BY CHAD SCHAEFFER, MS, FACHE

Talk to Me

Improve patient engagement; improve your cancer program

Patient engagement is a buzz word cancer program administrators are hearing more often as patients become increasingly aware of their ability to choose where they receive healthcare. In most markets, hospitals and physician practices face numerous competitors for healthcare dollars. Cancer care is no different. In fact, because of the acute nature of the disease, more cancer patients are open to seeking second opinions or identifying a specialist who they believe can best take care of their unique needs—even if that means looking for care outside of their community.

By definition, taking care of an individual patient's unique needs requires that healthcare providers actively involve the patient throughout the continuum of care. Today's cancer patients desire more than merely treatment for their disease, they want a cancer program that:

- Includes them in the decision-making process
- Educates them about their treatment options
- Keeps them updated on the progress of their care
- Treats them with a high level of respect and dignity.

The best cancer programs will be those that actively involve patients and their families in all aspects of their care. Indeed, if we are to be successful in competing for these patients, we must fully embrace the concept of patient engagement.

Patient Engagement Defined

The Center for Advancing Health defines patient engagement as "the actions individuals must take to obtain the greatest benefit from the healthcare services available to them."[1] This definition is framed from the patient's perspective. For patients to be "engaged," they must take steps to ensure that they are active participants in their healthcare. Simply put, engagement is an ongoing and mutually beneficial interaction between patients and providers. For this collaboration to occur, the physician and staff at the cancer program must be open and able to spend extra time with patients, as necessary, in order to ensure that patients are truly involved in their care plan. Ultimately, the goal is to develop a shared decision-making approach for each cancer patient and each visit.

Embracing the concept of patient engagement brings many benefits to your cancer program. For example, engaged patients effectively communicate their treatment goals to their providers, which is essential in ensuring that patients' needs are met throughout the course of their therapy. Engaged patients are also more likely to be compliant with scheduling appointments, and following other instructions properly when they are not in clinic (i.e., their oral chemotherapy medicines, other prescriptions, medication schedules, etc.).

Often cancer programs see improvements in patient safety when patients are actively involved in treatment decision making. Specifically, when providers stop and do a "time out" before a procedure—before giving chemotherapy or radiation oncology—they involve patients, affording them an opportunity to prevent a medical error.

