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Literacy and Language Barriers to Overcome in Laboratory Medicine

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INTRODUCTION

Meaningful Access

Patient–provider communication occurs through a variety of mechanisms, including Web-based portals and mobile phone applications. This is also true for patient communication with laboratory medicine, a multidisciplinary clinical service that includes preventative screening, diagnosis, disease management, and surveillance.¹ Increasingly, patients are gaining access to electronic health information, such as laboratory test results, clinical notes, and discharge summaries, immediately upon availability, often without a provider available to review the results, discuss, and help interpret this information. While increased access to electronic health information is an intended result of federal efforts (eg, Cures Act)² to empower patients to make informed decisions about their health and care, it is essential to recognize ongoing barriers and inequities in patient access and understanding of the information contained in online medical records—particularly as it pertains to the interpretation of complex or sensitive information, such as laboratory results.

The promise of immediate access to electronic health information also comes with the challenge and responsibility of ensuring this information, often designed to be interpreted and communicated by health care professionals, is comprehensible to all populations—

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including individuals with low health literacy and limited English proficiency (LEP). In 2015, the US Census Bureau estimated that over 350 languages are represented in the US population.³ A 5 year estimate (2018–2022) from the American Community Survey indicated that 60.4 million of the total US population (21.7%) speak a language other than English at home,⁴ with Spanish (13.3%) as the second most spoken language. Moreover, people with LEP (“Individuals who do not speak English as their primary language or who have a limited ability to read, speak, write, or understand English”)⁵ represent 40% of those who do not speak English as their primary language and 8.2% of the total population.^{6,7} Therefore, with the increased reliance on technology to access and interpret health information, it is critical to ensure that these advances do not create or exacerbate existing barriers to effective communication of health care-related information, particularly laboratory medicine.

The purpose of this review is to describe the associated practices, possible effects, and available solutions for mitigating 3 types of structural barriers to achieving equitable access to and understanding of health information produced within laboratory medicine in health care and public health settings for individuals with LEP.^{8–10} We describe 3 barriers^{11–13} to achieving (1) equitable *access* to health information in physical and online environments; (2) clear and effective *communication* of health information from public health practitioners, health care providers, and administrative staff that is appropriate for populations with varying levels of health literacy; and (3) *language responsiveness* to address LEP.

Addressing these barriers involves actions that account for socioeconomic and cultural factors to create long-lasting and protective effects as described by multiple public health models, such as the Health Impact Pyramid,¹⁴ while embracing the multilingual and multicultural nature of patient populations in the United States. Lastly, we present options to reduce and prevent these barriers in laboratory medicine beyond translation of reports into other languages.

Barriers and Inequities

In the United States, studies have long documented the adverse effects of low health literacy and LEP on access to and quality of care.¹⁵ This is of particular importance for aging and diverse populations that frequently require the use of laboratory services, and population groups that endure the disparities and adverse effects of specific health care inequities, such as insufficient responsiveness to ensure effective communication with populations with LEP.

Health literacy affects all populations to varying degrees. Limited personal health literacy is a social risk associated with adverse health outcomes.¹⁶ In contrast, organizational health literacy is a social determinant of health that can make it easier or more difficult for individuals to access and understand health information.^{17,18} The Centers for Disease Control and Prevention (CDC) defines organizational health literacy 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.”¹⁹

For personal and organizational health literacy concepts, poor health literacy adversely impacts health communication and may mediate the relationship between socioeconomic

status and health status.²⁰ Organizational health literacy should provide health literacy initiatives to foster understanding of health communication and to improve patients' health literacy. This article focuses on the need for organizational health literacy and its role in health communication, particularly in laboratory medicine.

Dissecting Barriers

Access: the need to achieve equity—Communicating timely and accurate laboratory test results is critical in disease diagnosis, management, and surveillance.¹¹ The Cures Act's final rule, which implements information-blocking provisions of the 21st Century Cures Act, supports patients' access to test results by mandating the immediate electronic availability of test results. A recent study reported that patients prefer immediate access to test results, but overall access preferences vary (especially for abnormal or sensitive results).^{21,22}

