

Implementing a Health Literacy Assessment to Customize Patient Education and Improve Protocol Adherence

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1. Background

The American Cancer Society expects there to be approximately 2.1 million new cancer cases and more than 626,000 deaths from cancer in 2026. Cancer mortality rates have steadily declined over the last 30 years, and the five-year survival rates continue to climb over the same time frame, reaching 70 percent. These numbers can be attributed in part to discoveries made through clinical trials. It is expected that the Rutgers Cancer Institute will enroll more than 700 patients in 2026.

Several gaps have been identified at Rutgers Cancer Institute: A health literacy (HL) assessment is not being utilized in the ambulatory oncology setting, and a knowledge deficit was found in the clinical trials staff regarding HL assessment and awareness of the impact on the patient's clinical trial journey.

Navigating clinical trials can be complex for many, and even more so for those with limited HL. Patients are influenced by how information is organized, presented, and communicated by nurses and other healthcare professionals. Information customized to the HL needs of the patient can boost patient outcomes and safety.

2. Goals

The goal of the project is to ascertain the overall HL of cancer patients within our catchment area, increase HL awareness among the research nurse clinicians (RNCs) across the organization, and use the HL score to customize education from the informed consent process throughout the life cycle of the clinical trial.

3. Solutions and Methods

First, education will be provided to clinical trials staff regarding HL and its impact on a patient's ability to understand information provided to make informed decisions about their care. Education will be completed through in-person presentations. Next, the Short Assessment of Health Literacy (SAHL) HL assessment will be implemented for all oncology research patients before the informed consent process occurs. Finally, a survey will be administered via Qualtrics with RNCs before the education is provided and after the SAHL has been implemented. The survey will consist of approximately eight to ten questions assessing knowledge and awareness.

SAHL will be administered using laminated cards that list 18 health-related terms. It is available in English and Spanish. A translator will be used for those patients who speak Spanish. Patients are scored based on the pronunciation and comprehension of the terms that are read aloud. Scores of 15 or higher indicate adequate HL, while scores of 14 or lower indicate limited HL. The score will be recorded in the electronic medical record and will be used to tailor education.

4. Outcomes

The project aims to increase RN awareness of HL, and by using patient HL scores to customize research patient education, improved protocol adherence may be achieved.

5. Lessons Learned and Future Directions

Future directions include collaborating with Rutgers community outreach and engagement to identify and develop tools for the patient population within the low HL literacy category to assist in further customization of patient teaching information for optimized patient care.