Advancing Health Equity Through Health Literacy Following Traumatic Brain Injury

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ACKNOWLEDGEMENTS

PINK CONCUSSIONS

My Brain Injury Journey

ACADEMY OF CERTIFIED BRAIN INJURY SPECIALISTS

A program of the Brain Injury Association of America

LEARNING OBJECTIVES

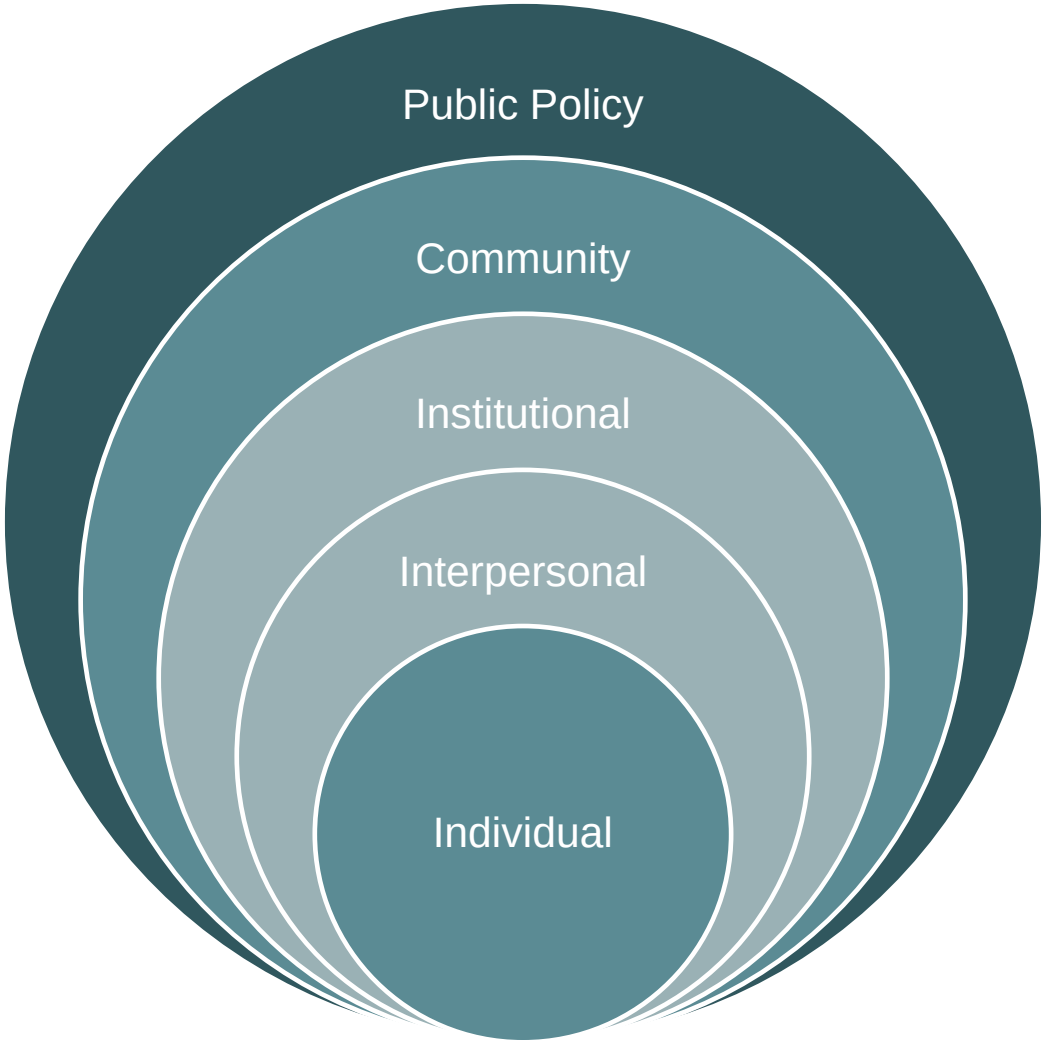
1. To distinguish individual and organizational health literacy.
2. To examine the role of health literacy in care and outcomes after brain injury.
3. To incorporate health literacy strategies in brain injury care and services to support persons with brain injury and their care partners.

HEALTH EQUITY

Achieved when every person has the opportunity to attain his or her (or their) full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.

CDC

SOCIAL ECOLOGICAL MODEL FOR HEALTH PROMOTION



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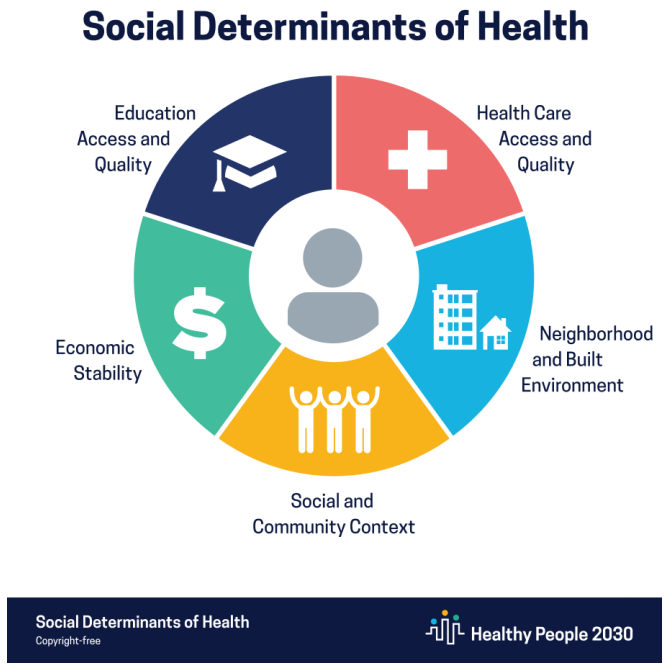
Adapted from McLeroy, K. R., Steckler, A. and Bibeau, D. (Eds.) (1988). The social ecology of health promotion interventions. Health Education Quarterly, 15(4):351-377

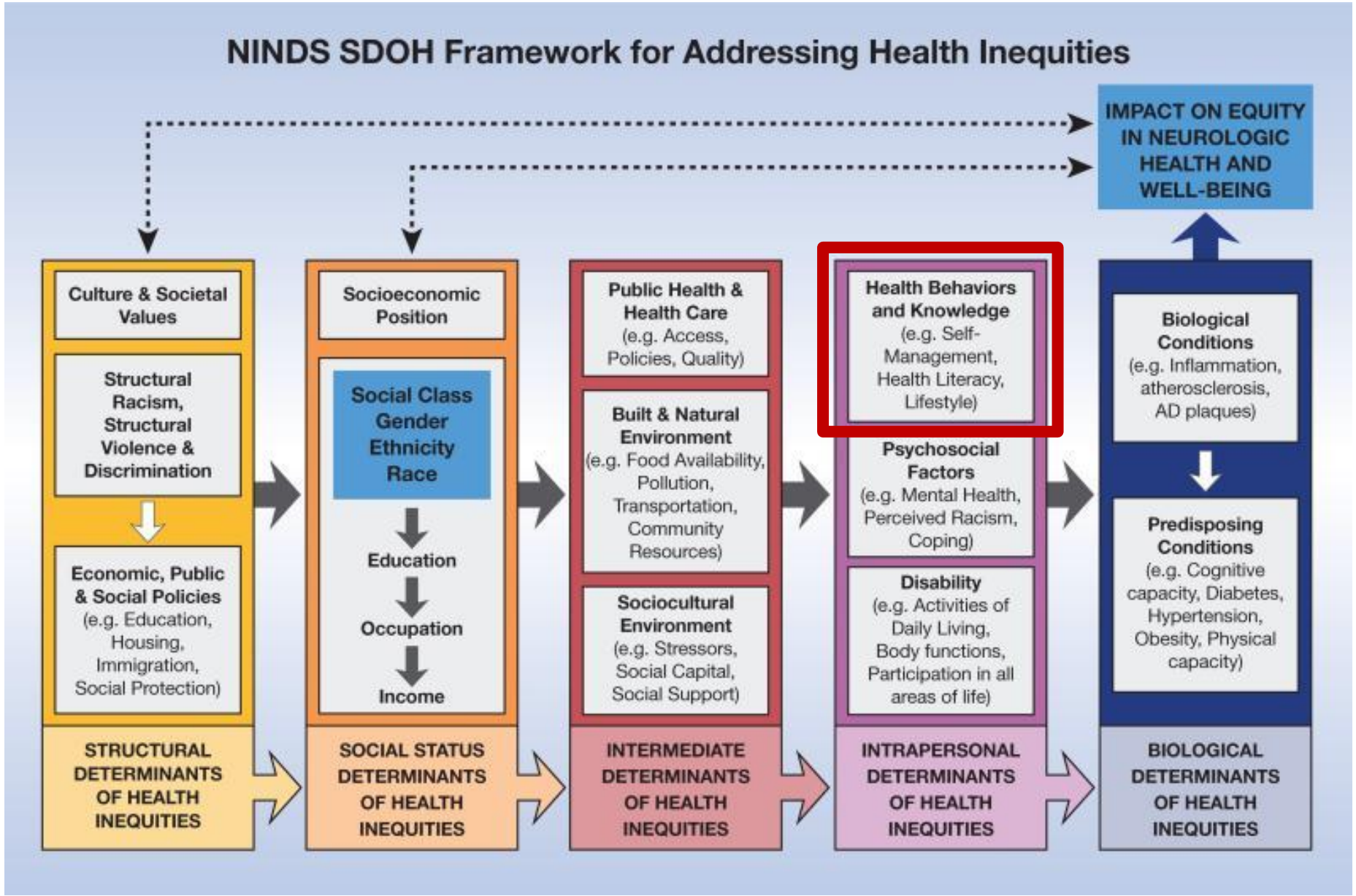
SOCIAL DETERMINANTS OF HEALTH

The economic and social conditions in our environments, where we are born, live, learn, work, play, worship, and age, and that affect our health, functioning, associated risks, and outcomes.

