

ASSOCIATION OF COMMUNITY  
CANCER CENTERS

# HEALTH LITERACY: FROM ASSESSMENT TO ACTION

ASSESS & IMPROVE HEALTH LITERACY  
AT YOUR CANCER PROGRAM



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# Acknowledgments

Funding and support provided by Lilly Oncology



Thank you to the project's Advisory Committee and partner organizations that came together to inform this work.

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### A special thanks to:

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# Introduction



Does your cancer program have tools and strategies in place to ensure that patients understand the health information you give them? Does your cancer program meet the attributes of a health literate healthcare organization as described by the National Academies of Sciences, Engineering, and Medicine (NASEM) (formerly named the Institute of Medicine) Roundtable on Health Literacy? The Association of Community Cancer Centers (ACCC) has developed an online health literacy gap assessment tool available at [acc-cancer.org/health-literacy](http://acc-cancer.org/health-literacy) to help you and your cancer program answer these and other questions about institutional health literacy.

**“It is important for healthcare professionals to be aware that low health literacy can affect anyone, even those with a college degree or a career in healthcare.”**

The ACCC health literacy gap assessment tool is part of a larger ACCC education initiative, “Let’s Be Clear: Communicating to Improve the Cancer Patient Experience.” This initiative seeks to boost health literacy awareness among cancer care providers to improve communication with patients and caregivers about cancer diagnosis, treatment plans, survivorship care plans, and follow-up. Achieving these goals will ultimately improve patients’ experience of care and help them to more fully participate in their care and in shared decision-making.

## Health Literacy Matters

According to the U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, approximately 90 million adults have trouble understanding or acting on healthcare information<sup>1</sup> and only 12 percent

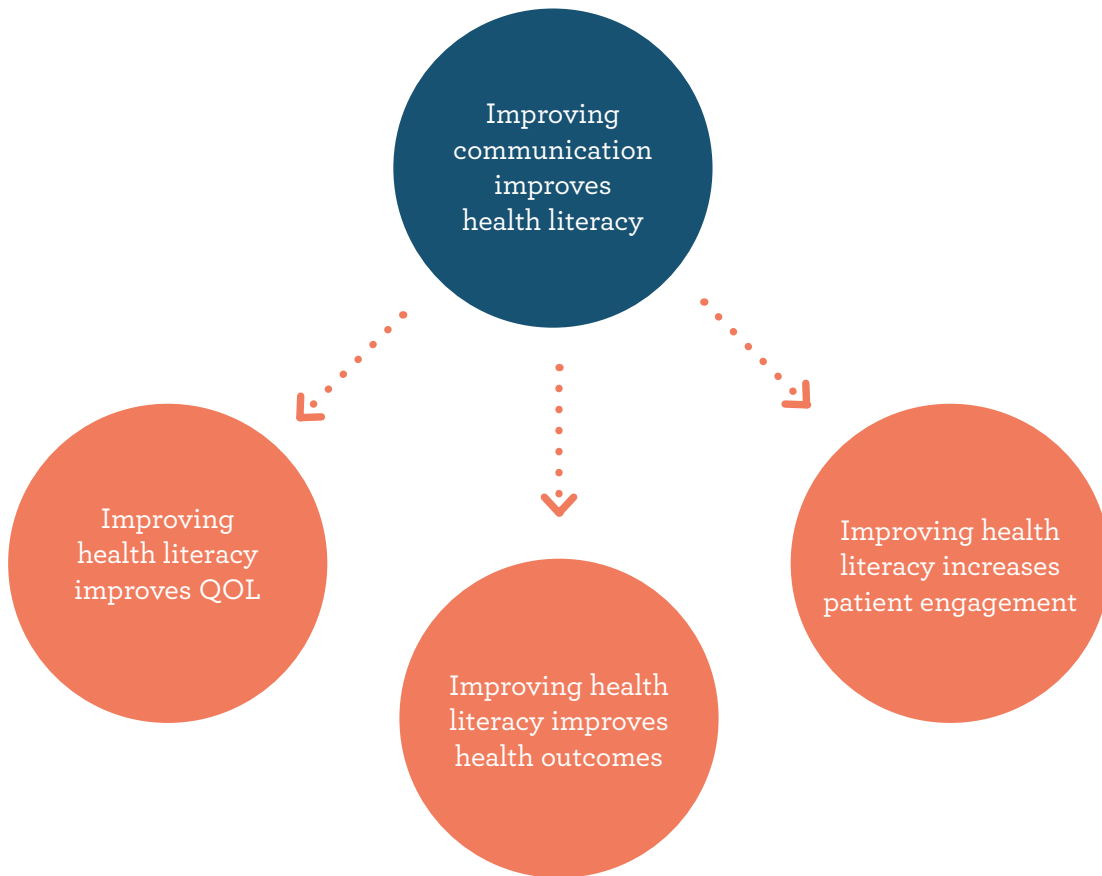
of U.S. adults have proficient health literacy.<sup>2</sup> The Agency for Healthcare Research and Quality (AHRQ) and the National Academies of Sciences, Engineering, and Medicine [formerly, the Institute of Medicine (IOM)]<sup>1</sup> define health literacy as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Although inadequate health literacy skills are common, they often go unrecognized by members of the cancer care team. Cancer programs serve a diverse patient population with varying health literacy needs. Some individuals at risk for low health literacy may be easier to identify:

