



U.S. Department of Health and Human Services



Agency for Healthcare Research and Quality

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Keep Your Eyes on the Prize: Health Literacy Research as a Means to an End

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Disclosures

- I work for the Agency for Healthcare Research and Quality
 - ▶ The statements in this presentation are those of the author, who is responsible for its content, and do not necessarily represent the views of AHRQ.
 - ▶ No statements in this presentation should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.



What AHRQ Does

- AHRQ invests in research to understand how to make health care safer and improve quality
- AHRQ creates materials to teach and train health care professionals and systems to improve care for their patients
- AHRQ generates measures and data used to track and improve performance and evaluate progress of the U.S. health system



Overview

- Review accomplishments and deficits in health literacy research
- Propose new research directions
- Address vulnerable populations



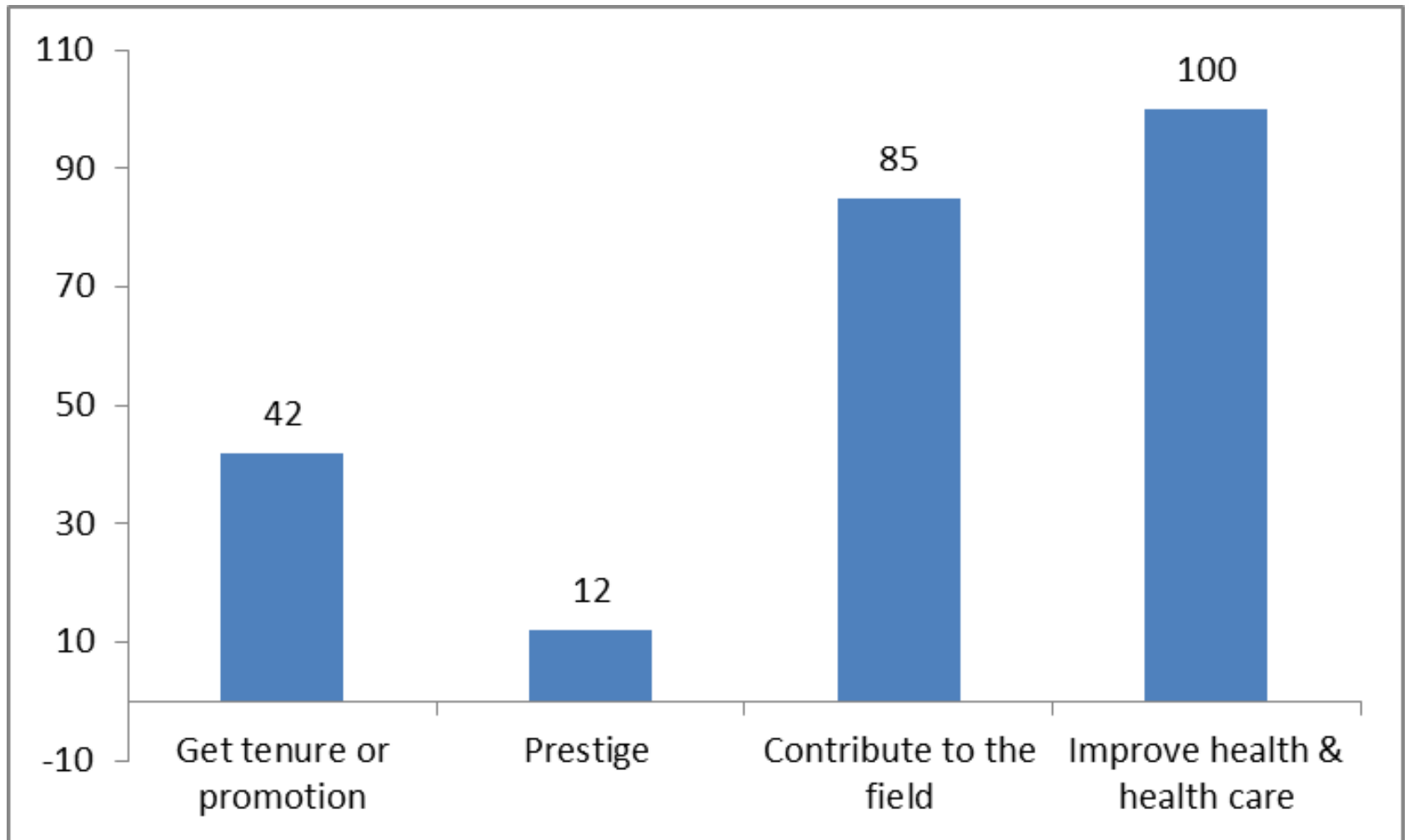
Polling Question

Why do you conduct health literacy research?

- A.** To get tenure or promotion
- B.** To gain prestige
- C.** Make a contribution to the field
- D.** Improve health and health care

You may select more than 1 option.

