

Health Literate Hawai‘i: A Blueprint to Empower Health and Wellbeing

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Abstract

Recent studies have identified high rates of chronic disease in Hawai‘i’s adults and youth. As the state responds to the COVID-19 pandemic and looks beyond it, the prevention and management of chronic diseases are critical for community health and wellbeing. Low health literacy is more common in rural populations, Filipinos, and Pacific Islanders in Hawai‘i, older adults, and many other groups with high rates of chronic disease. Promoting health literacy can reduce chronic disease burdens for individuals, families, and communities. Using the framework of the social-ecological model, which is important for visioning effective chronic disease management and prevention, this article provides a blueprint of layers of influence for building a health literate Hawai‘i generally and around chronic disease specifically. The article will close with a call to action informed by the National Action Plan to Improve Health Literacy for stakeholders and providers to address health literacy in the state of Hawai‘i in organizations, systems, and policy. These actions should address root causes of disease and help build more equitable health outcomes across the state now and in the future.

Introduction

Recent studies have identified high rates of chronic disease in Hawai‘i’s adults and youth.^{1,2} Chronic disease is associated with low health literacy,³ defined as a limited capacity to obtain, communicate, process, and understand essential health information and services in order to make appropriate health decisions.⁴ Low health literacy is more common among rural communities, older adults, as well as Filipinos and Pacific Islanders in Hawai‘i compared to other racial/ethnic groups.⁵ However, even those considered to have “adequate” health literacy may still struggle to obtain, process, and understand health information without effective support from providers, caregivers, health organizations, or social networks. This may be particularly true in times of stress, such as after a new diagnosis, or while navigating the complexities of a society transformed under COVID-19, which includes new health information, potentially unfamiliar remote technologies, and greater responsibility for self-management.

Health literacy challenges are of the utmost importance for individuals with chronic conditions.³ Chronic illness prevention and management encompass many skills, from reading prescription medicine and using social skills to find relevant health information, to evaluating and applying recent research findings and appraising treatment options. Chronic care management is enabled through partnerships with providers and often includes managing complex medicine regimens and medical bills, following restricted diets, changing physical activity habits, and staying vigilant even when feeling fine.^{3,6} Given this complexity, those with lower health literacy often have less understanding of chronic disease prevention, a higher

prevalence of illness, and poorer disease management than those with higher health literacy.³

As the state and its residents respond to the COVID-19 pandemic and look beyond it, the prevention and management of chronic diseases are critical for the health of Hawai‘i’s communities. Promoting health literacy can reduce chronic disease burdens for individuals, families, and communities and reduce health disparities.^{3,7} Using the framework of the social-ecological model (SEM), which is important for visioning effective chronic disease management and prevention,^{8,9} this article provides a blueprint of levels of influence and inflection points for building a health literate Hawai‘i generally and around chronic disease specifically. The article will close with a call to action informed by the National Action Plan to Improve Health Literacy (NAP) for stakeholders and providers to address health literacy in organizations, systems, and policy.¹⁰ The NAP (Table 1) has 7 broad goals and has been influential in research and practice. We use NAP framework to consider action steps to improve health literacy across levels of the SEM in order to build sustained and comprehensive change.

Health Literacy

Health literacy is one of the national goals of Healthy People (HP) 2030.¹¹ Within the HP 2030 definition, health literacy is conceptualized as a bidirectional synergy between personal and organizational health literacy.

Personal

Personal health literacy is defined by Healthy People 2030 as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”¹¹ Over the past 30 years, researchers and advocates have exposed an often hidden national burden of low health literacy.¹² Research has found that 36% of American adults have low health literacy and may have challenges with basic health information.¹³

Personal health literacy was first revealed by practical challenges often related to basic skills, such as being unable to read well enough to follow medication directions or to fill out medical forms.⁵ As a study participant in rural Hawai‘i noted: “The assumption is that everybody can read... But not everyone can read.”¹⁴ One-third of residents in several Hawai‘i communities self-reported a struggle with basic health literacy tasks.¹⁵