Laboratory test results are commonly reported through electronic patient portals. Despite this common practice, several studies have identified racial and ethnic disparities in who is offered access to their patient portal,²³ as well as differences by income, education, Internet access, and geographic location (ie, rural vs urban areas),²⁴ which likely contribute to disparities in patient portal access and use.²⁵ Other barriers to access include LEP, health literacy, and technological barriers (eg, limited Internet access or discomfort with computers). Preferences for using technology to interact with health care providers and perceived lack of need to mitigate those barriers are other factors that may contribute to differences in access to patient portals.²⁶

Provider–patient communication: conveying health information more effectively—LEP and health literacy impact communication between patients and health care providers. Here, we define language concordance as communication between patient and provider using the same language. With 21.7% of the US population speaking a language other than English, the availability of multilingual health communication efforts to achieve language concordance should be the norm as it is associated with better health outcomes and patient satisfaction.^{27,28} Language discordance and low provider capacity to adapt to differing patient health literacy levels may render such communication less effective and adversely affect health outcomes.^{29–31}

Patient–provider interaction involves multiple communication channels and occurs more frequently in online environments (eg, electronic patient portals and mobile applications).^{23,32} Patients prefer the use of mobile devices to see their laboratory results. However, access disparities are still present.^{23,32–35} Furthermore, LEP and literacy factors may interfere with a patient's ability to obtain information to interpret the results.³⁶ The provider must be educated regarding the patient's cultural context, literacy gaps, and linguistic needs to communicate medical information effectively. Standardized efforts to improve the Spanish competency of medical professionals can also improve information accessibility.³⁷

If organizational health literacy does not provide clear health communication, patients may look for information from unvalidated sources. Although the Internet offers abundant health information, it is difficult to discern which information is accurate (eg, misinformation,

disinformation) or from reputable sources^{35,38,39} and to avoid the infodemics or dissemination of false information.⁴⁰ One's ability to identify credible sources is impacted by language and literacy barriers and use of culturally competent health communication.^{41,42} Organizational health literacy efforts using plain language may help present information to populations in ways that increase the credibility of the health information during the patient's search for such information.³⁸

Language responsiveness: improving health communication in other languages to pursue equity—

The importance of health literacy in successful health communication is widely recognized independently and in combination with other social determinants of health.^{43,44} Although multiple efforts exist to raise awareness and address health literacy, many gaps remain, particularly in laboratory medicine.⁸ For example, poor health literacy leads to poor health outcomes in populations with LEP. Still, health literacy is rarely measured in public health or health care interventions, even though disparities are widely known.^{45–47}

Health literacy research should go beyond documenting and measuring literacy skills and the associated disparities.⁴⁸ Systematic efforts to address health literacy should consider overall social factors and foster approaches focusing on populations with specific needs to achieve equitable—not just equal—access.¹⁹ Operational and clinical approaches that are aimed to support a wide range of health literacy needs can contribute to more effective health communication globally. Current efforts include using plain language summaries to effectively communicate research findings to nonexpert audiences^{49,50} and other forms of health communication, such as written informed consents.⁵¹

CLINICAL RELEVANCE

The Total Testing Process

Lubin and colleagues¹¹ expanded the total testing process (TTP) representation to account for data application, quality practices, competent workforce, and multidisciplinary engagement. Lazaro⁹ described the need for effective communication in the pre-analytic and post-analytic stages of the TTP, particularly where patient engagement was required. The patient situations described later illustrate the effects of language discordance and poor health literacy on disparities in chronic diseases where laboratory medicine is widely used.

Actions Driven by Results

Understanding blood sugar and kidney function with laboratory test results often includes patient engagement, particularly during the reporting and interpretation of results, which can be impacted by language and literacy.⁵²

The following case illustrates the impact of inappropriately using race in calculating one of the standard diagnostic criteria for chronic kidney disease (CKD)⁵³ and highlights opportunities to advance organizational health literacy, particularly in disproportionately affected populations with specific linguistic and cultural needs.