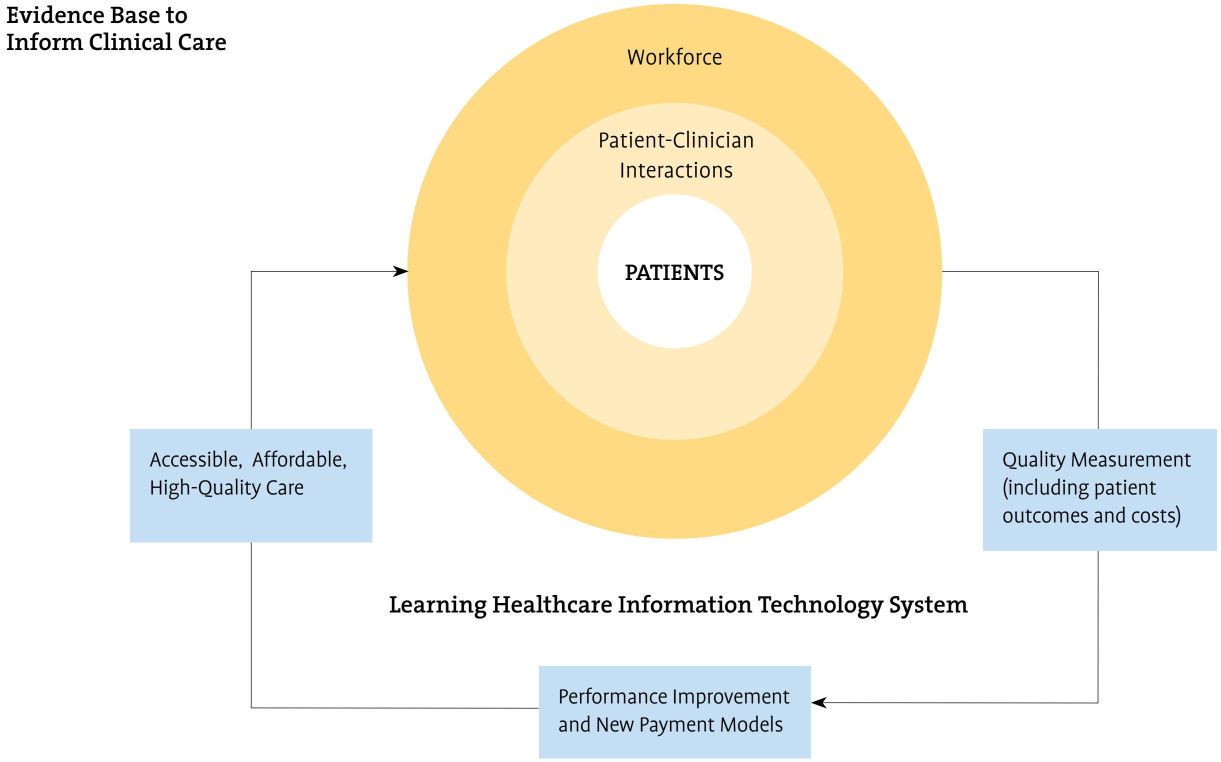
Our Industry's Track Record

Unfortunately, the news is not good when it comes to the healthcare industry's track record for engaging patients. The 2013 Institute of Medicine (IOM) report, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis makes two specific recommendations for cancer care providers concerning patient engagement. First, the cancer care team should provide patients and their families with:[2]

- Understandable information on cancer prognosis
- Treatment benefits and harms
- Palliative care
- Psychosocial support
- Estimates of the total and out-of-pocket costs of cancer care.

Second, in the setting of advanced cancer, the cancer care team should provide patients with end-of-life care consistent with their needs, values, and preferences.[2] However, most cancer programs are not meeting these recommendations with a high degree of consistency. Studies cited in the IOM report suggest that clinicians asked about patients' preferences in medical decisions only about 50 percent of the time.[3] Another study found that 70 to 80 percent of cancer patients with a poor prognosis incorrectly believed that their treatments were likely to result in a cure.[4] Unfortunately, if

Figure 1. The IOM Model for a High-Quality Cancer Care Delivery System



Source: The IOM report, Delivering High-Quality Cancer Care (2013) we were to give a letter grade for the industry's performance as a whole, it would be an "F."

A number of factors contribute to the healthcare industry's poor performance with patient engagement. One is that, historically, third-party payers have been the major source of payment for providers—not patients. However, this situation is rapidly changing in a post-Affordable Care Act (ACA) era that promises more transparency in costs, an increase in pay-for-performance measures, and new technology requirements for providers, such as having electronic health records (EHRs) that meet "Meaningful Use" requirements. That said, it is still difficult for consumers (patients) to find and evaluate quality and cost information on healthcare services.

Getting Started with Patient Engagement

To truly engage your cancer patients, it takes a commitment from everyone in your cancer program. All staff—from the front desk to the C-suite—must share a common vision. This vision must empower staff to always be concerned with providing patient-centered care, making patients the center of all of your daily practices and processes. Figure 1, left, shows the IOM recommendation for a model that has patients in the center with the healthcare workforce surrounding them and patient-staff interaction and communication in the key area in between. Adoption of this model is critical to patient engagement.

The IOM recommendation of this care delivery model is a paradigm shift for many hospitals and physician practices, which often have a physician-centric or staff-centric model. For instance, when establishing a physician clinic, typically the physician has the final say on the schedule, how operations will be staffed, and how services will be provided. In a patient-centered model, completely different choices may be made. In other words, what's convenient for the hospital staff or physician staff might be inconvenient for the patient. Cancer programs that make the decision to stay open later during the week or open on the weekend to accommodate working patients and caregivers are putting patient convenience before provider convenience.

With the understanding that patient engagement is not just a "flavor of the month" strategy, but a real commitment and effort that must be made throughout the cancer program, the following are some steps to help you get started on your journey of increasing patient engagement in your cancer center.

Make patient engagement a major part of your strategic plan. As part of your next strategic planning, take a hard look at your current program and identify opportunities to improve patient engagement. Have patients at the table early and often during the planning process, with a continuous feedback loop post-planning. To kick-start your planning, you might consider having a patient-engagement retreat where physicians, staff, and possibly board members can learn about some of the best practices to engage your cancer patients. During the retreat you might look at your cancer program's vision statement and consider refining it to include patient engagement and/or patient-centered care.

Monica Littlejohn, RN, with a pediatric cancer patient.

Designate a few staff and physicians as "patient engagement champions." In addition to leaders who are well-respected cancer program staff, cancer patients should also serve as champions of the patient engagement initiative. Such champions are important to build support and buy-in from others.