- When SDoH are unevenly distributed, the result is ***health disparities***.
- ***Health inequities*** are systematic differences in the opportunities groups have to achieve optimal health.

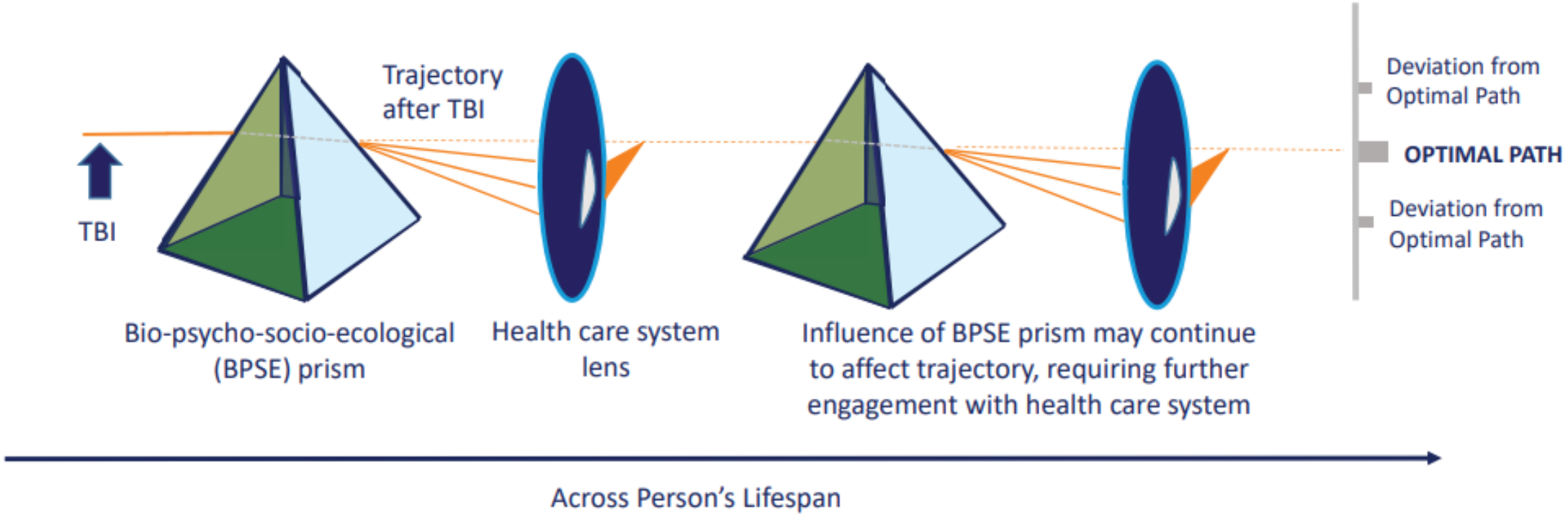


CDC
Lin et al., 2021
Healthy People 2030



Retrieved from: *Determinants of Inequities in Neurological Disease, Health, and Well-being: The NINDS Social Determinants of Health Framework*

BIO-PSYCHO-SOCIO-ECOLOGICAL MODEL



Source: National Academies of Sciences, Engineering, and Medicine 2022. Traumatic Brain Injury: A Roadmap for Accelerating Progress. Washington, DC: The National Academies Press. https://doi.org/10.17226/25394 .

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Common Misconceptions after TBI

- 1/3 out of 40 (~13 items)
- Misconceptions regarding amnesia and recovery.
- Spanish-speaking Hispanic adults with TBI report a greater percentage of misconceptions than English-speaking Hispanic and Black adults.

J Head Trauma Rehabil
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Focus on Clinical Research and Practice

Bruce Caplan, PhD, ABPP (Senior Editor); Jennifer Bogner, PhD, ABPP (Associate Editor)

Common Misconceptions About Traumatic Brain Injury Among Ethnic Minorities With TBI

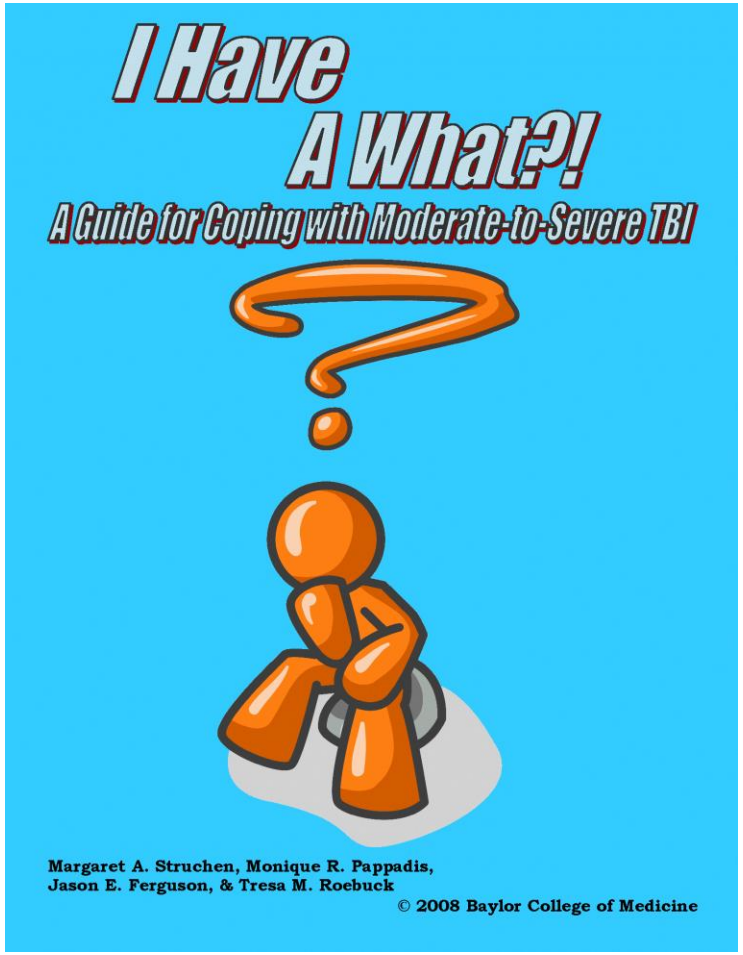
Monique R. Pappadis, MEd, CHES, CCRP; Angelle M. Sander, PhD; Margaret A. Struchen, PhD; Patrick Leung, PhD; Dennis W. Smith, PhD

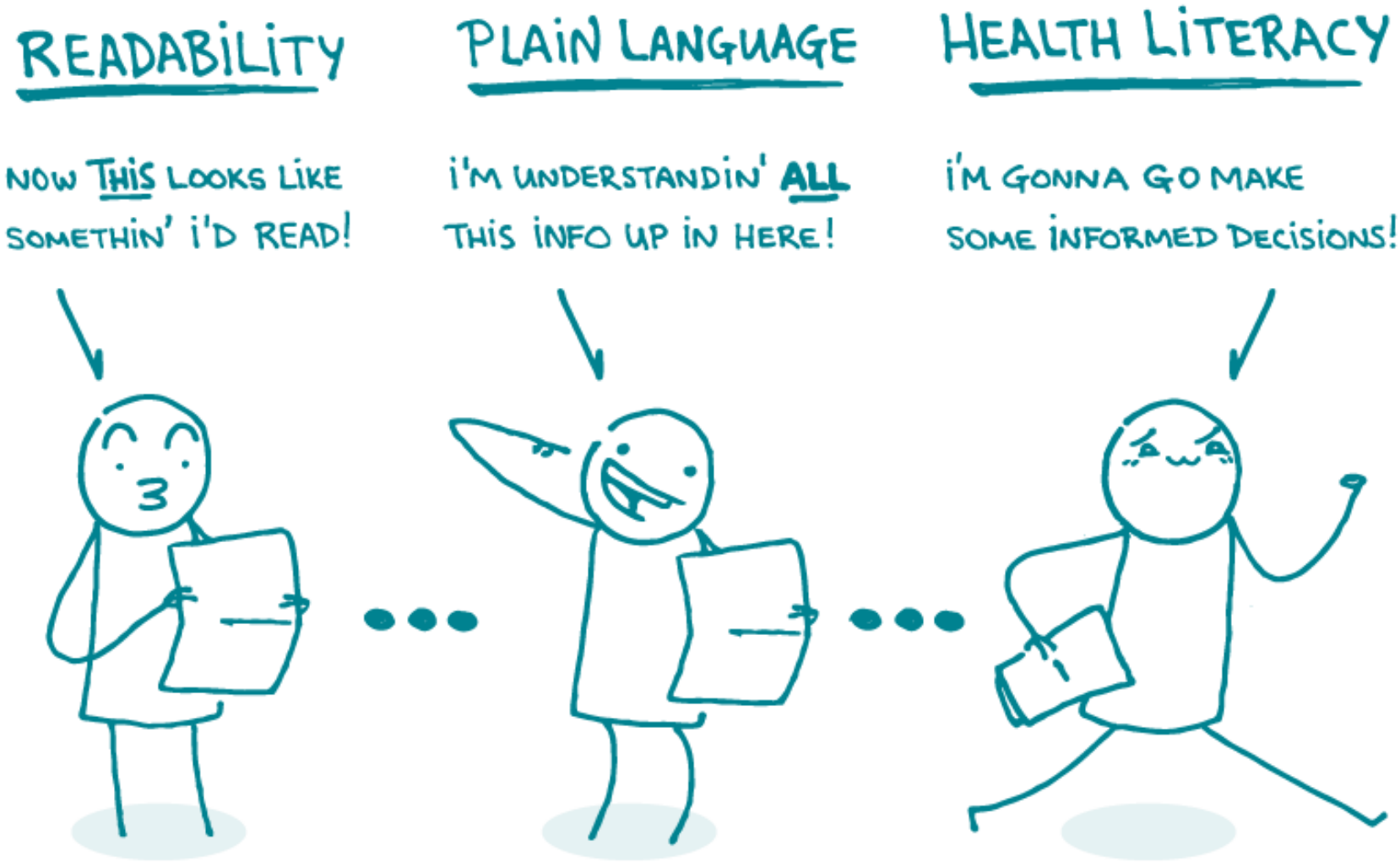
Effectiveness of an Educational Intervention on Reducing Misconceptions Among Ethnic Minorities With Complicated Mild to Severe Traumatic Brain Injury

Monique R. Pappadis, PhD[a,b,c], Angelle M. Sander, PhD[b,d,e], Beata Łukaszewska, PhD[f], Margaret A. Struchen, PhD[b], Patrick Leung, PhD[c], and Dennis W. Smith, PhD[a]

Addressing Common Misconceptions after TBI

- The intervention appeared to decrease TBI misconceptions.
- At 1-month follow-up, the wait-list control group reported more misconceptions than did the intervention group.




