ASOCIACIÓN LATINOAMERICANA DE AUTOCUIDADO RESPONSABLE

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# Self-Care Literacy Index

Improving health equity and access to care in Latin America

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# Foreword

Special thanks to EMOLUVA Partners for carrying out the literature review that led to the identification and selection of the self-care literacy indicators that make part of this index.

As we slowly emerge from a distressing pandemic that shook the world in 2020<sup>1</sup>, there is a need to re-establish the core value of health care to focus on the health and well-being of every individual as the main goal.

Integrated healthcare is an inclusive strategy that combines clinical, social, institutional, and regulatory changes to increase efficiency in health service delivery and ensure healthy outcomes<sup>2</sup>.

As an essential part of this strategy, **self-care** has a great potential to improve an individual's health by empowering them with knowledge, skills, and confidence to make the right decisions to proactively promote and maintain their health and utilize health systems more efficiently<sup>3</sup>. But as societies grow more complex and new ways to receive and send information become available, people are constantly confronted with the need to make the best decision. This is especially true for health decisions.

To achieve health equity and universal coverage, action is needed to improve the social determinants of health. As a modifiable social determinant, promoting health literacy may lead to improved equity and sustainability in public health as it embodies the skills and motivation needed to find, understand, evaluate, and use health information and improved health outcomes. Actions to improve health literacy must involve the whole of government and civil society. Very often, the problem is lack of data – both to assess the nature of the problem, and to monitor progress.

As the Latin American Association for Responsible Self-Care, we recognize the importance of measuring and improving health literacy as a means to support the empowerment and participation of individuals in their own self-care to enhance wellbeing. And so, we encourage policy makers and health organization partners to promote health literacy as a health priority and urge its appropriate inclusion in the context of people-centered health care



(IL<sup>3</sup>AF

# Summary

This white paper builds on the concept and assessment of self-care literacy, a term coined by the Global Self-Care Federation (GSCF) to describe a sub-domain of health literacy applied to the context of self-care.

Self-care literacy refers to the knowledge, motivation and competencies of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider<sup>3</sup>.

Strategies to integrate self-care literacy into policy and practice are needed. When individuals are empowered with knowledge and skills they enhance their self-efficacy in decision-making, healthy lifestyles and health promotion, and a better use of healthcare services.

The Latin American Association for Responsible Self-Care (ILAR) is launching a program for self-care literacy across Latin America based on the premise that self-care delivers the most value when there is also a high degree of health literacy and persons feel empowered to make good health decisions.

Because improved health policies and programs must be based on evidence and measures that capture the health and self-care literacy level and skills of their populations, developing a conceptual framework and a guide for the collection of this relevant data is a priority for ILAR.

The **Self-Care Literacy Index,** is an innovative research tool with the purpose of filling the information gap upon which health policies and programs can be developed, to improve health equity, ensure better use of health services, and increase health and well-being of individuals.

The 11 indicators developed are intended to help governments, policymakers, and others benchmark their progress and identify opportunities to address health education and promote self-care. These indicators are clustered into three domains: health services, health navigation and health promotion.

This white paper presents the Self-Care Literacy Index, why it was created, a review of its main findings which describes in greater detail its domains and indicators and concludes with a series of recommendations for state and non-state actors to position self-care literacy as a health policy priority for people-centered health, and to encourage dialogue and action toward better health for all.



# Abbreviations

- GSCF Global Self-Care Federation
- HCP Healthcare Professional
- HL Health Literacy
- HPV Human Papilloma Virus
- NHSC National health coverage system
- PAHO Pan-american Health Organization
- SCL Self-Care Literacy
- SCHLI Self-Care Health Literacy Index
- SDM Shared decision-making
- WHO World Health Organization





# Self-Care Literacy Index

# **PART I:** portance of

The importance of self-care literacy

# **Overview:** Challenges and Strategies to improve health outcomes in Latin America

The covid19 pandemic revealed weaknesses and areas of opportunity in health policies, health systems, and health promotion and prevention activities worldwide. In Latin America, the pandemic was particularly harsh, where a combination of social and health disparities and systems vulnerabilities led to unprecedented health and economic crises.

Vulnerable individuals in low-income and disadvantaged areas are commonly exposed to detrimental health, nutritional, and environmental factors, in addition to the stress from social marginalization, structural racism, and poverty. Unequal health care access played an important role in the increased covid19 mortality rates seen in Latin America compared with higher-income nations<sup>17</sup>.

A governmental commitment to reduce health disparities is critical for Latin American countries to adequately respond to future health emergencies. As components of social and public health promotion strategies, the transformation of health systems toward universal health coverage, and the healthcare shift from disease treatment to health promotion and disease prevention are warranted as means to save resources that can be reinvested in implementing additional social and equitable policies.

Integrated healthcare is a policy approved by the Pan-American Health Organization, in its 30th Pan American Sanitary Conference, that combines clinical, social, institutional and regulatory changes to increase efficiency in the delivery of services, ensure effective outcomes and improve people's experience and satisfaction<sup>2</sup>. An important strategic line of action of this policy is health promotion and **empower people to self-care** and to actively participate in decisionmaking about their own health<sup>2</sup>.

Self-care has always been present in some form in every society, and its relevance in responding to global crises such as the covid19 pandemic and other health challenges, has reinforced its place as an essential front-line resource to healthcare<sup>5</sup>. Self-care can be used by anyone seeking or using a health intervention, service or information; people caring for dependants; and communities or social networks<sup>18</sup>. According to the World Health Organization, the right to health for all can be advanced through self-care<sup>18</sup>.

Following the social ecological model approach, the WHO highlights the following key constructs that place self-care and health practices and behaviors, within the social context of the lives of individuals and communities<sup>18</sup>:

Promoting self-resilience, autonomy and agency as expressions of human dignity and development<sup>18</sup>;

Realizing that people having varying perceptions of health risks, and these may shape their values and preferences toward self-care interventions<sup>18</sup>;

Acknowledging that there are approaches to prevention, treatment and healina that are culturally and traditionally different among different societies and populations, and that offering choice in health decision making that is free of coercion, violence, stigma and discrimination is critical for improved health outcomes<sup>18</sup>:

Implementing a holistic view of health that integrates the roles of individuals as active agents in their own health decisionmaking; of social support and carers; and of human empathy, respect and caring in both health maintenance and in coping with ill-health<sup>18</sup>.