Review IOM recommendations for steps needed to better engage cancer patients. The IOM provides tactics to accomplish stated goals for patient engagement. These include:

- Improving decision aids and making them available through print, electronic, and social media.
- Providing professional educational programs for members of the cancer care team that include comprehensive and formal training in communication. The cancer care team should communicate and personalize this information for patients at key decision points along the continuum of cancer care, using decision aids when available.
- Improving communication with patients with advanced cancer. Clinicians should discuss option with these patients, including conversations about advance care plans, palliative care, psychosocial support, and maximizing quality of life (QOL) by providing timely use of hospice care. The IOM points out that

these difficult conversations do not occur as frequently or in as timely a manner as they should, resulting in care that may not be aligned with patient preferences.

- Ensuring members of the cancer care team receive education and formal training in end-of-life communication.
- Evaluating and potentially improving the current process for handling patients' advance care plans.
- Evaluating and potentially improving the current process for providing cancer patients with palliative care, psychosocial support, and timely referral to hospice care for end-of-life care.

Process mapping the patient (customer) experience. Mapping the steps that patients go through when accessing care at your cancer program helps in understanding not only how patients interact with staff, but also opportunities for improvement. Process mapping also helps you identify current gaps in the patient-engagement "ecosystem" and develop tactics to plug these gaps.

Creating an Engagement Ecosystem

The following are some potential areas that offer a chance to interact and engage with your patients. To be successful, your cancer program needs to explore every area that provides an opportunity for better communication with your patients.

Adopt a shared decision-making approach. According to the National Cancer Institute (NCI), patient-clinician communication plays an important role in optimizing the health outcomes for people who have or have had cancer. More support for this approach comes from a 2014 IOM report that describes shared decision making as a three-phase process:[5]

1. Information exchange
2. Deliberation
3. Reaching final decision.

The decision often extends beyond medical issues, and includes factors such as finances and the impact on employment and family.[5] Shared decision making may be a shift for many providers that tend to make decisions on behalf of their patients and typically do not take into consideration the patient's own preferences. This "paternal" model of physician-patient interaction is still highly prevalent throughout the U.S. and is clearly a barrier to effective patient engagement. For patients who face a number of treatment choices, use of decision-making tools may help improve patient engagement.

Introduce the entire care team early in the treatment process. For all new patients, establish up-front appointments with a financial counselor, social worker, and patient navigator. Patients should have contact information for these providers to easily reach them when they have questions during their course of therapy. As appropriate, additional appointments with dietitians, palliative care staff, chaplains and/or spiritual counselors, lymphedema therapists, and/or other supportive care services should be made.

Provide effective patient education. Patients get treatment information in a variety of ways. Patients can only absorb so much information during initial visits with their nurse and/or physician. While nothing equals actual face-to-face education, clinicians can use a number of other methods to reinforce the teaching and education that is provided in the clinic setting, including:

- Vetted print materials and online tools
- New patient classes
- Chemotherapy patient classes
- Video orientation
- Family and/or caregiver education classes.

If materials are available on your cancer program's website or on a patient portal, they can be viewed at any time, so patients can revisit the information as needed.

Encourage patient involvement with safety and error prevention. A very basic example of engaging patients in their own safety occurs prior to treatment, when patients are asked to verify their identity prior to treatment. However, you may want to consider involving patients and/or caregivers in other areas.

For example, ask patients for their assistance in monitoring physicians and other staff with hand hygiene practices. Our protocol is for providers to wash hands immediately upon entering exam rooms. If patients are aware of this practice, they can gently remind providers if they forget this safety step. This way, patients are involved in their own safety. Another safety area that patients can help with is a time-out procedure, which is recommended by The Joint Commission's Speak Up™ Program. Time-outs are usually done prior to surgery or certain procedures. The American College of Radiology's radiation oncology accreditation staff recommends that a time-out occur prior to the patient receiving radiation therapy treatments, and that patients be asked what site is to be treated.