- Non-English speaking patients
- Elderly patients with hearing and/or vision loss
- Patients with cognitive impairment
- Patients with lower education.

However, it is important for healthcare professionals to be aware that low health literacy can affect anyone, even those with a college degree or a career in healthcare.

As the U.S. population becomes increasingly diverse, the cancer care providers’ attention to health literacy proficiency must evolve to meet patient needs. By 2055, the U.S. will no longer have a single ethnic or racial majority.<sup>3</sup> At the same time, cancer treatments are becoming increasingly complex. The trend toward oral oncolytics means that more patients are self-administering their anti-cancer medications, which can be a cause of concern for cancer programs, especially in patients with low health literacy. In some instances, patients are living with cancer as a chronic disease, which requires even more long-term follow-up and communication.

Improved health literacy has been linked to improved patient outcomes and quality of life (QOL) and reduced



medical errors and hospitalizations.<sup>4</sup> Health literacy can impact cancer prevention as improved health literacy increases participation in healthy lifestyle choices and cancer screening.<sup>5</sup> In addition, higher health literacy improves cancer survivor patient engagement which may improve emotional health.<sup>6</sup> Not only does health literacy improve patient centeredness of care and individual patient outcomes, but health literacy initiatives are also relevant to accreditation standards and quality oncology care models.

Patients diagnosed with cancer are asked to share in complex decision-making about cancer treatments with potentially life-altering complications at one of the most vulnerable times in their lives. For these patients, health literacy can fluctuate with fatigue, fear, and symptoms—meaning that over the continuum of care even reasonably health

literate individuals are likely to be at risk for misunderstanding critical information, such as medication instructions.

Although many cancer programs have made significant headway in providing patient-friendly materials, organizational awareness of health literacy related to cancer diagnosis, treatment, and post-treatment follow-up requires on-going attention.

Since the development of AHRQ health literacy universal precautions in 2011, there has been steady improvement in health literate care and communication, but not to the extent needed.<sup>7</sup> An analysis of U.S. data on health literate programs found that over two-thirds of surveyed patients did not have their understanding of information checked with teach-back instructions and only 17 percent were always offered help with forms.<sup>7</sup>

# Health Literacy Gap Assessment Tool



The ACCC Health Literacy gap assessment tool is designed to help cancer programs and oncology practices evaluate their current efforts, prioritize steps for improvement, and help cancer programs “re-think” health literacy. To initiate this project, ACCC reached out to cancer survivorship and health literacy subject matter experts and organizations to form a multidisciplinary advisory committee. Members of the advisory committee guided and commented on several drafts of the gap assessment tool, with particular focus on defining the different levels within each of the tool’s domains.

The tool comprises six assessment domains, each consisting of 5 levels—from no/basic care for health literacy (Level 1) to best practice health literate organization (Level 5). The tool is intended to raise awareness and guide self improvement—not to provide a pass/fail score or grade.

