Actionable Patient Safety Solutions™ (APSS™):

Health Literacy

How to use this guide

This APSS provides evidence-based resources and recommendations for executives, leaders, clinicians, and performance improvement specialists to improve and family member patient health literacy. This document is intended to be used as a guide for healthcare organizations to examine their own workflows, identify practice gaps, and implement improvements. In it, you will find:

Best Practice Summary: A high level summary of evidence-based, clinical best practices. (page 2)

Executive Summary: Executives should understand the breadth of the problem and its clinical and financial implications. (page 2)

Leadership Checklist: This section is for senior leaders to understand common patient safety problems and their implications related to health literacy. Most preventable medical harm occurs due to system defects rather than individual mistakes. Leaders can use this checklist to assess whether best practices are being followed and whether action is needed in their organization around health literacy. (page 3)

Clinical Workflow: This section includes more specific information around health literacy across the continuum of care. Leaders should include the people doing the work in improving the work. This section outlines what should be happening on the frontline. Clinicians can use this section to inform leaders whether there are gaps and variations in current processes. This is presented as an infographic that can be used for display in a clinical area. (page 4)

Education for Patients and Family Members: This section outlines what frontline healthcare professionals should be teaching patients and family members about how lack of health literacy undermines the most robust clinician recommendations. Clinicians can inform leaders whether there are gaps and variations in current educational processes. (page 6)

Performance Improvement Plan: If it has been determined that there are gaps in current processes, this section can be used by organizational teams to guide them through an improvement project. (page 7)

What We Know about Health Literacy: This section provides additional detailed information about health literacy. (page 10)

Resources: This section includes helpful links to free resources from other groups working to improve patient outcomes and safety. (page 11)

Endnotes: This section includes the conflict of interest statement, workgroup member list, and references. (page 11)

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Patient Safety MOVEMENT

Best Practice Summary

- ☐ Recognize and challenge personal implicit biases that may impact communication with patients.
- ☐ Be aware of physical and emotional factors that may compromise patient communication and understanding of health information.
- ☐ Provide information in multiple ways (e.g., verbal, written, etc).
- ☐ Take time to understand the patient's preconceived notions and questions about their condition.
- ☐ Speak using plain language.
- ☐ Ensure communication with patients is as transparent and unambiguous as possible.
- ☐ Tailor information to the patient's specific condition, preferences, and needs.
- ☐ Use resources to enhance communication based on patient needs (e.g., translator).
- ☐ Suggest that patients list their questions and concerns prior to the appointment or hospital visit, if possible.
- ☐ Remain cognizant of body language that may indicate misunderstanding of health information.
- ☐ Employ teach back strategies, such as "Ask Me Three".
- ☐ Repeat information as needed and pause to assess patient understanding.
- ☐ Welcome questions and take time to respond thoughtfully.

Executive Summary

The Problem

Approximately 36% of U.S. adults have low health literacy (lack basic health information knowledge), with disproportionate rates found among lower-income Americans (Center for Health Care Strategies, 2013). Adults with low health literacy experience four times greater healthcare costs, nearly 10% more hospital visits, and an average of two additional hospital days due to their difficulty understanding how everyday decisions impact their long-term health (Center for Healthcare Strategies, 2013; Office of Disease Prevention and Health Promotion; Balakrishnan et al., 2017).

The Cost

The annual cost of low health literacy to the U.S. economy was $106 billion to $238 billion, which is approximately 7-17% of all personal healthcare expenditures (Low Health Literacy: Implications for National Policy).

The Solution

Healthcare literacy programs effectively used to decrease adverse events. This document provides a blueprint that outlines the actionable steps organizations should take to successfully improve effective communication with patients and family members through consciousness around healthcare literacy and summarizes the available evidence-based practice protocols. This document is revised annually and is always available free of charge on our website.

Leadership Checklist

Use this checklist as a guide to determine whether current evidence-based guidelines are being followed in your organization:

Clarify the relationship between health literacy and patient safety for all in the organization.

- ☐ Make sure all understand that the purpose of prioritizing health literacy is to ensure all people have the right health information to guide them in making informed, optimal decisions.
- ☐ Emphasize the need for ongoing orientation to the patient's understanding. See an example here.

Get staff buy-in.