Develop an up-front care plan. The American Society of Clinical Oncology's Quality Oncology Practice Initiative (QOPI) encourages a care plan that clearly states the patient's diagnosis, stage, recommended treatment plan, major side-effects of the regimen, and whether or not the regimen is for curative or palliative intent. This plan should be discussed with patients to ensure that they have a good understanding prior to chemotherapy. This information should be also included on the consent form. When developing this care plan, you may want to consider these findings from a national survey of older adults with chronic illness: 74 percent of respondents did not want treatment if it would cause functional impairment, and 88 percent did not want treatment if it would cause cognitive impairment, regardless of the impact on survival.[6]

Implement survivorship program components. Survivorship care planning, which is a service line offering at most cancer programs due to Commission on Cancer (CoC) requirements that went into effect in 2015, can help engage your cancer patients. Two key components of a survivorship program include developing a treatment summary for patients at the end of treatments and developing an ongoing surveillance plan for follow-up care. Both of these can serve to increase patient involvement and knowledge about the care they have received and the importance of returning to the cancer program to monitor for any recurrence of cancer. At some cancer programs, a survivorship coordinator not only provides "new" patient handbooks with information about specific cancers, common treatments, and supportive care services that might be needed during the treatment but also reviews treatment plans. Still other cancer programs have developed survivorship clinics managed by physicians and/or mid-level providers. All of these approaches are excellent for engaging patients.

Offer support and activity groups. Support groups and peer-to-peer programs are important for patients who may benefit from interacting with others going through (or who have gone through) a similar experience. If your cancer program can host or promote these types of programs, they can be very beneficial for patients and possibly lead to better outcomes.

Another area that can be sometimes overlooked is the formation of activity groups. Our cancer program partners with a local museum in a program called Arts in Medicine, whereby, the museum arranges for an art instructor to visit the infusion area for several hours each week. The art instructor provides materials and ideas for patients to do arts and crafts activities while they are receiving treatments. Patient response to this new program has been overwhelmingly positive.

The Arts in Medicine Program is a partnership between ECCC and the Huntington Museum of Art.

Use technology to engage patients. Many hospitals and practices are already using technology to help patients. Some offer online appointment scheduling; others have patient portals that offer two-way messaging with a patient's care team and/or allow patients to see lab or imaging results. In some cancer programs, patients use hand-held notebooks or pads to register, sign consent forms, receive patient education, or simply access entertainment.

Social media can be used to promote cancer screenings, health fairs, support groups, and community events.

Form a Patient and Family Advisory Council. If your cancer program doesn't already have one, a Patient and Family Advisory Council can help guide all aspects of your program. This council can serve as a barometer, helping your cancer program improve and monitor the progress with patient engagement. Our cancer program formed a Patient and Family Advisory Council in 2013, and it has made a tremendous improvement in our patient engagement. Below we share benefits realized through our Patient and Family Advisory Council, including lessons learned from the experience.

A Deeper Dive into a Patient and Family Advisory Council

Our journey to implementing a Patient and Family Advisory Council began in February 2013. Initially our council consisted of eight patients and two cancer center managers. We wanted patients and family members that mirrored our patient population, including representation from pediatric oncology, lung, breast, colon, and GYN oncology—our top disease sites. We also wanted the council to be a mix of patients in various stages of treatment—active and follow-up. Most of the council members were nominated by staff members and voted on by management. One member was recruited from the waiting area because he offered some good suggestions on improving signage; he turned out to be the council's first Chair.

At our first meeting, we adopted by-laws, which outlined the purpose of the council, membership requirements, meeting frequency, confidentiality issues, and decision and quorum requirements. We found the Institute for Patient and Family-Centered Care (ipfcc.org/) to be an excellent resource for helping a cancer program establish a Patient and Family Advisory Council. Council member responsibilities included:

- Attending scheduled meetings
- Participating to the fullest extent possible during each meeting
- Participating, as time and interest allow, on additional committees and taskforces
- Embracing the Mission, Vision, and Values of the cancer program, the hospital, and the Patient and Family Advisory Council
- Advocating the concepts of patient-family-centered care.

