# ASSOCIATION OF COMMUNITY CANCER CENTERS

**Assessing Cancer Program Alignment
with Health Literacy Metrics:**

**A Tool from the Association of Community Cancer Centers**



Association of Community Cancer Centers

# Presenter Disclosures

## Elana Plotkin

(1)    The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

NO RELATIONSHIPS TO DISCLOSE

The leading education and advocacy organization for the multidisciplinary cancer team.

# Multidisciplinary Membership



- Billers & Coders
- Financial Advocates
- Hospital President/CEO/COO/VPs
- Medical Directors
- Nurses & Nurse Practitioners
- Oncology Service Line Directors
- Program & Practice Administrators
- Pharmacists
- Medical, Radiation, & Surgical Oncologists
- Social Workers



25,000+ multidisciplinary practitioners
2,000+ cancer programs and practices nationwide

ACCC members work in every care delivery setting, from private practices to hospital-based cancer programs, large healthcare systems, and major academic centers.

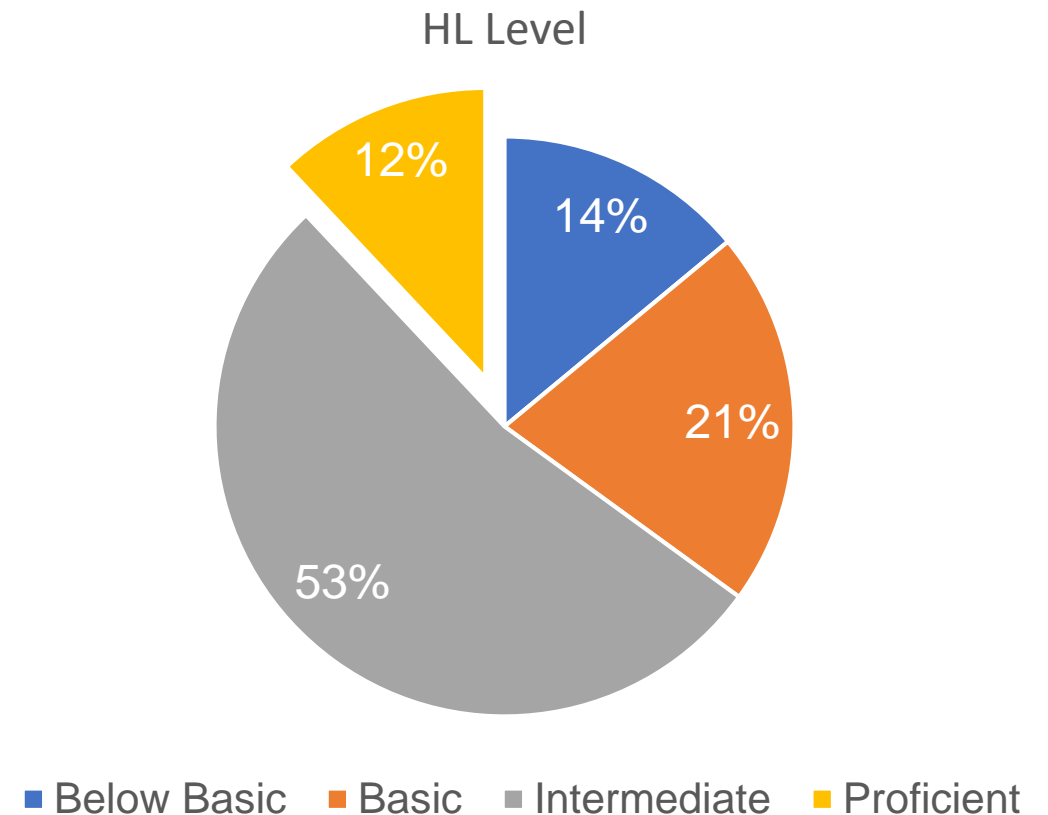# What Is Health Literacy?

Health literacy (HL) is the degree to which individuals have the capacity to:

- *obtain*

- *process,* and

- *understand*

basic health information and services needed to make appropriate health decisions.