## Domain 1

**Health Literacy Program** (8 questions)

## Domain 2

**Staff Training** (6 questions)

## Domain 3

**Health Information** (12 questions)

## Domain 4

**Navigation** (9 questions)

## Domain 5

**Technology** (6 questions)

## Domain 6

**Quality Measurement and Improvement** (4 questions)

The tool can be completed by any member of the team and can assess an entire cancer program or a specific disease-site area or service line. Three ACCC member programs were selected to pilot the tool—a single campus (Texas Oncology-Presbyterian Cancer Center Dallas), a flagship cancer center with multiple sites (Florida Hospital Memorial Medical Center Cancer Institute), and a large healthcare organization (Duke Cancer Network and Duke Cancer Institute). ACCC project team members conducted site visits to each of the pilot programs to interview selected staff members to better understand the organization’s health literacy need and their experience with the health literacy gap assessment tool. The on-site discussions focused on four areas:

**Importance of health literacy**—reasons for choosing health literacy as an initiative

**Gap Assessment Tool**—lessons learned from completing the assessment

**Planned changes**—area or focus for change based on gap assessment results

**Support needed**—resources needed to help support the desired change.

Learn more about the pilot sites, how they implemented the assessment tool, and what they learned from using the tool on pages 8-13.



# How to Use the Tool



This tool's domains incorporate the NASEM Roundtable's 10 attributes of a health literate healthcare organization listed below. Keep in mind that these attributes are aspirational. The Roundtable workshop summary notes that "becoming a health literate organization is a process and achieving each attribute moves the organization along the continuum closer to becoming a health literate organization."

- 1 Has leadership that makes health literacy integral to its mission, structure, and operations.
- 2 Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
- 3 Prepares the workforce to be health literate and monitors progress.
- 4 Includes populations served in the design, implementation, and evaluation of health information and services.
- 5 Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
- 6 Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
- 7 Provides easy access to health information and services and navigation assistance.
- 8 Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
- 9 Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
- 10 Communicates clearly what health plans cover and what individuals will have to pay for services.

## Step 1

Complete the online health literacy gap assessment at [acc-cancer.org/health-literacy](https://acc-cancer.org/health-literacy).

## Step 2

Receive your confidential gap assessment results. ACCC will immediately email your confidential report to a designated individual at your organization. The report will include scores that reflect the level at which your program is performing in each of the six domain areas, as well as a detailed breakdown of each score. Results are not shared with anyone except the designated individual at your program.

## Step 3

Use assessment results. Identify an achievable target level in one or more assessment area(s). Use the tool to customize short- and long-term goals for improvement. Goals can be tailored to accommodate cancer program-specific factors, such as administrative/leadership support, resources, and programmatic priorities. Keep in mind that, depending on the assessment area, Level 5 will be attainable for some programs and aspirational for others. While each assessment area is evaluated individually, as your cancer program begins to develop effective practices in one area, you will likely find that improvement in a single area often depends on a simultaneous improvement in other areas.

## Step 4

Use the post-assessment resource page at [acc-cancer.org/health-literacy](https://acc-cancer.org/health-literacy) for information and links to resources and tools to support your cancer program's health literacy improvement efforts.

## Questions?

Contact ACCC at [resources@acc-cancer.org](mailto:resources@acc-cancer.org).

# The Gap Assessment in Practice: Case Studies

Three ACCC member programs were invited to participate in the ACCC health literacy initiative to help the association, its membership, and other organizations better understand how the gap assessment tool and companion resources can impact the cancer program, care team members, and patients. Each program completed the gap assessment and then participated in a live focus group discussion with health literacy key stakeholders from their multidisciplinary team and representatives from ACCC. For a complete list of focus group participants, see page 2.

The following cancer programs served as case study sites:

- Texas Oncology-Presbyterian Cancer Center and Cancer Support Community North Texas, Dallas, Texas
- Florida Hospital Memorial Medical Center and Florida Cancer Specialists, Daytona Beach, Florida
- Duke Cancer Institute and Duke Cancer Network, Durham, North Carolina

These sites represent a range of practice sizes, geographic locations, patient demographics, and other key variables. While each cancer program had unique components, all case study sites shared a common goal: to improve the cancer patient experience through health literate communication.

## Texas Oncology-Presbyterian Cancer Center Dallas

Texas Oncology-Presbyterian Cancer Center Dallas is located in North Dallas in an area with an affluent, well-educated population. Outpatient services are provided by Texas Oncology, a large community-based practice with more than 175 sites of service and 420 physicians. Inpatient care is delivered at Texas Health Presbyterian Hospital Dallas, an 866-bed facility. Psychosocial support is offered free of charge through Cancer Support Community North Texas. Thus, cancer services are provided by three separate entities on one campus; however, from the patient perspective, care is seamless.