- ☐ Explain how effective patient communication strategies, such as teach back, can help clinicians (e.g., prevent misunderstandings that would affect treatment adherence, minimize after visit clarifying phone calls, etc).
- ☐ Consider short-term (e.g., patient understanding post-discharge) and long-term metrics (e.g., lowered A1C due to patient understanding of the importance). Short term to maintain engagement and enthusiasm and long-term to make a meaningful impact.

Evaluate what's happening on the frontline.

- ☐ Ensure adequate training and documentation of healthcare literacy competencies and skills, for both new employees and existing employees. Incorporate simulation and role play training routinely into education.
- ☐ Make the tools and tool training easily accessible for use on the frontline when they need it. Ensure that healthcare literacy protocols are embedded into clinical workflows, whether electronic or paper.
- ☐ Assess the staff members' comfort with using the tools available to them to help patients and family members understand their clinical information.
  - ☐ Are staff comfortable with understanding which tool to use and when?
  - ☐ Are they competent in applying the tools in the appropriate scenario?
  - ☐ Do those on the frontline think the tool is helpful? If not, why?
  - ☐ What new strategies are learned from using the tool?
- ☐ Systematically assess the literacy level of the organizational written materials using validated tools.
- ☐ Acknowledge the role of cultural competence in strengthening the patient-provider relationship and hire in alignment with the community served.
- ☐ Establish processes or hire personnel to ensure all educational material is at an appropriate reading level.
- ☐ Include patients and family members in the writing and review of educational materials. See Person and Family Engagement APSS.
- ☐ Ensure services and information are culturally and linguistically appropriate.
- ☐ See the Performance Improvement Plan for more detail.

Measure effectively and routinely report progress.

- ☐ Measure and report health literacy metrics monthly using validated tools.
- ☐ Routinely report this data back to those on the frontline in a timely manner.
- ☐ Track progress after implementation. Consider tracking patient outcomes after exit from the facility via survey to assess understanding from the patient's perspective and feed this data back to those from the sending facility.

Clinical Workflow

1. ALWAYS

- Acknowledge health literacy is essential for effective communication (explain all options to the patient, make a proposal, and ask the patient questions to determine their comprehension and what they think is best for them)
- Challenge any immediate assumptions you might have about a patient's ability to understand based on their appearance, wealth, etc. to avoid biases impacting communication (not explaining health concepts in detail)

Prior to Admission

- Identify the primary language of the patient and family members and coordinate a translator, if needed.
- Send patient leaflets (via mail or electronic methods) prepares the patient for the discussion
- Provide a prompt for patients to write down questions and concerns before their appointment.
- Make the recommendation to the patient to bring someone with them to help take notes, prioritize questions, etc. See Person and Family Engagement APSS.

2. ADMISSION/ENTRY

First Patient Encounter

- Deliver information at a time in which the patient can actually retain the information and be aware of factors that can compromise patient understanding (e.g., immediately post-anesthesia).
- Break down information in pieces and assess patient comprehension across individual information pieces
- Ask the patient how they learn best (e.g., written material, videos, etc) and accommodate as needed. Give the option to record the session to aid in memory.

- Understand the patient's preconceived notions about their condition and combat any misinformation. Ask about what information the patient currently has.
- Make the environment comfortable for the patient to help them understand the conversation (e.g., when discussing a miscarriage, be mindful about mother's current preferences concerning being around babies)
- Introduce patients to the Google question generating feature to help them identify the valuable questions

3. ROUTINE CARE

Routine Conversation with the Patient and Family Members

- Speak using plain language (e.g., instead of saying 'stool', say 'poop').
- Anticipate fear-provoking language (e.g., 'palliative care' can be misinterpreted as end of life care).
- Include the patient's family members in dialogue and understand varying degrees of family literacy level may differ among individual members. Adjust accordingly to help patients and their families understand.
- Make information given to patients directly relevant to them and their circumstance.
- Plan conversations at the ideal time (e.g., not immediately after diagnosis).
- Ask the patients for their list of questions and concerns. Allow patients to have a high level overview of the plan for the conversation by sharing a list of items to discuss first before diving into specific items
- Anticipate any ambiguity in how the message is received by the patient (e.g., If a patient is taking medication for hypertension, they may perceive that they no longer have hypertension).
- Prioritize key information to avoid overwhelming patient with information and giving them time to process
- Evaluate whether the patient's non-verbal communication aligns with their verbal communication.
- Leverage effective communication strategies during difficult conversations.