# Self-Care

According to WHO, self-care is the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health worker<sup>5</sup>.

In practical terms, self-care is the set of knowledge, skills, behaviors, actions and activities that people possess and do to take care of their health and to make the best decisions for their own benefit and their community throughout the life cycle.

Although self-care infers an individual approach, it is also influenced by environmental, economic and social determinants that allow and encourage (or not) individuals to engage in behavior to promote and preserve their health<sup>6</sup>. Therefore, self-care is a shared responsibility between the individual and the government and policymakers in creating environments that either enable or inhibit self-care.

Self-care is not one action, is a continuum, which scope includes health promotion, disease prevention and control, self-medication, providing care to dependent people, seeking professional care if needed, and rehabilitation, including palliative care<sup>5</sup>.

- Health Promotion Is focused on the conditions and settings that ensure health and well-being for all individuals.
- Disease prevention and control understood as the specific actions at individual and population level aimed at preventing diseases, reducing risk factors, and decreasing the burden of diseases, such as having good nutrition habits and using supplements in case of deficiencies.
- Self-medication involves using medicinal products, usually over-the-counter, to treat selfmanageable conditions or minor symptoms, or the intermittent or continued use of medication prescribed by a physician for chronic or recurrent diseases or symptoms.
- Seeking professional care recognizing when is necessary to seek professional advice and treatment, being part of the decision-making with the HCP, and following health recommendations to ensure recovery or proper health maintenance.

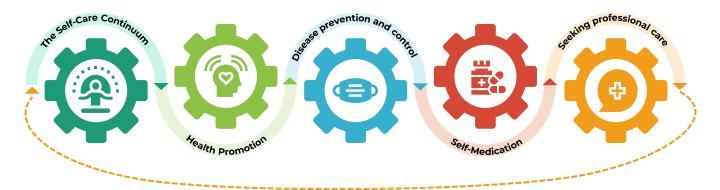


Figure 1. The self-care continuum.





# The value of **Self-Care** in Latin America

In Latin America and the Caribbean, the national health coverage system (NHSC) varies from low (e.g., 12% in Honduras and 24% in Paraguay) to high (e.g., 100% in. Brazil and 97% in Argentina)<sup>7,8</sup>.

There is low to moderate health services delivery and access in this region due to gaps in availability of healthcare providers, including physicians and pharmacists, as well as shortage of hospital beds. Out-of-pocket health expenses are higher than in the OECD<sup>7</sup>.

Non-communicable diseases are highly prevalent in the region accounting for more than 70% of all deaths<sup>7</sup>. Natural population growth and increased life expectancy in this region are placing greater demands on already limited health resources<sup>8</sup>.

Self-care, as an enabler for better health and wellbeing, offers a means to improve universal health coverage. 8 out 10 individuals in Latin America consider self-care very relevant and more than 90% declare they want more information and tools to put the concept into practice<sup>9</sup>.

Self-care offers several benefits for individuals, communities and health systems.

In 2022, the GSCF launched its Global Social and Economic Value of Self-Care study demonstrating that current self-care practices deliver significant economic savings and quality of life improvements for the region of Latin America<sup>8</sup>:

	Annual savings for health systems	<b>\$7.2</b> billion USD
<b>`</b> \$	Annual savings in productivity for individuals	<b>2.5</b> billion days
¢	Annual savings in welfare for communities	<b>\$79</b> billion USD
6	Annual individuals time savings	869 million hours
ශීං	Annual physicians time savings	122 million hours

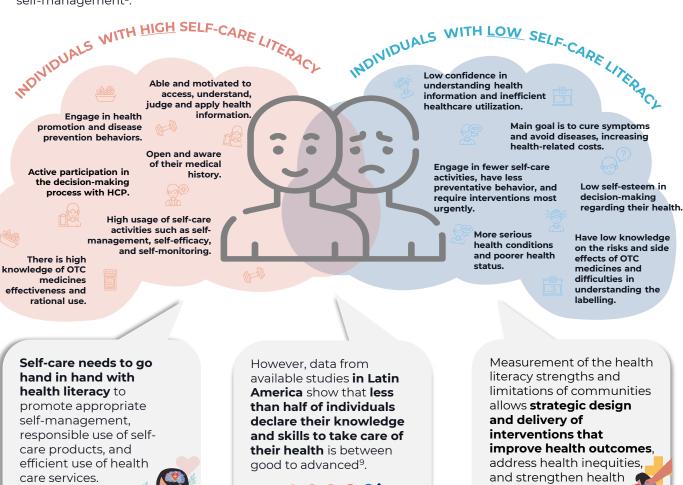


# **Health & Self-Care Literacy**

**Health literacy** entails the knowledge, motivation and competencies to access, understand appraise and apply information to form judgment and make decisions regarding health care, disease prevention and health promotion in everyday life to maintain and improve quality of life during the life course<sup>10, 11</sup>.

**Self-care literacy** describes the specific subdomain of health literacy related to self-care. It includes medication literacy, both over-thecounter (OTC) medicines and prescription medicines, as well as disease-related literacy, which also involves elements of self-care and self-management<sup>3</sup>. A scientific scoping literature review by the GSCF in 2021 revealed significant differences in the profile of individuals with high and low self-care literacy skills (Figure 2)<sup>3</sup>.

Studies evaluating the influence of health literacy on patient behavior and health outcomes in Latin America are few, regional, and demonstrate considerable variation, with reported rates of adequate health literacy ranging from 5.0% to 73.3%<sup>11</sup>.



systems<sup>12</sup>.

**Figure 2.** Profile of the health literate versus low health literate individual. Adapted from Global Self-Care Federation. (2022). Self-Care Literacy<sup>3</sup>.