### Population and Health Literacy Needs

Although this cancer center is located in a middle-class area, the team emphasized that they cannot make assumptions of health literacy even among wealthier, more educated patients. “Even people with a master’s degree can misunderstand medical information—when it comes to health words. Also, they are reading everything on the Internet and their friends in social circles are influential,” commented Nishia Livingston, Dallas County Program Manager, Cancer Support Community North Texas. Approximately 12 to 14 percent of the population is Spanish speaking and many individuals are bilingual. The cancer program has adequate translator services; however, through the gap assessment the team identified a need for more information and educational resources in Spanish and, in particular, materials with more pictures. The team also recognized that regardless of health literacy, people have different preferred learning styles, for example, auditory, visual, online, etc., or that encompass other methods of teaching.

Each patient is introduced to Cancer Support Community North Texas and its services, which not only include licensed professional counselors, resources, and education but also the Option to Options program. This research-proven program helps patients prepare a list of questions and/or concerns to share with their provider. The program also asks patients to describe their diagnosis in their own words. Patient can then take their descriptions back to their care team for confirmation or clarification. Further, Cancer Support Community counselors help identify patient’s health literacy level (low and high) and any specific or unique educational needs through

their one-to-one interactions and ongoing assessments during their many group and educational activities.

At Texas Oncology-Presbyterian Cancer Center Dallas, in the outpatient setting, the care team most often discuss and address patient needs during morning multidisciplinary huddles that are part of the program's Oncology Care Model (OCM) participation. One step that has improved communication between the patient and outpatient team is implementation of a wallet card. The card has the name and phone number for the patient's physician, a drug list, and information on when to call the cancer center immediately. This card is particularly helpful if patients are going out of town or are seen by a provider who is not currently involved in their cancer care.

In the inpatient setting, health literacy needs are often assessed by a masters-prepared clinician, who typically follows a caseload of up to 15 patients. Hospitalized patients present unique challenges which may affect their ability to obtain and understand information, particularly when it comes to discharge and follow-up instructions. As in most inpatient settings, only minimal health literacy assessment questions appear in the EMR (e.g., highest level of education, primary language), which do not adequately assess or communicate health literacy. The clinical nurse leader helps the team with anticipating patients' needs and assessing their understanding of discharge and medication instructions to help minimize readmissions and medication errors.

### Reaction to Gap Assessment Tool Results

Leadership in all three service areas (inpatient, outpatient, and support services) completed the assessment and, not surprisingly, the results differed by service area. The tool provided perspective on where gaps exist and how these differ among the areas. "Our score was shocking. We don't know what we don't know," commented Margaret Rhoads, RN. Focus group participants believe that many of their higher scores correlated with OCM requirements. "Some of the things we are doing are directly because of OCM," said Rhoads, for example, providing enhanced navigation services, treatment cost estimates for patients, triage management, and adherence to the OCM's 13-point care plan.

The team recognized that numeracy and computer literacy add another layer of complexity to health literacy, and they reported that the gap assessment tool helped raise their awareness of these components. "Although we have patient benefits representatives, at least one company requires the



patient to complete the form instead of the representative," commented Jackeline Castillo, LMSW. "So, we often have to assist the patient with the form or it does not get completed."

Some of the areas the cancer center would like to change [to enhance health literacy] are cost prohibitive, e.g., the cancer center's website. Another challenge that the inpatient services area anticipates in implementing health literacy change relates to organizational structure. As part of Texas Health Resources, a large network with 24 hospitals in the Dallas-Fort Worth metroplex, Texas Oncology-Presbyterian Cancer Center faces multiple layers of review and approval to make a change within the system.

### Next Steps

- 1 The Cancer Committee provides a platform that links all three service areas: inpatient, outpatient, support. Gap assessment results will be shared as the committee formulates goals for 2018.
- 2 Cancer Support Community North Texas applied for a Cancer Prevention Research Institute of Texas (CRPIT) grant to be more responsive to the health literacy needs of both those at risk of cancer and cancer survivors. Whether the grant funding is approved or not, it plans to implement health literacy training for its staff at all locations: Dallas County, Collin County, and Tarrant County. Using a "train the trainer" model, health literacy training will then be expanded to their partners and providers.