# Health Literacy in the U.S.

- **77 million U.S. adults have basic or below basic HL**
  - 12% proficient
- Average person
  - 8th grade reading
  - 20% below 5th
  - 50% African American and Hispanics read below 5th

HL Level



- Below Basic   - Basic   - Intermediate   - Proficient

14%
21%
53%
12%

# HL and Health Outcomes

↑ Hospitalization
↑ Emergency services
↑ Medication Errors

↓ Preventive Services
↓ Cancer Screening
↓ Participation in Care
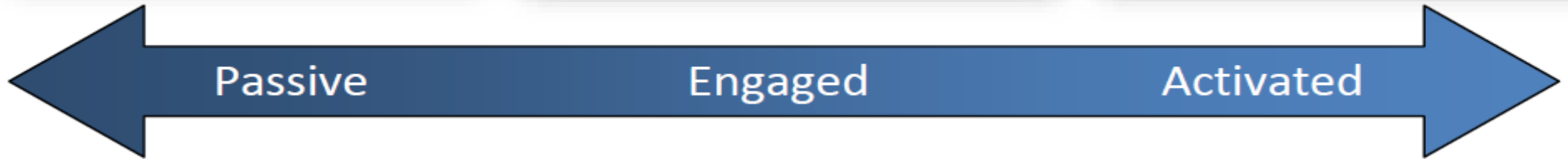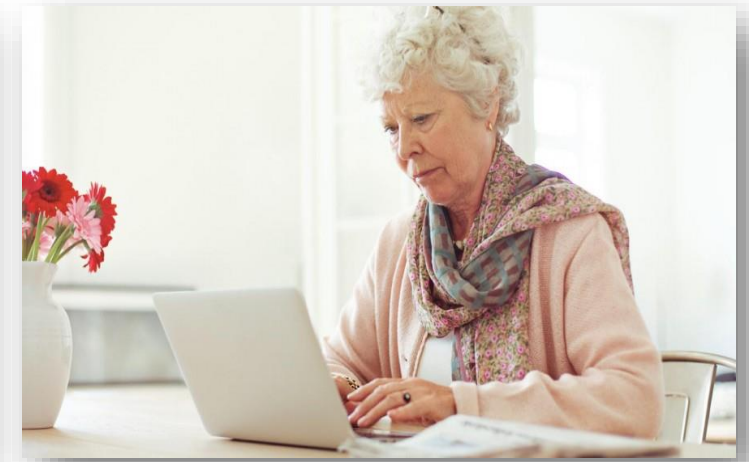
**POORER OUTCOMES**

↑ **$$$$**

Health literacy affects the quality of health care.

"Good quality means providing patients with appropriate services, in a technically competent manner, with *good communication*, *shared decision-making*, and *cultural sensitivity*."

IOM. *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001.

Passive — Engaged — Activated

"The doctor knows my medicines"

"I take a pain pill . . ."

"Doctor, I have a question . . ."

# 10 Attributes of a Healthcare Literate Organization Outlined by IOM Roundtable on Health Literacy

1. Leadership that makes health literacy integral to its mission, structure, and operations

2. Integrates health literacy into strategic and operational planning, quality improvement, goals, and measures

3. Prepares the workforce to address health literacy issues and monitors progress

4. Provides easy access to health information and services, and help finding the way in facilities

5. Addresses health literacy in high-risk situations, such as emergency preparedness, crisis and emergency response, and clinical emergencies or transitions.

6. Communicates clearly available health services and costs

# 10 Attributes of a Healthcare Literate Organization Outlined by IOM Roundtable on Health Literacy

7. Includes members of groups served in the design, implementation, and evaluation of health information and services

8. Meets the needs of audiences with a range of health literacy skills while avoiding stigmatization

9. Uses health literacy strategies in oral communication

10. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on

# Project Overview

We brought together thought-leaders and developed an assessment tool that will allow cancer programs to **measure the adequacy of their health literacy and education programs**, while **identifying gaps and areas for improvement**.

# Advisory Committee Partners

# Gap Assessment Tool

Cancer programs can identify educational needs, pinpoint areas where targeted education can improve patient care.

**6 Assessment Domains:**

1: Health Literacy Program (8QS)

2: Staff Training (6QS)

3: Health Information (12QS)

4: Navigation (9QS)

5: Technology (6QS)

6: Quality Measurement & Improvement (4QS)

Each user receives a personalized report with scores in each domain. Cancer programs are using this to customize goals for improvement.



