.

To fully support patients, UACC also considers the needs of caregivers, who often perform important supportive care functions, including managing appointments, medications, transportation, and more. Often, providers see as much depression in caregivers as in patients, and that depression can interfere with their ability to support the patient in decision-making. It's important, however, to not make assumptions about how involved caregivers are and what conversations they should be involved in. Sometimes patients may want to have a discussion with their care team members privately, and bring in their caregivers afterward. Patients must retain the autonomy to assess and manage who they want involved in their treatment decisions.



"I have patients who will tell me, 'I have a grandkid coming this fall. I want you to do whatever it takes to see if you can keep me going no matter what my quality of life is,' and some who straight up say, 'It doesn't matter, I'm not going to do it no matter what.' And the goals, they change. The grandkid wasn't here two years ago when we started that discussion."

Pavani Chalasani, MD, MPH, Associate Professor, Medicine; Program Director, Hematology and Medical Oncology Fellowship
University of Arizona Cancer Center

While patient engagement in decision-making is important at all stages, less is known about shared decision-making specifically in the metastatic disease setting, where there is often more uncertainty about treatment effectiveness and more concerns about quality of life.⁸

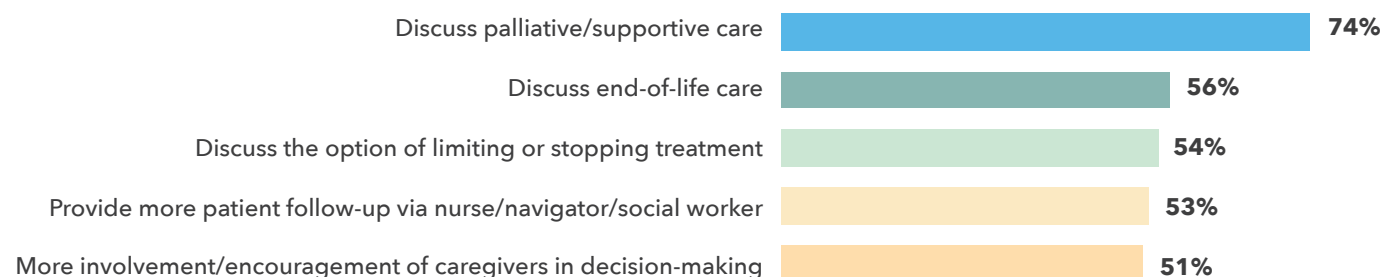
Supporting Patients with Frailty and Comorbidities

In the ACCC survey, respondents indicated that while advanced age (age 80 and older) might lead the team to conduct shared decision-making differently (36 percent), they are more likely to tailor their approach to patients exhibiting frailty (50 percent) and comorbidities (51 percent, generally coinciding with polypharmacy). While frailty and comorbidities are common in older adults, advanced age alone was not perceived by survey respondents as an issue in treatment decision-making. For example, the UACC care team has frequent contact with patients who take more than five medications because they have more issues with adherence, regardless of age. To better identify frail and comorbid patients, and those who take multiple oral medications, UACC has developed a dedicated oral antineoplastic program (OAP). The OAP has a dedicated nurse navigator who uses a tailored barriers assessment tool and a defined algorithm for patient follow-up to prevent, monitor, and mitigate any adverse events. The program also uses a dedicated pharmacy technician to improve access to medications. UACC clinicians report that this program, by working with the expanded interdisciplinary team, has resulted in a reduction in emergency room and urgent care visits.

While chronological age may not have an impact on treatment options, it can affect decision-making conversations. For example, older patients are more likely to have hearing and visual impairments, so UACC care teams use a number of strategies to better accommodate these patients. Care team members strive to keep questions short so patients can focus on what is most important. They ask open-ended questions to dissuade patients from “yes/no” answers. They use the teach-back method to ensure patient understanding, and they

FIGURE 6: Shared Decision-Making in Metastatic Disease

In the ACCC survey, more than 50 percent of respondents indicated that they were more likely to take the following actions with patients with metastatic disease compared to patients with early-stage cancer:



encourage patients to involve family members in their conversations. All these strategies can be helpful for patients with impairments, regardless of age.

Geriatric Populations



Current guidelines recommend conducting a comprehensive geriatric assessment (CGA) on older adults with cancer being considered for chemotherapy. Evidence supports the use of CGAs in older patients receiving other types of treatment as well. ACCC has tools to support cancer program implementation of CGA, no matter the resource level of your institution. The newly released [Geriatric Oncology Gap Assessment](#) allows any member of the care team to assess their team’s educational needs and pinpoint areas where targeted efforts may improve older adult patient care. Complementary publications, “Multidisciplinary Approaches to Caring for Older Adults with Cancer,” and “Practical Application of Geriatric Assessment: A How-To Guide for the Multidisciplinary Care Team” provide detailed suggestions and effective practices to optimize teams caring for older adults.

Considering Cultural Factors in Decision-Making

Patients treated at UACC come from diverse backgrounds that care team members take into account when helping with decision-making. The Un Abrazo Para La Familia (Embracing the Family) program supports caregivers and addresses health literacy concerns in lower-income monolingual Spanish-speaking communities. UACC care team members understand that different family members may take on different caregiver roles, depending on their culture. In the community served by the Abrazo program, for example, breast cancer

caregiver support more frequently comes from a sister or a daughter than a spouse. Asking patients who makes up their support system allows the team to tailor their approach.

Arizona is home to a large indigenous population with 22 Tribal Nations representing more than 300,000 individuals, located primarily within the boundaries of the state. The UACC care team understands the importance of traditional medicine in the Native American communities they serve, and they have found ways to integrate important aspects of that culture into their care. For example, UACC blesses their grounds before building on them to ensure the Native American population feels confident that their culture is valued. Integration of tribal medicine and cultures helps build an environment of trust and respect, which in turn creates the environment needed to foster patient engagement in care decisions.