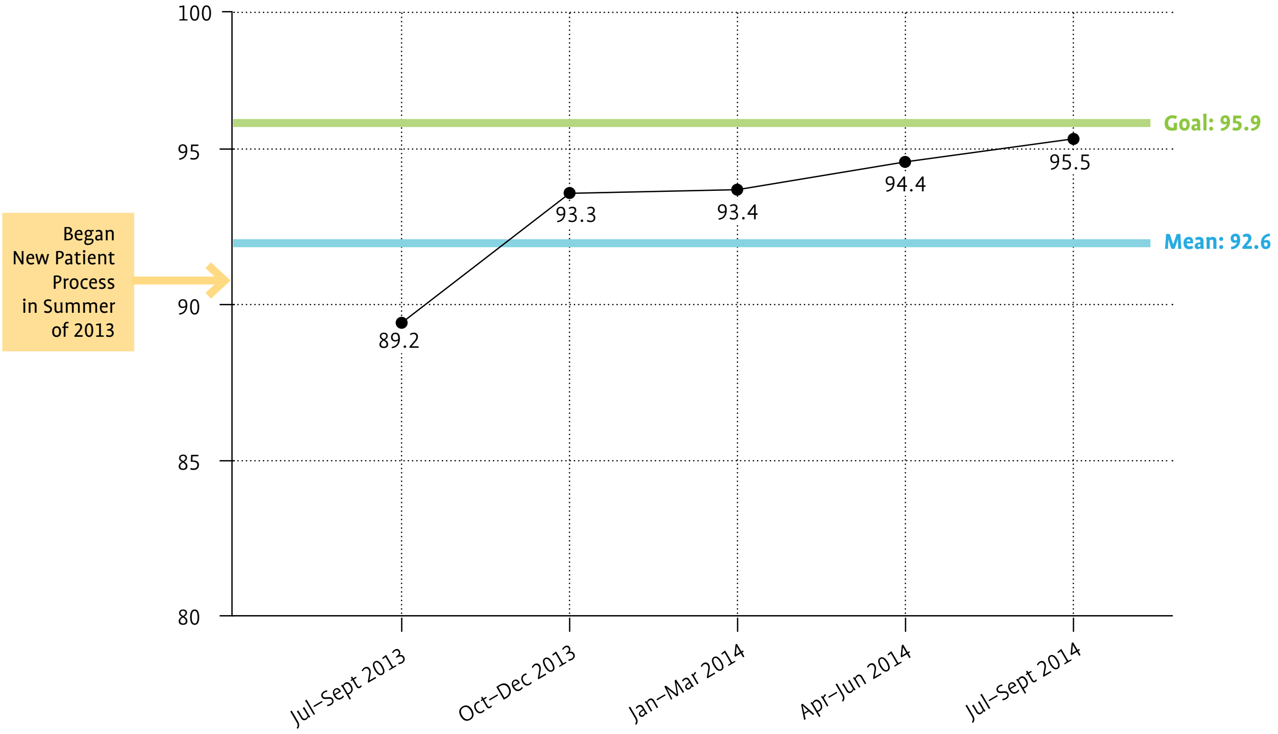
The first time the council met, we structured the meeting as an orientation so that the members learned about our cancer program, including its components, strengths, and opportunities for improvement. We wanted to be sure that the Patient and Family Advisory Council had all the information necessary to help the program improve its patient services.

Once established, the Patient and Family Advisory Council started by evaluating our supportive care offerings, but we soon learned that the Patient and Family Advisory Council had important input on almost every aspect of our program. For example, the council weighed in on what channels are most appropriate for the TV waiting areas, and what kind of food should be available in the chemotherapy infusion area. The cancer program's marketing department met with the Patient and Family Advisory Council to poll members on which marketing messages geared toward cancer screenings would resonate best with the general public. The council helped the cancer program review its educational videos and with planning its annual 5K run/walk fundraiser.

During its first year, the Patient and Family Advisory Council worked with the cancer program on one major goal—improving our patient satisfaction scores. This process involved asking council members to answer Press Ganey survey questions, including providing feedback about each answer. During that meeting, our cancer program made a major finding. Up until that night, we had always thought that we did a great job with our patients, and—for the most part—the Patient and Family Advisory Council confirmed that we did, once a patient was established. We learned, however, that our new patient process was not working. Almost

The Patient and Family Advisory Council at Edwards Comprehensive Cancer Center.

Figure 2. Press Ganey Patient Satisfaction Scores



every single council member agreed and some were even still upset about the new patient on-boarding process. This feedback hit us like a ton of bricks. We knew that our new patient processes had to change, and the Patient and Family Advisory Council was going to help us in this effort.

Based on the council's feedback, our cancer program decided to completely redesign its new patient process. After a deep-dive into every aspect of how new patients are on-boarded, we implemented a more user-friendly process that required pre-registration. Welcome kits were sent to the patient's home, and we also made new patient forms available online. Even before the first visit, our medical assistants and/or nurses now call patients to answer questions and welcome them.

Based on Patient and Family Advisory Council feedback, we added additional dedicated parking for the cancer center. For those patients who use the valet service, we instructed staff to call the valet service for them at the end of an appointment, so that their car would be retrieved while they exited the cancer center.