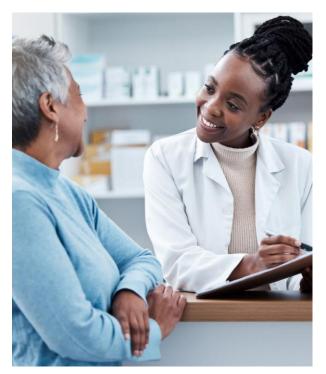
# Self-Care Literacy Index

Approaches to improving health for all have often focused on widening access to healthcare services, yet across Latin America health literacy and access to quality health information are significant barriers to healthcare and delivering on the full value of self-care, even as practices and policies are increasingly being considered and adopted in the region.

One of the first steps in building this program is to develop a way to monitor and measure health literacy in Latin America in the context of self-care. One of these mechanisms is the **Self-Care Health Literacy Index (SCHLI)**, which is a defined list of indicators and measurements to be utilized in survey instruments designed to collect data on health literacy in the region as it relates to specific self-care attributes.

To build the SCHLI, a pragmatic review of the academic medical literature was performed by EMOLUVA partners, using key word searches in Google Scholar and PubMed Central. Initial results were used to determine the many topics where self-care and health literacy overlap.

The list of topics was eventually narrowed to 11 with each organized under one of three distinct domains or dimensions (Table 1).

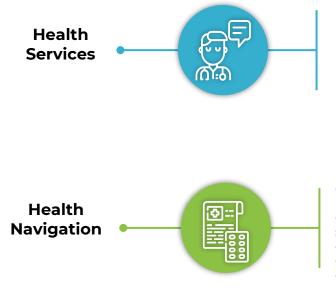


#### Table 1. Self-Care Literacy Domains and Indicators.

Table I. Self-Care Elteracy Domains and Indicators.			
	Health Services		
Screening	for preventable or treatable diseases and being up-to-date with public health screening recommendations is a proxy for self-care.		
Medication adherence & responsible use	is the general willingness to follow a medicines routine as indicated by a health care professional or product leaflet.		
Medical decision- making	is a person's ability to work with their health care provider so that decisions are shared and the chosen course of action is aligned with patient values and preferences.		
	Health Navigation		
eHealth literacy	is finding, evaluating, and using quality health information online. Increasingly, most health information is either delivered and/or sourced online.		
Self- management	is navigating an acute or chronic condition in parallel with the formal health system and includes confidence in the use of OTC products and community pharmacist guidance.		
e Per	Health Promotion		
Physical activity	is knowing the benefits of exercise and choosing an active lifestyle.		
Nutrition	is personal choice decisions around healthy diets and better eating habits.		
Positive mental health	is the avoidance of higher risk of mental health illness via social and emotional well-being.		
Vaccination	in the specific context of immunization by young adults and vaccination by the elderly.		
Health-related behaviors	around smoking, poor nutrition, harmful use of alcohol, inadequate physical activity, sufficient sleep, and overweight and obesity.		
Hygiene behaviors	around hands, face and body washing and cleaning and other hygiene practices.		



# Self-Care Literacy Index Self-Care Domains



A person's health literacy level impacts their access to and use of health services. In this dimension, HCPs are relied upon to oversee a person's access and use to services and treatment, thus the relationship between patient and provider is critical. The best evidence on the impact of health literacy in the self-care health services dimension was found with regard to a person's participation in disease screening, medication adherence, and empowerment for medical decisionmaking.

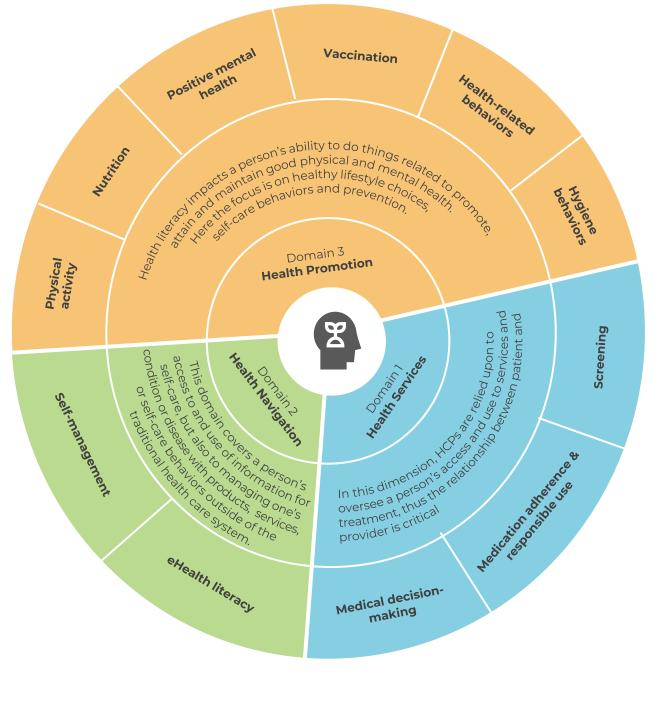
Health literacy impacts health navigation, which covers not only a person's access to and use of trusted information for self-care, but also refers to managing one's condition or disease with products, services, or self-care behaviors outside of the traditional health care system and typically not provided or overseen directly by a health care professional. The best evidence found on health literacy and self-care health navigation is related to symptoms self- management and the ability to skillfully use the internet to access and evaluate trusted health information.



Health literacy impacts a person's health promotion, and their ability to do things related to self-care necessary to attain and maintain good physical and mental health. Here the focus is on healthy lifestyle choices and prevention. The best evidence linking health literacy to self-care in this dimension was found for physical activity, nutrition, mental health, vaccination, and health-related behaviors.