## Florida Hospital Memorial Medical Center Cancer Institute

Florida Hospital Memorial Medical Center Cancer Institute includes a partnership between Florida Hospital Memorial Medical Center and Florida Cancer Specialists and Research Institute. Located in Daytona Beach, the cancer center is the flagship of the Florida Hospital system and is one of the largest facilities in central Florida. Outpatient medical oncology care is provided by Florida Cancer Specialists, which has nearly 100 locations in Florida, comprising the largest independent medical oncology and hematology practice in the U.S.

### Population and Health Literacy Needs

Due to their location, many patients are “snow bird” retirees migrating to the area, largely from the Northeast, during the colder-weather months and then returning home for rest of the year. As a result, while the cancer center’s patient volume fluctuates significantly, the population includes more elderly patients with comorbidities, including hearing and vision changes, and potential safety concerns, such as an increased risk for falls and medication errors. Some patients within this cohort do not wish to participate in shared

decision-making and simply defer to the medical expertise of their health provider; others have become accustomed to the abundant choices of healthcare facilities and providers they enjoy at home. The coordination of care is critical to the delivery of cancer care to these “seasonal” patients as they transition between their Florida providers and providers at their home base.

During the focus group discussion, participants from this cancer program explained that they were strategically preparing for a massive influx of patients from Puerto Rico as a result of Hurricane Maria. At the time the focus group was held, initial conversations were taking place between Florida Hospital care sites to assess the scope of the issue and potential impact before implementing a plan of action. Overall estimates were that 86,000 displaced persons had moved into their county, with the Federal Qualified Health Clinic seeing approximately 500 new patients a day. Among the cancer center’s current patient population are some individuals who speak Spanish as their primary language, and the cancer program anticipated seeing an increase in this number due to the change in population.

Insurance coverage is a challenge that comes with serving the elderly “snow-bird,” population, with more issues arising during open enrollment periods and when new deductibles go into effect. Care coordination is essential for



a smooth transition in patient care between the patients' northern home base and their winter Florida residence—e.g., getting medical records, reviewing, and preparing summaries for their return home. The cancer center anticipated even more hurdles with the expected volume of new patients from Puerto Rico. Not only could this influx of patients create a strain on staff and resources but also add challenges in providing adequate health literate care for those who may have cultural, linguistic, or health literacy barriers and no medical records.

Creating an additional layer of complexity to care and financial resource coordination, the Florida Hospital system has multiple locations in different counties that offer various resources only for residents of those counties. While promoting patient financial health literacy is a top priority for the organization, patients' health literacy needs vary at each location. For example, the population in one service area is primarily Hispanic, another serves a rural population, and another sees a greater number of local residents versus "transients or transplants." Thus, the team noted that health literacy solutions for one facility may not meet the needs of another facility, even though they are in the same health system and in close geographical proximity.

### Reaction to Gap Assessment Tool Results

The cancer center chose to complete the tool as a group since different individuals—service line administrator; Clarissa Moholick, MSHA, CCRP, CTR, regional director, Oncology Quality, Accreditation and Data Services, Florida Hospital Central Division, North (Volusia/Flagler Counties); Vanessa Hill, MSW, LCSW, financial counselors, and navigators—were able to contribute to answers in various domains. "It is also important to complete the tool from the perspective of a direct care provider (such as a nurse), as their perspective is so important," said Imelda Unto, RN, MSN, OCN, Regional Administrator, Adventist Health System Oncology Service Line Input from those providing bedside and/or chairside care often reveals a different perspective than an administrator. Leadership from the cancer center and Florida Cancer Specialists shared their initial findings during our focus group discussions.

The team noted that completing the assessment brought a new level of awareness that caused them to pause and agree to make health literacy a top priority based on the results. Although "there is a lot of opportunity here," all agreed that one major area of need was patient education.

They identified the following areas of concern:

- The massive volume of materials
- Consistency in education between inpatient and outpatient settings
- Reading level of patient materials
- Websites where patients gather information
- The timing and use of information.

Most of their patient education is in paper/print format, but the team wants to explore what types of media resonate with patients. Packets of information are expensive, and patients may overlook and/or discard information without ever reading it. Availability of technology such as a computer with interactive programs or videos was discussed as another means of delivering information to patients and families. An initial priority is to evaluate the resource room on each campus to ensure that materials match the population and to explore ways to improve utilization. The team discussed that some patients access unreliable information on the Internet and that healthcare professionals need to guide patients/family members to reputable websites. Another educational barrier identified by the team was lack of a consistent approach to patient education. Patients can travel from campus to campus and see multiple providers with varying health literacy skills, communication styles, and patient education materials.