4. DISCHARGE/EXIT

Understanding the impact of your communication with patients.

- Pause between each 'section' of information to allow the patient to indicate their understanding.

- Listen to questions patients keep asking and monitor their nonverbal body language as indicators of their understanding.
- Check the patient's understanding of the information given by asking the patient to:
  - Summarize the instructions/information just given.
  - Demonstrate necessary skills (e.g., equipment use).
  - Show competency in understanding new and related information (e.g., reading a nutrition label).
- Employ teach back strategies, such as 'Ask Me Three'.
- Watch for any red flags in the short term (e.g., looking confused) and in the long term (e.g., not changing their wound dressing between appointments) that may indicate that the patient did not understand their care instructions.

Education for Patients and Family Members

When meeting with patients, employ the strategies mentioned above. Start one week with using teach back. The next week, use teach back after delivering information in pieces, rather than altogether. The following week, deliver information in pieces, use teach back, and help the patient write things down alongside.

Here are two examples of typical information that is often conveyed to patients. Next to it is an example of how to better convey that information to aid in patient understanding:

HOW INFORMATION IS TYPICALLY CONVEYED TO PATIENTS	HOW TO IMPROVE
"We've sent a stool sample to the lab to determine whether or not you have C diff."	"You had explained that you were having stomach pain and diarrhea often. Sometimes, this means someone may have a stomach infection. We need to be sure we know what's going on before we can determine the best treatment. So, we've sent a poop sample to our team in the lab. They will be able to tell if you have an infection through testing. The results of these tests will come back to me, and I'll share them with you as soon as I can. We can discuss those test results together and talk about the best next steps as a team. What are your thoughts or questions?"
"This medication prescription for your hypertension should be taken orally twice per day with meals."	"You have hypertension, which means that your blood pressure is very high. This could be a problem because high blood pressure could contribute to problems with your heart in the future. But, with a few changes, we can work together to get that under control. First, I'm going to ask that you take this medication for your blood pressure. You should take it two times each day, once in the morning and once in the evening. Make sure you take this medication with meals, maybe breakfast and dinner. Taking this medication does not mean that you no longer have high blood pressure, but it will definitely help. Before we talk about what else you can do to control your blood pressure, like diet and exercise changes, let's talk about the best way for you to get this medication. Do you usually drive by a pharmacy on your way home from work?..."

Performance Improvement Plan

Follow this checklist if the leadership team has determined that a performance improvement project is necessary:

☐ **Gather the right project team.** Be sure to involve the right people on the team. You'll want two teams: an oversight team that is broad in scope, has 10-15 members, and includes the executive sponsor to validate outcomes, remove barriers, and facilitate spread. The actual project team consists of 5-7 representatives who are most impacted by the process. Whether a discipline should be on the advisory team or the project team depends upon the needs of the organization. Patients and family members should be involved in all improvement projects, as there are many ways they can contribute to safer care.

Complete this Lean Improvement Activity:
Conduct a SIPOC analysis to understand the current state and scope of the problem. A SIPOC is a lean improvement tool that helps leaders to carefully consider everyone who may be touched by a process, and therefore, should have input on future process design.

RECOMMENDED HEALTHCARE LITERACY IMPROVEMENT TEAM	
• Patients, family members, and community members	• Support staff
• Admitting and registration staff	• Public health specialists
• Quality and safety specialists	• Marketing and communication specialists
• Physicians	• Those designing patient portals
• Nurses	• Organizational policy makers
• Pharmacists	• Students
• Rehabilitation staff (Physical therapists, speech therapists, etc)	• Data Analysts
• Care coordinators and social workers	• Midwives

Table 1: Understanding the necessary disciplines for a healthcare literacy improvement team. The above team members should represent all facilities within the system (e.g., in-patient, long term care, etc).

☐ **Understand what is currently happening and why.** Reviewing objective data and trends is a good place to start to understand the current state, and teams should spend a good amount of time analyzing data (and validating the sources), but the most important action here is to *go to the point of care and observe*. Even if team members work in the area daily, examining existing processes from every angle is generally an eye-opening experience. The team should ask questions of the frontline during the observations that allow them to understand each step in the process and identify the people, supplies, or other resources needed to improve patient outcomes.

