



Policy Proposals to Address Health Literacy Gaps

Recommendations Across the
Healthcare Spectrum

Katherine Sacks, PhD

May 2023

Katherine Sacks

Associate Director, Health Economics

Research Department, Milken Institute

Education:

PhD, MA, University of North Carolina at Chapel Hill, Department of Public Policy

MSc, London School of Economics and Political Science, Department of Government

BA, Barnard College, Columbia University

About the Milken Institute

Learn about our mission

The Milken Institute is a nonprofit, nonpartisan think tank that helps people build meaningful lives, in which they can experience health and well-being, pursue effective education and gainful employment, and access the resources required to create ever-expanding opportunities for themselves and their broader communities.



Presentation Roadmap



Introduction to the health literacy landscape.

Information and awareness gaps.

Technology gaps.

Equity gaps and disparities.

Presentation Roadmap



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Health Literacy

An evolving definition

The Lancet Editorial

November 12, 2022

Why is health literacy failing so many?

Health literacy is vital to good health and wellbeing. It is fundamental to achieving the Sustainable Development Goals by 2030 and is a crucial tool to deliver universal health coverage. People need to know how to prevent disease and navigate health-care systems to ensure good health outcomes. However, many are not able to make healthy choices, even in countries with the strongest health systems. Why is this? Traditionally, health literacy has focused on an individual's ability to access, understand, appraise, and use information to maintain good health. Of course, such knowledge is important. But this approach neglects the societal and structural forces that shape our choices. In many parts of the world, health decisions occur within the family. The health of communities is often dictated by social and environmental factors outside the control of individuals. Research progress in these areas has been slow, and many health interventions still leave people behind. The result has been a health failure.

However, change is beginning to happen. Health literacy was recognised as a critical determinant of health in the WHO Shanghai Declaration in 2016, and has been recast as a collective practice of a community working to enable and build knowledge, rather than placing responsibility on the individual. A new WHO report on health literacy, published on Nov 6, advances this approach for non-communicable diseases, but its lessons apply across health care. The report calls for co-designed approaches, whereby the voices of users and of those who deliver interventions are incorporated into the design of the services. To deliver these services and make the health-care system more user friendly and accessible, front-line health and social workers must be better trained to engage and interact with the populations they serve. The report also calls for an integrative approach to develop health literacy interventions that involve a range of community-based organisations—not just medical centres—including schools, churches, sports groups, and workplaces. For example, health literacy programmes should be introduced in childhood and should be part of school curriculums. They should be designed and adapted to the needs of individual communities, through the involvement of local students and teachers. Ensuring health literacy must be a whole-of-society endeavour—

at the individual, community, and national level—and work across sectors, not just health.

This approach is right, but the WHO report glosses over fundamental challenges to this vision of health literacy; in particular, the commercial determinants of health—ie, the corporate influence on health behaviours. The private sector sets research agendas, shapes narratives, and markets its products in ways that compromise health literacy, not only by misleading individuals, but also by fostering unhealthy communities and societies. The most egregious examples come from the manufacturers of tobacco, alcohol, and junk food. Over the past five decades, the tobacco industry has actively given false information and used its power to increase profits, regardless of the consequences to health. Health-care stakeholders have often struggled to amplify their voices over the messages of the private sector. Alongside this challenge is the rise of misinformation, particularly on social media. False information, spread regardless of the intent to mislead, can leave people in a state of epistemic helplessness. Even the most rational individual cannot make sensible, healthy decisions when bombarded with incorrect information. How can people, families, and communities know which sources of information to trust amid contradictory advice? How can WHO and other health stakeholders ensure that their information is the source that is amplified and used? How can health literacy be achieved in a world awash with false and misleading information?

We urgently need effective responses to these questions. Every person has a right to health. The ability to realise that right depends on everyone understanding their health, being able and empowered to make healthy choices, and being able to access effective interventions. Without understanding the ways that neglected communities learn, more people will be left behind. Most importantly, policy makers need to understand health literacy and how their decisions will impact different populations. A whole-of-society approach to health literacy is needed to remedy these issues. But it will be doomed to failure if it does not account for and address the fundamental drivers of what shapes our understanding of health and what makes our societies unhealthy in the first place—not least, the commercial determinants of health. ■ *The Lancet*



For the WHO report see <https://www.who.int/publications/item/9789240055339>

For more on the Shanghai declaration see <https://www.who.int/publications/item/WHO-NMH-PND-17.5>

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Tshekiso Tebello/Xinhua via Getty Images

