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Optimizing health literacy to facilitate reproductive health decision making in adolescent and young adults with cancer

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Abstract

Despite being considered “standard of care” by many organizations, fertility and reproductive health communications and counseling practices remain inconsistent for adolescents and young adults (AYAs) newly diagnosed with cancer and during survivorship. One factor known to affect how information is provided and received in the medical setting is health literacy. Providers should consider health literacy to optimize reproductive health communication with AYAs as they cope with their diagnosis, understand what it means for their future, process information about treatment options, learn about their potential harmful effects on fertility, make quick decisions about fertility preservation, and navigate a future family planning course. Thus, the objectives of this manuscript are to: a) summarize literature on reproductive health literacy; b) describe health literacy frameworks; c) examine ways to assess health literacy; and d) identify ways to enhance clinician-patient communication in the AYA oncofertility setting.

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An expanding body of literature has focused on fertility impairment after cancer therapy and its negative psychosocial implications. Although there are an increasing number of technologies available for fertility preservation and assisted reproduction, access to timely and comprehensive fertility and reproductive health care still remains a challenge in many cancer centers across the United States and beyond. Despite being considered “standard of care” by many organizations,^{1,2} fertility and reproductive health counseling practices and communications remain inconsistent for adolescents and young adults (AYAs) newly diagnosed with cancer and during survivorship.³

Research shows health care providers, parents, and patients often experience difficulties in communicating with one another about fertility and reproductive health in the cancer setting.⁴ Even when discussions do occur, there are frequent reports of: 1) discordance between what patients/families are told by providers and what they perceive (e.g. about level of infertility risk⁵); 2) discordance between adolescents’ reproductive attitudes/goals and those of their parents^{6,7}; 3) poor recall of information about fertility and reproductive health among AYAs and families⁸; 4) uncertainty about fertility status and misconceptions about various reproductive health topics⁹ (e.g. risk of future offspring having cancer); 5) overall dissatisfaction with reproductive communications regarding fertility, contraception, and sexual health; and 6) scarce printed and digital educational resources. Limited research has been conducted to clarify why these gaps exist or to examine how these issues impact reproductive health decision-making and outcomes.¹⁰

One factor known to affect how information is provided and received in the medical setting is health literacy. Health literacy is defined by the U.S. Department of Health and Human Services 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.¹¹ Other definitions further depict health literacy as a constellation of essential skills required to understand and assimilate information, and perform health-related tasks and behaviors. For example, health literacy may affect a patient/parent’s ability to understand the current and future impact of cancer on sperm production or ovarian reserve, generate questions to ask a reproduction specialist, make decisions about fertility preservation options, or access and understand resources for supplemental information and/or guidance. Health literacy may also impact a patient’s understanding of medical terms related to reproductive health; for instance, a patient may incorrectly perceive “sterile” to mean “clean”¹² or believe that if there is need to preserve fertility, then contraception is not needed.

Several factors affect health literacy including^{13,14}: 1) baseline knowledge of providers and patients and communication skills of providers and patients/families; 2) patient age, developmental stage and cognitive capacity; 3) cultural and religious perspectives of providers and patients; 4) literacy of patients/families; and 5) competing psychological/emotional demands related to increasingly complex health care situations. Furthermore,

individuals across any socioeconomic strata (high or low education or income) are at risk for low health literacy due to the many system demands placed on them once they become immersed in a health care system. For AYAs with cancer, the potential for low health literacy is coupled with the need to quickly gain understanding of diagnosis and treatment as well as fertility/infertility, preservation, and contraception. AYAs with cancer are often faced with making decisions about fertility preservation and family planning in a very short window of time (24–48 hours), in the setting of physical/psychological distress related to a new cancer diagnosis, and often at ages/ developmental stages where capacity for future oriented thinking is limited.¹⁵

Providers should consider health literacy in order to optimize reproductive health communication with AYAs as they cope with their diagnosis, understand what it means for their future, process information about treatment options, learn about their potential harmful effects on reproduction, make quick decisions about fertility preservation, and navigate a future family planning course. Thus, the objectives of this manuscript are to: a) summarize literature on reproductive health literacy, b) describe health literacy frameworks, c) examine ways to assess health literacy, and d) identify ways to enhance provider-patient communication in the AYA oncofertility setting.