### Next Steps

- 1 Based on their gap assessment results, for 2018 the cancer center plans to map care delivery "as a whole" with a focus on education. It anticipates different maps will be needed for different disease sites.
- 2 In response to educational materials concerns, the cancer program plans to conduct an inventory of its patient education materials throughout the cancer continuum—from screening through end of life. It intends to assess current materials, identify differences between campuses, and track the touch points when patients are receiving education, as well as identify who is delivering the education. A champion was named for this initiative and the team plans to create a steering committee.



## Duke Cancer Institute

Duke Cancer Institute in Durham, North Carolina, is one of the original eight National Cancer Institute-designated Comprehensive Cancer Centers. A national leader in health literacy and quality of care, the Duke Cancer Institute receives patients from all over the world. The Institute encompasses the Duke Cancer Center, a state-of-the-art patient care facility, and collaborates with community healthcare organizations through the Duke Cancer Network, which offers a variety of affiliation options. The Duke Cancer Institute is a national leader in health literacy and quality of care. In 2017 Nadine J. Barrett, PhD, from the institute's Office of Health Equity and Disparities accepted an ACCC Innovator Award on behalf of Duke Cancer Institute in recognition of its forward-thinking five-step roadmap for conducting health assessments designed to reduce cancer disparities and improve population health through community partnerships.

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**“One key to the success of Duke Cancer Institute’s health literacy initiative is assessment of its community.”**

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### Population and Health Literacy Needs

Duke Cancer Institute operates on the philosophy of improving health literacy even before someone is diagnosed with cancer. They have collaborated with many community partners, such as local churches, to “build and re-build trust,” provide education, and promote health. The institute serves a strong faith-based community. “The second person someone tells that they have cancer is their pastor,” commented focus group participant Valarie Worthy, MSN, RN, of the Office of Health Equity and Disparities. Staff go out into the community to provide numerous health promotions and conduct clinical trial education and awareness. These outreach programs help expose the cancer center’s population to health terminology, resources, and the basics of how the healthcare system works and how to navigate it. In addition, the community is invited to participate in annual campus-based or partnered activities such as the Men’s Health Initiative, the Women’s Health Awareness Day, and monthly resource fairs held in the cancer center’s resource room.

Currently, Duke Cancer Institute has a 17-member Community Advisory Council—soon to expand to 20 members—comprised of patients, caregivers, and representatives from local and state-level governmental and non-governmental organizations and initiatives that cut across racial, ethnic, and religious lines. The Office of Health Equity and Disparities works with diverse partners from the African American, Latino, and Asian communities, and is building relationships with the Muslim and LGBTQ communities as well. All these efforts are aimed at eliminating barriers to care on the front-end.

Patients at the Duke Cancer Institute are screened for distress at every visit. Although there is no formal health literacy screening tool, “staff are trained to look for red flags [of low health literacy],” said Worthy, such as patients who ask fewer questions, patients who cannot name medicines or provide a medical history, patients who hand materials directly to their caregiver, or those who have poor adherence or follow through with appointments or instructions. Health literacy training for internal staff is a high priority.

Cancer institute staff are required to complete a health literacy module on the organization’s learning management system with their annual required competencies. Navigators receive intense onboarding training that includes patient communication strategies and financial considerations. Navigators also often receive ongoing education related to health literacy through the North Carolina Navigation Association. Building on the cancer institute’s expertise, the Duke Cancer Network team uses annual chemotherapy validation to assess nursing staff’s ability to educate a diverse patient population—assessing use of teach-back methods and language to clarify a patient’s understanding of information. Drug education is individualized based on the patient’s learning style and health literacy: 1) standard education, 2) need for more pictures, and 3) advanced education with selected references are considered.

All Duke University Health System patient education materials must follow a clearly outlined process for patient and family education. A checklist for patient education materials, created by the Department of Clinical Education and Professional Development, includes rigorous health literacy requirements. All patient education materials are checked using the Flesch-Kincaid grade-level prior to submission for approval.



Dr. Barrett believes that one key to the success of Duke Cancer Institute's health literacy initiative is assessment of its community. Through a variety of programs and partnerships, the institute has been able to enhance community outreach, cancer screening, and research participation, particularly among high-risk, underserved, minority populations.<sup>8</sup> This information is critical to meet the ongoing health literacy needs of their community and continuously improve their services. Valarie Worthy added, "We constantly look for unconventional places for education as the cancer setting is not as comfortable." For example, Duke Cancer Institute is partnering with local libraries to provide education resources in the community which continually builds patient and provider trust.