Clinical example: chronic kidney disease and estimated glomerular filtration

rate—According to the CDC, it is estimated that more than 1 in 7 people (14%) have CKD.⁵² Among them, CKD is more common in women (14%) than men (12%), people aged 65 years or older (34%), African American persons (19.5%), Hispanic persons (13.7%), and Asian persons (13.7%).⁵² The 2 most prominent risk factors for CKD are diabetes and high blood pressure,⁵⁴ which are highest in African American and Asian populations (first and second, respectively), and Hispanic populations (third and fourth highest prevalence).^{55,56} Such elevated risks and their consequences are explained mainly by social determinants of health, such as built environment, food insecurity, and socioeconomic status, among other forms of structural inequities.^{57,58}

The complexity of CKD starts with its diagnosis. Alfego and colleagues⁵⁹ found that 80.3% of over 28.2 million at-risk patients (with diabetes, hypertension, or both) did not receive a guideline-concordant assessment of CKD. More recent publications and the national societies that the authors were associated with^{60–62} have encouraged the removal of race as a variable to calculate estimated glomerular filtration rate (eGFR). These recommendations aim to reduce inequities in eGFR interpretation and subsequently CKD outcomes, such as reducing the wait time for preemptive kidney transplantation waitlist eligibility in African American persons and disparities in their cardiovascular care.^{60,63,64}

Once diagnosed, a patient with CKD requires frequent laboratory testing, which involves a clear understanding of pretest instructions and post-analytic results. Laboratory testing for CKD reflects the complex relationship among electrolytes, kidney function, and other risk factors. The diagnosis and management of CKD warrant health communication approaches that account for the general population, but particularly for disproportionately affected populations where low health literacy and LEP exacerbate the adverse effects of CKD.^{54,65,66}

Although chronic kidney disease epidemiology collaboration (CKD-EPI) 2021 became the recommended equation to calculate eGFR without using race as a coefficient in 2022,⁶⁰ not all laboratories in the United States have implemented the recommended equation. In a 2022 College of American Pathologists survey, only 65.8% of laboratories reported adopting the CKD-EPI 2021 equation.⁶⁷ This lagging presents an opportunity for laboratory professionals to drive the total adoption of the recommended equation through the TTP, particularly through the reinforcement of clinical and laboratory professional engagement. This effort also requires collaborative work with insurance payers, regulatory agencies, and organizations to address health equity issues in diagnosing CKD earlier through confirmatory testing.⁶⁰

CKD presents an opportunity to reflect on the implications of race and other social factors (eg, culture, language), in organizing a person's identity and his/her critical role in preventing the onset of complex chronic diseases. This is particularly relevant in regard to patient populations with LEP and high-risk factors.^{55,56}

REVIEWING PLAUSIBLE SOLUTIONS TO OPERATIONALIZE ACCESS

Although patient portals serve multiple purposes, we focus on how to use organizational health literacy to improve the patient experience on patient portals as it relates to laboratory testing: ensuring all patients are provided information about where to find and how to use the portal (access), improving patient portal designs through diverse usability group validations (language responsiveness), and contextualizing health information through patient feedback (health communication).

Increasing Patient Portal Access through Patient Engagement

The increased availability of methods for accessing test results via Web-based portals and health applications has contributed to the significant progress in patient access to online medical records.^{32,33} Offering online access to patient portals is an essential precursor to enabling subsequent access and use, and greater health care provider involvement can also contribute to increased patient access.²³ This points to the critical role health care providers play when they meaningfully engaging in health communication and foster patient-provider trust. Among patients who were offered and encouraged to register to patient portals, Black and Hispanic individuals were more likely than White individuals to use portals to download or transmit information.²³ Achieving patient portal registration equitably, especially among populations with LEP and low health literacy, may represent the first step to enhancing patient-provider communication systematically.

Improving Patient Portals Using a Patient Experience Design

The Civil Rights Division of the US Department of Justice published a technical assistance guide to improve access for people with LEP and highlight the critical need for entities (eg, federal, state, and local governments, health care, and educational institutions) collecting and monitoring language data from public-facing Web sites and digital portals.⁶⁸ This document provides resources to implement language data collection systems and effective digital portals to address digital literacy and access disparities, particularly for speakers of languages other than English.⁶⁹

Multilingual options for Web sites are standard across the US government⁷⁰ and state departments.^{71–73} Approaches for multilingual Web design are available, including language selector guides to create multilingual content.⁷⁴ Table 1 lists guidelines and regulations related to language access and health literacy. Operationalizing access to health communication in laboratory medicine, accounting for existing disparities due to language discordance and low health literacy, entails a multidisciplinary approach that learns from patient's needs and responds with contextualized, patient-experience designs (PXD). A PXD approach addresses systemic access disparities in populations that have been marginalized by making information via mobile devices accessible.^{26,32,33} Additionally, health communication efforts in laboratory medicine can be improved by validating a contextualized version of user interface (UI)/user experience that integrates patient feedback and multidisciplinary collaboration into the final design.⁷⁵