**Expert Staff** (Select One):

**Level 1:** No staff trained to assess, prepare, and simplify electronic or print materials

**Level 2:** A team member trained to do at least one action: assess, prepare, and simplify electronic or print materials

**Level 3:** A team member trained to assess, prepare, and simplify electronic or print materials

**Level 4:** At least 2-3 team members trained to assess, prepare and simplify electronic or print materials

**Level 5:** A team of interdisciplinary staff trained to assess, prepare, and simplify electronic or print materials

**Survivor Input** (Select One):

**Level 1:** No cancer survivors input on HL resources

**Level 2:** Plans in place to develop cancer survivors input on HL resources

**Level 3:** Limited cancer survivors input on HL resources

**Level 4:** Developing plans for frequent, consistent cancer survivors input on HL resources

**Level 5:** Formal plan in place and used that integrates extensive cancer survivors input into the needs of the organization or staff related to HL resources

**Caregiver Input** (Select One):

# Read the Case Studies in our Publication

- Learn more about the assessment tool
- Three case studies from ACCC member programs
  - Texas Oncology – Presbyterian Cancer Center
  - Florida Hospital Memorial Medical Center
  - Duke Cancer Network
- Applying the results of the gap assessment

**accc-cancer.org/healthliteracy**

ASSOCIATION OF COMMUNITY CANCER CENTERS

HEALTH LITERACY: FROM ASSESSMENT TO ACTION

ASSESS & IMPROVE HEALTH LITERACY AT YOUR CANCER PROGRAM

ACCC
Association of Community Cancer Centers

# Case Study:

## Texas Oncology-Presbyterian Cancer Center

| HL Landscape | Assessment Results | Next Steps |
|---|---|---|
| • North Dallas = affluent/well educated population<br>• 12-14% Spanish Speaking<br>• Outpatient services provided by Texas Oncology, a large community-based practice<br>• Inpatient care delivered at Texas Health Presbyterian Hospital Dallas<br>• Psychosocial support offered (free of charge) through Cancer Support Community North Dallas<br>• 3 entities – seamless care from patient perspective | • "Shocked" by their score; face red tape with multiple organizations at the table<br>• Regardless of HL, patient education preferences are different (print, online, audio, video<br>• Numeracy and computer literacy add another layer of complexity<br>• OCM participants – attribute areas of high scores to this program: Enhanced navigation, EMR use, care plan, triage management | • Cancer committee links the three service areas and sets goals → HL became a focus of 2018 once score was presented<br><br>• CSCNT received CPRIT grant and is implementing staff training for HL at all locations |

# Case Study:

## Florida Cancer Specialists, Daytona Beach

| HL Landscape | Assessment Results | Next Steps |
|---|---|---|
| • Snowbirds, transition of care<br>• Geriatric population with special needs and comorbidities<br>• Influx of refugees from Puerto Rico<br>• Differences in HL needs vary significantly by county/site | • Different scores in different departments - perception that other groups are performing education, but not necessarily coordinated/formalized<br>• Lack of Spanish Speaking Staff<br>• Consistency needed in education between inpatient and outpatient settings | • **Map care delivery "as a whole" – more big picture**<br>• **Different maps for different disease sites**<br>• **Scheduled inventory of patient education materials**<br>• **Multidisciplinary goal setting and discussion** |

# Case Study:

## Duke Cancer Institute

| HL Landscape | Assessment Results | Next Steps |
|---|---|---|
| • ACCC Innovator Award Winner: Come Together: A Health Disparities & Equity Cancer Program Built on Community Collaboration<br>• Constantly assesses their community<br>• Strong faith-based community<br>• Training for staff is high priority<br>• Onboarding training includes communication strategies<br>• (SEE GOLD STARS NEXT SLIDE) | • Highest score but concerned it wasn't perfect<br>• High scores in leadership support and resources to create a culture of HL<br>• Lack of consistency across providers | • **Duke to invite their network sites to take the assessment to benchmark data and assess need for QI**<br>• **Continue to strive to meet unique minority needs in the community including LGBTQ, Muslim, Asian, African American and Latino** |

# Case Studies

★ Patients screened for distress at every visit

★ Drug education is individualized based on the patient's learning style and health literacy

★ Cancer institute staff required to complete a Health Literacy Training Module with their annual required competencies

★ Assess provider use of teach-back methods

★ Navigators receive intense onboarding training that includes patient communication strategies and financial considerations

★ Patient Education Materials must follow a clearly outlined process, checked for grade level

# GAP ASSESSMENT DATA

Association of Community Cancer Centers

# User Profile

**What oncology subspecialty are you completing this assessment for?**

- 45% Medical Oncology
- 25% Radiation Oncology
- 20% Surgical Oncology
- 10% Other

**Completed the assessment for:**

- Majority - Entire cancer program
- 12- Breast Dept.
- 1- Lung Dept.
- 2- Other

- **114 users with complete assessments** (as of 9/13/18)
- **27 states represented!**