Develop and disseminate health and safety information that is accurate, accessible, and actionable.	<ul style="list-style-type: none"> • Provide health information across languages, especially Pacific Islander and Asian languages, with cultural relevance. • Provide reliable, official information that is easily accessible without requiring visits to multiple websites and calls to non-answered phone numbers. • Remind people of the importance of managing their chronic disease even in the stress and complexity of the pandemic. • Empower the community. As the Islander Institute highlights in the #spreadALOHANotCOVID campaign: everyone can be a first responder and everyone can be a healer.⁸⁰
Promote changes in the healthcare delivery system that improve information, communication, informed decision-making, and access to health services.	<ul style="list-style-type: none"> • Follow the "Ten Attributes of Health Literate Health Care Organizations" to create an environment that enables people to access and benefit optimally from health-care services.⁸¹ • Perform a health literacy self-assessment. • Design signage, forms, websites, and apps from a health literacy perspective.^{32,82} • Assist patients with accessing the care they need (e.g., making referrals easy) and with understanding health care bureaucracy and cost. • Provide simple guides for medications and other health self-management practices.^{83,84} • Reinforce what patients are doing well and partner with them to develop strategies that will help them achieve goals safely.³² • Provide access to materials and linkages to address social needs as well as health needs. • Community-clinical linkages are critical. Community health workers, who bridge critical gaps between health care and community needs, are fundamental to this effort.⁸⁵⁻⁸⁷ • Recognize the importance of social connections in interventions and incorporate social networks and social context in interventions for individuals with chronic illness, a perspective that may be particularly meaningful for Native Hawaiians and Other Pacific Islanders.³⁰
Incorporate accurate and standards-based health and developmentally appropriate health and science information and curricula into child-care and education through the university level.	<ul style="list-style-type: none"> • Ensure that there are health standards in Hawai'i public health settings and public schools at all levels⁴⁰ • Recognize that equity is critical, particularly as the pandemic is exacerbating educational disparities in Hawai'i that may have consequences that last a lifespan, and even beyond as educational inequities can be intergenerational.
Support and expand local efforts to provide adult education, English-language instruction, and culturally and linguistically appropriate health information services in the community.	<ul style="list-style-type: none"> • Continue critical outreach efforts even in the pandemic when volunteers for non-COVID-19 activities are strained. • Utilize social media to deliver relevant messages in different languages by influential and trusted individuals.⁸⁸ • Consider cultural liaisons and multilingual community health workers as a link between individuals, communities, and healthcare organizations.
Build partnerships, develop guidance, and change policies.	<ul style="list-style-type: none"> • Support the new cross-sector relationships that have been made in COVID-19. • Continue linking community with health care organizations to build partnerships that provide relevant resources for chronic disease and COVID-19 management. • Integrate clear communication and health literacy into public health planning, funding, policy development, research, and evaluation as recommended by the CDC.⁴⁰
Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.	<ul style="list-style-type: none"> • Fund research into Hawai'i-specific communication needs, which are understudied and underfunded. • Include population-based needs assessment and program evaluations with disaggregated Asian American and Pacific Islander populations to understand needs and outcomes.
Increase the dissemination and use of evidence-based health literacy practices and interventions.	<ul style="list-style-type: none"> • Continue to gather and promote consolidated resources around health literacy in Hawai'i.^{89,90} • Sustain the growing collaborations in the time of COVID-19, including HDOH, grassroots organizations, health care organizations, build natural partnerships for sustainable locations for testing and disseminating evidence-based health literacy approaches across a variety of real-world settings

Over time, the global understanding of what personal health literacy encompasses has expanded to include other capabilities that promote and maintain wellbeing, such as being able to evaluate and apply recent information to changing circumstances; to use social skills to find and communicate relevant health information; and to understand and use health data and statistics (numeracy).¹⁶ These challenges are often coupled with additional barriers to health communication, including limited English proficiency (LEP).¹⁷ According to the US Census classification, 1 out of 8 people (12%) in Hawai'i speak English "less than very well."¹⁸

The pandemic has exacerbated inequities related to health literacy. For instance, clear messaging to those with LEP has been a major issue in pandemic health communication in Hawai'i and beyond.¹⁹ Furthermore, digital health literacy is a prominent and growing issue, particularly critical in the time of this pan-

demie, which has occurred alongside an infodemie—a tsunami of complex, conflicting, and overwhelming information that is rapidly changing and often biased.^{20,21} Low personal health literacy has been associated with poorer health outcomes and less health-related knowledge,²² and these relationships may grow even stronger in the pandemic.