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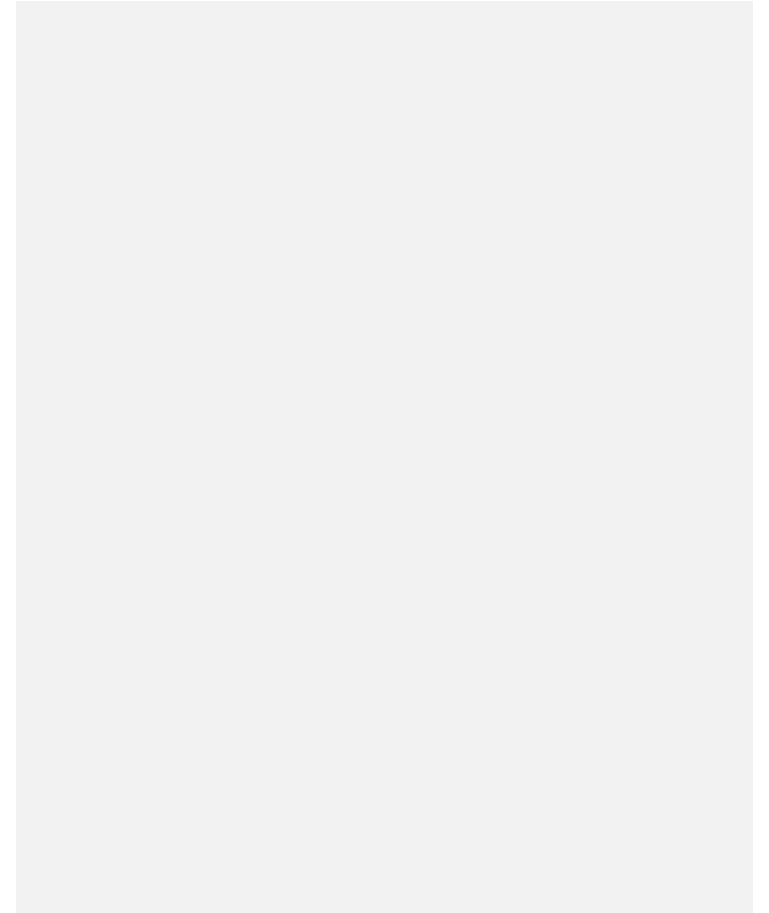
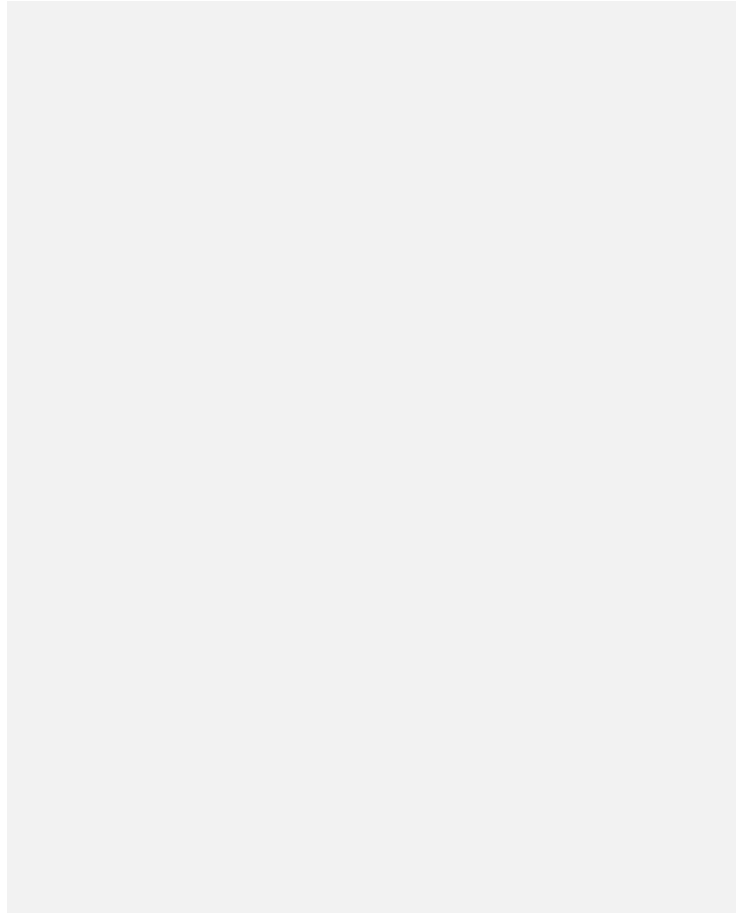
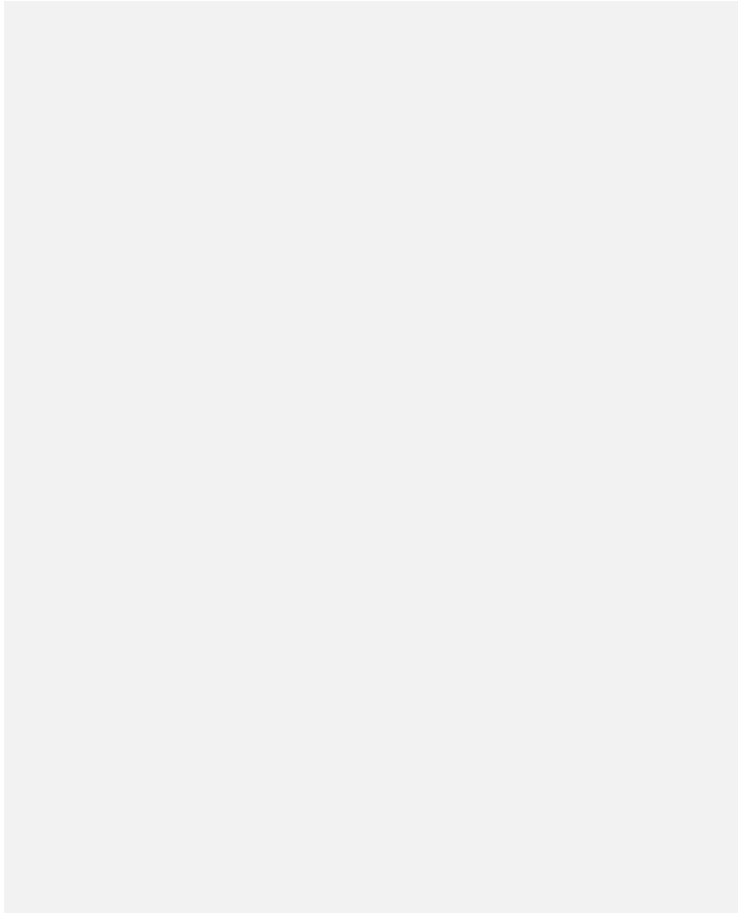
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“Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”



Health literacy is not merely an individual trait. Health literacy is **context-dependent**; it varies according to the system in which a person is making health-care decisions.