### Reaction to Gap Assessment Tool Results

Several key individuals completed the assessment including navigation leadership, staff from the Office of Health Equity and Disparities, an executive from quality outcomes, and the Duke Cancer Network team. As might be expected, scores were high in leadership support and resources to create a culture of health literacy. Strengths included: staff health literacy training, community partnerships, guidelines for health literate patient education, strong minority focus, and identification of success measures. Even as a recognized leader in health literacy, Duke Cancer Institute and Duke Cancer Network members found completing the gap

assessment tool helpful in identifying areas for improvement. For example, various participants noted that individual physicians often have their own ideas about what constitutes the best patient education. In an institution with so many different healthcare professionals, including fellows, achieving consistency from everyone within a department can present challenges. Development of strong leadership for the Duke Cancer Network and uniform patient education requirements for the Duke Cancer Institute have helped, but all agreed that—even with a high-level of institutional health literacy—there was opportunity for improvement.

### Next Steps

- 1 Duke Cancer Network plans to invite all of its affiliate locations to complete the tool so it can compare from site to site. The goal is to create benchmark data allowing them to focus on areas to further support the affiliate members. Additionally, the Duke Cancer Center Network believes individual hospital data could be used in planning cancer center goals or quality improvement in support of CoC accreditation efforts.
- 2 Analyze Project PLACE data to better meet the needs of its community.

# Practical Tips from the Case Study Sites



In general, the case study sites found that completing the online gap assessment takes about 15 to 30 minutes. Each of the three programs chose different approaches to completing the assessment. Texas Oncology-Presbyterian Cancer Center elected to do three separate assessments of their main areas of care: inpatient, outpatient, support services. Florida Hospital Memorial Medical Center Cancer Institute took the assessment as a group to represent the entire cancer center. Duke Cancer Network completed the assessment through the lens of a single facility within its network but plans to complete the survey across its other facilities to benchmark data internally.

**Before starting the assessment, the case study sites recommend answering the following questions:**

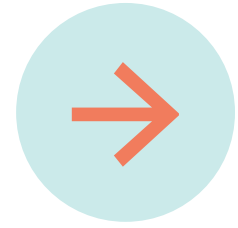
- 1 Is there one person, or group of people, who should complete the tool?
- 2 Are you completing it for a department, service line, organization, or health system?
- 3 Where would you find a rough estimate of the percentage of your patients in each of the following health literacy categories: below basic, basic, intermediate, proficient?
- 4 Do you know how many analytic cases your cancer program sees annually?

**ONE ADDITIONAL TIP:** Try not to over-analyze the questions. Only one designated individual at the cancer program will receive the assessment results. Keep in mind that the tool outlines levels to strive for; the score is intended to help identify opportunities for improvement. It is not a grade.



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# From Assessment to Action: Next Steps



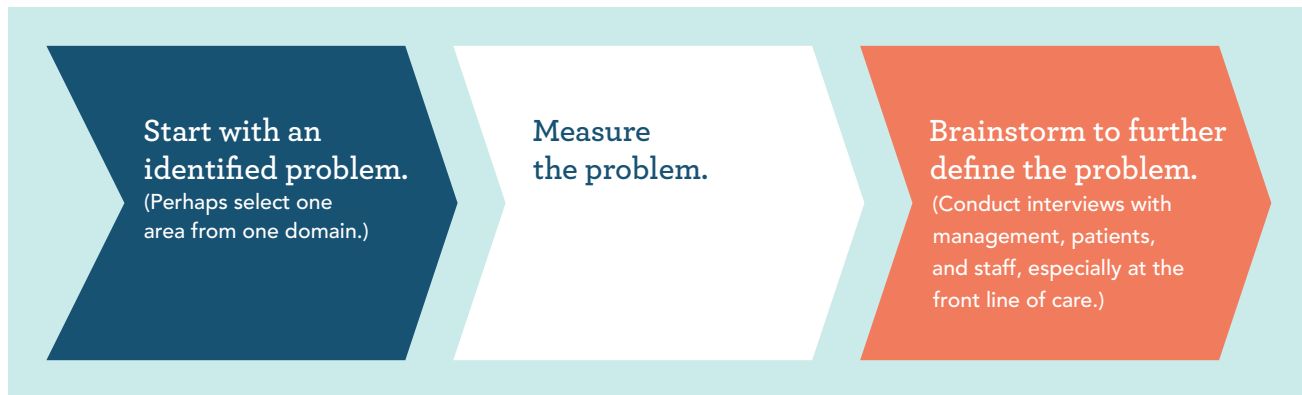
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## Step 1

Don't get overwhelmed. Each of the case study programs identified multiple opportunities for improvement. Just by completing the assessment, cancer programs can bring forward awareness of organizational health literacy.