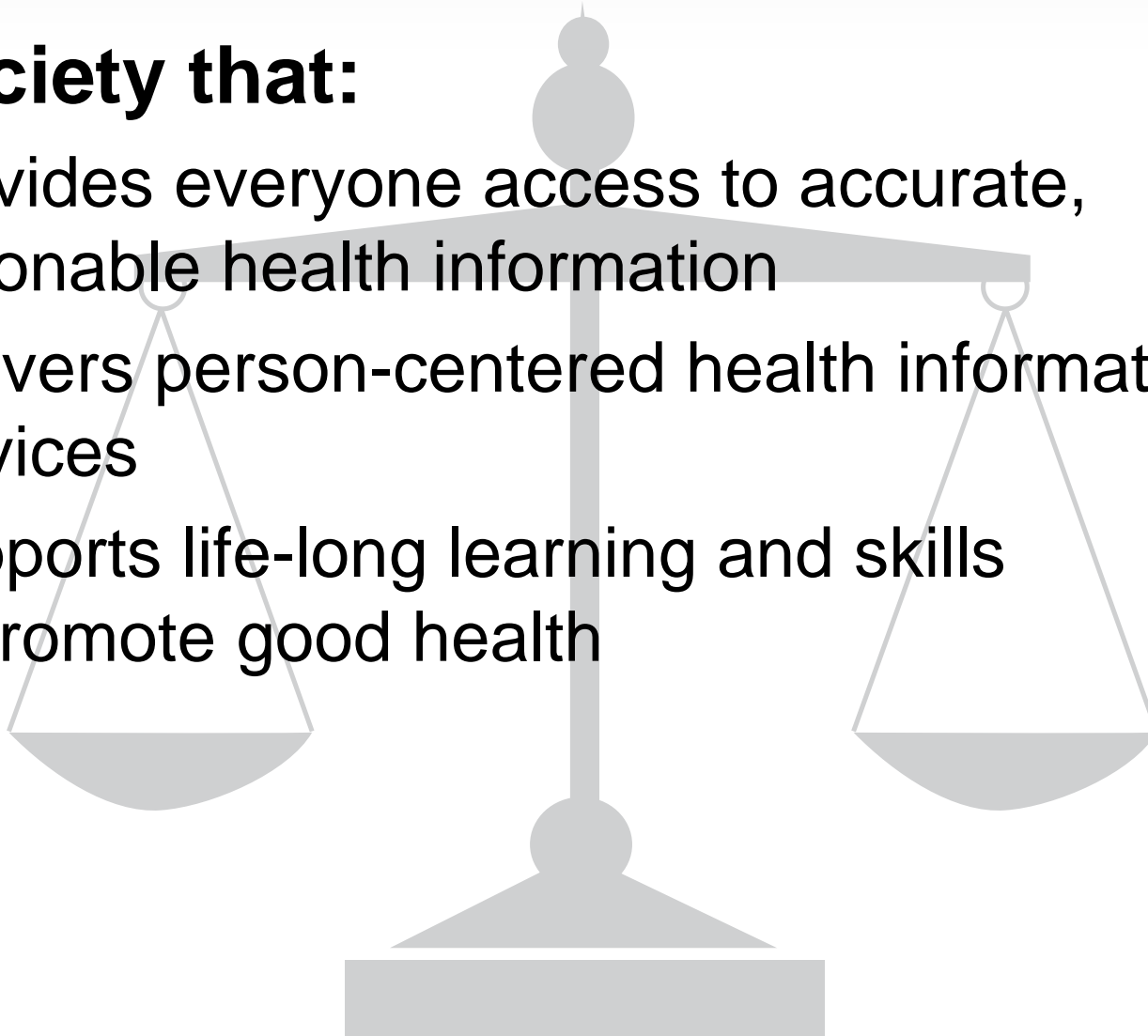
Results



The Prize

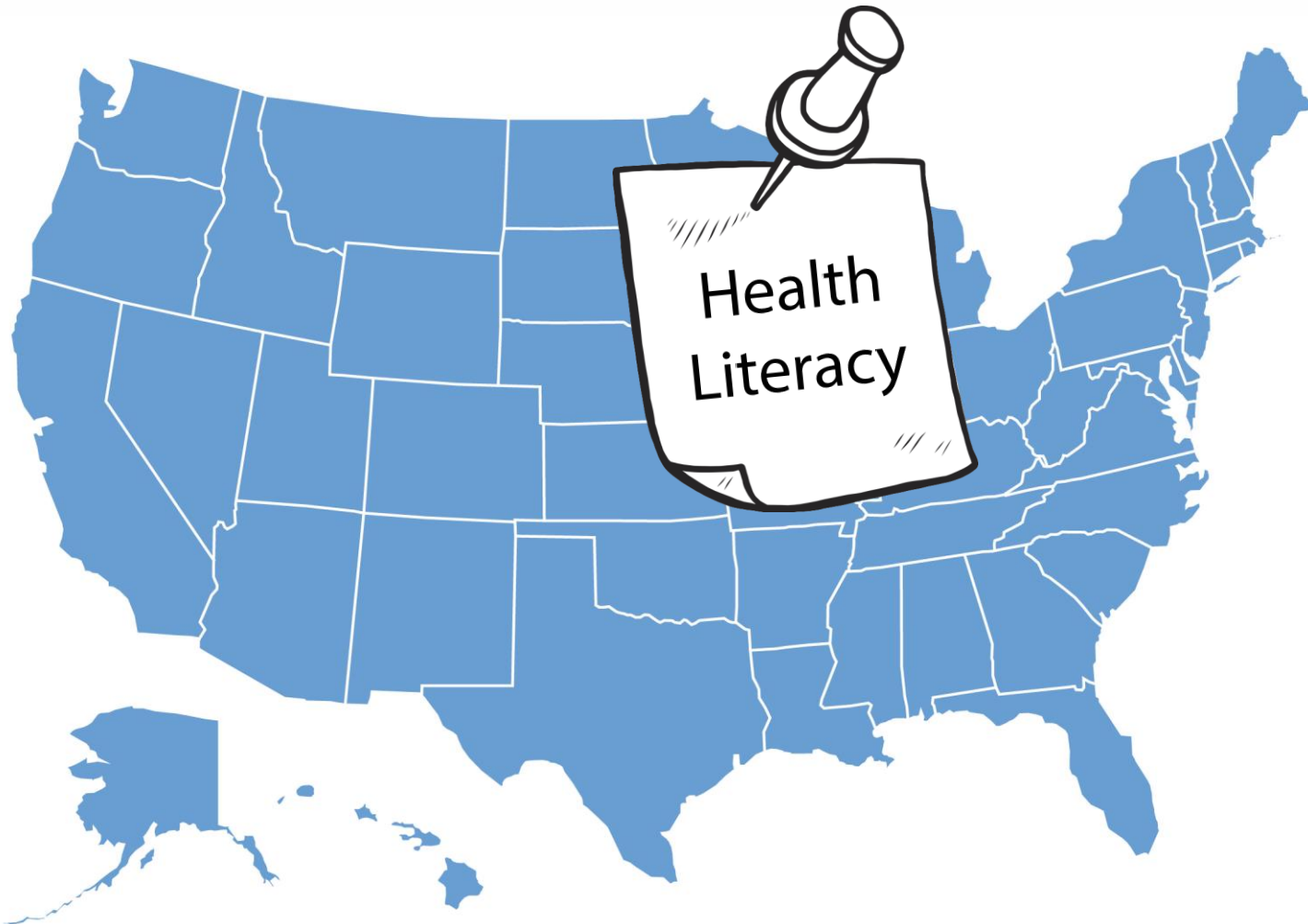
A society that:

- Provides everyone access to accurate, actionable health information
- Delivers person-centered health information and services
- Supports life-long learning and skills to promote good health





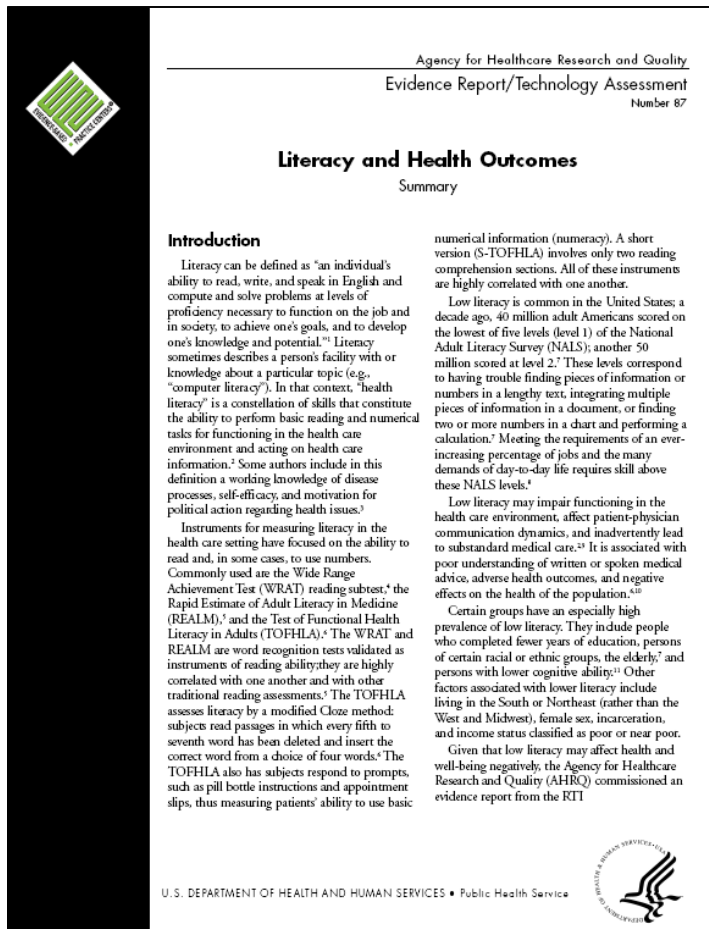
Researchers Put Health Literacy on the Map





Health Literacy: Growing the Field





The image shows the front cover of a report from the Agency for Healthcare Research and Quality (AHRQ). The cover is white with a black header and footer. The AHRQ logo is in the top left corner. The title 'Literacy and Health Outcomes' is prominently displayed in the center. Below the title is a subtitle 'Summary'. The cover also features a small graphic of a green diamond with the words 'EVIDENCE REPORT' and 'TECHNOLOGY ASSESSMENT' inside. The footer contains the text 'U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • Public Health Service' and a small graphic of an eagle.

Agency for Healthcare Research and Quality
Evidence Report/Technology Assessment
Number 87

Literacy and Health Outcomes

Summary

Introduction

Literacy can be defined as "an individual's ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society; to achieve one's goals; and to develop one's knowledge and potential."¹ Literacy sometimes describes a person's facility with or knowledge about a particular topic (e.g., "computer literacy"). In that context, "health literacy" is a constellation of skills that constitute the ability to perform basic reading and numerical tasks for functioning in the health care environment and acting on health care information.² Some authors include in this definition a working knowledge of disease processes, self-efficacy, and motivation for political action regarding health issues.³

Instruments for measuring literacy in the health care setting have focused on the ability to read and, in some cases, to use numbers. Commonly used are the Wide Range Achievement Test (WRAT) reading subtest,⁴ the Rapid Estimate of Adult Literacy in Medicine (REALM),⁵ and the Test of Functional Health Literacy in Adults (TOFHLA).⁶ The WRAT and REALM are word recognition tests validated as instruments of reading ability; they are highly correlated with one another and with other traditional reading assessments.⁷ The TOFHLA assesses literacy by a modified Cloze method: subjects read passages in which every fifth to seventh word has been deleted and insert the correct word from a choice of four words.⁸ The TOFHLA also has subjects respond to prompts, such as pill bottle instructions and appointment slips, thus measuring patients' ability to use basic numerical information (numeracy). A short version (S-TOFHLA) involves only two reading comprehension sections. All of these instruments are highly correlated with one another.