READABILITY
NOW THIS LOOKS LIKE SOMETHIN' I'D READ!
PLAIN LANGUAGE
I'M UNDERSTANDIN' ALL THIS INFO UP IN HERE!
HEALTH LITERACY
I'M GONNA GO MAKE SOME INFORMED DECISIONS!

ORGANIZATIONAL AND PERSONAL HEALTH LITERACY

HEALTH LITERACY

Personal health literacy "the degree to which individuals have the ability to find, understand, and use information and services needed to inform health-related decisions and actions for themselves

and

Organizational health literacy "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."

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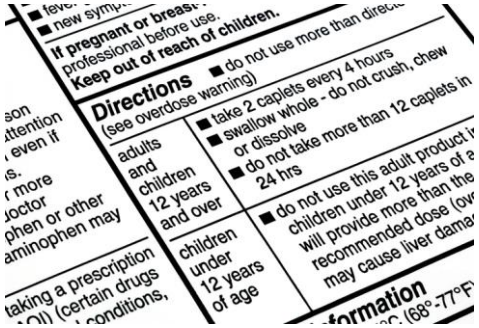
Health Literacy Types

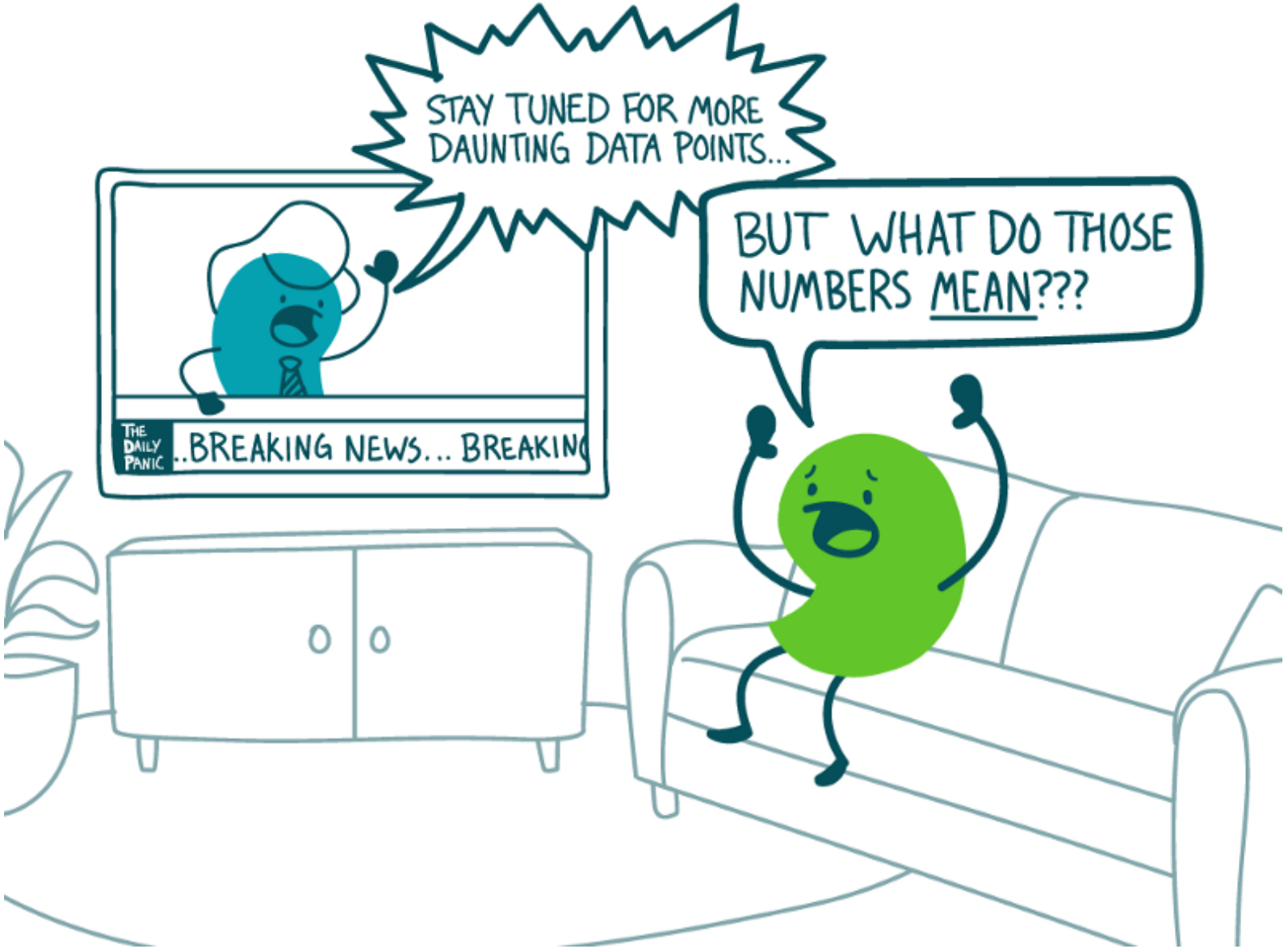


- **Prose**: understanding and use of information from texts.
  - Examples: brochures, newspaper, instructions, etc.
- **Document**: locate and use information from forms, tables, graphs, etc.
  - Examples: Drug or food labels, maps, job application
- **Quantitative**: apply arithmetic operations using numbers embedded in printed materials.

NUMERACY – DOCUMENT AND QUANTITATIVE

In Healthcare:

- Managing diet and nutrition
- Measuring medicine doses
- Adhering to a medicine schedule



https://communicatehealth.com/wehearthealthliteracy/numeracy-101-making-sense-of-numbers-during-covid-19/

HEALTH LITERACY IS MORE THAN READING & COUNTING

Reading and Writing

Numeracy

Critical Thinking

Decision-making

Navigating the healthcare system

Oral/Aural Communication

or

Patient-Provider communication

NATIONAL ASSESSMENT OF ADULT LITERACY (NAAL)

- 71% of adults aged 60+ had difficulty in using print materials
- 80% had difficulty using documents such as forms or charts
- 68% had difficulty with interpreting numbers and doing calculations

12% of adults in the US

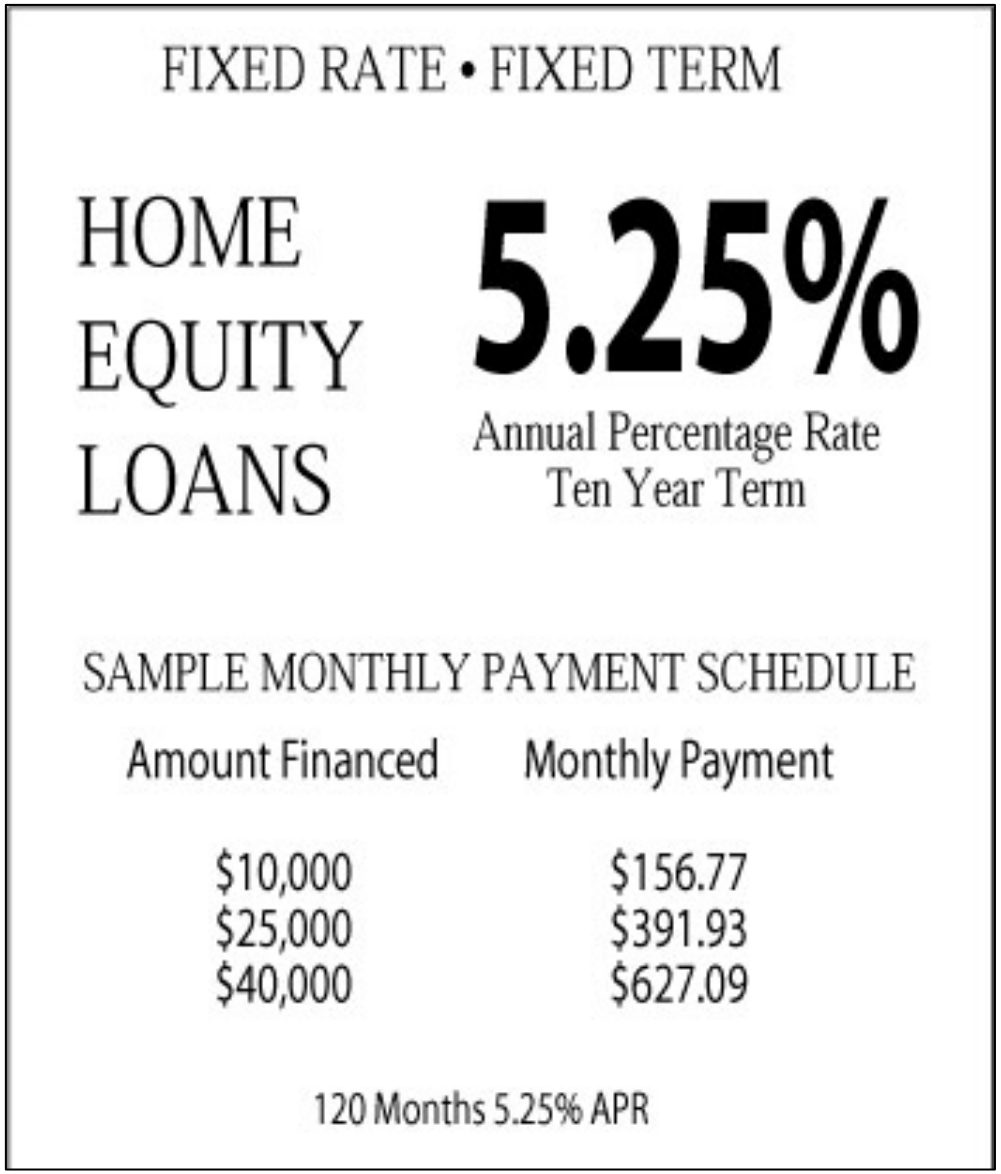
who make health decisions for themselves and their families

have proficient health literacy.