Contextualizing Health Information to Improve Health Communication

Mass communication of public health and health care messages was a daunting challenge during the COVID-19 pandemic. Although the English language is standard to communicate science globally, communicating daily and critical messages (including scientific research) are challenged by the linguistic and cultural nuances of the listeners/readers and the rapid spread of misinformation and disinformation (false information intended to mislead) primarily through social media networks.^{76–78}

Kusters and colleagues⁷⁹ compared information broadcast during the COVID-19 pandemic in English and Spanish and identified that COVID-19 information available in Spanish was inferior compared to similar information in English. The limited type and delivery of scientific information in Spanish added to the vast spread of false information and exacerbated the reliance on informal and immediate sources of information from the United States and other countries, which could contribute to the disinformation and misinformation among Spanish speakers and speakers of other languages.^{76,80}

This combined misinformation and disinformation spreading through digital environments, also known as infodemics, is expected not only during outbreaks or pandemics but also during routine health communication (eg, communicating preparation instructions for laboratory testing and laboratory test results). Specific actions are needed to bridge communication among laboratory professionals, digital environments, and the patient's information needs, for example, engaging patient communities to improve UIs and access to information using a PXD approach.

FUTURE DIRECTIONS

Community Engagement

Community engagement is founded on principles of community, equitable partnership, and collaboration that address barriers specific to improving patient health literacy and understanding of digital health information. Engaging patients and community representatives with a personal investment requires cultural humility and transparency by health systems and health care providers beyond what is commonly taught in medical training.³⁷ Brewer and colleagues⁸¹ described approaches consistent with the American Medical Informatics Association in June 2020, when they unanimously agreed to create a diversity, equity, and inclusion task force. Bakken⁸² wrote an editorial on this decision, highlighting the urgency for a discipline of social informatics. A review of 71 studies found greater efficacy for risk assessment, health care utilization, and health outcomes when individual-level social determinants of health data were incorporated into electronic health records.⁸² Ensuring options for patient language preference and adopting universal health literacy measures into electronic health records encourages patient engagement⁸³ (see Table 2 for health literacy and language access resources).

The community-based participatory research (CBPR) model is a collaborative approach that involves community members and organizational representatives to address multiple structural factors (eg, social, physical).⁸⁴ Laboratories may consider using a CBPR approach to validate that communication of laboratory results accessed through patient portals is

equitable. There is a growing body of rigorous examinations of CBPR approaches in the context of laboratory medicine and research. Brewer and colleagues⁸¹ described several of these cases whereby the central characteristic was the inclusion of individual-level social determinants of health (nonclinical) data that influence a patient's life and health as related to laboratory medicine.

Artificial Intelligence

There are multiple applications where artificial intelligence (AI) is used in health care (eg, laboratory studies, genetics, diagnostic imaging). Still, its future remains in continuous development⁸⁵ from probabilistic models (AI 1.0) to deep learning (AI 2.0) to generative text (AI 3.0).⁸⁶ Despite this evolution, optimizing equity for the use of AI in laboratory medicine must address unequal representation of training data and biased algorithms that may perpetuate (or create) inequities through communication technologies (eg, chatbots) that do not fully capture the cultural and linguistic nuances of US populations, automation, and assistive AI.^{87,88} Chatbots should be optimized using the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care to enhance language responsiveness and address health literacy issues.^{89,90}

The Health Literacy Objectives: Advancing Health Literacy Policy

Healthy People 2030, the fifth iteration of the decennial initiative for health promotion and disease prevention, added 2 health literacy definitions (personal and organizational) and 6 objectives. The 6 objectives are aligned with this review, but immediate actions have addressed only 3 objectives (those with available baseline data). We are confident that there will be opportunities to implement long-term initiatives that address linguistic and literacy factors systematically and track measurable progress when data become available for the remaining objectives.

The 3 objectives with available baseline data involve *checking for understanding* (teach-back method), *reducing patients reporting poor communication with their provider*, and *involving patients in decisions as much as patients wanted*. The only objective that showed improvement, using 2020 as the most recent data, was the one involving patients in decisions. The remaining 3 objectives are made of 2 objectives in development (addressing public health issues with high priority with no reliable baseline data available yet), aim to increase the proportion of people who say their online medical record is easy to understand and the proportion of adults with LEP who say their providers explain things clearly. The last objective is in research status, indicating it is a high-priority public health issue without reliable baseline data or developed evidence-based interventions to address it. The research objective aims to increase the population's health literacy.⁴⁷

The 6 objectives involve high-priority public health issues that are deeply rooted in the daily processes in health care and laboratory medicine. They offer a national approach to advancing health literacy. However, the limited improvement in health literacy highlights the need for commitment to systematic actions that implement organizational health literacy policies within all health systems.