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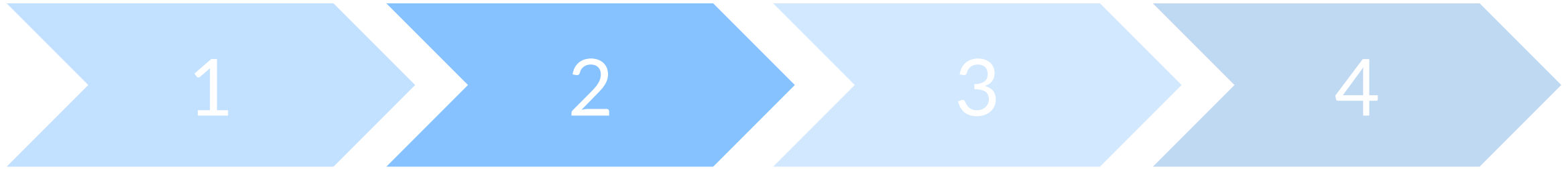
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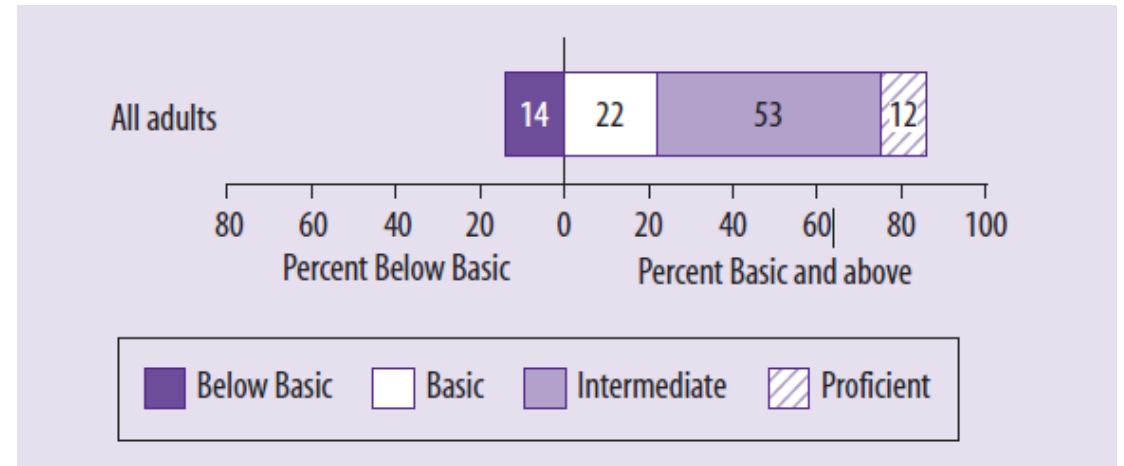
Health Literacy Data at the Population Level

The National Assessment of Adult Literacy

- Nationally representative
- Surveyed only English-speakers and Spanish-speakers with some English
- Consisted of prose and document literacy as well as a quantitative scale (numeracy)
- Included a health literacy-specific section
- Last conducted in 2003

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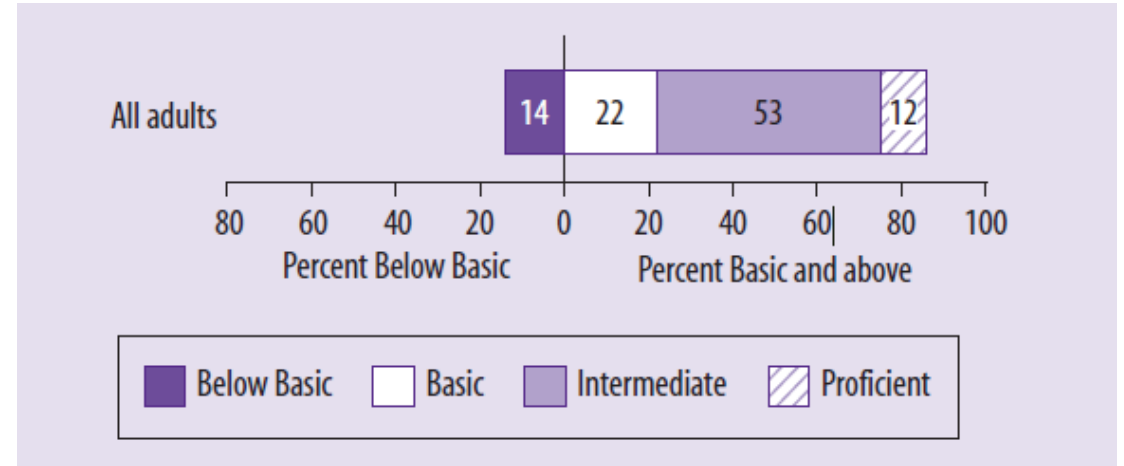
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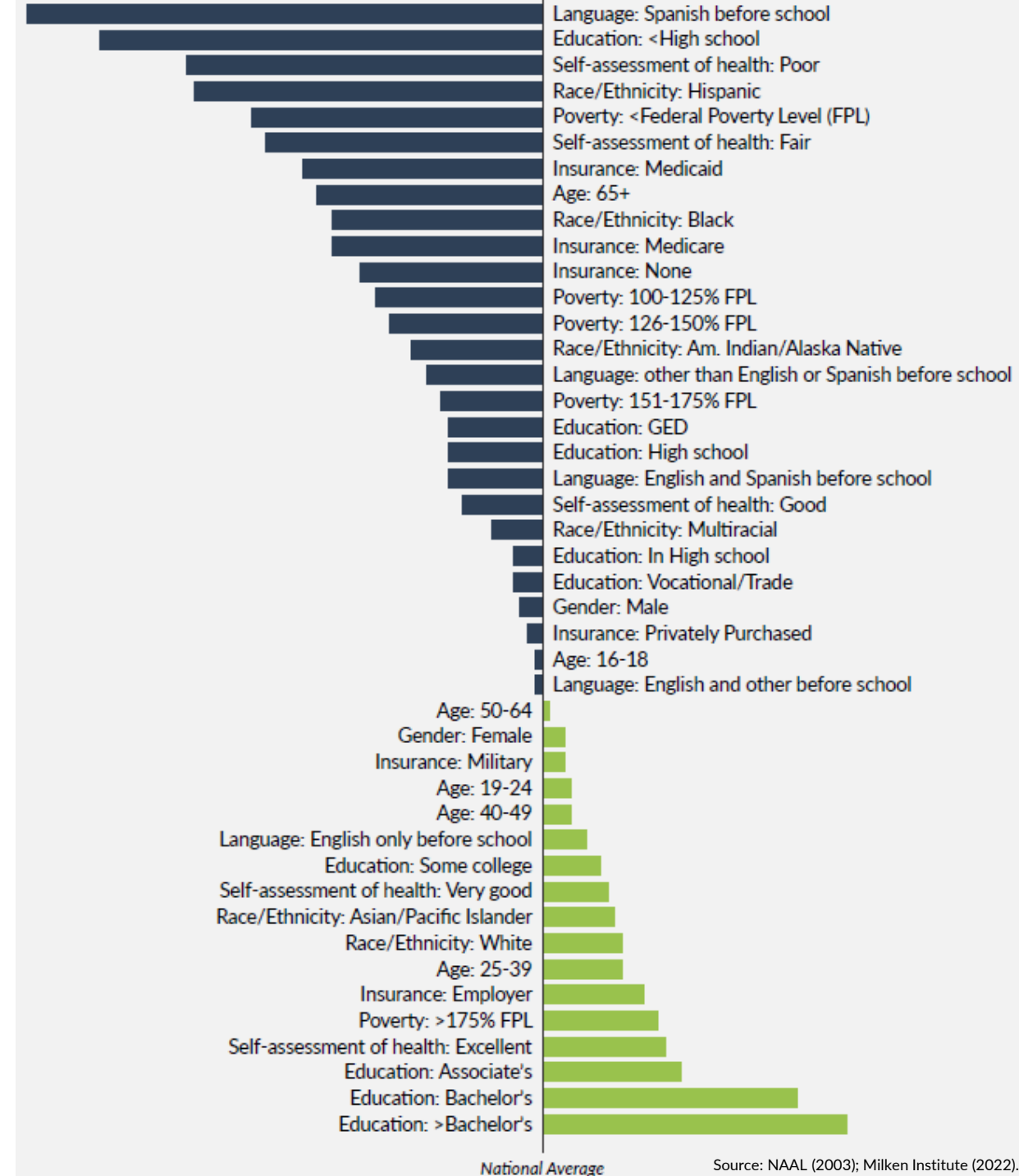
Source: NAAL (2003); Kutner et al. (2006).