CDC

NUMERACY IN EVERYDAY LIFE

Problem:
You need to borrow $10,000. How would you compute the total amount of interest charges?



Solution:
$156.77 x 120 months= $18,812.40
-$10,000 = $8,812.40

WHAT ABOUT ORGANIZATIONS?

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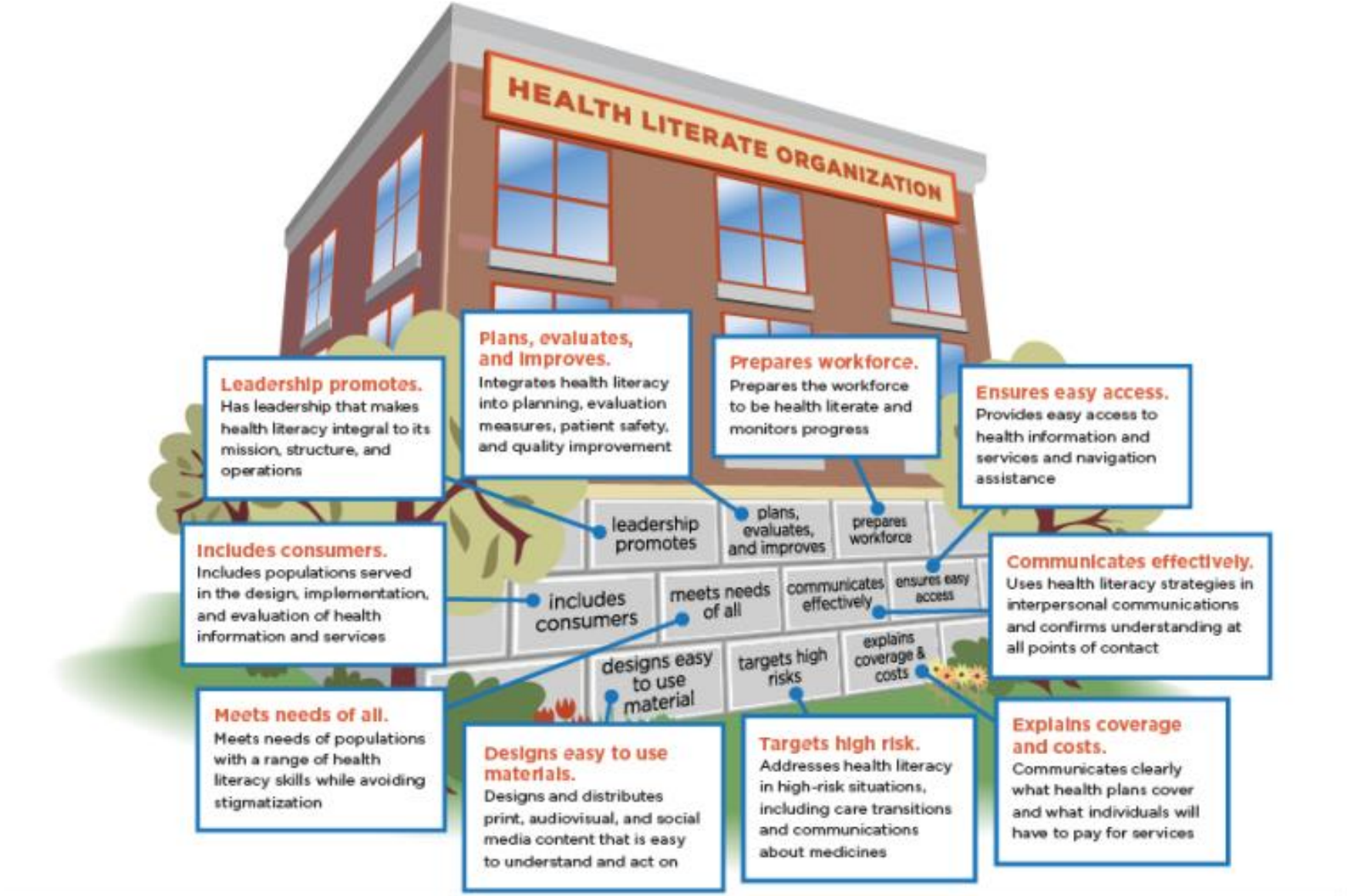
HEALTH LITERATE ORGANIZATION
Leadership promotes.
Has leadership that makes health literacy integral to its mission, structure, and operations
Plans, evaluates, and improves.
Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement
Prepares workforce.
Prepares the workforce to be health literate and monitors progress
Ensures easy access.
Provides easy access to health information and services and navigation assistance
Includes consumers.
Includes populations served in the design, implementation, and evaluation of health information and services
Communicates effectively.
Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
Meets needs of all.
Meets needs of populations with a range of health literacy skills while avoiding stigmatization
Designs easy to use materials.
Designs and distributes print, audiovisual, and social media content that is easy to understand and act on
Targets high risk.
Addresses health literacy in high-risk situations, including care transitions and communications about medicines
Explains coverage and costs.
Communicates clearly what health plans cover and what individuals will have to pay for services
leadership promotes
plans, evaluates, and improves
prepares workforce
includes consumers
meets needs of all
communicates effectively
ensures easy access
designs easy to use material
targets high risks
explains coverage & costs
This graphic reflects the views of the authors of the Discussion Paper "Ten Attributes of Health Literate Health Care Organizations" and not necessarily of the authors' organizations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.
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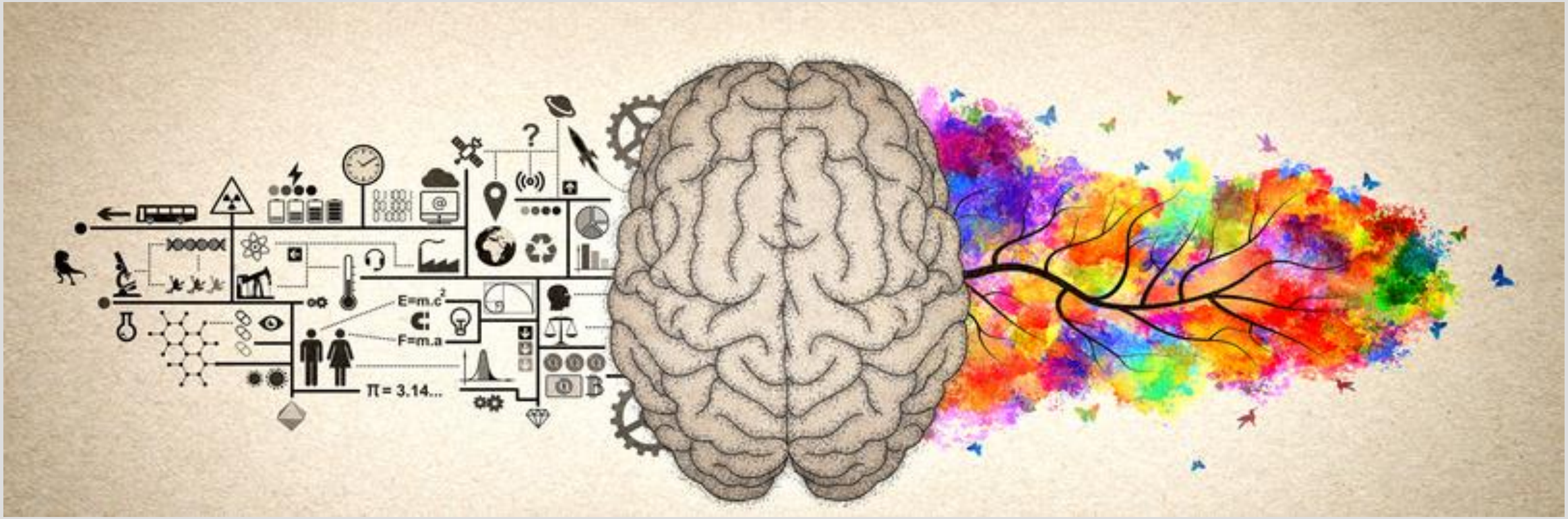
ROLE OF HEALTH LITERACY IN CARE AND OUTCOMES IN TRAUMATIC BRAIN INJURY



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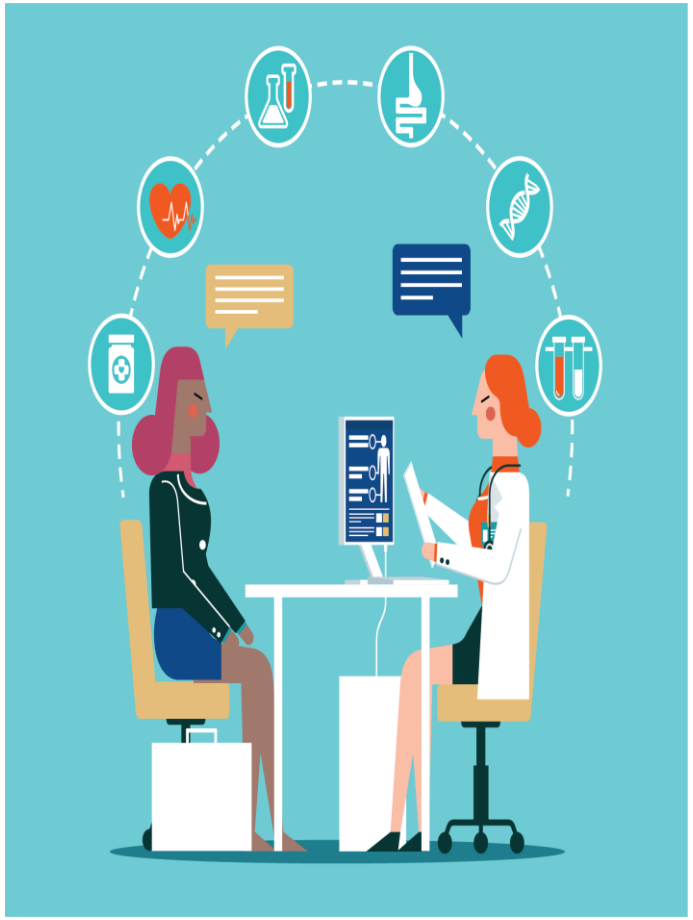
HEALTH LITERACY AFTER TBI