SUMMARY

Access, health communication, and language responsiveness are interconnected and are personified by millions of patients needing equitable access to health communication.

The growing preference to access information through mobile devices is not unique to English speakers. Engaging patient communities and multidisciplinary teams of professionals are needed to produce Web-based and mobile-based patient portals with appealing designs to foster easier access, avoiding a lengthy registration process, language responsiveness, and contextualized communication to enable patients to make informed health care decisions.

Using unbiased AI should enhance health communication and provide additional disease diagnosis and surveillance options.

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KEY POINTS

- Access, health communication, and language responsiveness are interconnected and are personified by millions of patients needing equitable access to health communication.
- The growing preference to access information through mobile devices is not unique to English speakers.
- Engaging patient communities and multidisciplinary teams of professionals are needed to produce web-based and mobile-based patient portals with appealing designs to foster easier access, avoiding a lengthy registration process, language responsiveness, and contextualized communication to enable patients to make informed healthcare decisions.
- Using unbiased AI should enhance health communication and provide additional disease diagnosis and surveillance options.

Table 1

Guidelines and regulations related to language access and health literacy

Topic	Purpose/Goal	Guideline/Regulation
Content	Digital experience Multilingual content Principles human-centered design standard US government information in Spanish	21st Century Integrated Digital Experience Act ⁹¹ Introduction to translation technology ⁹² ISO 9241–110 Principles of the Human-Centered Approach ⁹³ USA.gov ⁹⁴
Plain Language	Use of plain language	Federal plain language guidelines ⁹⁵
Language Access	Improving access for people with LEP Updated language access plans of US federal agencies Language selector in government Web design	Language Access in Digital Portals and Data Collection Systems ⁹⁶ Language Access Plans ⁹⁷ US Web Design System ⁹⁸
Equity	Executive order to strengthen racial equity and Support for Underserved Communities Across the Federal Government)	Executive Order to Strengthen Racial Equity and Support for Underserved Communities Across the Federal Government ⁹⁹
Artificial Intelligence	Executive order on artificial intelligence Principles to address algorithm bias in health care (Guiding principles to address the impact of algorithm bias on racial and ethnic disparities in health and health care ¹⁰¹) Algorithm transparency and information sharing	Executive Order on Safe, Secure, and Trustworthy Artificial Intelligence ¹⁰⁰ Guiding principles to address the impact of algorithm bias on racial and ethnic disparities in health and health care ¹⁰¹ HealthIT.gov ¹⁰²

Table 2

Health literacy and language access resources

Source	Resource	Goal
AHRQ: Universal Health Literacy Precautions ¹⁰³	Tool 4: Communicate Clearly Tool 9: Address Language Differences Tool 14: Encourage Questions Tool 15: Make Action Plans	Strategies for clear communication ¹⁰⁴ Assess language preferences and language assistance needs ¹⁰⁵ Encourage patients to ask questions ¹⁰⁶ Easy steps created by patient and clinician to attain a health goal ¹⁰⁷
CDC	Create a Health Literacy Plan Develop and Test Materials The CDC Clear Communication Index Assess and identify barriers to address and opportunities to improve health literacy. Health Literacy Activities by State Health Literacy Collaborations Find Training	Organizational improvement ¹⁰⁸ Make health information accurate, accessible, and actionable ¹⁰⁹ Develop and assess public communication materials ¹¹⁰ Assess health literacy in your organization ¹¹¹ List state and local collaborations and organizations with a health literacy focus ¹¹² Identify organizations to work together to improve health literacy ¹¹³ Identify training opportunities in health literacy, plain language, culture, and communication ¹¹⁴
US Department of Health and Human Services	National Action Plan to Improve Health Literacy	Improve health literacy ¹¹⁵
LEP.gov	Language Access Plans Language Access Planning How to create multilingual content	List of updated language access plans from federal agencies ¹¹⁶ Resources to develop language access plans ¹¹⁷ Multilingual content ⁷⁴