Low literacy is common in the United States; a decade ago, 40 million adult Americans scored on the lowest of five levels (level 1) of the National Adult Literacy Survey (NALS); another 50 million scored at level 2.⁹ These levels correspond to having trouble finding pieces of information or numbers in a lengthy text, integrating multiple pieces of information in a document, or finding two or more numbers in a chart and performing a calculation.¹⁰ Meeting the requirements of an ever-increasing percentage of jobs and the many demands of day-to-day life requires skill above these NALS levels.¹¹

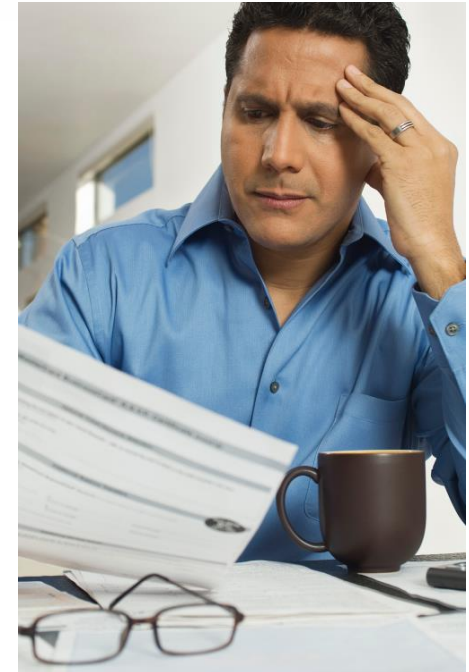
Low literacy may impair functioning in the health care environment, affect patient-physician communication dynamics, and inadvertently lead to substandard medical care.¹² It is associated with poor understanding of written or spoken medical advice, adverse health outcomes, and negative effects on the health of the population.¹³

Certain groups have an especially high prevalence of low literacy. They include people who completed fewer years of education, persons of certain racial or ethnic groups, the elderly,¹⁴ and persons with lower cognitive ability.¹⁵ Other factors associated with lower literacy include living in the South or Northeast (rather than the West and Midwest), female sex, incarceration, and income status classified as poor or near poor.

Given that low literacy may affect health and well-being negatively, the Agency for Healthcare Research and Quality (AHRQ) commissioned an evidence report from the RTI

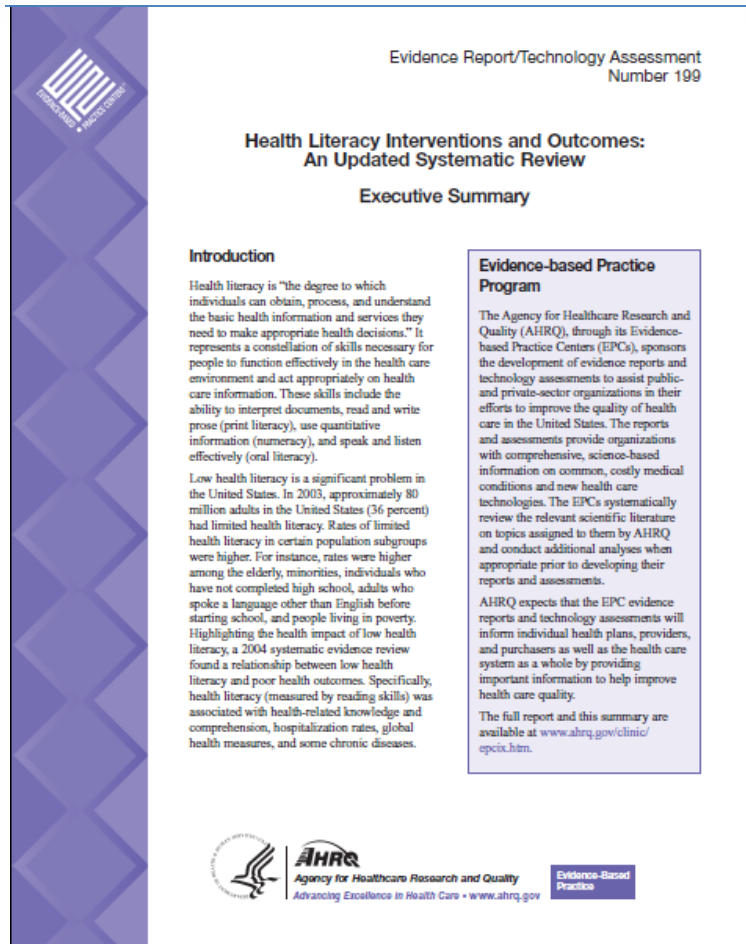
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • Public Health Service

- 73 articles, 29 on interventions
- Limited literacy linked to poor health outcomes
- Effectiveness of interventions not supported – few studies, fair quality
- No studies on costs of interventions



Skills/Abilities x Difficulty/Complexity = Health Literacy

2011 AHRQ Evidence Review Update



Evidence Report/Technology Assessment
Number 199

**Health Literacy Interventions and Outcomes:
An Updated Systematic Review**

Executive Summary

Introduction

Health literacy is "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions." It represents a constellation of skills necessary for people to function effectively in the health care environment and act appropriately on health care information. These skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy).


Low health literacy is a significant problem in the United States. In 2003, approximately 80 million adults in the United States (36 percent) had limited health literacy. Rates of limited health literacy in certain population subgroups were higher. For instance, rates were higher among the elderly, minorities, individuals who have not completed high school, adults who spoke a language other than English before starting school, and people living in poverty. Highlighting the health impact of low health literacy, a 2004 systematic evidence review found a relationship between low health literacy and poor health outcomes. Specifically, health literacy (measured by reading skills) was associated with health-related knowledge and comprehension, hospitalization rates, global health measures, and some chronic diseases.

Evidence-based Practice Program

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

The full report and this summary are available at www.ahrq.gov/clinic/epcix.htm.

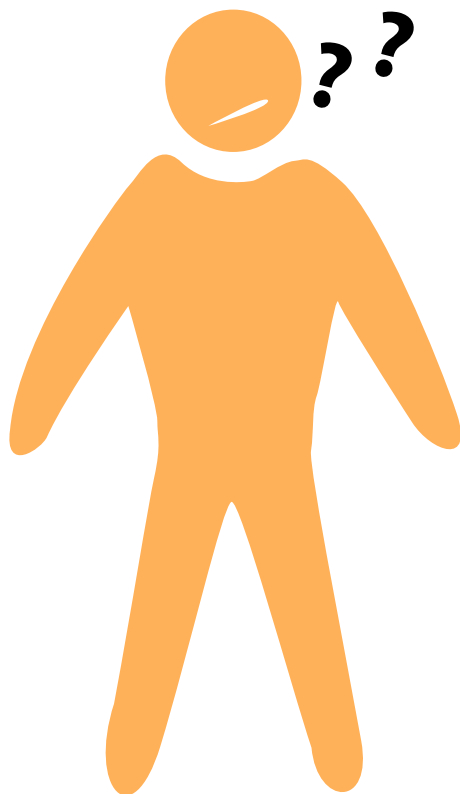
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Evidence-Based Practice

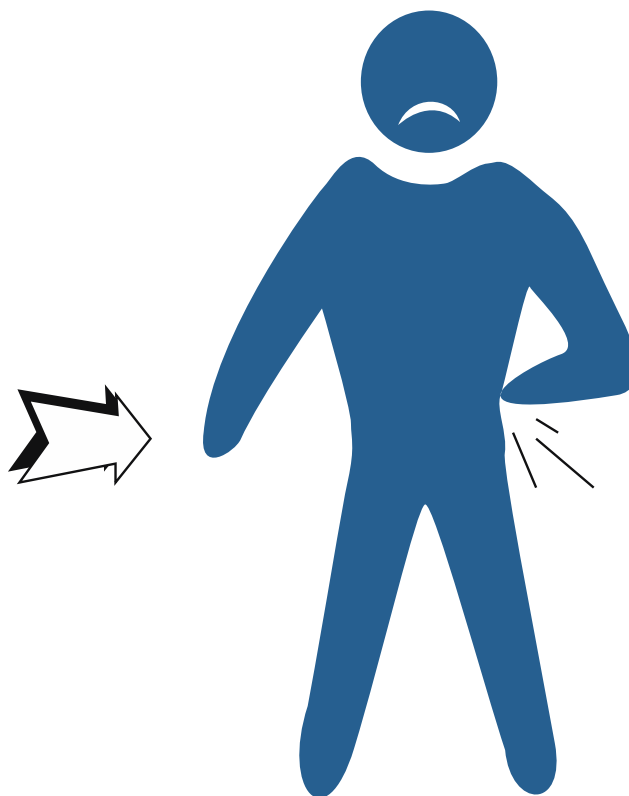
- 114 new articles: 13 on numeracy, 33 on interventions
- Possible causal pathways: knowledge, self-efficacy, and social stigma
- Low or insufficient evidence for specific design features
- Moderate evidence for combo interventions: intensive self-management & adherence
- 2 contradictory studies on cost