Health literacy models and communication frameworks

A number of health literacy conceptual theories, models, and frameworks have been developed (Table 1) which can be used as the basis for the development and validation of health literacy measures (Table 2).^{16–19} They include different moderator factors that influence the development of health literacy such as age, education level, and socioeconomic status and different mediator factors which influence patient's relationships between health literacy and health outcomes.¹⁹ These can be divided into personal factors such as attitudes, beliefs systems, personal experience, and motivations and external factors such as support systems and environmental factors. Unfortunately, no unifying framework exists and the currently available frameworks use various definitions of health literacy so they are not directly comparable.^{19,20} Nutbeam's Model of Health Literacy (2000), offers an attractive empowerment approach because of its three progressive levels of health literacy: functional/basic, interactive and critical thinking (Table 1).²¹

Considerations at the time of cancer diagnosis

Patient perspective/Parent perspective

Even without a cancer diagnosis, reproductive health literacy of AYAs is limited,^{22,23} and most AYAs have not discussed reproductive health values with their parents/caregivers.^{7,24} Establishing health literacy about fertility impairment and preservation not only requires receiving and understanding the information provided but also thinking critically about this information in order to make decisions^{21,24} about possible future scenarios within a short timeframe. Prior to a cancer diagnosis, many AYAs are developing emotional and cognitive maturity and are starting to make independent decisions. When initially diagnosed with cancer, AYA patients become increasingly reliant on their parents/partners to guide discussions and share in decision-making.²⁵ A recent model of health literacy supports

distribution of health information and decision-making among patients and their families in order to optimize information acquisition and utilization.²⁴ This framework is highly relevant at the time of cancer diagnosis when most AYA patients hear information and make decisions collaboratively with their parents/partners.²⁶

There is limited research dedicated to reproductive health literacy of AYA patients at the time of a cancer diagnosis. Research has shown adolescents and their parents inaccurately report and estimate their infertility risk within one week of the discussion, highlighting significant barriers to adequate healthy literacy.⁵ Both male and female AYAs have discordant views from their parents on the subject of fertility preservation; current research shows parents are poor predictors of their child's wishes and are less likely to prioritize future biological children in comparison to AYAs.^{6,7,27} AYA males are more likely to attempt sperm-banking based on provider or parental recommendation^{28,29} and parents, in turn, rely on informed providers for comprehensive information and advice.³⁰ In comparison, adolescent females tend to have thought more about future parenthood at the time of diagnosis and therefore show greater interest in fertility preservation; however, cost and the need to delay treatment have been shown to be barriers.^{31–33} Efforts to improve family/caregiver health literacy can favorably modify health outcomes.³⁴ In one study, parental self-efficacy to coordinate/facilitate sperm banking was associated with increased likelihood to pursue fertility preservation.²⁹ These studies underscore the importance of considering both the patient and parents' health literacy during fertility consultations.

Providers/system perspective

Although there is a consensus as to the timing and level of fertility preservation information that should be provided to patients by a clinician at the time of diagnosis,³⁵ poor clinician knowledge (e.g. regarding impacts of cancer treatment on future fertility, fertility preservation options and logistics to completion), low clinician confidence or discomfort, alongside clinician biases and misconceptions all negatively impact fertility discussions.^{36–38} Clinicians have reported a lack of education and a desire for further guidance in communicating with patients about fertility,^{39–42} indicating a need for clinician training and guidelines to aid in clinician health literacy. There is also ambiguity at times as to whose role it is to assist the patient in navigating oncofertility care given the multi-disciplinary approach that is required. Patient care navigators can be useful assets to the clinical team, in coordinating services, informing patients of treatment options and ensuring timely referral for fertility preservation.^{43,44}

There is a paucity of research into how clinicians consider patient health literacy when communicating risk of infertility and fertility preservation options at the time of a cancer diagnosis. Oncology clinicians perceive the emotional distress of patients and parents/caregivers of pediatric patients to hinder fertility risk information comprehension³⁷ and thus this factor may impact health literacy.⁴⁵ Positive clinician-patient rapport and sound clinician communication skills may improve interactions with AYA cancer patients and assist in health literacy.^{46,47} Taking a patient-centered approach and providing oncofertility written materials and age appropriate information may assist with effective information communication.⁴³