- Found that health literacy is closely related to general literacy
- Scores were correlated with sociodemographic factors, chiefly age, race/ethnicity, and education level

NAAL Results

Factors associated with lower health literacy scores, on average

- Those who scored lowest, on average, were those who spoke *only* Spanish in the home prior to the onset of schooling.
- We have no data about health literacy for those who did not speak fluent English or Spanish.
- Data are 30 years out of date.





“Organizational health literacy is 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.”

Organizational Health Literacy Data

To date, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) is the only systematic data that exists on OHL.

CAHPS provides information on the quality of provider communication, i.e. “How often does your provider explain things in a way that was easy to understand?”

There is no agreed-upon measure for how “health literate” an organization is.

**AHRQ does provide Ten Attributes of a Health Literate Organization.*

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10. Communicates clearly what health plans cover and what individuals will have to pay for services.

Health Literacy Data at the Individual Level

Health Literacy Screening

- Within the US, the NAAL is the only data we have that is valid beyond an individual level.
- Other tests were primarily developed for clinical use, rather than population assessment.
 - * *Some of these clinical measures have been validated for broader use in certain contexts.*
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- Rapid Estimate of Adult Literacy in Medicine (REALM); revised 2003 (REALM-R)
- Test of Functional Health Literacy for Adults (TOFHLA); abbreviated (S-TOFHLA)
- Newest Vital Sign (NVS)
- Chew items, e.g., Brief Health Literacy Screen (BHLS) or Single Item Literacy Screener
- eHealth Literacy Scale (eHEALS)
- Health Literacy Questionnaire (HLQ)

Health Literacy Screening

For more information on HL measures, visit the Health Literacy Toolshed:

<https://healthliteracy.bu.edu/>



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We cannot improve health literacy if we cannot measure progress, target weaknesses.

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Make the results of organizational health literacy evaluations public.

Require entities such as providers and payers to utilize the organizational health literacy measures, and monitor their achievement of goals and benchmarks.

Clinicians – Select a health literacy screener that effectively measures what you want to know

And be sure you know what each screening tool *does not* evaluate

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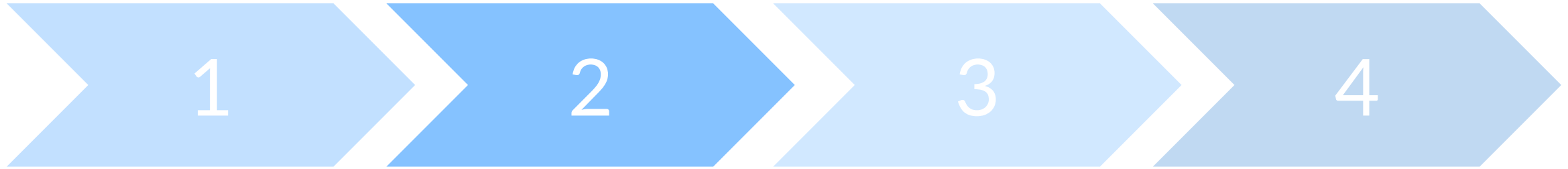
Understanding a patient's level of health literacy allows practitioners to tailor the information they give and to ensure that they are understood.