Create a process map once the workflows are well understood that illustrates each step and the best practice gaps the team has identified (IHI, 2015). Brainstorm with the advisory team to understand why the gaps exist, using whichever root cause analysis tool your organization is accustomed to (IHI, 2019). Review the map with the advisory team and invite the frontline to validate accuracy.

HEALTHCARE LITERACY PROCESSES TO CONSIDER ASSESSING

- Interaction when a patient and provider first meet one another
- Patient-provider interaction at the beginning of routine care visits
- Shared decision making conversations
- Use of structured tools for facilitating communication with patients or family members
- Adjusting communication to receiver needs (e.g., 'flipping the switch' between communicating between providers and with patients)
- Consent processes and conversations
- Environments in which shared decision making conversations occur (e.g., Is it private? Quiet? etc.)
- How information is delivered (e.g., piece by piece or all at once)
- What types of information the patient is receiving from different team members
- Follow up with patients
- Promotional messaging to education patients, family members, and the general public about where to go if they have a health issue and what services they can expect in each facility

Table 2: Consider assessing these processes to understand where the barriers contributing to healthcare literacy may be in your organization

☐ **Prioritize the gaps to be addressed and develop an action plan.** Consider the cost effectiveness, time, potential outcomes, and realistic possibilities of each gap identified. Determine which are priorities of focus for the organization. Be sure that the advisory team supports moving forward with the project plan so they can continue to remove barriers. Design an experiment to be trialed in one small area for a short period of time and create an action plan for implementation. Ensure action plan has clear timelines.

The action plan should include the following:

- Assess the ability of the culture to change and adopt appropriate strategies
- Revise policies and procedures
- Redesign forms and electronic record pages
- Clarify patient and family education sources and content
- Create a plan for changing documentation forms and systems
- Develop the communication plan
- Design the education plan
- Clarify how and when people will be held accountable

TYPICAL GAPS IDENTIFIED IN HEALTHCARE LITERACY

- Patients don't understand the information conveyed to them.
- Information is not reinforced multiple times, in multiple ways.
- It is difficult to understand if the receiver truly understood the information conveyed to them.
- Patients have language barriers.
- Patients don't want to seem ignorant.
- There are different levels of situational preparedness (e.g., emergency visit versus routine care visit).
- Healthcare workers assume that other healthcare workers are literate in a specialty other than their own just because they are healthcare workers.
- It is difficult to combat misinformation patients may have seen or heard.
- Patients without access to or savvy with digital technologies are left out of health literacy efforts.
- Conversation setting or circumstance is not optimal for understanding.
- Workers are not sensitive to the patient's previous healthcare experiences that may influence their understanding and perceptions.
- Workers don't know how to orient to another's perspective.
- Information is shared with patients when they are too emotionally overwhelmed to understand.
- There is no relationship between the patient and the provider beyond the day to day business of the clinical environment.
- Patients can't understand their health because they don't have basic literacy skills (e.g., reading, math, etc).

- Patients are threatened by providers who are in a perceived position of power.
- There are different levels of familiarity with the provider, which influences comfort and mutual understanding.
- Some clinical disciplines perceive that health literacy is not within their job description.
- Tools for health literacy are not used by those for whom it was intended.
- Data tied to health literacy is not analyzed, or the analysis is not shared, to inform practice.

Table 3: By identifying the gaps in healthcare literacy, organizations can tailor their project improvement efforts more effectively

☐ **Evaluate outcomes, celebrate wins, and adjust the plan when necessary.** Measure both process and outcome metrics. Outcome metrics include the rates outlined in the leadership checklist. Process metrics will depend upon the workflow you are trying to improve and are generally expressed in terms of compliance with workflow changes. Compare your outcomes against other related metrics your organization is tracking.

Routinely review all metrics and trends with both the advisory and project teams and discuss what is going well and what is not. Identify barriers to completion of action plans, and adjust the plan if necessary. Once you have the desired outcomes in the trial area, consider spreading to other areas (IHI, 2006).

It is important to be nimble and move quickly to keep team momentum going, and so that people can see the results of their labor. At the same time, don't move so quickly that you don't consider the larger, organizational ramifications of a change in your plan. Be sure to have a good understanding of the other, similar improvement projects that are taking place so that your efforts are not duplicated or inefficient.