# Figure 3. The Self-Care Literacy Index







# Self-Care Literacy Index

# **PART II:** Recommendations & measurements



- Mass screening involves the observation and monitoring of apparently healthy populations to track a certain condition early through different examinations.
- Screening breaks with medicine's traditional distinction between sick and healthy, disrupting a long tradition in doctor-patient relationships, diagnostic construction, and patient centred practices.
- In countries where the public health system predominates, they have better results in the implementation of screening than in countries where social security or private insurance predominates.
- Evidence indicates that only half of Latin American countries have the necessary technologies to effectively implement cancer screening programs. In these, they are mostly in the private sector.
- The situation is similar for identifying prediabetes and type-2 diabetes, or new cases of depression where many countries recommend screening for higher-risk individuals in primary health care settings, but not population-based screening.
- In addition, there is some research on cancer prevention beliefs especially in low- and middle-income settings that could play an important role in whether individuals choose to participate in cancer screening or to take other preventative actions.
- In Latin America individuals with low health literacy, lower education levels, and of lower socioeconomic status were found to be more likely to hold fatalistic cancer prevention beliefs (i.e., prevention is not possible, and cancer is fatal).

- ☑ The self-care health literacy index should include population-based screening for preventable or treatable diseases given that an individual's participation in being completely up to date with local public health screening recommendations (screening currency) is a strong proxy for self-care.
- ☑ It might also be useful for the index to include a measurement of baseline disease prevention beliefs as these can have a role in whether someone chooses to be screened in the future.

#### PROPOSED MEASUREMENT "SCREENING"

- Percentage of adults within appropriate age ranges who are upto-date on local public health recommended screening tests.
- Percentage of adults within appropriate age ranges who have been screened once (at one point in time) for local public health recommended screening tests..
- Percentage of adults who have a fatalistic belief about diseases in that they cannot be prevented and are fatal.

LOW LITERATE

HIGH

LITERATE





- Many literature review studies on health literacy and medication adherence and responsible use show a generally positive and directional relationship, but the evidence of the impact of health literacy is many times not strong enough unless you also consider patient beliefs about medicines and other patient demographic factors such as socioeconomic status and education levels.
- Prescription and non-prescription medications can help treat diseases, symptoms, and conditions, But taking these medications as indicated is important. Following products{s directions, asking questions to HCPs, and sharing your medical history are all ways to help reduce the risk of side effects and ensure a responsible use.
- Research shows that functional health literacy (basic reading and writing skills) is less important for adherence and responsible use than the higher-level communicative health literacy skills where the patient has an ability to identify and discuss information with others, has the confidence to act on medical advice independently, and to interact successfully with health systems and providers.
- Here, there is substantial overlap with the indicator for self-management. For instance, an elderly
  person with cardiovascular disease might be adherent with taking medicines as indicated but
  perhaps not so much with necessary lifestyle changes that are also part of the treatment plan. It
  may be the opposite for a younger person with cardiovascular disease risk.

- Medication adherence can be an important indicator for the self-care health literacy index but should encompass a generalized sense of selfreported willingness to follow a medicine routine as indicated by the HCP or product's leaflet.
- ☑ Disease- specific treatment measures are not recommended at this time, but measuring the extent of a person's selfreported communicative health literacy skills regarding medicines use can add important context for this indicator.

#### HIGH PROPOSED MEASUREMENT LITERATE "MEDICATION ADHERENCE AND RESPONSIBLE USE"

- Given the last two or more reasons for seeing a health professional and/or purchasing an OTC medicine(s), the percentage of adults who followed the indicated medicines routine:
  - a) wholly,
  - b) mostly,
  - c) somewhat,
  - d) not at all.
- In general, is your level of confidence high, medium, or low in your ability to identify, assess and apply health information successfully with health systems and HCPs when it comes to medicines use?



LOW LITERATE



- Evidence in the academic literature has consistently pointed to a relationship between health literacy levels and more active involvement in medical decision-making when under the care of a health care professional.
- Higher health literacy generally means being more empowered and able to find, use, and share information with a physician, including the capacity to discuss one's values and preferences when evaluating the pros and cons of different treatment options. This higher active involvement, or patient empowerment, tends to be associated with better health outcomes.
- Self-efficacy or the belief in one's own ability to change a behavior or mobilize resources for greater motivation is sometimes measured, as is a person's health locus of control, or whether they believe their own efforts (internal) or external forces have more relative power in shaping their health situations.
- Others have said the key intermediate factor is a patient's decision-making ability (DMA), which is not only affected by health literacy but by socioeconomic status and financial barriers, education level, and social support structures, among others, that all combine as factors to determine if and how much involvement a person has with the medical team in his or her own care decision- making.
- Other research is helping to advance the notion that health literacy is not only an individual construct, but is dependent on whether a health care system is accessible, medical personnel are good at communicating, and health information is understandable and relatable. In this context, the level of shared decision-making (SDM) or "joint empowerment" of patient and physician is now increasingly viewed as an important factor in improving health outcomes.

- ☑ The self-care health literacy index should include an indicator of a person's sense of active involvement or self-reported decision-making ability when it comes to collaborating with health professionals for their own health care.
- ☑ A measure of shared decision-making would help to identify gaps in either the patient factors required for good decision-making or whether health professionals and systems are becoming more accommodating for those with lower health literacy skill sets.

#### HIGH PROPOSED MEASUREMENT "MEDICAL DECISION-MAKING"

- Percentage of adults who selfreport a high, medium, or low level of capacity to be actively involved and engaged with their health care provider or medical team on major health decisions.
- Percentage of adults who believe health decision- making is a shared responsibility of patient and physician.
- Percentage of adults who say their physician or medical team believes health decision-making is a shared responsibility







## Health Navigation eHealth Literacy

- Research is clear on the relationship between health literacy levels and the ability to find, evaluate, and utilize health information online.
- Lower health literacy is associated with using lower quality websites, television, and social media for health information.
- Additional studies have linked low HL to lower eHealth Literacy scale (eHEALS) scores and have shown individuals with low HL were more likely to use search results position, photo quality, use of celebrities, and website authorship to evaluate online health information, all of which are contrary to expert guidance.
- Young kids are viewed as "digital natives" with skills and abilities to navigate the internet from a
  variety of devices, but the results actually show a large number of them are challenged by search
  engines and lack of information appraisal strategies. Adolescents are an important target for eHealth
  literacy intervention precisely because of their reliance on the internet for health information that can
  become the basis for good lifestyle choices and a healthy transition into adulthood.
- In a study of 600+ Twitter users in South Korea, higher HL was shown to be associated with the ability to identify, fact-check, and potentially correct negative health misinformation spread purposefully on the social media site.