Organizational

Organizational health literacy is defined by Healthy People 2030 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."¹¹ The organizational context is important as the complexities and demands of health care and public health systems impact how easy or difficult it is to be health literate.²³ Limited personal and organization health literacy lead to higher

health care expenditures.^{24,25} Following organizational health literacy principles not only supports health literacy, but can also promote patient-centered care, better patient-provider engagement, as well as effective and culturally relevant communication in treatment, diagnosis, prevention, education, research, and outreach.²⁶ Health care settings with organizational health literacy offer patient education materials in plain language, an opportunity to ask questions, a confirmation of understanding through teach-back methods, and follow a universal precautions approach in health information exchange, meaning all patients are treated as if they are at risk of not understanding.²⁷

While the relationship between personal and organizational health literacy is critical, achieving health literacy is a multilayered and dynamic process across many other layers of influence.²³ Individual health literacy skills and abilities interact with health care organizations, within a family, community, and policy context impacting health and well-being.

Layers of Influence for Achieving a Health Literate Hawai'i

The SEM is an influential model that contextualizes individual health outcomes, knowledge, and behaviors across multiple levels of influence: individual (e.g., modifiable and non-modifiable personal health factors); interpersonal (e.g., family, friends); organizational (e.g., health care environment); community (e.g., neighborhood context); and policy (e.g., state and federal). Chronic disease prevention and management is best considered within the context of the SEM for optimal outcomes for individuals and populations.^{8,9} Below, health literacy across the levels of the SEM are considered as a blueprint for areas where action to build health literacy are needed.

Individual

Health literacy is associated with demographic factors, including age, education, race/ethnicity, location of residence, and language.²³ Chronic illnesses are similarly associated with demographic factors in the US. Those who are older, have less education, of minority race/ethnicity, have rural residence, and have LEP are more likely to have poor health outcomes.²³ To build stronger health literacy and improve chronic disease health outcomes, health systems must be equitable for individuals regardless of individual characteristics. Individuals need to be able to access culturally appropriate information about chronic disease prevention and management, other health-related topics, and information to address social needs in formats and languages they can understand and trust.²⁸ Chronic illnesses are hard to manage, and behavior change is hard to sustain. Individuals need to know when a situation is a health emergency and when it is time to see a health professional²⁹ as well as where, and when, to get physical and mental health care to manage diet, exercise, and stress. Increasingly, individuals access medical care online. Taking care of chronic conditions at home necessitates not only

clear, relevant patient education but also patient empowerment. In the COVID-19 pandemic and beyond, individuals need accessible, easy-to-understand and follow health information to discern which activities are “essential” and safe for the health of family members and communities, and health systems must support people unfamiliar with finding health information online or participating in telehealth.

Interpersonal

Like chronic disease prevention and management, health literacy is built and sustained through relationships and conversations. Thus, health literacy has been considered “distributed,” a capacity embedded within social networks and interpersonal relationships.⁶ Similarly, a recent study noted that “greater inclusion of social and familial networks can help address health disparities among people with chronic illness and enhance culturally relevant healthcare.”³⁰ Some critical interpersonal relationships to consider are provider-patient, caregivers, and social networks.

Provider-Patient

All patients should feel welcomed and comfortable at each stage of their health care encounter – from a telephone call, to reception, examination, procedure or inpatient room, and to finance area. Providers can help build health literacy and reduce chronic disease by being inclusive of health literacy principles in their practice, especially by remembering to use plain language in every interaction, even over telehealth, and including teach-back or show me methods.^{31,32} Health communication should be effective, conducted in a shame-free environment, summarized into 3 to 5 key points, include visual cues, models, pictures, and/or videos. As much as possible written materials should be written at a fourth- to sixth-grade reading level, use short sentences and simple words, provide clear instructions, and include pictures.³³ For example, providers can ask patients how they will take their medication tomorrow or how they will explain their treatment to their family or friends, instead of asking, “Do you understand?” as most patients will automatically say “yes.” The Centers for Medicare and Medicaid Services has a toolkit to support the development of effective health information materials³⁴ and Agency for Healthcare Research and Quality (AHRQ) has a tool to assess already developed patient education materials.³⁵