Enough Research on Associations

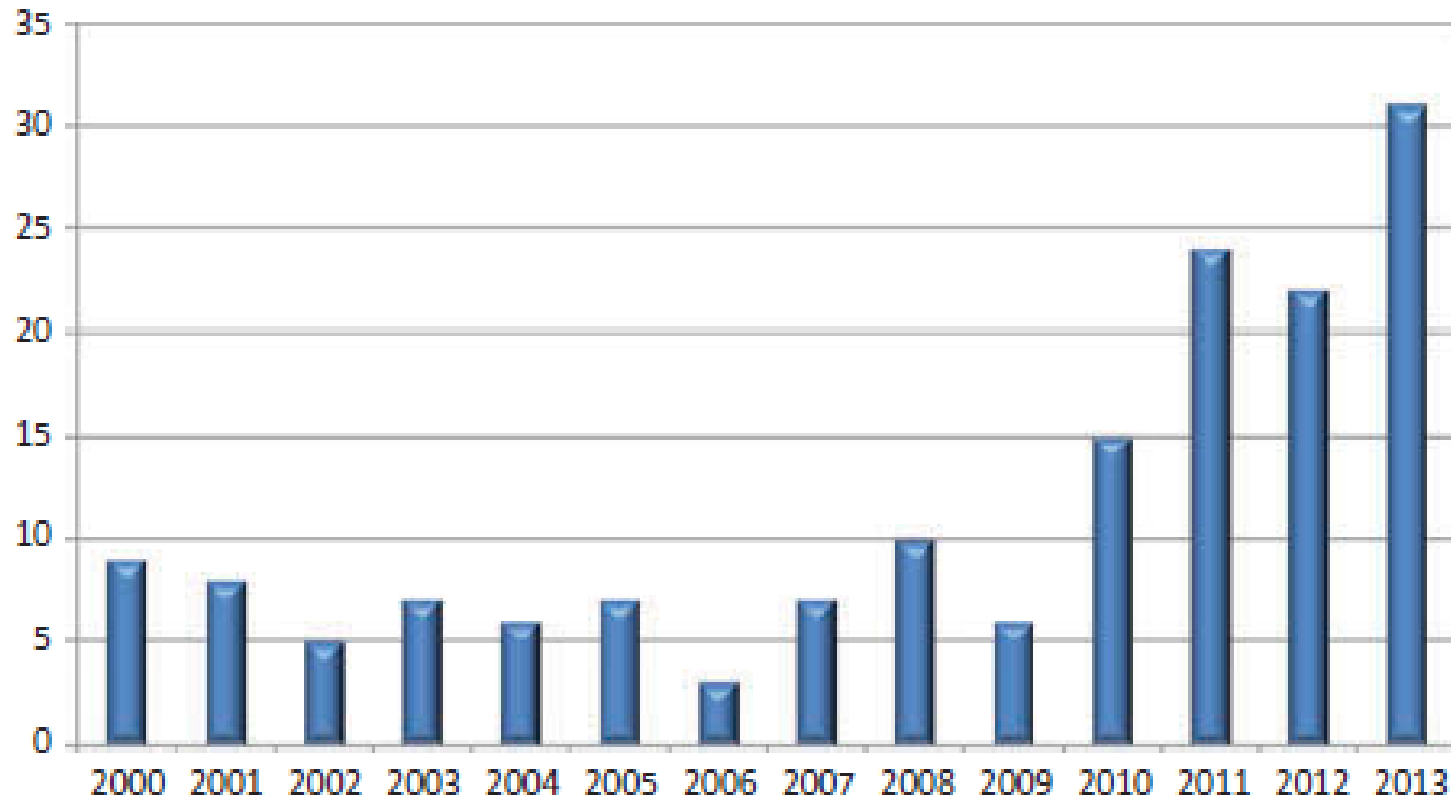
Low Health Literacy



Poor Health Outcomes

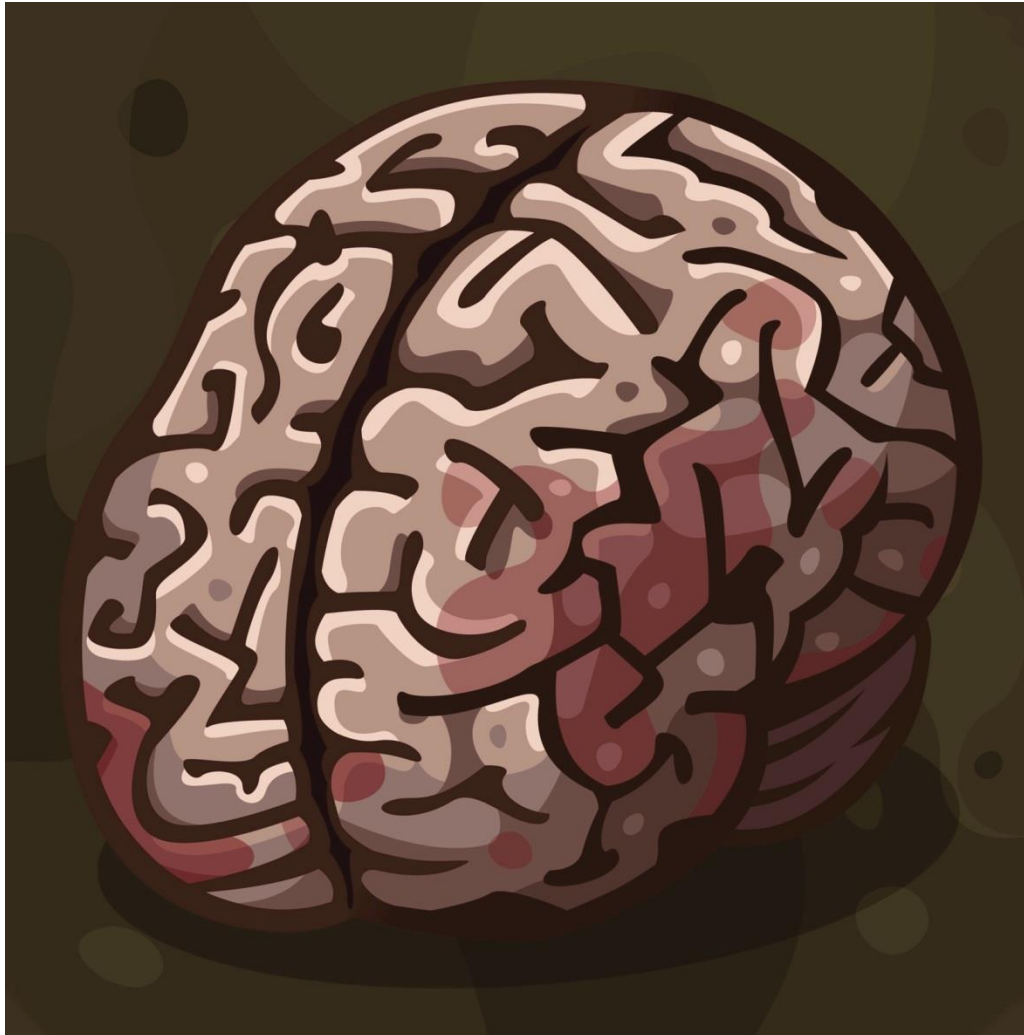


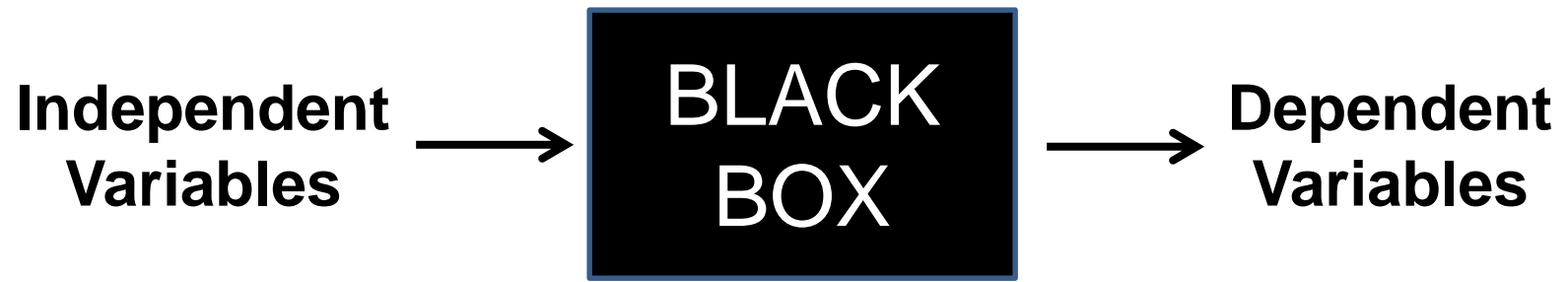
Number of Articles Assessing Readability of Written Materials