If you *do* want to evaluate a patient's level of health literacy, be clear about what you are evaluating and *why* you are doing so.

Select an instrument that is context-appropriate.

Make sure the instrument you use has been validated in the relevant population.

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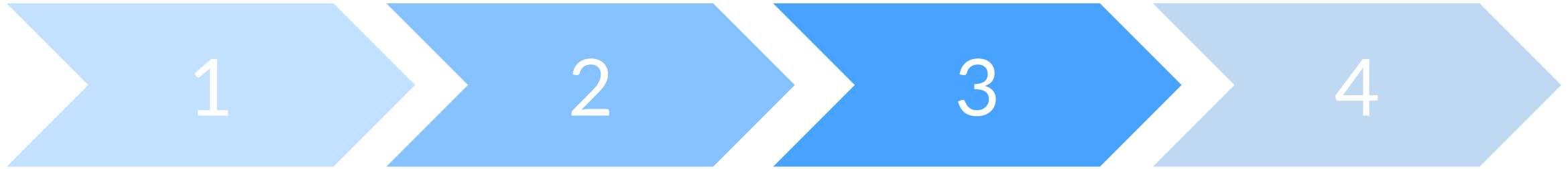
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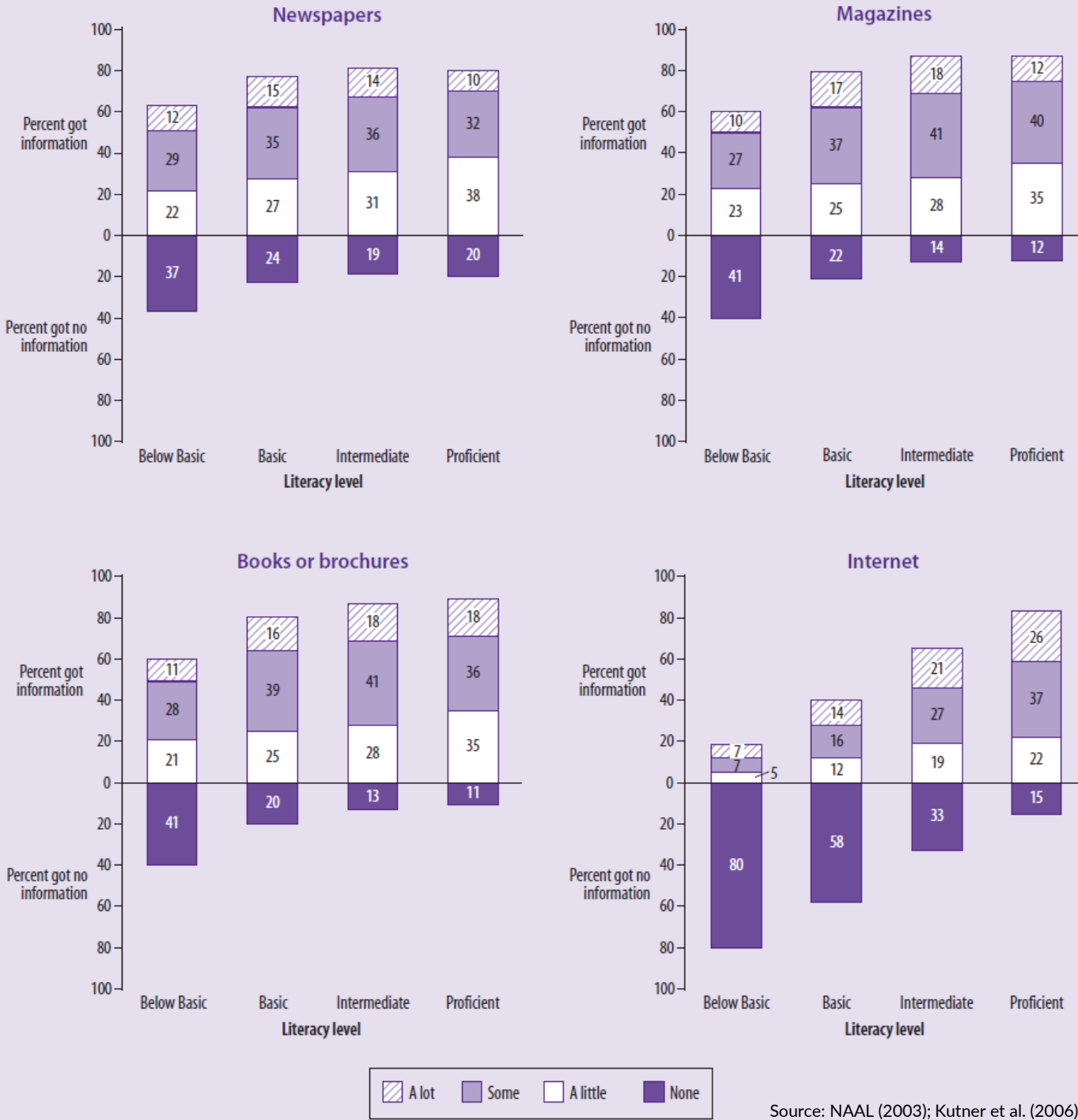
Digital Health Literacy