Considerations during and after oncological treatment

During and after the completion of cancer therapy, patients and families often have questions about reproductive health and the possibility for future fertility. To provide accurate counseling regarding infertility risk, providers may discuss cancer therapy exposures associated with infertility (e.g. alkylating agents, radiation to the gonads), offer opportunities for assessment of fertility status (e.g. hormone levels, semen analysis, or antral follicle count), and present potential options for future family-building. These discussions often require patients to have some underlying knowledge of reproductive processes including pubertal development, and related terminology, therefore health literacy is particularly important to consider among both patients and parents. Among adult women in the general population, health literacy is related to reproductive health knowledge,⁴⁸ and increased health literacy has been associated with an understanding of fertility and assistive reproductive technology.⁴⁹ While there has been little research exploring reproductive health literacy among survivors of childhood cancer, or their parents, there are several factors that may influence health literacy in this population.

Among survivors of childhood cancer, health literacy may be influenced by individual factors, patient age and developmental stage, and the receipt of neurotoxic cancer therapy. Individual factors can include functional literacy and educational attainment; among healthy adolescents, educational attainment and academic success are positively associated with health literacy.⁵⁰ Educational attainment and academic milestones are often delayed among survivors due to cancer diagnosis and cancer treatment.⁵¹ Understanding different levels of risk for infertility can be challenging and, depending on the value placed on fertility by the patient or parent, emotions can also impact understanding of risk. The emotions attached to an outcome may influence the reaction to risk communication and health decision-making.⁵² Infertility is a highly emotional and distressful outcome of some pediatric cancers⁵³; education regarding infertility risk should address the emotional distress related to potential infertility and incorporating low health literacy approaches may be helpful.

Age and developmental stage will influence survivors' understanding of reproductive health and desire for information about their potential future fertility. Survivors and their parents may be more interested in discussing infertility during later adolescent years and near the time of transition to adult healthcare. Male and female AYA survivors often report inaccurate perceptions of risk for infertility after treatment^{54–56} and desire repeated and more comprehensive information regarding their reproductive health.⁵⁷ As AYA cancer survivors transition from a pediatric-centered institution to the adult healthcare system, they often continue to have questions about their reproductive health.⁵⁸ Survivors who received neurotoxic therapy may have poorer health literacy due to their neurocognitive deficits.⁵⁹ Cranial radiation, intrathecal chemotherapy, and brain tumor/brain surgery are known to impact attention and executive functioning.^{59,60} Survivors with neurocognitive deficits may require interventions using low health literacy models to ensure they understand their reproductive health risks.

How to assess and improve health literacy

A number of countries have prioritized the availability of health literacy measures and health system awareness of health literacy.^{61,62} Clinicians agree the identification of health literacy is important in clinical practice but no consensus exists on a ‘gold standard’ measure and what components of health literacy should be tested. The literature identifies numerous formal and informal ways to assess health literacy. For example, some tools are currently available that offer significant correlations between the measure and a value of individual patients’ health literacy.²⁰ However these tools mainly assess reading proficiency and do not comprehensively assess other components of health literacy which include print literacy (reading, writing, numeracy); communication (listening, speaking and negotiating;) and information seeking and eHealth (navigating health services).¹⁸ Many tools are emerging in languages other than English and Spanish.^{63,64} Table 2 provides examples of measures of health literacy, based on theoretical frameworks/models that may be useful in developing communication and educational patient-centered information.

An informal approach that has been increasingly used to assess health literacy are the Single Item Literacy Screener (SILS) measures.^{65,66} These items can be easily incorporated into patient’s assessment intake forms. Examples of questions are: How would you rate your ability to read?; How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?; How confident are you filling out medical forms by yourself?

Various strategies can be implemented at a local national and international level to improve the development and implementation of health literacy measures to improve patient education (Tables 2 and 3).^{16–18,67} It is also important to look at organizational health literacy barriers that reduce the implementation of these measures once they have been developed and validated, such as a lack of commitment and priority, work place culture not supporting implementation, lack of training, lack of time and lack of awareness or need.^{16,17} The American Health Research and Quality has created a helpful resource toolkit: <https://www.ahrq.gov/health-literacy/quality-resources/tools/literacy-toolkit/index.html> Another strategy for improving literacy is re-educating patients and parents/caregivers at different time points (with the patient’s consent), as patients’ needs and circumstances change over time. This strategy has the added benefit of providing multiple opportunities to support families and validate what they already know.