- Collaborative Module Project funded by NIDILRR grant #90DPTB0016 - Texas Traumatic Brain Injury Model System of TIRR
- Collaborating TBI Model System Centers
  - North Texas TBI Model System- site PIs: Simon Driver and Kathy Bell
  - Northern New Jersey Model System- site PI: Anthony Lequerica
  - The Ohio Regional TBI Model System- site PI: John Corrigan
  - University of Alabama at Birmingham TBI Care System- site PI: Laura Dreer
- Australia (PI: Jennie Ponsford)



Health Literacy after TBI – Background

- TBI has been conceptualized as a chronic condition requiring monitoring of health and function over the life span.
- Self-management may be affected by TBI-related consequences of injury.
- Certain groups report less proficiency in health literacy, such as men, racial/ethnic minority adults, older adults, those with less education, income below poverty level, and low occupational health.
- Cognition and health literacy are related, but not the same.

Health Literacy after TBI – Background

- Health literacy is associated with a variety of poor health behaviors:
  - Poor medication management
  - More Emergency Department use
  - Less preventative Services
  - Poor decision-making about choosing rehabilitation programs
  - Worse health (comorbidities and behavioral health)
  - Less mobility
  - Greater anxiety

Health Literacy after TBI – Study Aims

- To characterize health literacy among individuals with traumatic brain injury (TBI) at least one-year postinjury.
- To explore its relationship of health literacy to sociodemographic factors, injury severity, and cognition.
- To examine the relationship between health literacy and health outcomes (chronic health conditions, perceived physical and mental health, depression, anxiety).

Health Literacy after TBI – Sample (n=305, 61/center)

Age	44.43 (16.24; 18-89; 31-56)
Education (n;%)	
<12th	31 (15.12)
High school or GED	50 (24.39)
Above high school	124 (60.49)
Sex	
Male	140 (68.29)
Race/Ethnicity (n;%)	
White	142 (69.27)
Black	38 (18.54)
Hispanic	25 (12.2)
Injury severity (n;%)	
Complicated mild/moderate	28 (13.66)
Severe	177 (86.34)

*compared to TBIMS sample, younger (<45) and live in suburban area (vs. urban)

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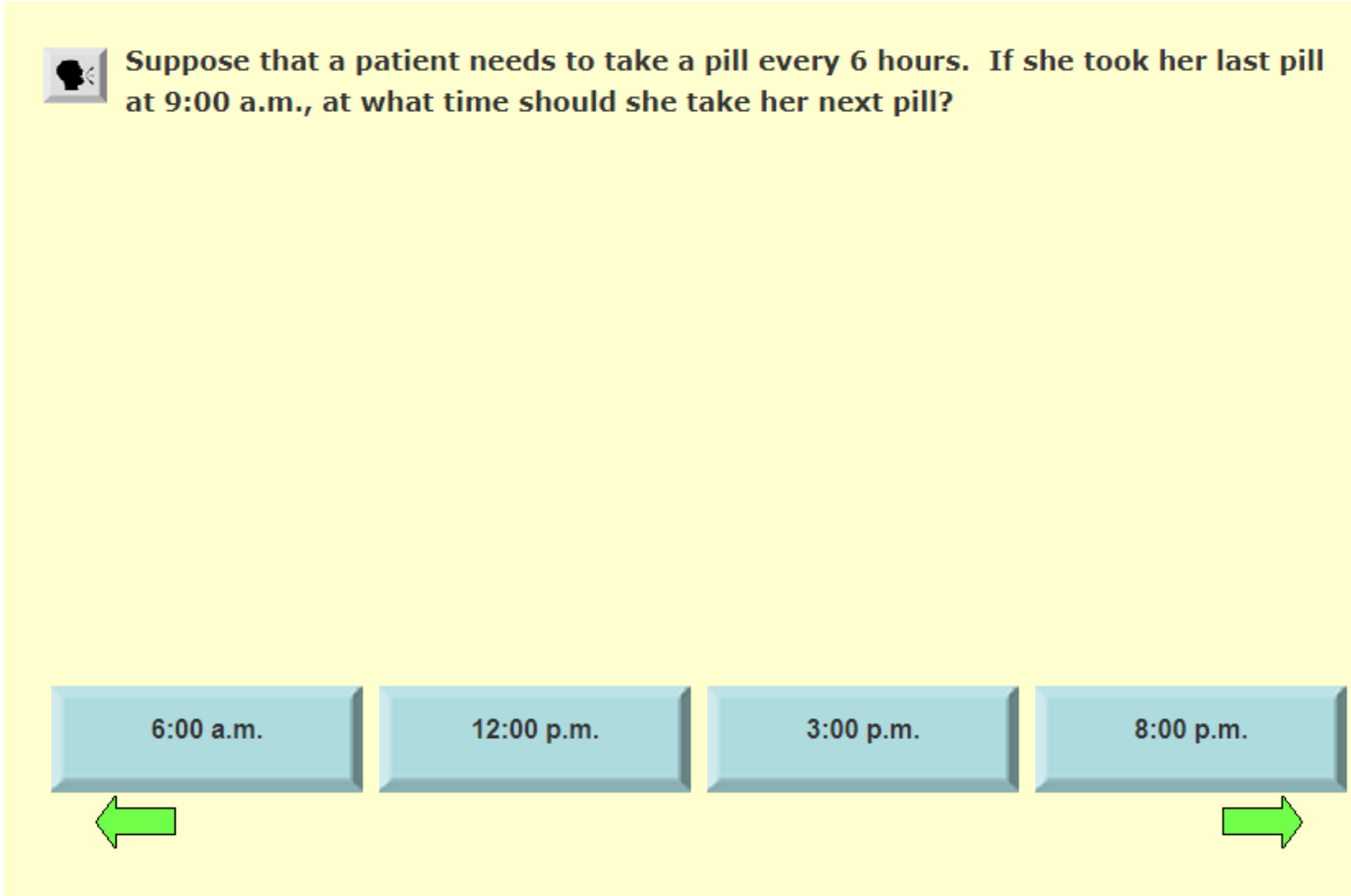
Health Literacy Assessment Using Talking Touchscreen Technology - HealthLITT

- Developed by Dr. Elizabeth A. Hahn and colleagues
- Self-administered multimedia touchscreen test
  - Adapted for use with REDCap
- Original: 82 items; **Short-Form**: 14 items
- Available in English and Spanish
- Assesses 3 types of literacy: Prose (short passage), Document (chart or label), Quantitative (text or image with calculations)
- T-score of 55+ = adequate health literacy

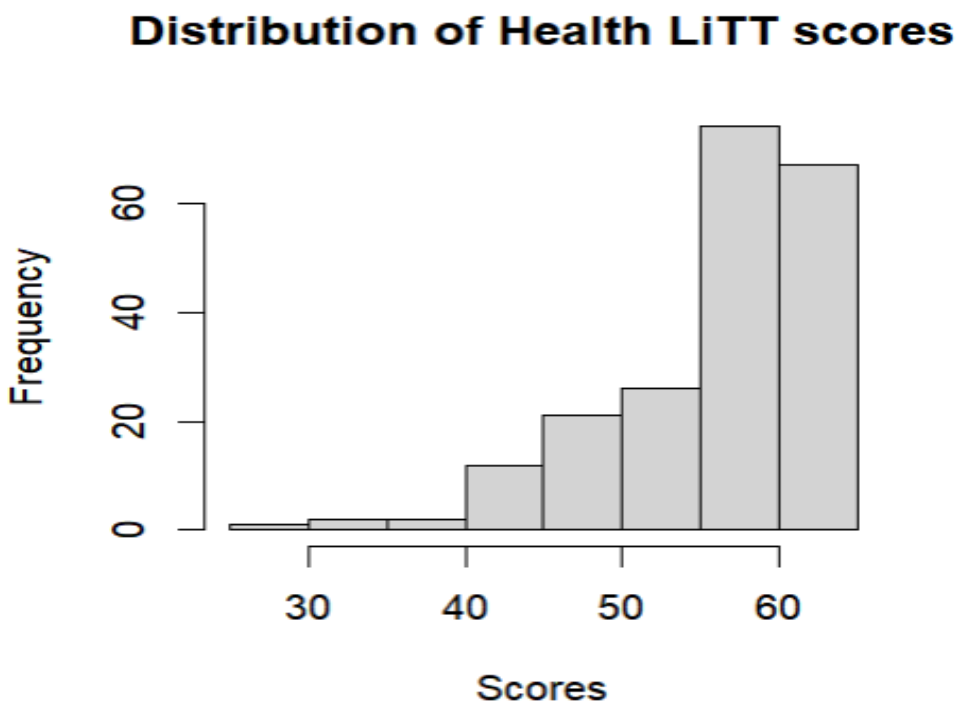
HealthLITT – Health Literacy Measure - Example