## Step 2

Identify a focus area(s) for improvement. To select a starting place, Steve Powers, Administrative Director of Quality and Outcomes, Duke Cancer Institute, recommends that programs follow the process below:



Before implementing any change, be sure to assess the problem from all angles. In addition to conducting interviews and focus groups, Duke Cancer Institute uses their Oncology Patient Advisory Council to solicit feedback and gain perspective from the patient and caregiver point of view, along with input from their Community Advisory

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**“Another potential starting point . . . could be to evaluate if any readmissions are due to health literacy.”**

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Council. Following this approach, Florida Hospital Memorial Medical Center Cancer Institute has identified patient education as a problem area of focus. For their post-assessment “next steps” (see page 11), it plans to further define the

problem by conducting an inventory of all its patient education materials and mapping the education process.

On the other hand, in reviewing their assessment results, Cancer Support Community North Texas found that before it can clearly define a problem, education is needed, as it currently has no health literacy training. Its post-assessment goal is to provide staff and partner training that will include pre- and post-assessment of knowledge gained, changes in practice as a result of training, and its potential impact on survivors.

Another potential starting point, said Powers, could be to evaluate if any readmissions are due to health literacy. Low health literacy is associated with higher hospitalization rates, more frequent emergency department visits, and increased overall health service use. When possible, he suggests that programs connect their health literacy interventions and

improvements to The Joint Commission or American College of Surgeons Commission on Cancer requirements. Quality metrics that cancer programs are already collecting for Press Ganey, HCAHPS (the Hospital Consumer Assessment of Healthcare Providers and Systems) or CG-CAHPS (Clinician

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**“Look for “low hanging fruit” that can be easily corrected and to follow the best practice of writing SMART (Specific, Measurable, Achievable, Relevant, Timed) goals.”**

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and Group Consumer Assessment of Healthcare Providers and Systems) may encompass items you want to measure pre- and post-health literacy improvement efforts, noted Powers. Some current patient experience or patient satisfaction tools can even be tailored to include more health literacy-centered questions.

Dr. Barrett encourages all programs to look for “low hanging fruit” that can be easily corrected and to follow the best practice of writing SMART (Specific, Measurable, Achievable, Relevant, Timed) goals. In addition, she suggests that whenever possible, conduct health literacy research in tandem with the cancer program’s quality initiatives. In particular, there is a need for research in underserved communities or special populations.<sup>8</sup>

### Changing Demographics of Cancer

Any cancer program—regardless of size or health literacy—can identify areas for improvement in providing the best possible health literate cancer services as both cancer care and the demographics of patient populations continue to evolve. Complete the ACCC health literacy gap assessment tool for an initial baseline assessment, or as a re-assessment of your health literate organization. Use the results to help identify and meet your specific programmatic needs and goals. Like the three cancer centers featured in this report, you may be surprised at the “many opportunities for improvement.”

### Step 3

Share your experience. If your program implements a health literacy improvement effort as a result of taking the gap assessment, let ACCC hear from you.

Contact [resources@acc-cancer.org](mailto:resources@acc-cancer.org).

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## About ACCC

The Association of Community Cancer Centers (ACCC) is the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 24,000 cancer care professionals from 2,100 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. Not a member? Join today at [acc-cancer.org/membership](http://acc-cancer.org/membership) or email: [membership@acc-cancer.org](mailto:membership@acc-cancer.org).

For more information, visit the ACCC website at [acc-cancer.org](http://acc-cancer.org). Follow us on Facebook, Twitter, and LinkedIn, and read our blog, ACCCBuzz.

Access the gap assessment tool and more resources from the ACCC *Let's be Clear: Communicating to Improve the Cancer Patient Experience* program at [acc-cancer.org/health-literacy](http://acc-cancer.org/health-literacy).

# Association of Community Cancer Centers

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