### RECOMMENDATIONS

- ☑ Finding, evaluating, and using quality health information online is fundamental for self-care and health literacy has been shown to be an important factor.
- Perceived levels of eHealth literacy among adolescents could be an important proxy for self-care choices and attitudes later in life..

HIGH LITERATE

#### PROPOSED MEASUREMENT "eHEALTH LITERACY"

- Self-reported ability (low, medium, or high) to navigate, evaluate, and use health information online (eHEALS)
- Self-reported (low, medium or high) propensity to fact- check and correct health misinformation on social media
- Self-reported confidence levels of adolescents ages 13-18 (or of one or both of their parents) in eHealth literacy skills and abilities

LOW LITERATE





### Health Navigation Self-Management

- Academic research suggests health literacy is an important factor in one's ability to develop the kind of self-management skills needed for overall treatment adherence and ongoing successful management, especially of chronic diseases.
- Low health literacy is linked to less likelihood that a patient will do all that they need to do to be considered adherent to a recommended course of action or treatment.
- Public health is also impacted by how patients understand and use OTC products/medicines and complementary or alternative forms of therapy (CAM) to self-manage. There is research on the impact of low health literacy on the ability of parents to choose correctly among OTC cough and cold medicines for their children, for instance, as well as studies on low health literacy and a lack of awareness among chronic pain sufferers of different ways to treat and manage pain outside of medications.
- Functional health literacy (numeracy skills, reading and writing) is linked to greater confidence in seeking guidance from others, including pharmacists, but not necessarily with better individual recognition of symptoms or overall self-management skills.
- On the other hand, the higher-order skill set of evaluating information, engaging with providers, interacting with the health system, is more likely to result in successful self-management and effective disease or symptom control.
- It should be noted, however, that some research shows higher health literacy associated with greater use of CAM (vitamins and supplements, mostly) perhaps because greater awareness.

### RECOMMENDATIONS

- A self-report of one's skills in selfmanagement, including confidence in the use of OTC products and seeking guidance from a community pharmacist are important.
- ☑ A general assessment of self-efficacy in the face of a real or hypothetical chronic disease is also recommended, but needs to be defined more precisely.
- For now, perhaps a person's self- report of a real or theoretical ability to adapt one's life to a chronic disease makes the most sense.
- ☑ Disease-specific self- management might be too detailed for the current index, but could be considered for future versions

#### HIGH LITERATE

#### PROPOSED MEASUREMENT "SELF-MANAGEMENT"

- Percentage of adults who self-report high, medium, or low confidence in selfmanaging an illness or acute condition with OTC products..
- Percentage of adults who self-report a) high, b) medium, or c) low likelihood of asking a community pharmacist for guidance on managing their illness or acute condition.
- Percentage of adults who self-report a) high, b) medium, or c) low confidence in their ability to adapt their lifestyle, behaviors and emotions to successfully self-manage a real or hypothetical chronic or acute illness







- Research generally shows a positive relationship between health literacy and reported levels of physical activity across different age groups typically measured as the total time over several days of a person's engagement in exercise activity.
- Higher HL means more knowledge about the health benefits of exercise and the development of skills to maintain an active lifestyle choice.
- Some research also shows higher health literacy among individuals contemplating or actively planning to become more physically active.
- A broader concept of physical literacy has emerged and continued research on its many domains will likely lead to new indicators, new measurements, and better interventions to increase physical activity levels and thus better health at the individual, institutional, and societal levels. However, academic consensus is still coalescing around this broader conceptual approach.

- ☑ Despite emergence of several different domains of physical literacy, most of the published evidence supporting a positive relationship between higher health literacy, physical activity, knowing the benefits of exercise, and choosing an active lifestyle comes from measuring individual levels of self-reported physical activity or plans to become more active.
- ☑ For purposes of a self-care health literacy index, these measurements also seem the most appropriate

#### 

#### PROPOSED MEASUREMENT "PHYSICAL ACTIVITY"

- Percentage responding "no" to a question about participating in physical activity (outside of work) over the past month or week (provide examples such as running, gardening, or walking for exercise; this is a measure of sedentary lifestyle borrowed from the U.S. CDC)
- Number of self-reported minutes over the past 3 or5 days engaging in physical activity outside of work setting (provide examples with question).

LOW LITERATE





- Six of the top ten leading causes of death are chronic diseases preventable by consuming a healthy diet. Research on health literacy and nutrition has evolved into the two distinct subsets of nutrition literacy and food literacy.
- Additional research on the definitions and conceptual frameworks for nutrition literacy and food literacy argues that both are subsets of health literacy but that nutrition literacy is mostly in the functional HL realm (ability to absorb nutrition facts and information) while food literacy definitions are more in the interactive HL (using knowledge to choose healthy and develop skills to prepare healthy food) and critical HL (recognizing complex effects of personal food choice and behaviors on society, for example understanding the importance of healthy school lunch menus).
- Nutrition literacy is being measured especially as it relates to nutrition-related diseases and conditions. A study to validate the Nutrition Literacy Assessment Instrument (NLit) for instance shows that nutrition literacy was the most significant predictor of diet quality in adults with nutrition-related chronic diseases in a primary care setting.
- Going one step deeper, researchers have also explored the association of health literacy on actual dietary intake of unhealthy things like salt, sugar, and fat. A review of studies found some evidence tying HL to sugar intake especially with regard to sugar-sweetened beverage consumption.

- ☑ Nutrition literacy research seems more directly relevant to self-care than the wider concept of food literacy when it comes to personal choice decisions around healthy diets.
- ☑ A self-care health literacy index can therefore borrow elements from existing nutrition literacy measurement surveys for appropriate data collection.