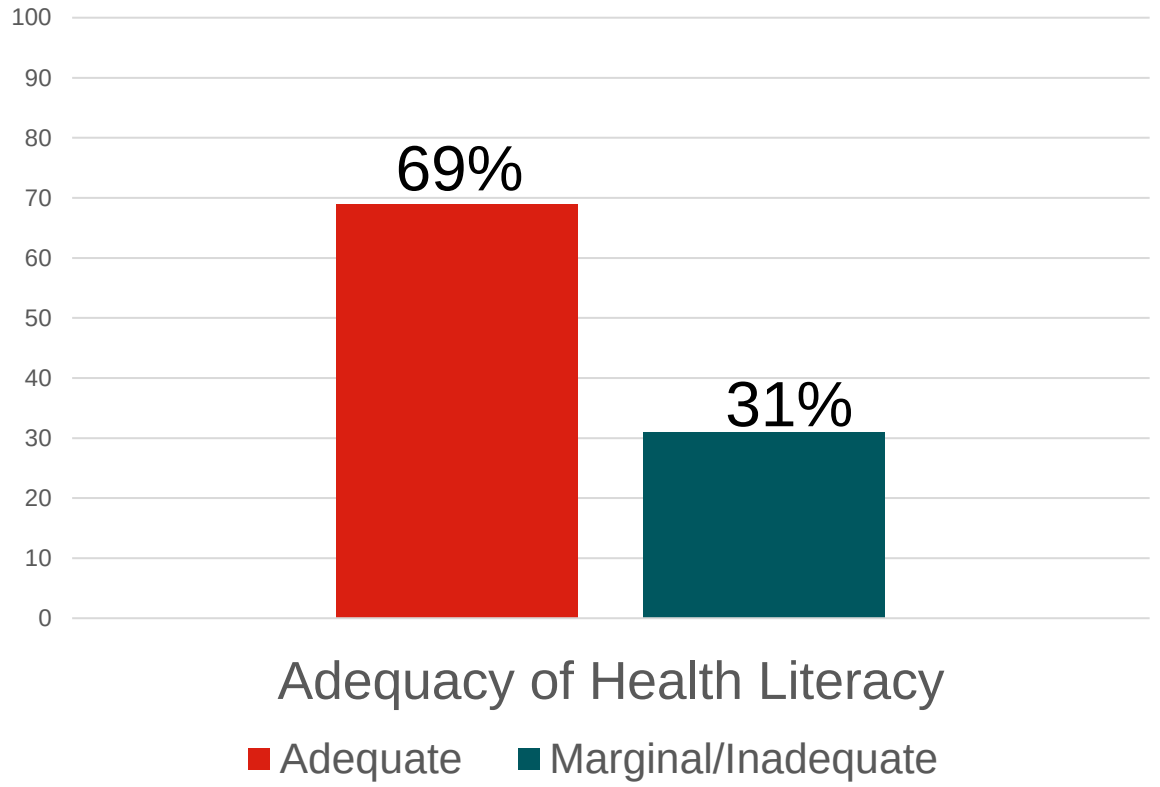
Measures

- **Injury Severity** (TBI Model System Criteria)
- **Cognition**: Brief Test of Adult Cognition by Telephone (BTACT)
  - 20-minute assessment of episodic verbal memory (RAVLT), working memory span-backward digit span (WAIS-III), category fluency (animals), inductive reasoning, speed of processing, and task switching.
- **Comorbidities**: Medical and Mental Health Comorbidities Interview (physical, such as hypertension, stroke, and mental health, such as PTSD, depression, ADD/ADHD)
- **Depression**: Patient Health Questionnaire-9 (PHQ-9)
- **Anxiety**: Generalized Anxiety Disorder-7 (GAD-7)

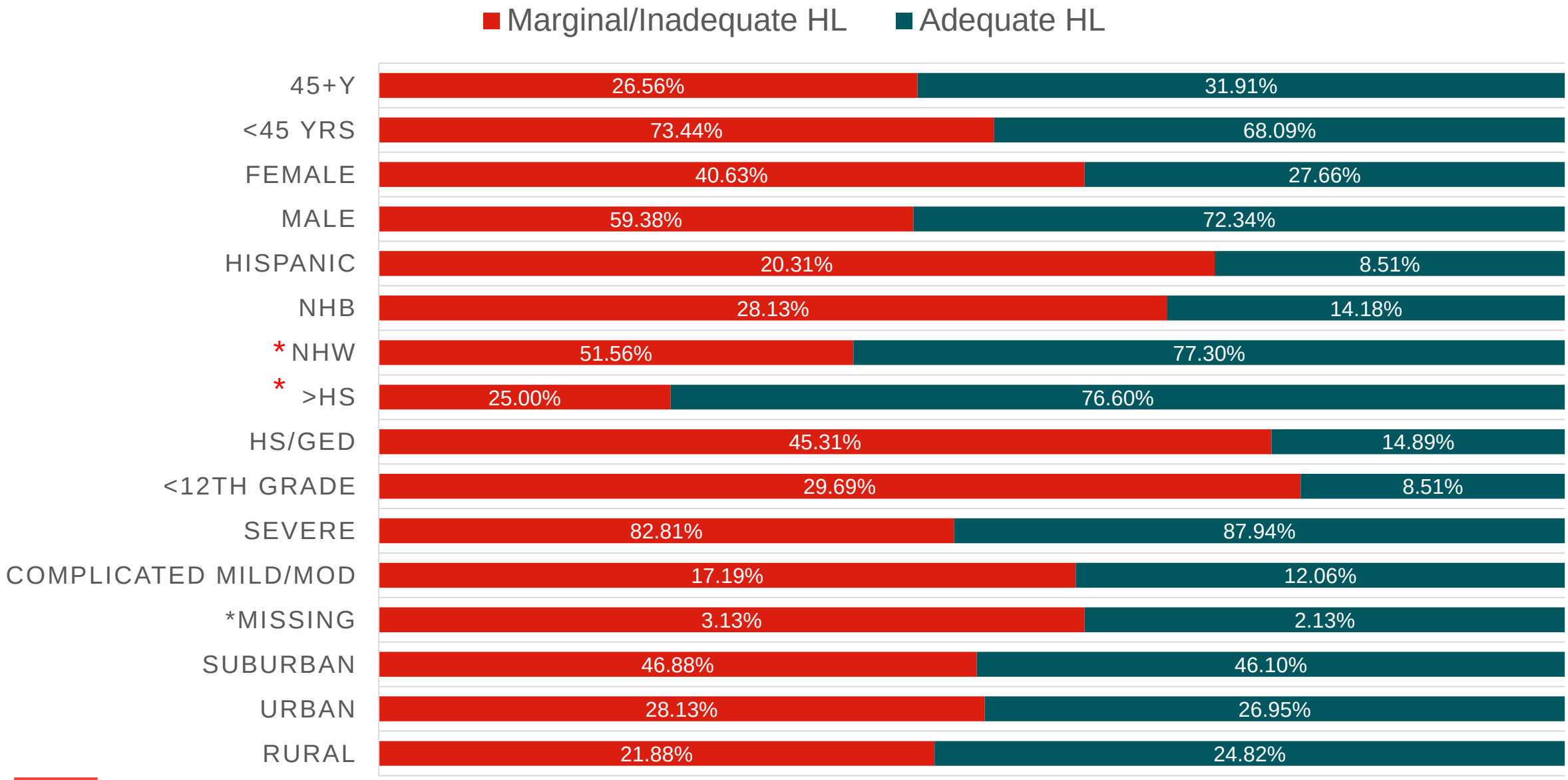
HealthLITT Scores



Average score: 56.67 (SD=7.23, 28.08 - 63.73)



SOCIODEMOGRAPHICS AND HEALTH LITERACY



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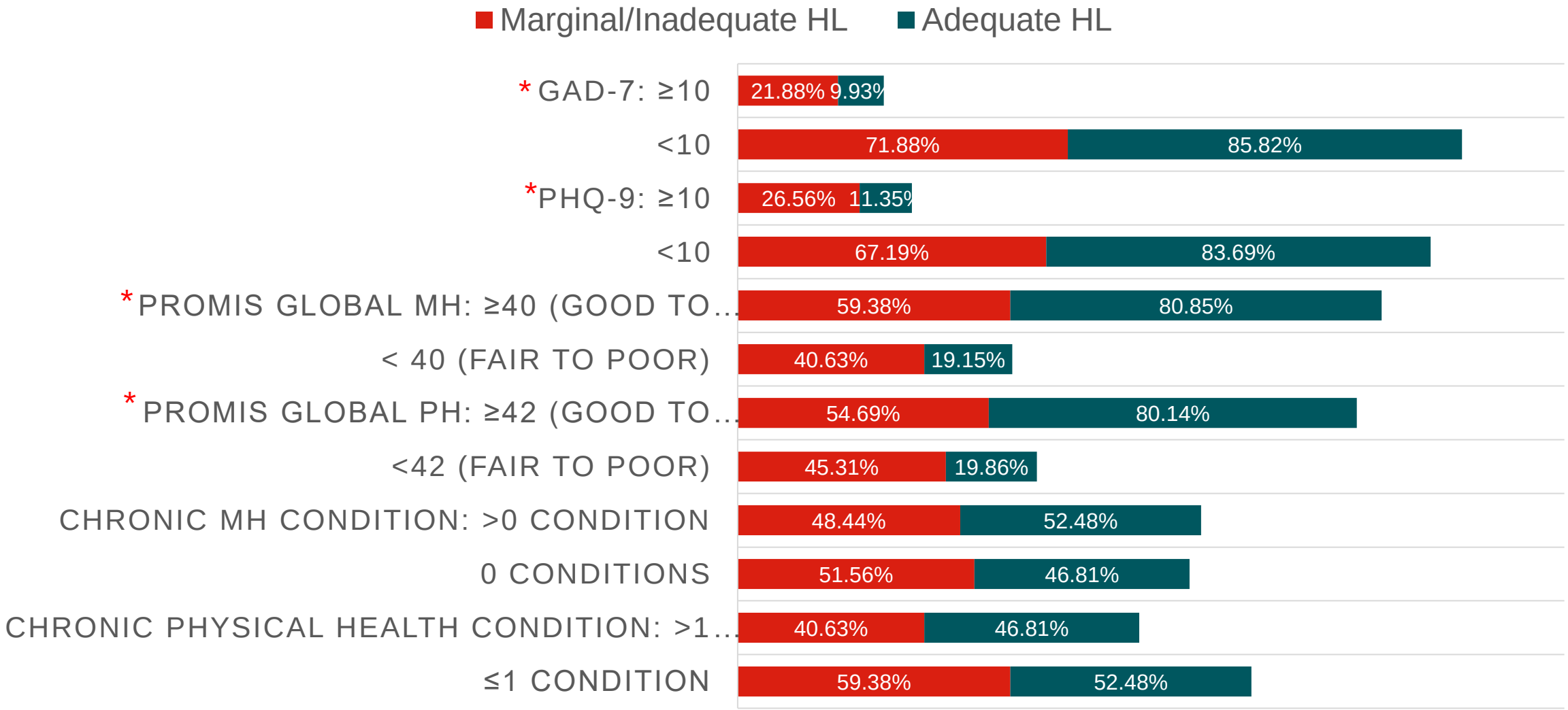
Health Literacy: Predicting Adequate Health Literacy