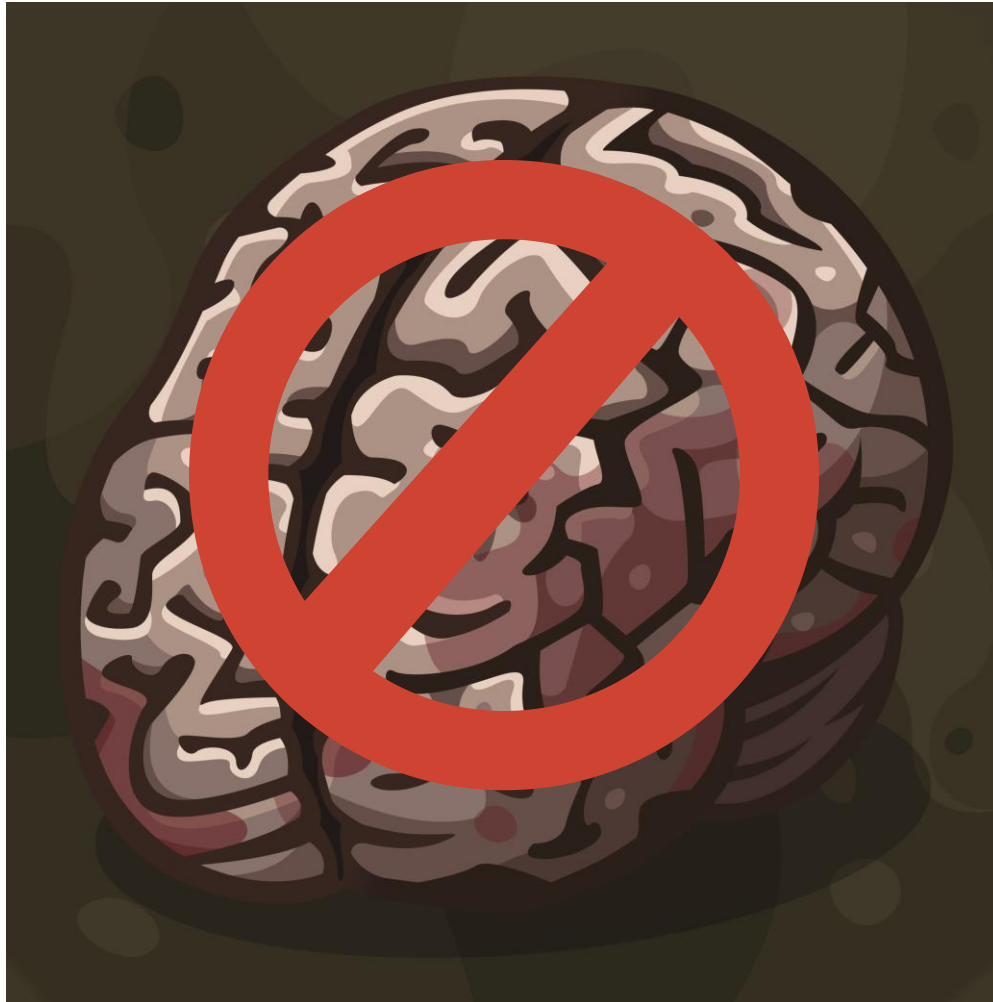
Weiss 2015

Brain Dead Research





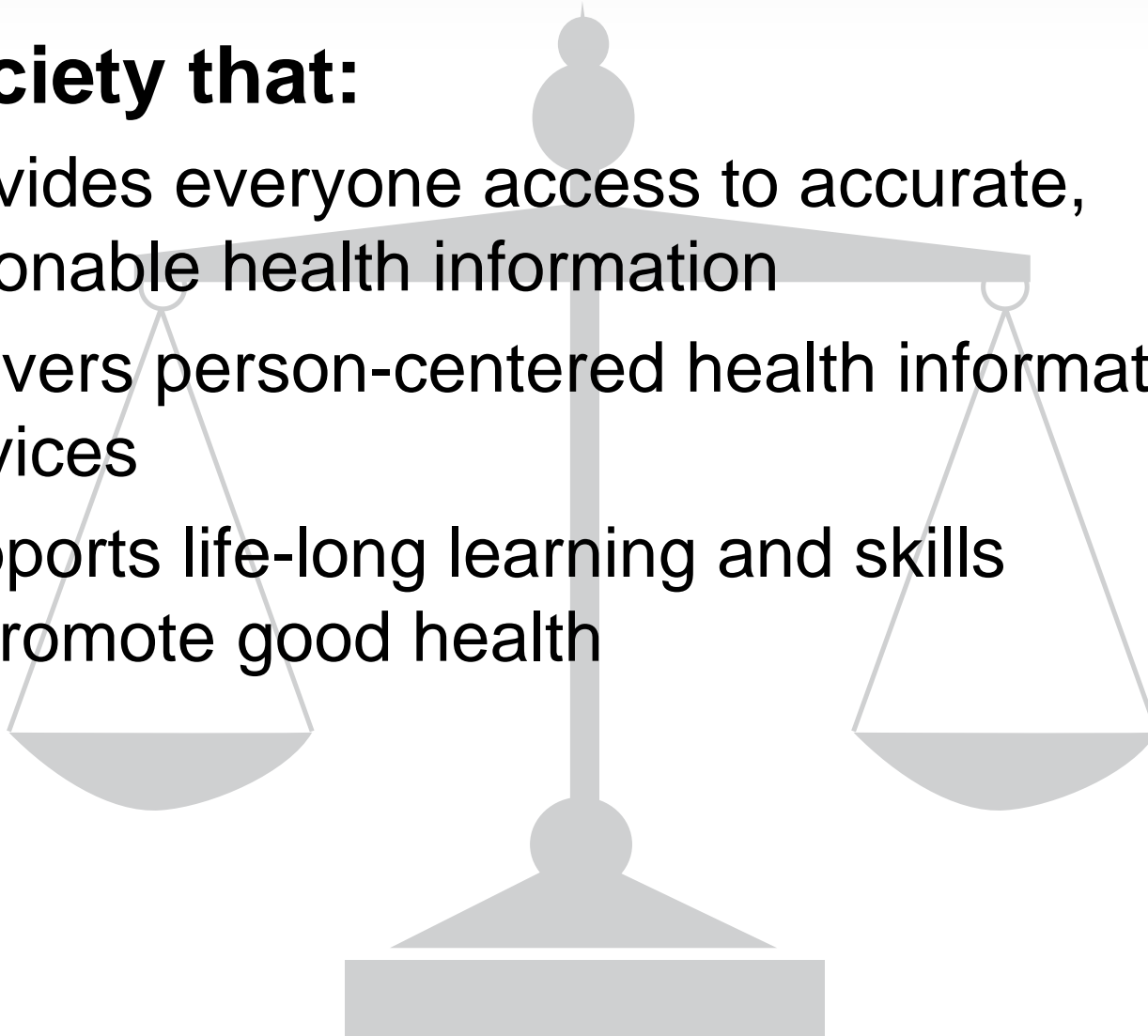
Brain Dead Research



Keep Your Eyes on the Prize

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3 Antidotes to Brain Dead Research

1. Conduct actionable research
2. Try new methods
3. Study systems

Actionable Research

- User-driven research: answer questions that would-be users are asking
- User-informed research: involve would-be users in design of research





Partner With Health Care Systems

- What are the operational managers' burning questions?
- What data sets do they have and how could they improve them?
- Test feasibility of interventions
- Take advantage of natural experiments
- Learn about implementation



Partner With Communities

- Engage communities in choice of research questions, not just recruitment
- Conduct hypothesis generating as well as hypothesis testing research
- Collaborate on development of interventions
- Gain insight into how to translate research results into practice

2. Try New Methods



False Precision



Qualitative Research

Explain causal network settings test behavior Themes Inductive Observation
culture focus groups case particular inquiry concepts strategies specific change Understanding
trustworthy representative interviews dynamic evidence perceptions
relationships notes patterns consequences uncertainty Action
grounded theory coding process Context views questions

Research Paradigms

Quantitative

- Assumes fixed, measurable reality
- Deductive
- Independent and dependent variables
- Probabilistic sampling
- Generalizable
- Biases unknown
- Truth

Qualitative

- Assumes dynamic and negotiated reality
- Inductive
- Holistic, interdependent system
- Purposive sampling
- Trustworthy
- Biases stated
- Understanding

Alternatives to the RCT

- Positive Deviance
- Most Significant Change
- Harvesting Outcomes
- Fuzzy Set Qualitative Comparison Analysis
- Interrupted Time Series
- Step-wedge Design



Examples of Mixed Methods

Door-to-Balloon Time

- Purposive sampling using national registry data
- Conducted in-depth interviews
- Used constant comparative method to ID effective strategies
- Conducted survey and regression to ID best strategies & effect size

Care Coordinated Demos

- Purposive sampling using admissions data
- Conducted interviews and site visits
- Identified common features
- Compared cost of program with savings from averted hospitalizations + natural experiment