#### PROPOSED MEASUREMENT "NUTRITION"

- HIGH LITERATE
- Number of adults and/or adolescents considered likely health literate based on ability to read a nutrition label.
- Number of adults considered nutrition literate based on ability to navigate nutrition information and identify healthy foods.
- Number of adults and/or adolescents who can access and study food supplements information and make appropriate decisions regarding selection and consumption

LOW LITERATE





### Health Promotion Positive Mental Health

Research studies link health literacy to mental health on three levels. First, research shows that those who suffer from mental illness or substance abuse disorders are more likely to have lower levels of HL, which can affect recovery and disease management outcomes given limitations in the ability to find, evaluate, and apply information effectively. Second, research connects health literacy levels and the likelihood of suffering from mental health disorders, mostly affective disorders like anxiety and depression. Those with lower HL it seems are more at risk for these conditions, which of course can have an impact on lifestyle choices and one's perception of current and future wellness.

Finally, the idea of positive mental health literacy as a subcomponent of mental health literacy is understood as a process of building the knowledge and skills to obtain and maintain emotional and social well-being. Research shows that greater positive mental health literacy levels are associated with engaging in self-care and with a higher likelihood of seeking out useful resources in the external environment (from family, the community, or the healthcare system). Attributes of positive mental health literacy include self-esteem, emotion control, positive connections with others, problem-solving skills, positive thinking, motivation, and resilience.

### RECOMMENDATIONS

- ☑ The attributes of positive mental health literacy and the avoidance of higher risk of mental health illness are what seem to be most aligned with the concept of self-care and should be included in the self-care health literacy index.
- ✓ The Mental Health Continuum Short Form (MHC-SF) is an assessment tool for mental health and well-being categorized as either flourishing, moderate, or languishing. Flourishing is a proxy for a higher level of positive mental health literacy, and as compared to non-flourishing has been shown in some studies to reduce the risk of mood disorders and anxiety.

HIGH LITERATE

#### PROPOSED MEASUREMENT "POSITIVE MENTAL HEALTH"

- Percentage of individuals with positive mental health literacy or found to have "flourishing" mental health (MHC-SF)
- Percentage of individuals who self-report a certain number of attributes consistent with positive mental health literacy.







- Accordin to a UNICEF report, in the last 10 years, Latin America and the Caribbean has gone from having one of the highest childhood vaccination rates in the world to one of the lowest.
- The State of the World's Children 2023 highlights that worldwide there has been a decline in confidence in vaccination and the perception of the importance that vaccines have for children has decreased in some countries of the world.
- A 2018 systematic review described the current relationship between HL and vaccination (including attitude to vaccines, intention to vaccinate, and vaccine uptake), and showed that the role of HL in predicting vaccine hesitancy or acceptance seems to be influenced by a few key factors, such as age, and type of vaccine.. With a positive relationship between HL and influenza vaccination in the elderly (> age 65) and between HL and HPV vaccination in young adults
- Vaccine literacy is not simply knowledge about vaccines, it requires certain literacy and numeracy skills, which is why communicating the information to patients is a challenge, particularly if the patients have low HL, and it can influence vaccine uptake.
- The lack of a clear answer is due to few published studies, different HL measurement methods, different population targets and varied outcome measures. Causation is a very difficult prospect given the factors involved, and some studies actually show a relationship between higher levels of literacy and vaccine hesitancy in very specific population groups. Study authors say an intervention may not be possible aimed at improving health literacy to increase vaccination uptake in the general population, but targeted interventions for certain vaccines in specific age groups could work

- ☑ There is evidence health literacy impacts vaccine uptake in the case of young adults, as well as in the elderly.
- ☑ High levels of uptake or at least increasing vaccine uptake at a population level could be an indicator for the self-care health literacy index.

HIGH LITERATE

#### PROPOSED MEASUREMENT "VACCINATION"

- Percentage of adults who selfreport high, medium, or low confidence in vaccine safety
- Influenza and covid19 immunization coverage rates (percentage) for adults and young adults.
- HPV immunization coverage rates (percentage) for young adults.



LOW LITERATE



## Health Promotion Health-Related Behaviors

- Research generally supports the idea that HL is an important factor in health-related behaviors and risk factors commonly grouped together and referred to as SNAPW: smoking, poor nutrition, harmful use of alcohol, inadequate physical activity and overweight and obesity.
- But it has proven very difficult to tease out the exact relationship between HL levels and each individual behavior given that many other factors like socioeconomic status can mediate or have a role in risky behaviors.
- Instead of looking at individual behaviors, it seems the evidence of the effect of HL is strongest when behaviors are grouped together as either health-promoting or health-supporting.
- Thus, studies show higher HL associated with healthy eating and regular exercise combined with self-reported levels of stress management, a greater sense of health responsibility, and better interpersonal relationships, for example. In still other studies, higher health literacy was linked to combined higher scores on combined behaviors such as cigarette smoking, vaping, nutrition and eating habits, levels of physical activity, safety behaviors, sexual behavior, social support, life appreciation, health responsibility, and stress management.

### RECOMMENDATIONS

- ✓ Health-promoting or healthsupporting behaviors are certainly important in the concept of self-care and the evidence suggests health literacy plays an important mediating role especially when several behaviors are grouped together to provide an overall behavior profile.
- ☑ Differences are notable by age group. We recommend the self-care health literacy index include a short list of health-related behaviors that can be measured together for adults and adolescents, respectively.

#### HIGH LITERATE

#### PROPOSED MEASUREMENT "HEALTH-RELATED BEHAVIORS"

- Percentage of adults that achieve a high, medium, and low combined score on questions related to healthy eating, physical activity, sufficient sleep, sense of health responsibility, stress management, and life appreciation.
- Percentage of adolescents that achieve a high, medium, or low combined score on questions related to healthy eating, physical activity, perceived health status, sufficient sleep, and safe sex.







## Health Promotion Hygiene Behaviors

- There is a good amount of evidence that shows that appropriate hand, oral and body hygiene is the single most effective action to stop the spread of infection.
- Health Literacy to promote hygiene behaviors and practices, although widely learnt from school by peers and teachers, are also supported by domestic and social conditions that contribute to their learning and adoption.
- Studies in different countries, using cross-sectional descriptive studies show that health literacy is significantly associated with increased hand hygiene knowledge and behavior. During one study in Norway health information sources and knowledge and health literacy were assessed during the initial phase of the Covid-19 pandemic highlighting that in adolescents, television and family were indicated to be the main sources for pandemic-related health information; and health literacy and handwashing knowledge and behavior were significantly associated.
- In Latin American population, a study by Calvasina et al., 2016 showed that Brazilian immigrants in Canada with limited oral health literacy resulted in less participation in healthcare and have a harder time making use of health services.