- **Education**:
  - Completed more than HS
- **Race**:
  - Non-Hispanic Blacks are **less likely** compared to Non-Hispanic White adults with TBI
  - Hispanics **less likely** compared to Non-Hispanic White adults with TBI.
- **Cognition**:
  - Higher Executive Function
  - Higher Episodic Memory
  - Episodic memory for those with mild-moderate TBI

- Not significant : Sex, Urbanicity, Injury Severity

HEALTH LITERACY AND OUTCOMES



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Chronic Physical and Mental Health Conditions

Health Literacy – not significant

- **Chronic Physical Health Conditions (>1)**
  - Age: Older adults (≥45)
  - Time post injury: Greater time post injury
- **Chronic Mental Health Conditions (>0)**
  - Age: Older adults (≥45)
  - Time post injury: Greater time post injury
  - Race: Non-Hispanic White adults
  - Injury severity: mild-moderate TBI

PROMIS Global Physical Health and Mental Health

Physical Health (>1)

- Health Literacy: Adequate health literacy

Mental Health (>0)

- Time post injury: less time post injury

Depression and Anxiety

Depression (PHQ-9 ≥ 10)

- Inadequate/marginal health literacy more likely (3.5 times)

Anxiety (GAD-7 ≥ 10)

- Age: Younger adults (<45) more likely (4.26 times)

Australian Comparison Study (PI: Jennie Ponsford)

- Victoria, Australia
- 209 adults with complicated mild-severe TBI
- 206 controls
- Minimum 1 year - 30 years 6 months post injury

	Unmatched sample	Matched sample	
	Individuals with TBI (*n* = 209)	Individuals with TBI (*n* = 196)	Controls (*n* = 206)
	M (s.d.), Range	*M* (s.d.), Range	*M* (s.d.), Range
Sex (*n*, %)			
Male	145, 69.4%	133, 67.9%	76, 36.9%
Female	64, 30.6%	63, 32.1%	130, 63.1%
Current age (years)	50.23 (15.3), 23.1–84.1	49.5 (15.2), 23.1–84.1	43.55 (16.8), 18.23–83.1
Education (years)	13.5 (2.4), 3–18	13.6 (2.5), 3–18	14.9 (2.1), 9–20
Country of birth (*n*, %)			
Australia	178, 85.2%	167, 85.2%	129, 62.6%
Outside Australia	31, 14.8%	29, 14.8%	77, 37.4%
Ethnicity (*n*, %)			
White	200, 95.7%	187, 95.4%	149, 72.7%
Ethnic minorities	9, 4.3%	9, 4.6%	56, 27.3%
Language spoken at home (*n*, %)			
English	206, 98.6%	193, 98.5%	189, 91.8%
Language other than English	3, 0.5%	3, 1.5%	17, 8.3%
Marital status (*n*, %)			
Single	44, 21.1%	43, 21.9%	82, 39.8%
Married	96, 46.0%	87, 44.4%	84, 40.8%
Cohabiting	33, 15.8%	31, 15.8%	18, 8.7%
In relationship, not cohabiting	10, 4.8%	10, 5.1%	5, 2.4%

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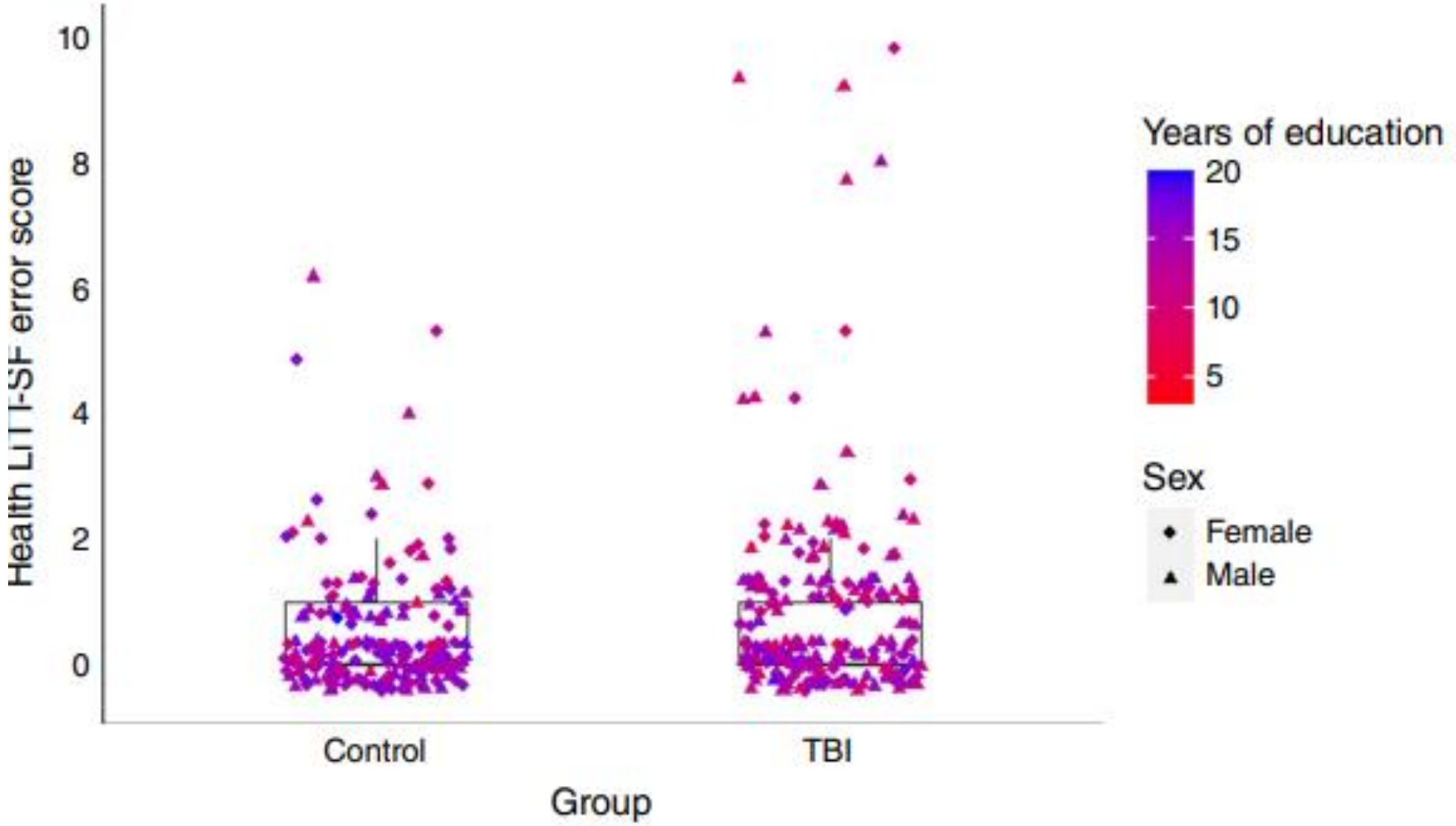

No differences between persons with TBI and controls. However, greater years of education was associated with fewer errors on the Health LiTT-SF. Only 6.2% had marginal/inadequate health literacy.

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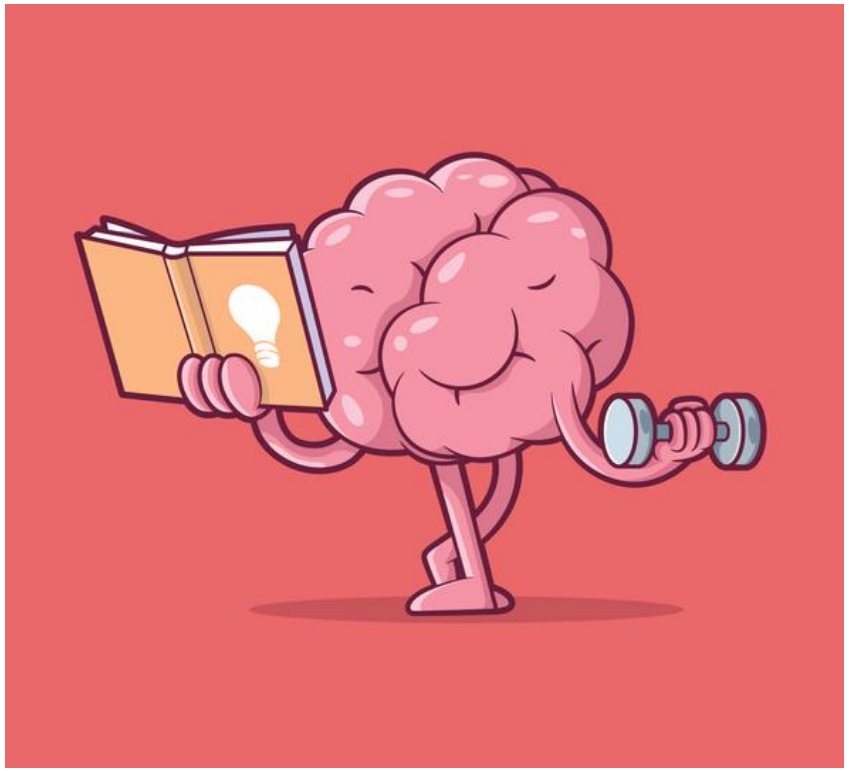
AUSTRALIAN SAMPLE:
ONLY 5 INDIVIDUALS WITH TBI HAD POOR HEALTH LITERACY SCORES