**40%** of respondents say they have no or very limited resources for addressing health literacy in their patients

2%

6%

23%

34%

36%
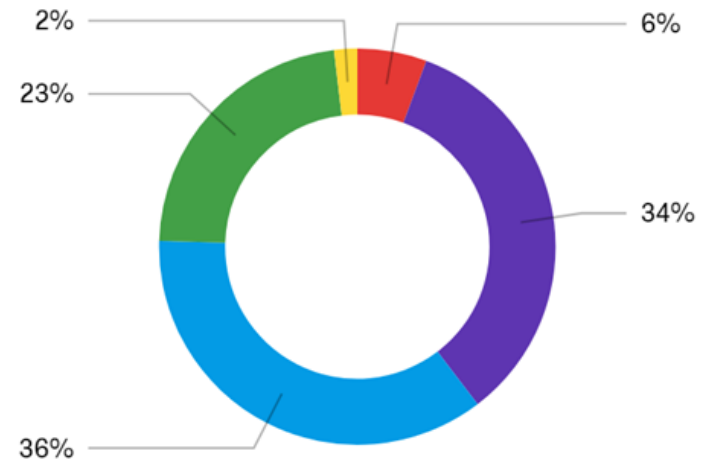
■ Level 1: No resources for addressing HL and no plan to develop these.

■ Level 2: Very limited resources for addressing HL; minimal plan to enhance current or develop new resources

■ Level 3: Some resources for addressing HL; initial plan to enhance current or develop new resources

■ Level 4: Active development of new or enhanced resources for HL underway

■ Level 5: Extensive use of resources for HL

**70%** of respondents indicate that they do not have effective processes in place to address the diverse health literacy needs of their patients

4%

26%

23%

32%

15%
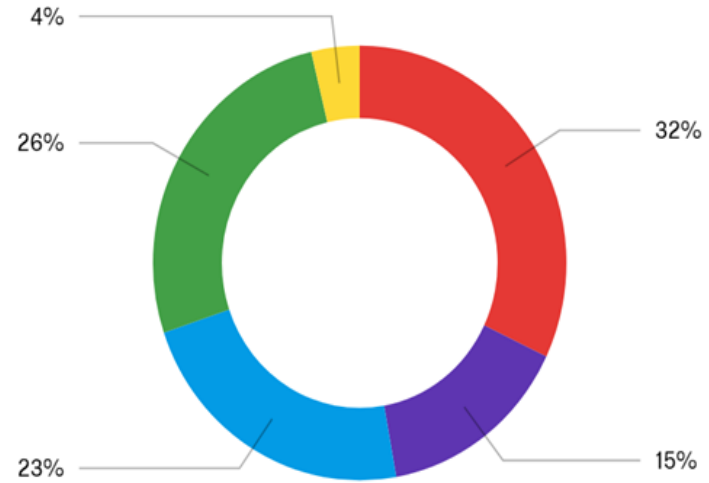
- Level 1: No written plan to address patients' diverse HL needs
- Level 2: Incomplete and ineffective plan to address patients' diverse HL needs
- Level 3: Rudimentary or outdated plan in place to address patients' diverse HL needs but does not reflect current national HL standards
- Level 4: Process in place to update existing HL plan and implemented for some cancer services (eg. breast cancer)
- Level 5: Formal plan implemented across all cancer services to address patients' diverse HL needs based on national HL standards

# Stats

- 53% report that they do not offer any type of formal staff education or training in HL

- 43% report that formal shared decision-making (SDM) processes are not used consistently

- 20% report that they are consistently using methods like "teach back" or "show me" or "re-stating" to assess and verify patients' understanding of diagnosis

- 33% report that financial counselors meet with patients only on request; 52% indicate that financial counselors meet with all patients prior to the start of treatment to discuss patients' understanding of financial responsibility

- 61% report they have no or very limited digital resources for patient education

- Across the six different HL domains, assessment scores were highest for Navigation and Health Information and lowest for Staff Training and Quality Measurement and Improvement

# User Feedback

"We are so excited about this project. We have completed the gap assessment, worked on the post assessment tool, already incorporated Ask Me Three in education resources, and have talked about bringing in a speaker to do a program for the staff on health literacy. We have even started to review new materials to ensure that they are an appropriate level and understandable. Thanks for these great resources. "

Chryl Corizzo, RN, BSN, OCN
Clinical Quality Director, Cancer Services
**St. Tammany Cancer Center,** Covington, LA

Take the Assessment!
accc-cancer.org/health-literacy