Cultural differences do not only refer to ethnicity. The UACC team has also worked hard to balance integrative medicine approaches for patients seeking integrated approaches to care or who are skeptical of modern medicine. There is an integrative oncology specialist on the team who works to combine alternative approaches in a complementary way. UACC strives to make it acceptable for patients to talk about alternative approaches, and for the care team to share information and evidence rather than judge. While some people will opt to not pursue conventional treatment, it is important to be able to re-engage with them in a non-judgmental way if they return.



Bilingual Navigation

In 2016, the Levine Cancer Institute received grant funding for a bilingual navigator to support Spanish-speaking patients, English-speaking patients who are more comfortable with Spanish, and patients who have a family member who only speaks Spanish. As a certified medical translator, the bilingual navigator helps patients and families understand their options in real time during their first visit with the doctor. She also helps families with end-of-life conversations by communicating cultural issues and concerns with the healthcare team. Because she is a nurse, her communication is more effective than a translator’s would be. Patients and physicians both report that the service has been extremely helpful.

Building an Organizational Culture that Supports Shared Decision-Making

According to the National Quality Forum, “strong leadership is essential to the success of a healthcare organization’s efforts to integrate shared decision-making as a standard of care across the healthcare continuum”.⁹ Leaders at the programs discussed above have created conditions in which person-centered service initiatives and patient engagement strategies have thrived. At Levine Cancer Institute, executive leaders support system-wide structures that effectively encourage clinical staff and patients to approach decision-making together. At Southern Illinois Healthcare, senior leaders value what the cancer care team is doing to engage patients, and the cancer team feels supported and valued as a result. SIH’s system-wide prioritization of standardized care comes from the managers who support clinicians and other staff with resources when they identify needs. Building an organizational culture that supports shared decision-making requires leadership that empowers staff to identify and lead initiatives they deem critical to patient care.

“Quality metrics and the changes we make to processes come from providers. They identify areas that aren’t working for our patients, and then we sit down to fix it.”

Dana West, Administrative Director, Oncology and Breast Services, Southern Illinois Healthcare

SUMMARY

The ACCC multidisciplinary team survey and site interviews indicate that although shared decision-making and patient engagement are priorities for cancer programs, more can be done to integrate those priorities into practice. Focusing on developing training and tools to overcome barriers, addressing health literacy, supporting psychosocial care for patients, and integrating tools into the clinical workflow will all help further foster patient engagement. Creating effective processes that help patients and providers better communicate and work together to make treatment decisions consistent with the patient's values, preferences, and goals benefits not only patients, but also care team members and the healthcare system overall.



Kris Blackley, RN, MSN, BBA, OCN, Director of Navigation, Levine Cancer Institute

“Ultimately, when a patient is involved in the decisions around their care, not only does it make them more satisfied, when we work together, we can improve compliance which, in turn, leads to better outcomes.”

For more tools and resources on how to use shared decision-making in your cancer program or practice, scan this QR code or go to acc-cancer.org/shared-decision-making.



Strategies for Engaging Patients in Decision-Making

Cancer programs of all sizes and budgets can take steps to improve patient engagement in treatment decision-making. Use these ideas to identify a shared decision-making implementation plan that works for your cancer program's resources and needs.

Easy, First Steps

- Create binders for patients with photos, background, and contact information for all care team members so patients can get to know their care team early.
- Provide a reliable way for patients to get their questions answered through a specific point of contact, such as a navigator.
- Assess barriers to care to determine if there are issues in a patient's life that may interfere with certain treatment options.
- Ask patients questions to invite them to participate in the decision-making process: What do you want your role to be in the decision? Are there others who will help you decide?
- Formally document conversations with patients about treatment goals and preferences in the EHR to ensure all care providers know what the patient wants.
- Encourage patients to use the Institute for Healthcare Improvement's Ask Me 3[®] framework to ask three simple questions every time they talk with a care team member about healthcare decisions.
- Use the teach-back method to assess and build patient understanding of information.
- Develop grand rounds presentations on topics related to engaging patients in decision-making, such as cultural competence, having difficult conversations, and elements of shared decision-making.

Medium, Moving Ahead

- Make high-quality and consistent patient education information available to all patients.
- Use patient education resources designed to address health literacy, such as using plain language, pictures, and diagrams.
- Engage financial navigation from the first patient visit to assess potential financial toxicity and identify available resources to support the patient's treatment options.
- Establish and formalize multiple touchpoints to talk to patients about their goals, values, and preferences.
- Create a form outlining a goals-of-care discussion and integrate it into your EHR.
- Incorporate patient preference discussions into multidisciplinary tumor boards.
- Identify and reach out to local cancer support groups to obtain insight into what patients want or need from your program.
- Develop eLearning modules or continuing education for care team members to learn how to use decision aids and practice shared decision-making skills.

Large, Focused Effort

- Establish a Patient and Family Advisory Council to provide feedback on resources, policies, and operations that impact patients.
- Hire bilingual navigators if there are specific non-English language groups heavily represented in your catchment area.
- Engage a health librarian to develop and/or evaluate patient-facing materials.
- Integrate high-quality patient education information and appropriate decision aids into the clinical workflow to review with patients.
- Create a process to integrate patient feedback into operational changes through regular quality improvement initiatives.
- Systematically evaluate how shared decision-making is being implemented in your cancer program using validated questionnaires like the shared decision-making Q9, which measures patient involvement in decision-making.
- Develop hands-on skills workshops for care team members to practice shared decision-making skills and effective use of decision aids.

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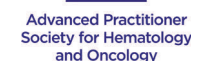
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