- **<u>Qualitative assessment:</u>**
  - Low Education
  - Older Age (>60 years)
  - Severe TBI
  - Cognitive Impairment
  - Emotional and physical health problems

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INCORPORATING HEALTH LITERACY STRATEGIES

THE CDC HAS A FEW POINTERS REGARDING HOW WE CAN HELP PEOPLE NOW:

Create and provide easily understood information

Work with educators and others to help people become more familiar with health information and services and build health literacy skills over time

Build your own health literacy skills over time to be a good communicator

Work with trusted messengers to share information

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THE CDC HAS A FEW POINTERS REGARDING HOW WE CAN HELP PEOPLE NOW:

Build health-literate organizations

Consider the cultural and linguistic norms, environment, and history of your intended audience when developing messaging and information

Use certified translators and interpreters who can adapt to your intended audience's language preferences, communication expectations, and health literacy skills

DEVELOP AND DISSEMINATE HEALTH AND SAFETY INFORMATION THAT IS ACCURATE, ACCESSIBLE, AND ACTIONABLE

- **Contributors of poor health information**:
  - Technical and medical terminology in public communications
  - Confusing or unnecessary statistics
  - Nuanced or unclear recommendations and explanations of risk
  - Over-reliance on written communication
  - A focus on awareness and information rather than action and behavior
  - Limited use of cultural preferences and practices when targeting and tailoring information and interventions

https://odphp.health.gov/sites/default/files/2019-09/Health_Literacy_Action_Plan.pdf

DEVELOP AND DISSEMINATE HEALTH AND SAFETY INFORMATION THAT IS ACCURATE, ACCESSIBLE, AND ACTIONABLE

- **Strategies**:
  - Participate in **ongoing training in health literacy** that focuses on improving clear communication and information design practices
  - **Involve members of the target population**—including persons with limited health literacy—in planning, developing, implementing, disseminating, and evaluating health and safety information
  - Ensure that health and safety information is **culturally and linguistically appropriate** and motivating
  - Issue **plain language** guidance for the development of all public health and safety information
  - **Include specific steps for taking action** and aligning information with services and supports available in the community
  - **Build networks** with community and faith-based organizations, social service agencies, and nontraditional partners—such as foster care services, poison control centers, and literacy service providers— to deliver health and safety information to different points in the community

DEVELOP AND DISSEMINATE HEALTH AND SAFETY INFORMATION THAT IS ACCURATE, ACCESSIBLE, AND ACTIONABLE

- **Strategies**:
  - **Leverage technology and electronic health tools** to deliver health information and services at the time, in the place, and in the multiple formats people need and want
  - Ensure **access to the Internet** and devices that deliver health information services
  - **Promote health literacy** improvement efforts through professional and advocacy organizations
  - Create documents that demonstrate **best practices in clear communication** and information design
  - **Test consumer health information and Web sites** to ensure that consumers understand the information and can take appropriate actions

PROMOTE CHANGES IN THE HEALTH CARE DELIVERY SYSTEM THAT IMPROVE HEALTH INFORMATION, COMMUNICATION, INFORMED DECISION-MAKING, AND ACCESS TO HEALTH SERVICES

- **Contributors of limited health literacy**:
  - Lack of coordination among health care providers
  - Confusing forms and instructions
  - Limited use of multimedia to convey information
  - Insufficient time and incentives for patient education
  - Differences in language and cultural preferences and expectations between doctors and patients
  - Overuse of medical and technical terms to explain vital information

PROMOTE CHANGES IN THE HEALTH CARE DELIVERY SYSTEM THAT IMPROVE HEALTH INFORMATION, COMMUNICATION, INFORMED DECISION-MAKING, AND ACCESS TO HEALTH SERVICES

- **Strategies**:
  - **Use different types of communication** and tools with patients, including vetted pictures and models and scorecards, to support written and oral communication with patients and their caregivers
  - **Use existing programs**, such as *AHRQ's Questions Are the Answers*, to prepare patients and providers for visits and structure their communication
  - **Use direct and developmentally appropriate communication** with children to build better understanding of their health and health care
  - Use proven methods of **checking patient understanding**, such as the *teach-back method*, to ensure that patients understand health information and risk and benefit tradeoffs associated with treatments, procedures, tests, and medical devices
  - Ensure that pharmacists provide the **necessary counseling to consumers** in language they understand for dispensed medications as required by law

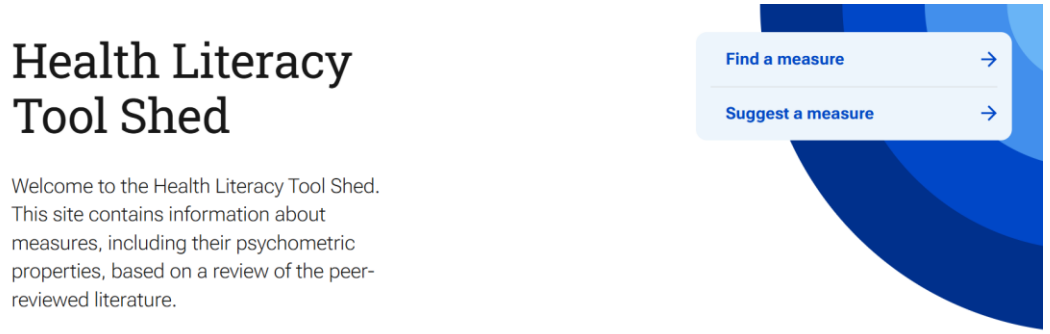
PROMOTE CHANGES IN THE HEALTH CARE DELIVERY SYSTEM THAT IMPROVE HEALTH INFORMATION, COMMUNICATION, INFORMED DECISION-MAKING, AND ACCESS TO HEALTH SERVICES

- **Strategies**:
  - **Use patient-centered technologies** at all stages of the health care process to support the information and decision-making needs of patients
  - **Use technology**, including social media, to expand patients' access to the health care team and information
  - Participate in **ongoing training** in health literacy, plain language, and culturally and linguistically appropriate services (CLAS) and encourage colleagues and staff to be trained
  - Advocate for requirements in **continuing education for health care providers** who have been working in the field but have not participated in health literacy, cultural competency, and language access training
  - **Create patient-friendly environments** that facilitate communication by using architecture, images, and language to reflect the community and its values
  - **Refer patients to public and medical libraries** to get more information and assistance with finding accurate and actionable health information

INCREASE BASIC RESEARCH AND THE DEVELOPMENT, IMPLEMENTATION, AND EVALUATION OF PRACTICES AND INTERVENTIONS TO IMPROVE HEALTH LITERACY

- **Strategies**:
  - Identify and address gaps, such as numeracy and visual communication, in health literacy research
  - Collaborate to **develop a national research agenda** and include health literacy innovations and interventions in research plans and goals
  - Develop more rigorous and comprehensive methods to **measure individual and population health literacy skills** that capture the full range of skills, including listening and speaking, writing, numeracy, and cultural and conceptual knowledge
  - Develop methods to **measure or estimate health literacy** skills at local levels
  - Develop methods to **measure the full range of health literacy** skills of health professionals and organizations
  - Conduct **studies of the economic impact** of limited health literacy
  - Explore **technology-based interventions** to improve health literacy
  - **Assess barriers and strategies to improve access** to health information and navigation of the health care system
  - **Support systematic reviews** and evaluations of effectiveness and implementation of health literacy interventions

HEALTH LITERACY MEASURES



- **Health Literacy Shed:**
  - The Tool Shed is maintained by Tufts Medicine Center for Health Literacy Research & Practice at Tufts Medical Center. The Health Literacy Tool Shed was developed in collaboration with CommunicateHealth, Boston University, and RTI International. Funding was provided by the National Institutes of Health's National Library of Medicine.
  - https://www.tuftsmedicine.org/research-clinical-trials/research-institutes-research-department/center-health-literacy-research-and-practice/find-a-measure

HEALTH LITERACY MEASURES

- **Brief Health Literacy Screener (3 items)**
  1. How often do you have somebody help you read hospital materials?
  2. How confident are you filling out medical forms by yourself?
  3. How often do you have problems learning about your medical condition because of difficulty understanding written information?
  4. How often do you have a problem understanding what is told to you about your medical condition?

  "How confident are you filling out medical forms by yourself?"
- **Single Item Literacy Screener**
  - "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from you doctor or pharmacist?" Responses are rated from "1" (never) to "5" (always). Responses above 2 identify patients who may need health literacy support.
- **Short Assessment of Health Literacy, Rapid Assessment of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA)**

NEWEST VITAL SIGN

- Developed by Pfizer Inc.
- Ice Cream Nutritional Label
- 6 questions
- Valid and reliable
- English and Spanish
- Scores 0-1 indicate a high chance (50% or more) of limited literacy.

Nutrition Facts

Serving Size	½ cup
Servings per container	4

Amount per serving

Calories	250	Fat Cal	120

	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

SUMMARY

- Organizations and providers should commit to improving the health literacy of patients.
- Sociodemographic factors, cognition, and injury-related factors are associated with health literacy.
- Health literacy is associated with anxiety, depression, and physical and mental health.
- Numerous strategies exist to promote health literate organizations and patients.
- Commit to taking a minute or two to assess a patient's healthy literacy and be prepared to address with interventions or communication strategies.

THANK YOU!

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utmb Health