Decision support tools, resources, and training

Healthcare providers and healthcare systems can assess and optimize patient and parent understanding of personal risk for infertility by proactively addressing health literacy in their plans for patient education (Table 3). However, health literacy is not just education – it requires an assessment of comprehension and the ability to use the information and make critical decisions.⁶¹ Koh and colleagues describe The Arc of Health literacy and recommend clinicians “assume” patients may not understand unless proven otherwise and they suggest the use of the *Teach Back method* and language that welcomes questions.⁶⁸ An example of this would be “*I’ve just given you a lot of information about your contraception options –*

what questions do you have? Can you tell me how you will explain what you have learned to your partner?"

By nature of the technical nomenclature commonly used within the reproductive health field (e.g., oocyte, premature ovarian failure, pre-implantation genetic testing) this area of cancer care is especially steeped in communication complexities. As such, deconstructing (breaking down) or substituting these difficult terms is key for improved communications. Oncofertility patient educational materials are recommended as supplements to the initial fertility consultations. However, a minority of clinicians routinely provide fertility preservation patient educational materials to patients¹⁴ and there are discrepancies in the quality of materials available.⁶⁹ As such, there is a need for clinicians to be aware of how to access appropriate patient education resources, while considering preferred information type/language, and level of health literacy.⁷⁰ Moreover, further rigor in the development of these resources is required moving forward, to ensure consistency and clarity in information provision. Proposed strategies and steps to enhance literacy in the reproductive setting are outlined in Table 3.

Systems like the Oncofertility Consortium are well positioned to create working groups of experts in the field to develop materials that are mindful of health literacy. These materials can take the complex information around fertility/infertility and fertility preservation and reduce them into digestible components that can be used to make an actionable decision. Key concepts can be identified that the patient/parent should understand. Materials used in education sessions should be developed using recommended developmental processes and should be pilot tested.¹⁷ In general, less jargon and less complex terminology should be used, more attention should be given to common faulty assumptions, and reading level and numeracy skills should be accommodated.^{17,18,19} Once finalized, the Oncofertility Consortium could disseminate the materials throughout their global network of providers, thus improving provider and patient communication in a consistent amplified manner.

Decision support tools can also be utilized to guide fertility preservation clinician-patient conversations and assist decision-making processes at diagnosis and after oncological treatment.⁷¹ Clinician administered decision trees allow clinicians to select appropriate preservation options; considering factors such as urgency to commence oncological treatment, fertility risk and patient's desire for family planning.⁷² Decision aids used at the time of diagnosis can augment reproductive health literacy and should not only include evidence-based educational materials but must incorporate values clarification exercises to stimulate discussion of a previously unaddressed topic.⁷³ Parents have responded positively to decision aids at the time of diagnosis when they otherwise would have been too focused on immediate cancer diagnosis and treatment.⁷³ In a recent study, parents and AYA males described that the use of a family-centered decision aid promoted conversation and consideration of future fertility goals.⁷⁴ The use of this framework of distributed health literacy is more likely to limit decisional regret.⁹ Preliminary findings from randomized controlled trials investigating the utility of online fertility preservation decision aids, either alone^{75,76} or combined with care navigation,⁷⁷ in comparison to standard care (fertility consult, counselling or brochure), indicate that decision aid resources significantly benefit decision-making outcomes. However, historically clinician utilization of such tools has been

low,⁷⁸ many decision aids remain unavailable for clinical use,⁷⁹ and few tools consider low health literacy.⁸⁰ In an ideal, resource rich setting, we would recommend developing, validating, and adapting tools for diverse cultures and languages (Table 3), with formal assessments of clinical impact.

In addition to provision of written materials and decision aids for patients and families, creating reproductive health communication training opportunities for clinicians is essential. The Enriching Communication Skills for Health Professionals in Oncofertility (ECHO) program offers comprehensive training for social workers, psychologists, nurses, and physician assistants to improve communication skills about reproductive health with AYA patients and their families.^{81,82} This program has a validated curriculum and has shown to significantly improve knowledge, confidence, and practice behaviors among allied health professionals. The Oncofertility Consortium is another source of training, offering on-line access to educational materials, patient testimonials, and training opportunities. The ASCO “Focus Under Forty” also offers physician-based training to improve and enhance discussions of fertility preservation for AYAs diagnosed with cancer.