### RECOMMENDATIONS

- ✓ Hygiene behaviors are certainly important in the concept of self-care and the evidence suggests health literacy plays an important role in understanding and giving meaning to basic hygiene concepts and improving these practices to prevent disease.
- ☑ We recommend the self-care health literacy index include a short list of hygiene related behaviors that can be measured together for adults and adolescents, respectively

HIGH LITERATE

#### PROPOSED MEASUREMENT "HYGIENE BEHAVIORS"

- Percentage of adults that achieve a high, medium, and low combined score on questions related to hygiene practices related to hand washing, oral health, and general body hygiene.
- Percentage of adolescents that achieve a high, medium, or low combined score on questions related to hygiene practices related to hand washing, oral health, and general body hygiene..







# Self-Care Literacy Index

**PART III:** Self-Care Literacy Policy Draft

# OPPORTUNITIES TO IMPROVE HEALTH- AND SELF-CARE LITERACY TO ADVANCE HEALTH EQUITY IN LATIN AMERICA.

Universal health coverage will only be a reality when inclusive access to health care is achieved. To this end it is necessary that health resources are accessible, easy to navigate, affordable, and of decent quality.

Health literacy has long been focused on individual capabilities and responsibility to understand, navigate and adapt to complex systems in which health related information is provided, consequently neglecting the role of the system.

Managing one's health can also be challenging in times of stress. When individuals are overwhelmed with too much information, their ability to absorb, recall, and use health information can decline, compromising their ability to manage their health.

The infodemic, defined as the rapid spread of vast numbers of reliable and unreliable information accompanying the COVID19 pandemic, served as an example. Limited HL in pandemic times lead to information overload, and the difficulty of deciding which information (source) is trustworthy<sup>13</sup>. This surpasses the individual responsibility and requires greater accountability by different stakeholders.

As social individuals whose knowledge and actions are shaped and affected by social and environmental factors, there is a great potential for policy-makers, health organizations and providers, and other stakeholders to recognize the value of health and self-care literacy for individuals, but also, within their own organizations, in order to design and target interventions and communications to suit a diversity of needs and audiences and improve access to care.

In Latin America, key challenges to consider when promoting HL include socioeconomic inequality, social/geographic isolation, cultural-, language-, and policy-related barriers, which disproportionately affect indigenous populations and individuals living in rural areas<sup>11</sup>. ILAR seeks to engage with governments and health stakeholders with a shared interest in health literacy, to determine how HL opportunities could be explored and applied in Latin America to advance self-care, reduce health disparities, and achieve universal health coverage.



# HEALTH LITERACY UNIVERSAL PRECAUTIONS

Low health literacy is common and is hard to recognize, which is why it is recommended to use health literacy universal precautions. Health practices should assume that all patients and caregivers may have difficulty understanding health information and should communicate in ways that anyone can understand<sup>14</sup>

Health literacy universal precautions are aimed at:



Simplifying information and communication for all individuals, to minimize the risk of misinterpretation



Making the health care system easier to navigate and self-care products information, such as OTCs labels and leaflets, user friendly and suitable for people with different capacities.



Supporting patients' efforts to improve their health and self-care.



## **POLICY BUILDING & INFORMATION &** ENHANCEMENT

Increase individuals' health knowledge and empowerment and facilitate better use of health resources through the assessment and application of health and self-care literacy in public health strategies, action plans, and programs that improve self-care, disease prevention and health promotion

#### Culture, customs, and science must be equally addressed in health and self-care literacy initiatives and policies to address key challenges in Latin America.

#### a. Measure health and self-care literacy status and progress.

Apply concise, valid, and reliable measures for health and self-care literacy assessment and evaluations as well as performance indicators in public health programs.

#### b. Incentivize health and self-care literacy research.

Identify and address health and self-care literacy needs in disadvantaged and at-risk populations, particularly culturally and linguistically diverse communities, working with the local community to create people-centered health materials.

#### c. Mobilize health and self-care literacy advocates.

Establish alliances of health literacy and selfcare advocates such as patient organizations, healthcare organizations, local governments and national health authorities, and academia to make the case that investments in self-care and self-care literacy result in healthier populations and economic improvements for health systems and societies.

#### d. Increase health and self-care literacy agendasetting.

Increase advocacy through different means to align approaches and join efforts with relevant stakeholders and community leaders towards the value of health and self-care literacy as a key driver of better health outcomes and reduced health disparities.

# COMMUNICATION

Increase health and self-care literacy requires that all relevant health actors—from health authorities to private industry and academia—know how health literacy affects individuals and consistently make health information work to and communication clearer and easier <sup>3, 10, 11, 12.</sup>

Using clear oral and written communication strategies can help individuals to better understand health information. feel more involved in their health care and increases their likelihood of engaging in health promotion activities.

#### a. Improve clear health information

Enhance use of simple text and illustrations in health products and booklets materials to improve clarity of language and comprehension, considering that a large part of low health literate population also faces challenges with literacy as well. Involve communities in the planning, design, and delivery of materials to ensure that they meet their needs and wants regarding health and selfcare literacy.

b. Enhance quality of media and marketing

Adapt health-literate messages through the media (print, radio, TV, and the internet) to help improve community health, strengthen the quality of health-related information by providing easy-to-understand reliable. and timelv information for individuals to facilitate the decision-making process.

c. Target at-risk groups to reduce health literacy inequalities.

Identify and target specific needs of people in vulnerable situations such as older adults and low socioeconomic status individuals to bridge the health literacy gap and increase equity and inclusion.