We created new signage specifically for new patients and, as needed, nurses began to call patients at home after their first visit to follow-up and ask if they had additional questions that were not answered while at the center. We tasked staff to be extra sensitive to patients who came to their first visit without a diagnosis to help ease their anxiety and fears. All of these initiatives really paid off in terms of our Press Ganey scores. We moved immediately in the right direction and reached our goal in about 12 months (Figure 2, above). (The primary goal was to improve our patients' overall experience when visiting our cancer center; our measureable goal was to reach a Press Ganey patient satisfaction score of 95 percent or higher. Prior to the formation of the Patient and Family Advisory Council, our scores were hovering just below 90 percent.)

The Patient and Family Advisory Council is now helping our cancer program monitor our quality improvement (QI) programs, while continuing to work on patient satisfaction. This past month, we installed suggestion/comment boxes throughout the cancer center, inviting patients to contact the Patient and Family Advisory Council directly with any comments, questions, or concerns.

Patient Engagement Key Success Factors

For your cancer program or oncology practice to make significant improvements in patient engagement, you must have a high level of support from everyone in your organization. It is critical that there is institution- or practice-wide commitment from leadership, as well as staff. You must have physician champions who can help to influence the patient engagement behaviors of your medical staff. It is also important to note that the cancer program must properly budget for any proposed or new initiatives. Finally, keep

OUR PROGRAM AT-A-GLANCE

The Edwards Comprehensive Cancer Center (ECCC) at Cabell Huntington Hospital – Huntington, W.Va., is a 70,000-square-foot facility that houses an adult oncology center with infusion stations; medical and surgical oncology exam and consultation rooms; minor procedure rooms; a diagnostic breast center and physician offices; and a children's oncology and hematology treatment center with infusion stations, pediatric oncology clinics, and physician offices. Each year the cancer program sees about 1,000 new cancer cases and has approximately 70,000 patient visits. ECCC offers patients state-of-the-art cancer treatment, including PET/CT scanning, image-guided radiation therapy (IGRT), 3D mammography, stereotactic breast biopsy, and the da Vinci® Surgical System. Services include:

- Breast Oncology
- Cancer Risk Assessment
- Clinical Trials
- Colorectal Cancer Program
- Comprehensive Lung Nodule Program
- Genetic Testing/Board Certified Genetics NP
- Gynecologic Oncology
- Medical Oncology
- Multidisciplinary Lung Cancer Program
- Neuro-Oncology
- Orthopedic Oncology
- Pediatric Oncology
- Radiation Oncology
- Fellowship-Trained Surgical Oncologist
- Survivorship Program
- Urologic Oncology.

On the third floor is the Charles H. McKown, Jr., MD, Translational Genomic Research Institute (TGRI), which allows scientists to work in close proximity to clinicians, fostering collaboration and improving bench to bedside treatments. This facility supports the Marshall University Joan C. Edwards School of Medicine and clinical researchers by enabling them to conduct a greater number of investigator-initiated clinical trials and rapidly translate genome-based laboratory research into clinical applications that will improve patient care.

in mind, that developing a Patient and Family Advisory Council is a long journey—not a quick-fix solution. If done right, the Patient and Family Advisory Council should feel like a permanent culture change and not just the implementation of one or two initiatives.

While the pathway to better patient engagement is not an easy one, the benefits of caring for engaged patients will far outweigh the time and cost. Most important, your patients will thank you!

Chad Schaeffer, MS, FACHE, is executive director, at the Edwards Comprehensive Cancer Center at Cabell Huntington Hospital – Huntington, W.Va.

References

1. Center for Advancing Health. Engagement Behavior Framework. Available online at: cfah.org/engagement/research/engagement-behavior-framework#participate. Last accessed Nov. 16, 2015.

2. IOM. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Washington, D.C. The National Academies Press; 2013.

3. Lee C, et al. Decision making about surgery for early-stage breast cancer. *J Am Coll Surgeons*. 2012;214(1):1-10.

4. Weeks JC, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367:1616-1625.

5. Alston C, et al. 2014. Shared Decision-Making Strategies for Best Care: Patient Decision Aids. Discussion Paper, Institute of Medicine, Washington, D.C. Available online at: http://nam.edu/perspectives-2014-shared-decision-making-strategies-for-best-care-patient-decision-aids/. Last accessed Nov. 16, 2015.

6. Fried TR, et al. Understanding the treatment preferences of seriously ill patients. *N Engl J Med*. 2002;346(14):1061-1066.