Conclusion

Reproductive health literacy is a complex topic requiring clinicians to use judgement about the amount and type of information required at the time of a cancer diagnosis for AYAs and their parents/partners to make informed decisions about fertility preservation, family building goals and contraceptive needs. Assessing patient/family health literacy is critical to the care of AYA patients and awareness of the variety of factors such as patient age, developmental status, pubertal status, congruence of patient/caregiver perspectives, urgency of cancer treatment and disease stage which may impact these conversations is paramount. There are several resources available to improve reproductive health literacy which include training physicians/providers on how to have these difficult conversations and creating patient educational materials that facilitate decision-making. Although there is no ‘gold standard’ for assessing and improving health literacy, a plethora of resources, tools and strategies exist to optimize health literacy, which can be applied to the reproductive health setting. To illustrate how these best practices can converge, we have developed a framework that brings together multi-level perspectives (caregiver/family, provider, and system/organization) for enhancing the AYA clinical environment (Figure 1).

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Abbreviation

AYAs Adolescents and young adults

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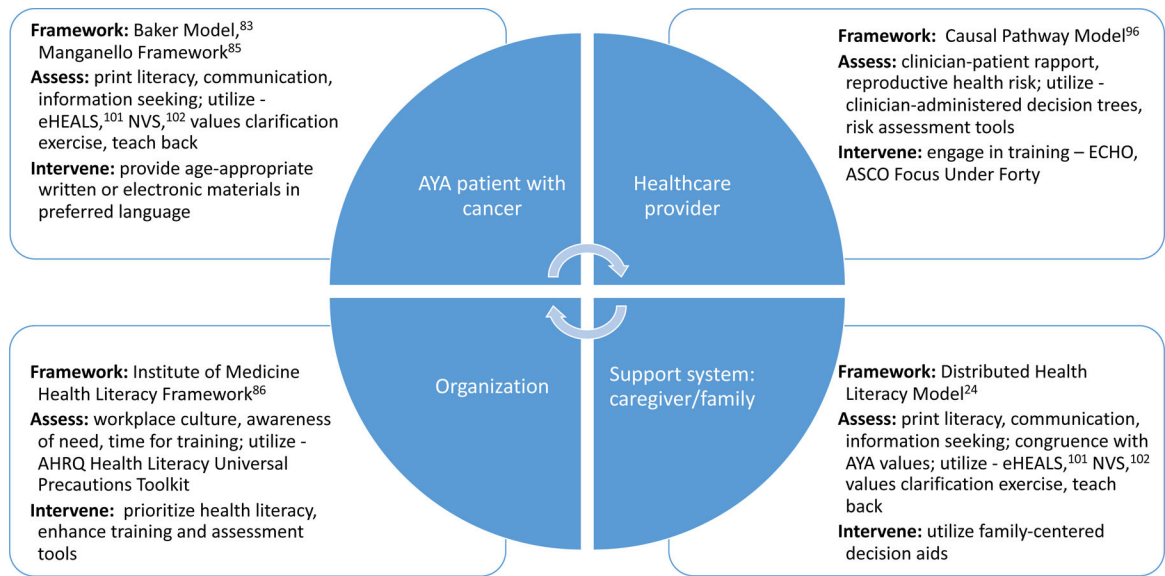


Figure 1. Integrative Framework to Enhance Literacy

AYA – adolescent and young adult; eHEALS – eHealth Literacy

Scale; NVS – Newest Vital Sign; AHRQ – Agency for Healthcare

Research and Quality (<https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2.pdf>); ECHO –

Enriching Communication Skills for Health Professionals in Oncofertility (<https://echo.rhoinstitute.org/>); ASCO – American Society of Clinical Oncology

Table 1.