Read this paper from the Institute for Healthcare Improvement to understand how small local steps

HEALTHCARE LITERACY METRICS TO CONSIDER ASSESSING

Process measures:

- Percent of patients who receive and understand written summaries of hospital care and post discharge instructions
- Percent of patients who are asked to 'teach back' written/verbal discharge instructions

Outcome measures:

- Percent of patients with an ED visit within 15 days of discharge
- Percent of patients who miss follow up care visits
- Medication adherence
- Readmission rates by demographic
- Percent of patients with complications due to uncontrolled chronic conditions

Patient-reported measures:

- Percent of patients who report continued tobacco/substance use at follow up
- Percent of patients who report breast milk as a primary feeding preference at the time of newborn delivery
- Percent of patients who are considered good historians of care received during hospitalization and in the 30 day post discharge period
- Percent of patients who report accessing preventive care services within 90 days post discharge
- Percent of patients who report ever accessing preventive care services at the time of admission
- Percent of patients who report poor adherence to any prescribed medications at the time of admission or post discharge
- Percent of patients who self-report fair or poor overall health status

Table 4: Consider evaluating related metrics to better understand healthcare literacy performance and barriers to improvement. Consider short-term (e.g., patient understanding post-discharge) and long-term metrics (e.g., lowered A1C due to patient understanding of the importance).

What We Know About Healthcare Literacy

In any situation, a person decides what to do based on an understanding of facts, issues, options for action, and consequences. In the context of healthcare, this understanding is encompassed by the term "health literacy", and its huge importance is demonstrated by the fact that improving health literacy is one of the U.S. government's Healthy People 2030's Foundational Principles and Overarching Goals (Healthy People 2030, 2021). The scope and variation of the health literacy problem across the U.S. is revealed by findings that even in the best performing counties 15% to 27% of the population had limited health literacy, while in the lowest performing counties the number was 36% to 59% (United Health Group, 2021).

Inadequate health literacy is an issue plaguing communities on a global scale, and it is crucial that when aiming to improve a communities health literacy levels that it is done in a way that is specific towards the community in which it is being targeted. Health literacy and culture work synchronously such that communities and culture influence the ways in which health literacy is built and sustained (World Health Organization, 2013).

Personal health literacy affects a patient's ability to navigate the healthcare system, locate providers and services, fill out complex medical forms, and engage in chronic disease management and self-care. Limited literacy results in higher than necessary morbidity and mortality, with research demonstrating links in a number of serious and costly areas including medication errors, delayed diagnosis, decreased use of preventative services, increased rates of hospitalization, poorer health status, and limited self-management skills. The CDC estimates that improving health literacy could prevent nearly 1 million hospital visits and save over $25 billion yearly (CDC, 2021).

Efforts to increase health literacy are an organizational imperative. In addition to personal health literacy, the CDC stresses the importance of organizational health literacy, defined as "the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (CDC, 2021). The Joint Commission embeds the concept of health literacy into several of its requirements and initiatives, emphasizing that improving practitioner-patient communication must be a priority across the continuum of care, and even that improved communication must be promoted through policy changes.

Resources

For Health Literacy Improvement:

- Center for Health Care Strategies: Health Literacy Fact Sheet
- Plainlanguage.gov
- Health Literacy Tool Shed
- The Newest Vital Sign: A Health Literacy Assessment Tool for Patient Care and Research
- AHRQ: Health Literacy Universal Precautions Toolkit, 2nd Edition: Plan-Do-Study-Act (PDSA) Directions and Examples
- Health Literacy and Shared Decision-making: Exploring the Relationship to Enable Meaningful Patient Engagement in Healthcare
- Examining the Impacts of Health Literacy on Healthcare Costs: An Evidence Synthesis

For General Improvement:

- CMS: Hospital Improvement Innovation Networks
- IHI: A Framework for the Spread of Innovation
- The Joint Commission: Leaders Facilitating Change Workshop
- IHI: Quality Improvement Essentials Toolkit
- SIPOC Example and Template for Download
- SIPOC Description and Example

Endnotes

Conflicts of Interest Disclosure

The Patient Safety Movement Foundation partners with as many stakeholders as possible to focus on how to address patient safety challenges. The recommendations in the APSS are developed by workgroups that may include patient safety experts, healthcare technology professionals, hospital leaders, patient advocates, and medical technology industry volunteers. Workgroup members are required to disclose any potential conflicts of interest.

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