## **CAPACITY BUILDING**

#### Build health and self-care capacity at individual, community, organizational and system levels <sup>3</sup>, <sup>10, 11, 12.</sup>

## a. Include health and self-care literacy training in educational curricula.

Incorporate education on health literacy as early as preschool and continue through university studies and beyond.

## b. Increase health literacy at organizational level through the health workforce.

Motivate employers and healthcare workers to make health literacy training available through professional education and continuing professional development as well as into workforce accreditation standards.

#### c. Incentivize health literate organizations.

Promote organizational health literacy training and self-assessment to improve understanding, practices and capabilities of the health literacy needs within their catchment populations, and to critically evaluate their own cultural backgrounds as well as the organizational practices and assumptions that guide their work.

#### d. Improve digital health and self-care literacy

Support individuals on how to use computers, patient portals, and telehealth services to access health care and information especially among individuals living in rural areas. Improve and scale-up people-centered, digital health solutions.

## e. Empower different health professionals to provide health and self-care literacy support.

Involve other healthcare providers, besides physicians, in the communication process with individuals. Pharmacists, nutritionists and other easily accessible professionals can expand their role in society by providing not only health knowledge but improve health literacy by empowering patients to self-care with regard to their health.

## INCLUSIVITY & CULTURAL COMPETENCE

A focus on social determinants of health, identification of vulnerable populations and increased cultural competence at organizational level leads to more inclusivity and improved health outcomes<sup>15</sup>.

#### a. Emphasize a "health in all policies" approach

Assess and consider impact on health in every social, environmental, and economic policy and program, promote a multi-sectoral collaboration focused on legitimacy, accountability, transparency, access to information, participation, and sustainability<sup>16</sup>.

## b. Identify and remove policies that promote segregation, racism and discrimination.

Have processes to identify harmful practices at organizational level and promote a self-assessment environment systematizing cultural competence and health literacy by ensuring health information and health services delivery are accessible and adaptable to different cultures and socioeconomic levels.

## c. Promote multi-disciplinary and multi-cultural health teams at community level.

Incentivize organizations that empower and enable multidisciplinary and multicultural teams to address health challenges, promote health- and self-care literacy, engage communities, and dismantle cultural barriers to care.

#### d. Measure inclusivity rates by assessing health and self-care literacy and health services experience.

Ensure that health programs have monitoring processes embedded in them, track inclusivity by monitoring levels of health- and self-care literacy, service-user metrics and health outcomes at population level.





# Self-Care Literacy Index

**PART IV:** Additional communication materials.

# HOW CAN DIFFERENT ACTORS SUPPORT SELF-CARE LITERACY IN LATIN AMERICA.

#### INDIVIDUAL

Have an active participation in decision-making on programs and interventions that have a direct impact on health, placing greater emphasis on self-care and health promotion through sufficient and appropriate information.

#### **GOVERNMENTS**

Develop policies on the promotion of health, health literacy, and self-care, including sustained funding, systematic intervention and surveillance. Review and improve existing policies and regulations that make it difficult to use all kinds of health information (eg, general health, healthcare coverage, and informed consent).

#### NGOs AND HEALTH ORGANIZATIONS

Work together to bring different knowledge, experiences, and abilities to influence communitybased health education and communication efforts in all types of settings throughout the life course.

#### HEALTHCARE PROFESSIONALS

Participate in ongoing health literacy training that focuses on improving clear communication and information design practices. Make sure health and safety information is culturally and linguistically appropriate and engaging.

#### HEALTH SYSTEM

Create a responsive environment that removes barriers to clear communication for a diverse individuals and usable and understandable healthcare services. Support professionals learning, skills developments and cultural competence to promote good health and self-care.

#### ACADEMIA

Develop and improve methods for measuring health literacy, collect and distribute best practice examples in the development of health and self.care literacy interventions.

#### **PRIVATE SECTOR**

Promote greater health literacy within the organizations to promote better campaigns that generate awareness about selfcare and responsible use of products and services.

#### **REGULATORY AGENCIES**

Standardize the labels and leaflets of medicines and other self-care products and ensure that users understand this information, guaranteeing safe and effective use. Take advantage of technology and eHealth tools to provide up-to-date information and for different audiences.

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# Self-Care 🖀

is the set of knowledge, skills, behaviors, and actions that people do to take care of their health and to make the best decisions for their own benefit and their community throughout the life cycle.

8 out 10 individuals in Latin America consider self-care very relevant and more than 90% declare they want more information and tools to put the concept into practice<sup>2</sup>.

#### Individuals with high self-care literacy

engage in health promotion and disease prevention behaviors. They are able and motivated to access, understand, judge and apply health information as well as make a responsible use of self-care products such as OTCs<sup>3</sup>.

#### Individuals with low self-care literacy

engage in fewer self-care activities, and have fewer preventative behaviors, their main goal is to cure symptoms and avoid diseases, increasing health-related costs<sup>3</sup>.

Measurement of the self-care literacy in the population allows strategic design and delivery of public health interventions that improve health outcomes, address health inequities, and strengthen health systems. The Self-Care Health Literacy Index is a defined list of indicators and measurements to be utilized in survey instruments designed to collect data on health literacy in the region as it relates to specific self-care attributes:

#### **HEALTH SERVICES**

A person's health literacy level impacts their access to and use of health services. The best evidence was found with regard to a person's participation in disease screening, medication adherence, responsible use, and empowerment for medical decisionmaking.

literacy impacts navigation, which covers not only a person's access to and use of trusted information for self-care, but also refers to managing one's condition or disease with products, services, or self-care behaviors outside of the traditional health care system

health

**HEALTH NAVIGATION** 

Health

Health literacy impacts a person's health promotion, and their ability to do things related to self-care. The best evidence linking health literacy to self-care in this dimension was found for physical activity, nutrition, mental health, vaccination, and health-related behaviors

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**ILAR** is the Latin American Association for Responsible Self-Care, a nongovernmental organization that leads the promotion of responsible self-care as the best way to be and stay healthy, as well as ensuring proper access and use of self-care products in Latin America. ILAR is an NGO with consultative status with the UN Economic and Social Council (ECOSOC) and members of the Global Self-Care Federation..