Caregivers

The health literacy of caregivers is increasingly important in the time of COVID-19 as patients may be less willing to attend primary care visits and/or more reliant on online health information and their caregivers’ support. Caregivers must be supported with information for their own health literacy, including access to community and educational resources. Activities that promote health and wellbeing can engage families and social networks

to decrease isolation and loneliness. In COVID-19, these social activities may need to be creatively carried out to remain safe, but can also engage individuals across distances in innovative ways that can be deeply meaningful.³⁶

Social Networks

Many individuals with low health literacy specifically draw upon social networks to better understand health care concerns.³⁷ Recent studies highlight the critical importance of incorporating social networks and social context in interventions for individuals with chronic illness, including among Native Hawaiians and Other Pacific Islanders, who have higher rates of chronic disease. Many individuals had social network members engaged in their health decisions and in the management of their chronic disease. However, in these particular studies of vulnerable adults, networks were often small and most members were family.^{30,38} A social network lens is important to health literacy, but important variations exist in strengths, size, and diversity of these networks that may impact health literacy, chronic care management, and knowledge.^{30,38,39} This links with the need to support caregivers, as sometimes the only social network member is the caregiver. Of note, some individuals are “isolates” with no social network members.³⁰ In these cases, they may need augmented support from the health system or other services to confirm health literacy and prevent and manage chronic conditions.²⁹

Organizational

Health systems are critical levers for health and wellbeing and should follow health literate principles. Public health organizations must also be health literate to advance population health to all the citizens in their communities.⁴⁰

Health Systems

Organizational health literacy is particularly important for those with chronic illness who spend a considerable amount of time in the health care system. To reduce chronic disease, our health systems must be patient-centered and user-friendly, even as they expand into the digital health technologies. Digital health technologies, including telehealth and remote monitoring systems are new to many people, especially the elderly, and often not self-explanatory. Health literacy inequities may be exacerbated by new technology and its complexities, costs, and access challenges. Both patients and health providers would benefit from more guidance on how to use these services. Telehealth has known inequities^{41–43} and new ones are likely to be revealed during COVID-19.⁴⁴

Public Health Systems

Public health systems need to work closely with communities to provide easy-to-understand and culturally relevant informa-

tion across languages to support chronic disease prevention and management. Departments of health must engage with community knowledge to advance health equity and support population health literacy. COVID-19 has revealed challenges in our public health sectors, which have been significantly underfunded,⁴⁵ as well as amazing commitment and engagement in the response to meet dynamic community needs.⁴⁶ Public health systems must be funded at higher levels to allow the outreach to meet community needs to build health literacy and better chronic disease outcomes. The pandemic cannot be an excuse to cut preventive health systems even more or there will be poorer health outcomes over time and communities will be more vulnerable to future pandemics due to higher chronic disease and associated preventable illnesses.^{45,47}

Community

Health literacy can be explicitly community-oriented, comprising the knowledge and tools to build trust and advocate for collective wellbeing and chronic disease management. Community level health literacy is independently associated with health outcomes.¹⁵ As currently described by the World Health Organization, health literacy is explicitly community-oriented, comprising the knowledge and tools to advocate for collective wellbeing.⁴⁸ Community social norms are critical to building healthy environments that promote wellness and reduce chronic disease.⁹ This perspective is highly relevant in the COVID-19 pandemic, which has exposed collective strengths and synergistic relationships, making the urgency of efforts to build health literacy for all within communities clear.⁴⁹ Many individuals, especially those with LEP, remain out of the informational cycle or trapped in conflicting health information.⁵⁰ Answers to build health literacy for groups at risk may come from communities themselves as they know their strengths and top concerns, including how to make health information relevant.

Policy

Policy changes that would help build health literacy are critical for sustainable change. We consider several areas of particular importance for policy change to achieve health literacy.

Infrastructure

Equitable access to technology is critical to build health literacy in our digital age, especially in the pandemic. We must address the need for access to the tools such as computers, broadband, smart phones, and technical assistance. People cannot equitably become consumers of information and participate in telehealth without access to consumer tools. This issue is particularly acute for rural communities in Hawai‘i.