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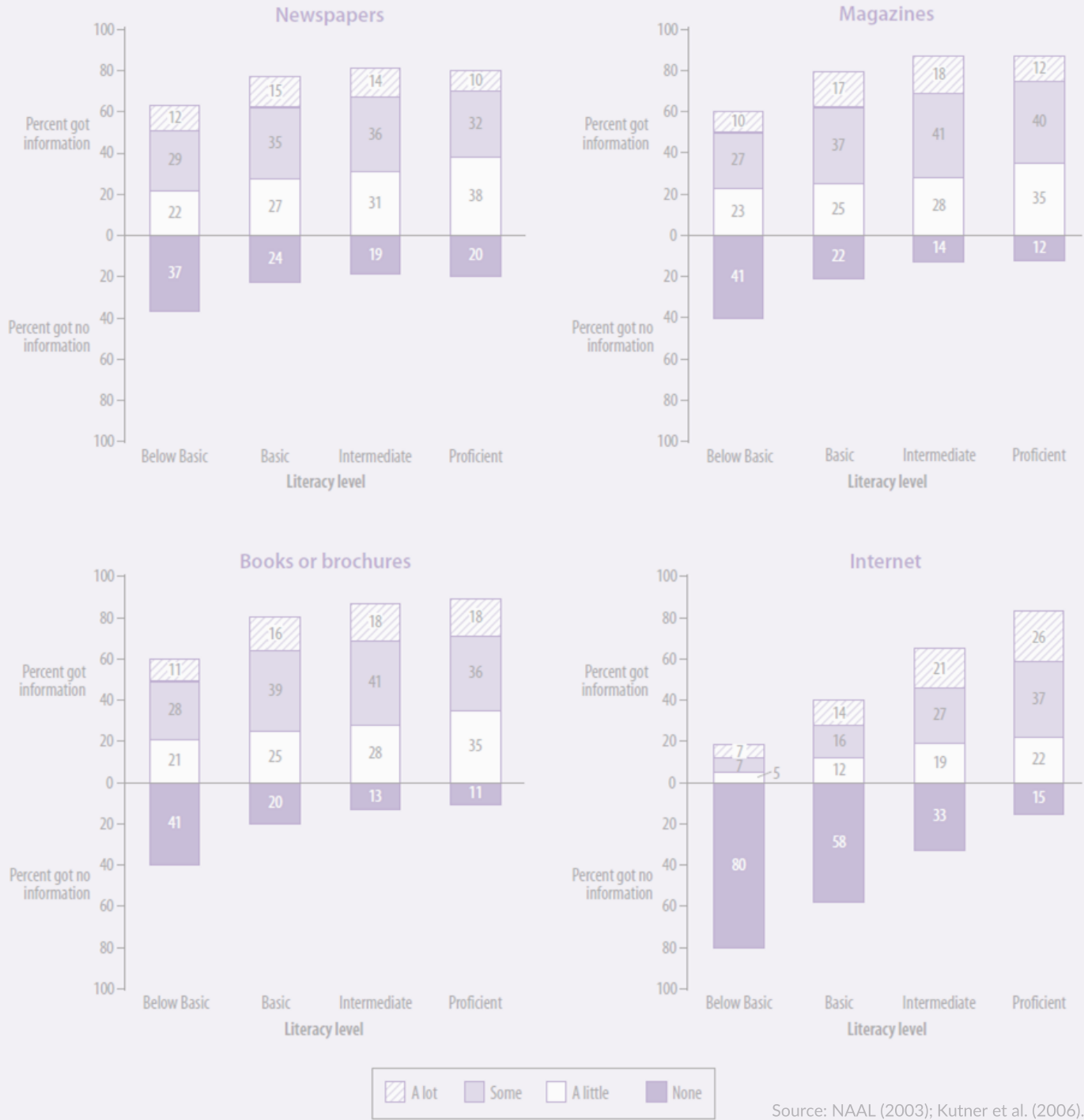
Digital literacy applies to health information.

Get accurate and relevant health information to people from the sources they are most likely to consult.

The rise of the internet and social media.

Misinformation and disinformation.

Compounded risk for low health and digital literacy.



Source: NAAL (2003); Kutner et al. (2006).

Technology & Health Literacy

Technology can help.

Electronic Health Records (EHRs) enable communication between patients and providers before and after office visits, allowing HCPs to check patients' understanding and adherence to recommendations.

eHealth programs can target information based on diagnosed health literacy level or based on those identified as high-risk for lower health literacy.

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Telehealth is fantastic, where it is applicable.

Health communications are especially fraught when digital.

They can also be especially effective.

The goal of health communication is to convey accurate information in an understandable way.

Understand where people are getting their information, and then *meet them there*.

Digital technology creates opportunities to increase understanding using modern communication methods.

Providers and health-care systems should integrate technology effectively.

Adopt EHRs on a more widespread basis and collect copious information.

HCPs don't just need to know and record a patient's health information, they need holistic knowledge of a patient's circumstances, including sociodemographic information.

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If patients are filling out digital paperwork, health literacy screeners can be easily added.

These systems can indicate to providers when additional health-literacy support is needed.

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Rather than serving as a barrier, technology can increase accessibility through adaptive solutions.

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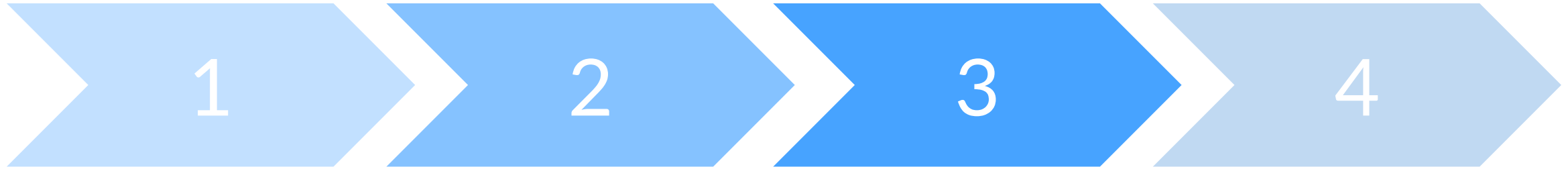
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Technology is only as useful as it is useable.

Unequal access to technology limits its ability to dampen the impacts of lower health literacy.

Target any technological recommendations to an individual's circumstances.