Health Literacy Conceptual Frameworks

Health Literacy Conceptual Framework/Theory	Main Theoretical Concepts of Framework
Baker Model ⁸³	This model identifies moderators and mediators and emphasizes the role of prior health knowledge.
Health literacy, social support, and health Framework ⁸⁴	This framework focuses on identifying intermediate factors through which health literacy affects outcomes such as disease knowledge, health risk behavior and compliance with medication.
Manganello Framework ⁸⁵	This framework includes modifiable factors which may influence an adolescents' health literacy.
Institute of Medicine (IOM) Health Literacy Framework ⁸⁶	This framework focuses on culture and society, education and health system as factors in the development of health literacy skills which can be modified.
Nutbeam Conceptual Model of Health Literacy ²¹	This model adopts an empowerment approach that identifies three progressive levels of health literacy which include basic/functional skills (ability to read and write); communication/interactivity literacy (ability to coordinate social skills and literacy and participate in communication; critical literacy (ability to evaluate information that has been given).
Media Literacy conceptual Framework ⁸⁷	This framework uses the ability to critically evaluate media messages across a number of different platforms.
Expectancy theory ^{88,89}	Patients engage in certain behaviors based on three determinants which include expectancy (the amount of effort in achieving an outcome; instrumentality (the intrinsic or extrinsic rewards a person gets when they achieve their goals and valence (the value a patient places on the outcome).
Expanded Model of Health Literacy ⁹⁰	This model is characterized by four domains – fundamental literacy (the skills required in reading, speaking, writing and interpreting information); science literacy (the level of understanding of science and technology); civic literacy (patients understanding on public issues which may influence decision making); and cultural literacy (to be ability to recognise and use collective beliefs and customs to interpret information).
Concept Analyses of Health Literacy ⁹¹	This model uses concept analysis to clarify attributes (reading, numeracy, comprehension, decision making and capacity to use the information, antecedents (literacy and health related experience) and consequences of health literacy (improvements in health outcomes, reduce health costs and reduced in and outpatient admissions).
Media Health Literacy Theoretical Framework ^{92,93}	Two different models which combine health and media literacy together and include domains such as identification, influences, analysis, understanding and action.
Outcome Expectation from Social Cognitive Theory ⁹⁴	Asserts that behavior is shaped by individuals' anticipation of consequence and rewards.
Combination of Interpretation Model and Social Cognitive Theory ⁹⁵	Asserts that behavior is a product of interaction between cognitive and social environmental influences.
Causal Pathway Model ⁹⁶	This model focuses on pathways between health literacy and outcomes influenced by access and uptake of health care, patient clinician relationship, and patient self-care.
Distributed Health Literacy Model ²⁴	This model utilizes a patient's social networks and family caregivers as a potential resource for managing one's health, communicating with health professionals, and making health decisions.

Table 2.**Measures to Assess Health Literacy**

I.	Rapid Estimate of Adult Literacy in Medicine (REALM) ⁹⁷ is a word recognition health literacy measure for an adult that takes 3 minutes to complete. It is administered orally and tests the recognition/pronunciation of 66 medical words but not the comprehension of these words.
II.	Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen) ⁹⁸ is a modified version of the REALM health literacy measure for adolescents from year 6–12 in school. This tool is also administered orally with patients tested on 66 commonly used adolescent health words.
III.	Test of Functional Health Literacy in Adults (TOFHLA) ⁹⁹ is a validated health literacy instrument which provides a more detailed assessment of health literacy. It consists of 50 item reading comprehension, 17 numeracy ability test and 3 prose passages. It takes 22 minutes to administer.
IV.	Short Test of Functional Health Literacy in Adults (S-TOFHLA) ¹⁰⁰ is a validated abbreviated health literacy instrument adapted from the TOFHLA. It has 4 numeracy items and 2 prose passages and takes 12 minutes to complete. Although frequently used the S-TOFHLA is limited in its ability to record all aspects of health literacy and hence may under report patients who need additional support.
V.	eHealth Literacy Scale (eHEALS) ¹⁰¹ is an 8 item health literacy measure that tests patients skills and understanding of information from electronic sources. This measure has been validated in adolescent patients.
VI.	Newest Vital Sign (NVS) ¹⁰² is a health literacy tool with 6 questions that takes about 3 minutes to complete. This brief health literacy tool is administered orally to patients and tests both literacy, comprehension and numeracy information.

For a comprehensive listing of available health literacy tools, go to the Health Literacy Toolshed, an online database of health literacy measures compiled by the National Library of Medicine (https://www.nlm.nih.gov/news/health_literacy_tool_shed.html).

Table 3.

Options to Enhance Literacy

1	Integrate the existing definitions and frameworks to create universal standards that will reduce the variability in concepts;
2	Ensure that available health literacy measures take into consideration the specific needs of different patient population based on socioeconomic, cultural, gender and age differences;
3	Increase the availability of tools comprehensively assessing different components of health literacy (print, communication and information seeking);
4	Develop and validate health literacy tools that have been adapted to specific clinical situations;
5	Measure the benefits of improving health literacy on clinical care;
6	Implement broader health literacy strategies that have been shown to improve clinical care;
7	Increase the availability of tools in different languages.

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