Social/Economic Needs

By acknowledging the fact that social factors impact health, we can build social safety nets and address institutional and structural barriers to health, including social marginalization. Understanding health information is not sufficient if one is not able to apply this knowledge due to social vulnerabilities.²⁹ Policies that recognize these connections and build ways to address health and social needs together are critical. For instance, social factors included into electronic health records can help identify the needs of individual patients and provide data that, when analyzed, can help us understand community-level barriers to better health outcomes and inform policies. Social needs such as housing are critical to giving individuals a stable chance to address and manage their chronic health conditions.⁵¹ Housing-first policies have been successful in supporting individual and community health.⁵²

Reimbursement Structures

Policy should support community health workers and community-clinical linkages that address gaps between patients knowledge and understanding and the high demands of the health care system in culturally relevant ways.⁵³ Health care organization can reimburse community health workers or other trusted liaisons that help address community health literacy, which requires sustainable payment structures.

Educational System

Health literacy is often built upon basic skills learned in school. As noted by the CDC: “Public health has a special responsibility to make sure children and adolescents have the health literacy skills - including math and science literacy - they need to prevent early-onset chronic health problems and protect themselves from infectious diseases, violence, and injury.”⁴⁰ Incorporating health literacy throughout schools demands policy and systems change.⁵⁴ To address the root-cause of limited health literacy, we should advocate for an equitable education system that includes comprehensive learning and skills across digital and socioeconomic divides. This should include health education about health promoting behaviors as well as when and how to access both physical and mental health care. National best-practice guidelines exist from early childhood education into college and there are many useful international models. Our educational system must continue to foster critical reading and thinking skills in all students, including how to appraise health information. Educational equity is tied to health equity, which is vital to community health and wellbeing. Critically in the time of the pandemic, educational inequity is increasing.⁵⁵ School health centers are also a place where health literacy can be created, as are adult basic education settings.⁵⁶ Locally, we have the “Hawai‘i Keiki” program, which is a partnership between UH Mānoa School of Nursing and Dental Hygiene and the Hawai‘i Department of Education that provides school nursing services to children.⁵⁷

A Health Literate Hawai‘i

Table 1 presents an action plan for a health literate Hawai‘i based on these levels of influence in the SEM, particularly the outer layers, which then can support individual and interpersonal wellbeing across all demographic and individual characteristics. A transformation to a health literate Hawai‘i can provide a foundation for building health equity. A health literate Hawai‘i would include clear and accessible information on meeting social needs, like acquiring healthy food, employment, and childcare. Achieving a health literate Hawai‘i includes making it easy for patients to read medication bottles and fill out health insurance forms, but also includes providing ways for patients to learn new skills and knowledge, such as how to fill prescriptions virtually and how to see a doctor for a telehealth appointment. A health literate Hawai‘i can be achieved by using plain language in medicine; building strong and fair health and educational systems; providing clear and accessible information on social needs; and creating easy-to-follow, culturally relevant health materials drawn from community knowledge. It also means taking collective action. Academia and government should help sustain these efforts to support and protect vulnerable communities (e.g., those in long-term care, those with LEP). Stakeholders and providers must continue to promote patient empowerment through health literacy even while eHealth, telemedicine, and remote care expands. A health literate Hawai‘i will help reduce chronic diseases by fostering collective and individual health and wellbeing.

Conclusions

Health literacy is more important than ever in the time of COVID-19.^{58,59} In Hawai‘i, the pandemic lessons have helped build collective health literacy on many topics. This includes the importance of trust, clarity, consistency, and cultural relevance in effective health communications⁶⁰⁻⁶² and the devastating consequences when these goals are unmet;⁶³ the fact that health is dependent not just on medical care, but on education, income, childcare, and other social factors including relationships, connectivity, and solidarity; and the value of understanding and interpreting data, including what data can hide or reveal.^{64,65} Large political structures can affect health,⁶⁶ economic prosperity depends on community health, and institutionalized racism and police violence are public health issues.⁶⁷ Given this, health equity across factors like education, income, English language proficiency, social support, and access to medical care are critical objectives for the collective wellbeing in an interdependent society.

Recognition of these factors should spur energy to conceptualize and build a health literate Hawai‘i. The people of Hawai‘i sacrificed and worked hard together to keep the communities safe and informed. They have created an extraordinary output of community-driven resources⁶⁸⁻⁷² in response to the emerging needs and challenges⁷³⁻⁷⁵ while engaging with government organizations, existing non-profits, and grassroots organiza-

tions.⁷⁶⁻⁷⁹ Hawaii's collectivist culture is a notable strength of this state along with its diversity. We should use these lessons to build a health literate Hawai'i and create more health opportunities for us all.

Conflict of Interest

None of the authors identify any conflict of interest.

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