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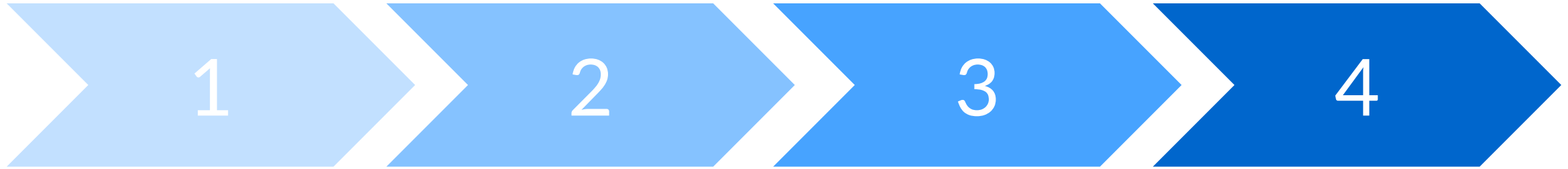
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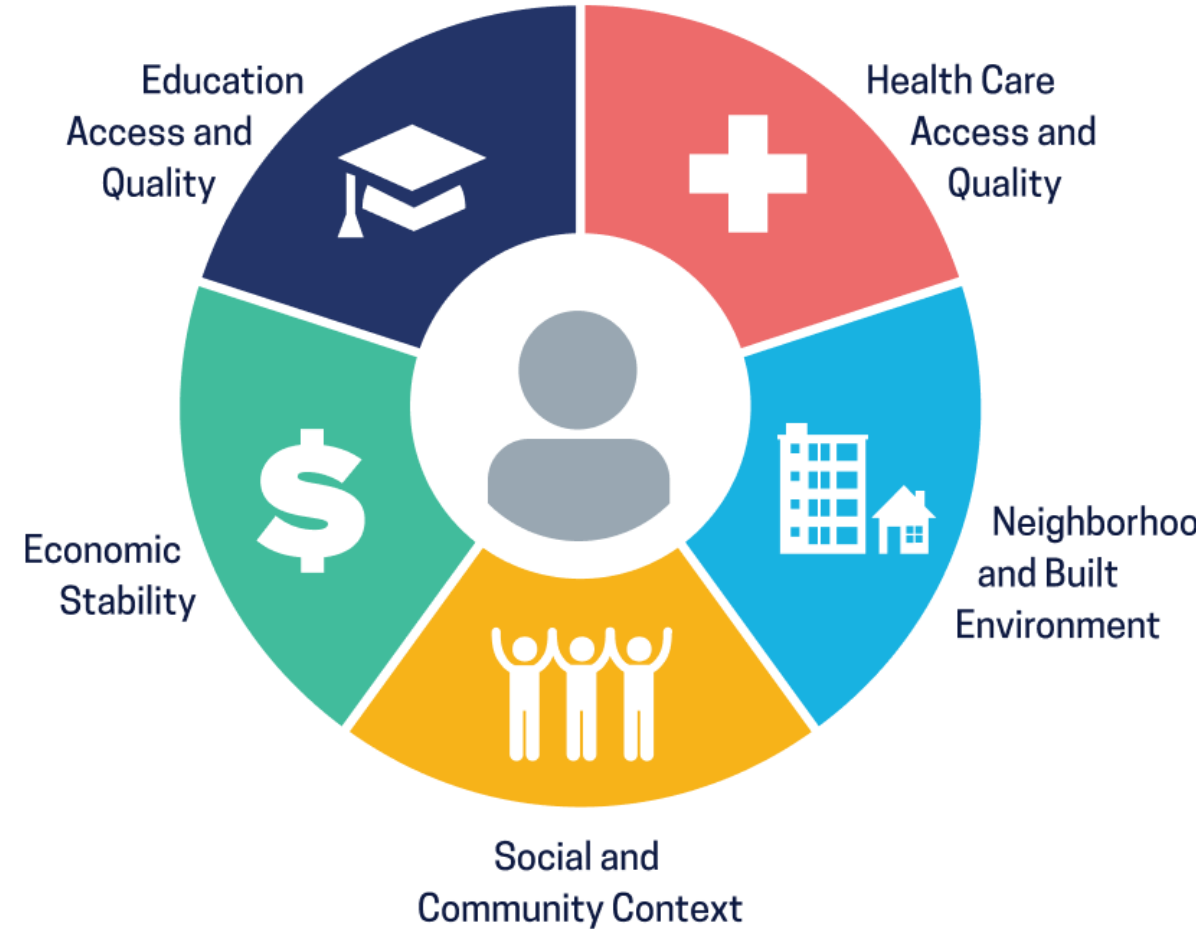


Social Determinants of Health

Does health literacy qualify?

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Social Determinants of Health



Health disparities are often the result of SDOH.

Groups facing social or other forms of marginalization have worse health outcomes.

Improving health literacy as a way of potentially ameliorating health disparities.

Health literacy can be thought of as a property of *communities*, rather than just individuals.

Large-scale actions targeting health literacy are growing but still insufficient.

National Action Plan to Improve Health Literacy Goals

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable

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6. Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.
7. Increase the dissemination and use of evidence-based health literacy practices and interventions.

Any health literacy intervention should center equity.

Interventions should be grounded in CBPR principles.

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Interventions should take place in the community.

Non-traditional venues for healthcare interventions can be very effective.

Meet people where they’re at.



Health literacy is not merely an individual trait.
Health literacy is **context-dependent**; it varies
according to the system in which a person is
making health-care decisions.

Organizational health literacy planning

Making Health Literacy Real: The Beginnings of
My Organization’s Plan for Action

[https://www.cdc.gov/healthliteracy/pdf/planning_](https://www.cdc.gov/healthliteracy/pdf/planning_template.pdf)
[template.pdf](https://www.cdc.gov/healthliteracy/pdf/planning_template.pdf)



Factor	Opportunities for Health Literacy Improvement
Health Information (e.g., forms and factsheets)	
Communications with Clients, Partners, and Community	
Relationship with Media	
Physical Environment	
Program Development, Implementation, and Evaluation	
Internal Communication and Policies	

CLAS implementation

Checklist of National CLAS Standards Implementation Practices

Theme 3: Engagement, Continuous Improvement, and Accountability

Select your organization's stage of implementation for each practice	Currently implementing	Planning to implement	Not planning to implement at this time
3.9 Incorporate CLAS into mission, vision, and/or strategic plans by determining how organization acknowledges and addresses concepts such as diversity, equity, inclusion, and practices such as asking individuals about preferences for care/services.	☐	☐	☐
3.10a Tailor existing evaluation efforts to include measures of CLAS implementation (e.g., patient/client satisfaction measures can include questions about CLAS; outcome data can be stratified by REAL data to determine demographic differences).	☐	☐	☐
3.10b Complete a CLAS-related organizational assessment of the cultural and linguistic needs of populations served and of organizational resources to address these needs.	☐	☐	☐
3.11a Collect race, ethnicity, and language (REAL) data (at a minimum) from all individuals receiving services, either by tailoring existing data collection approaches or creating a new data collection process.	☐	☐	☐
3.11b Use REAL data to identify needs, describe current care and service provision trends, and improve care and service provision.	☐	☐	☐
3.12 Collaborate with stakeholders and community members in community health needs assessment data collection, analysis, and reporting efforts to increase data reliability and validity.	☐	☐	☐
3.13 Include community members in the process of planning programs and developing policies to ensure cultural and linguistic appropriateness by convening town hall meetings, conducting focus groups, and/or creating community advisory groups.	☐	☐	☐

An Implementation Checklist for the National CLAS Standards with a CLAS Action Worksheet and CLAS Testimonials

<https://thinkculturalhealth.hhs.gov/clas/standards>



Plain language best practices

CMS guidelines for effective writing

<https://www.cms.gov/outreach-and-education/outreach/writing-guidelines>

See also: [plainlanguage.gov](https://www.plainlanguage.gov)



Don't say:	Say this instead:
assist	help
commence	begin, start
consequently	so
endeavor	try
facilitate	ease, help
for a period of	for
in an effort to	to
in order to	to
in the event of	if
previously	before
prior to	before
utilize	use
until such time as	until
with the exception of	except for



The Lancet Editorial

November 12, 2022

Why is health literacy failing so many?

Health literacy is vital to good health and wellbeing. It is fundamental to achieving the Sustainable Development Goals by 2030 and is a crucial tool to deliver universal health coverage. People need to know how to prevent disease and navigate health-care systems to ensure good health outcomes. However, many are not able to make healthy choices, even in countries with the strongest health systems. Why is this? **Traditionally, health literacy has focused on an individual's ability to access, understand, appraise, and use information to maintain good health. Of course, such knowledge is important. But this approach neglects the societal and structural forces that shape our choices.** In many parts of the world, health decisions occur within the family. The health of communities is often dictated by social and environmental factors outside the control of individuals. Research progress in these areas has been slow, and many health interventions still leave people behind. The result has been a health failure.

at the individual, community, and national level—and work across sectors, not just health.

This approach is right, but the WHO report glosses over fundamental challenges to this vision of health literacy; in particular, the commercial determinants of health—ie, the corporate influence on health behaviours. The private sector sets research agendas, shapes narratives, and markets its products in ways that compromise health literacy, not only by misleading individuals, but also by fostering unhealthy communities and societies. The most egregious examples come from the manufacturers of tobacco, alcohol, and junk food. Over the past five decades, the tobacco industry has actively given false information and used its power to increase profits, regardless of the consequences to health. Health-care stakeholders have often struggled to amplify their voices over the messages of the private sector. Alongside this challenge is the rise of misinformation, particularly on social media. False information, spread regardless of the

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Tshekiso Tebello/Xinhua via Getty Images

For the **WHO report** see <https://www.who.int/publications/i/item/9789240055339>

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responses to these issues. The ability of everyone understanding how to make healthy choices will be left behind. It is not enough to understand the consequences of health decisions will impact on society approach to address these issues. But it does not account for and is of what shapes our societies. At least, the commercial sector

Instead...

Editorial

Improving health literacy: how to succeed

Don Nutbeam^{a,b}

^a School of Public Health, University of Sydney, NSW, Australia,

^b Corresponding author: don.nutbeam@sydney.edu.au

Article history

Publication date: 15 March 2023

Citation: Nutbeam D. Improving health literacy: how to succeed. Public Health Res Pract. 2023;33(1):e3312301. <https://doi.org/10.17061/phrp3312301>

Introduction

A recent editorial in *The Lancet* led with the provocative title: "Why is health literacy failing so many".¹ Although a useful provocation, the title represented a fundamentally flawed interpretation of health literacy. The editorial defined the "failure" of health literacy in terms of its perceived focus on the responsibility of the individual and because it "neglects the societal and structural forces that shape our choices" and "social and environmental factors outside the control of individuals".¹ This proposition fails to adequately reflect most contemporary interpretations of health literacy.

Health literacy is a concept that continues to evolve as we learn from research and practical experience how it can best be defined, measured, and improved. It is generally understood as an observable set of personal skills and capacities that enable people to find, understand, appraise and use health information. Importantly, contemporary definitions of health literacy also recognise that a person's health literacy skills are substantially mediated by the environmental demands and complexities that are placed on them.²

It follows that if health literacy is understood as an observable set of personal skills, this necessarily focuses our attention on improving individuals' skills and capacities through communication and education. Recognising the demands and complexities of different environments also focuses attention on reducing those demands, for example, by simplifying communication, reducing organisational complexity that limits access to health information and healthcare, and regulating the information environment. Both dimensions represent important methods for reducing the impact of poor health literacy in our health systems and the wider community.

It is those of us involved in health communication and the systems in which we operate that too often fail people, not "health literacy".

Instead...

Improving health literacy: how to succeed

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