Keep Your Eyes on the Prize

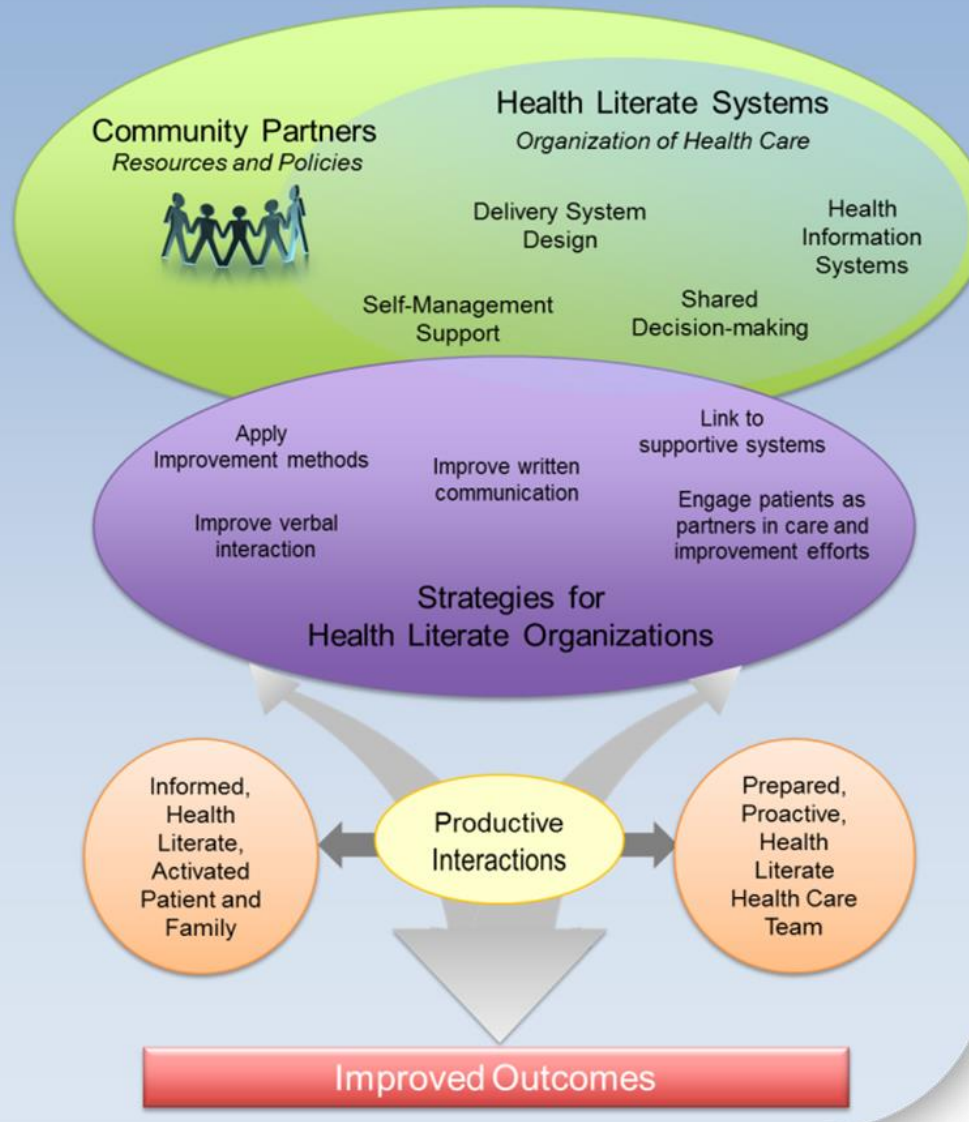
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Health Literate Care Model

A Universal Precautions Approach



Based on
Koh, Berwick et
al. 2013



Systems-level Research Questions

- Which system-level changes most effectively help care teams routinely confirm understanding?
- Which organizational communication strategies can help reduce the burden on individuals to coordinate their own care?
- How can information systems best engage individuals with easily understandable personalized medical record data?

Take Chances! Get Messy!





[Brach et al. 2012](#)

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.

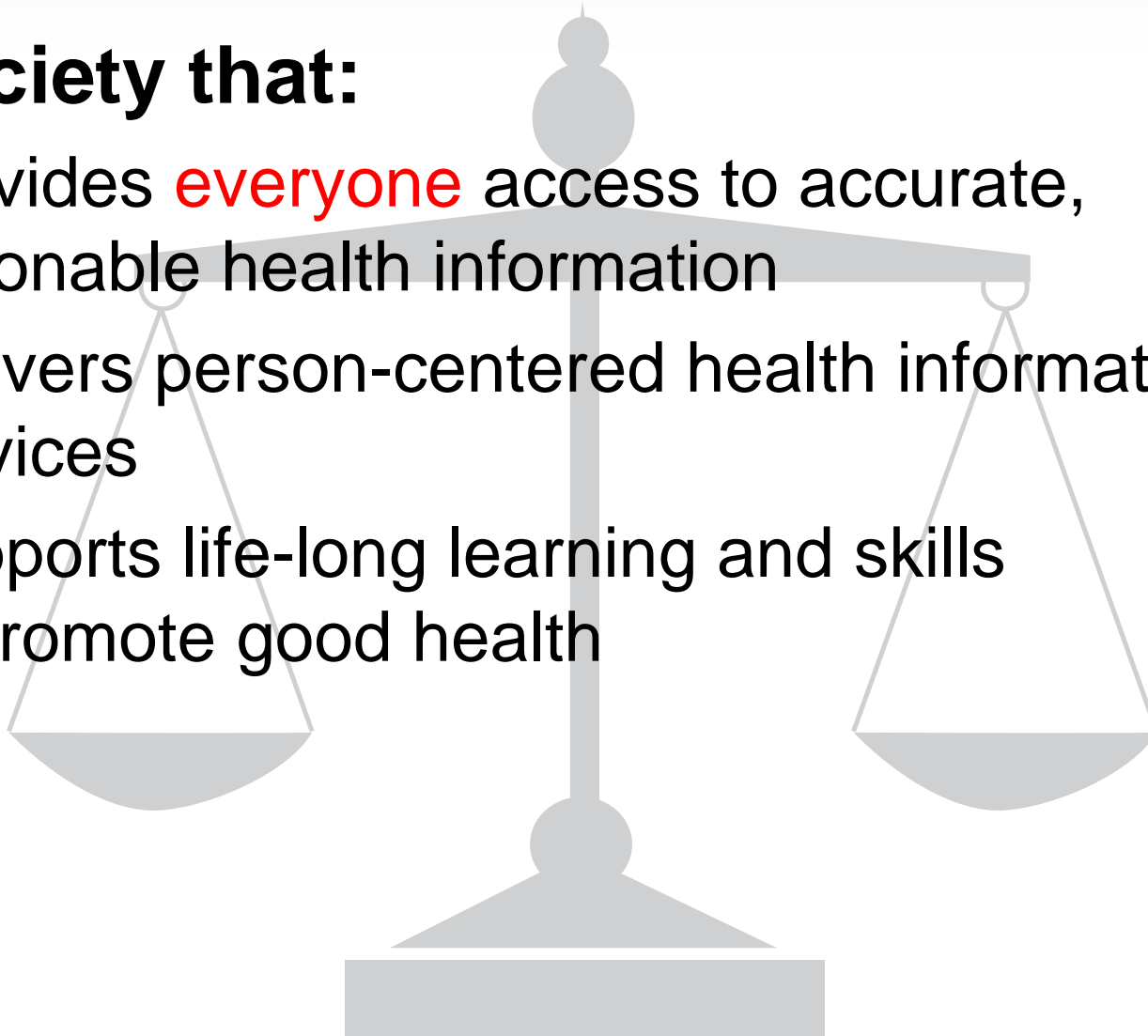




Keep Your Eyes on the Prize

A society that:

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Vulnerable Populations

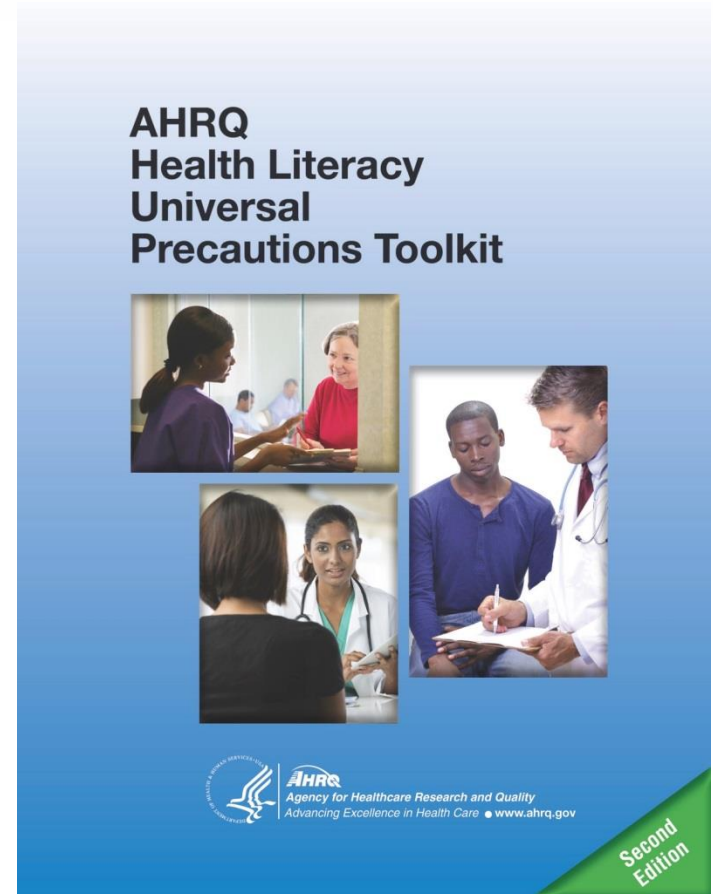
HHS Mission: To enhance and protect the health and well-being of **all** Americans

HHS 2016 Performance Plan: **especially for those who are least able to help themselves.**



AHRQ Health Literacy Universal Precautions Toolkit, 2nd Edition

- Communicate Clearly
- Follow-up with Patients
- Use Health Education Material Effectively
- Link Patients to Non-Medical Support
- Make Referrals Easy
- **Now with 21 tools and companion guide!**



<http://ahrq.gov/qual/literacy>



Polling Question

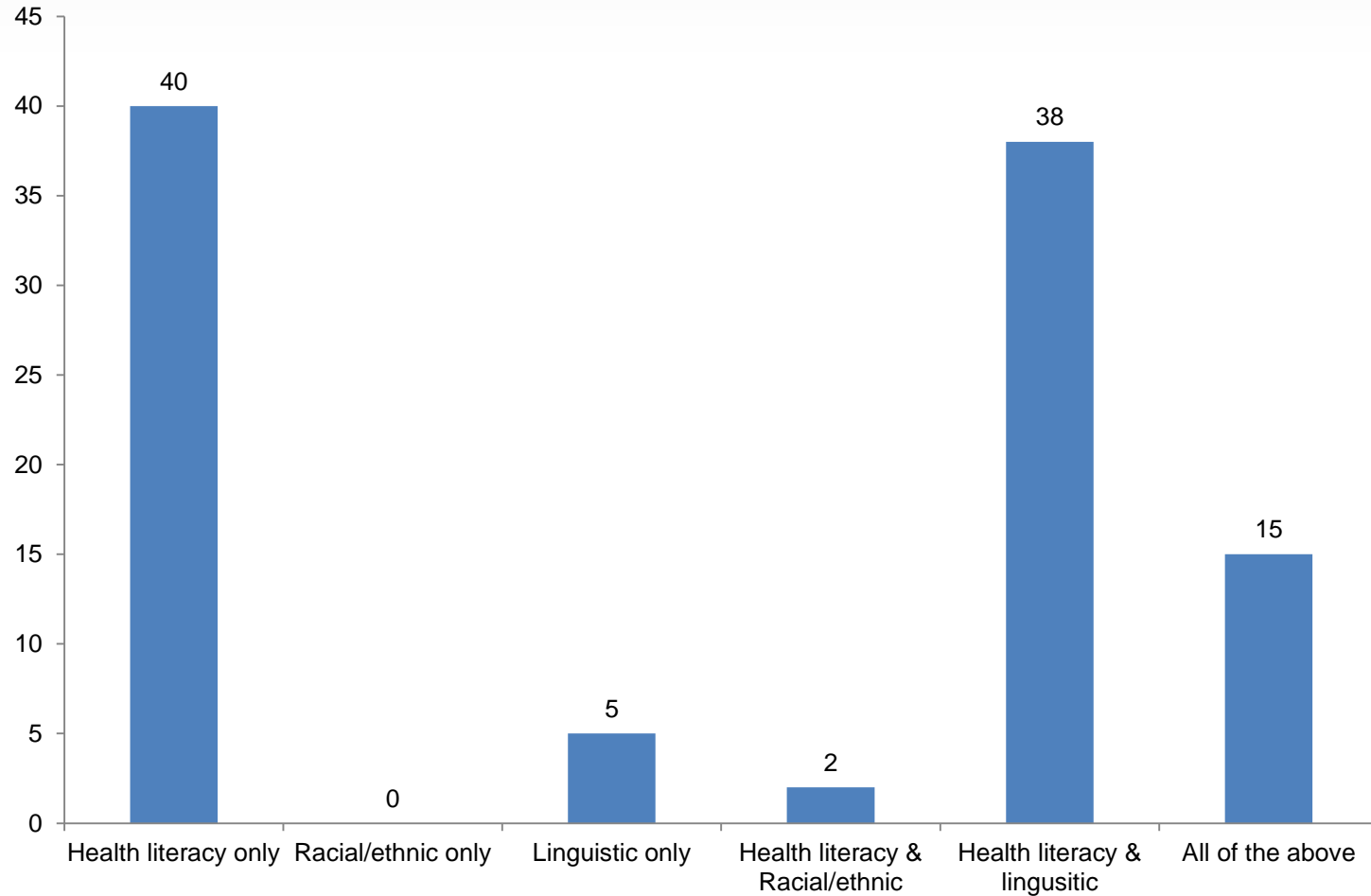
Which disparities should health literacy research reduce?

- A.** Health literacy
- B.** Racial and ethnic
- C.** Linguistic
- D.** A and B
- E.** A and C
- F.** All of the above

Select 1 option.

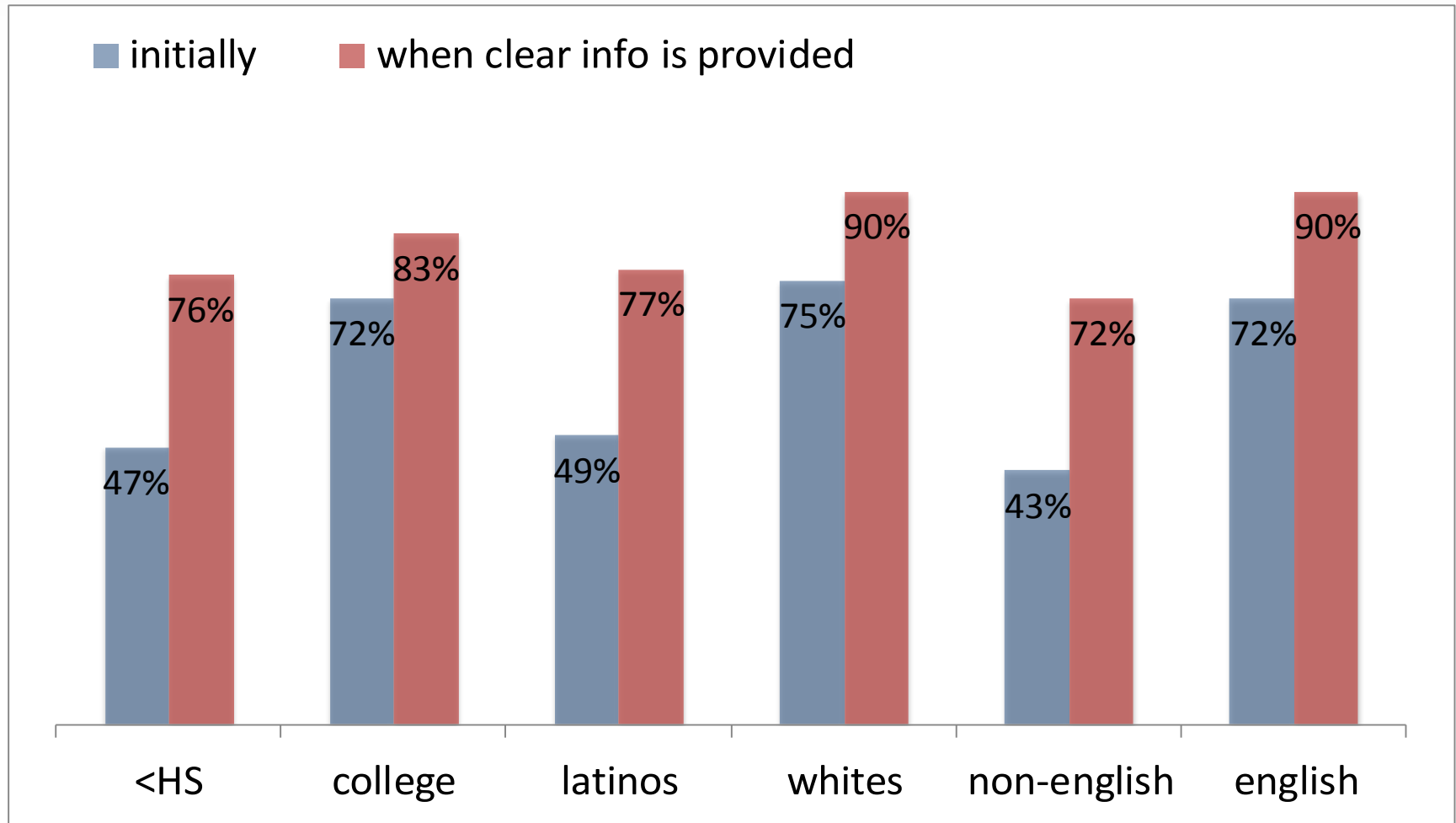


Results: Health Literacy Research Should Impact:





Clear Information Decreases Group Differences in Preferences for Shared Decision Making



[Langer et al. 2012](#)

Re-Engineered Discharge Program (RED)

Re-Engineered Discharge (RED) Toolkit



- Evaluated their current discharge process and re-engineered using health literacy principles
- Randomized control trial: 30% reduction in subsequent emergency visits and readmissions
- Tested only with English speakers



New RED Toolkit for Serving Diverse Populations

- Integrated into all RED implementation tools
- Separate tool for serving diverse populations

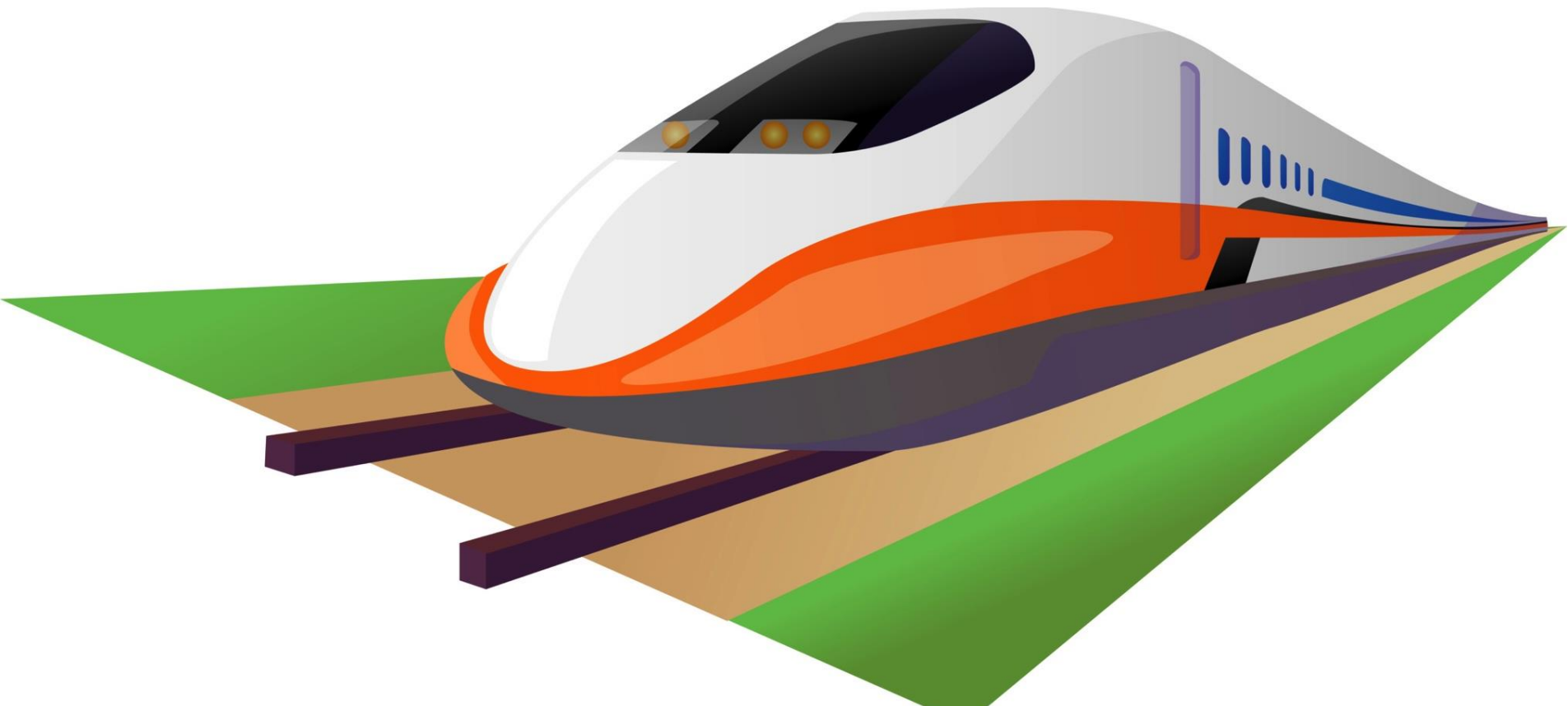


New RED Toolkit for Serving Diverse Populations

- Integrated into RED implementation tools
- Separate tool for serving diverse populations
- Added 12th component: Ascertain need for and obtain language assistance

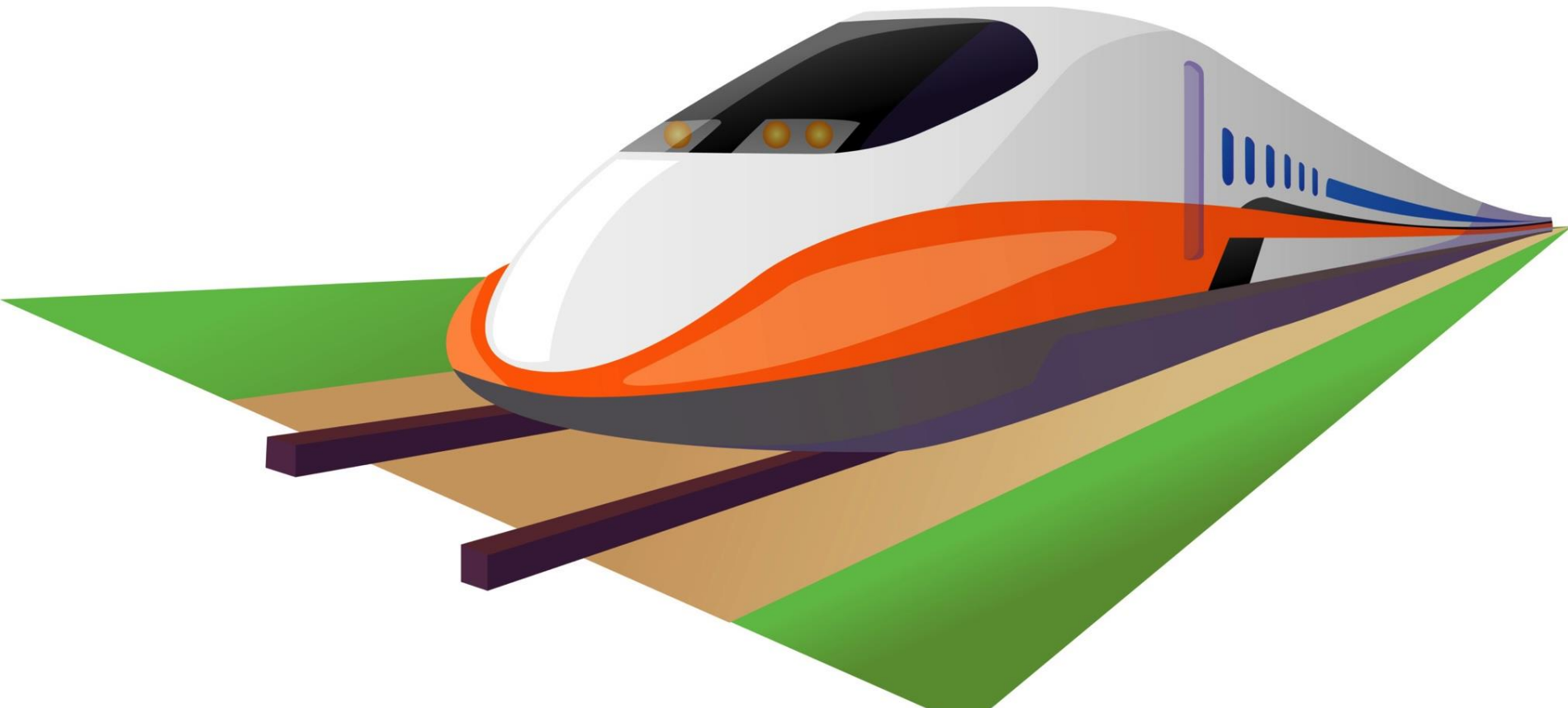


Catch the Moving Train



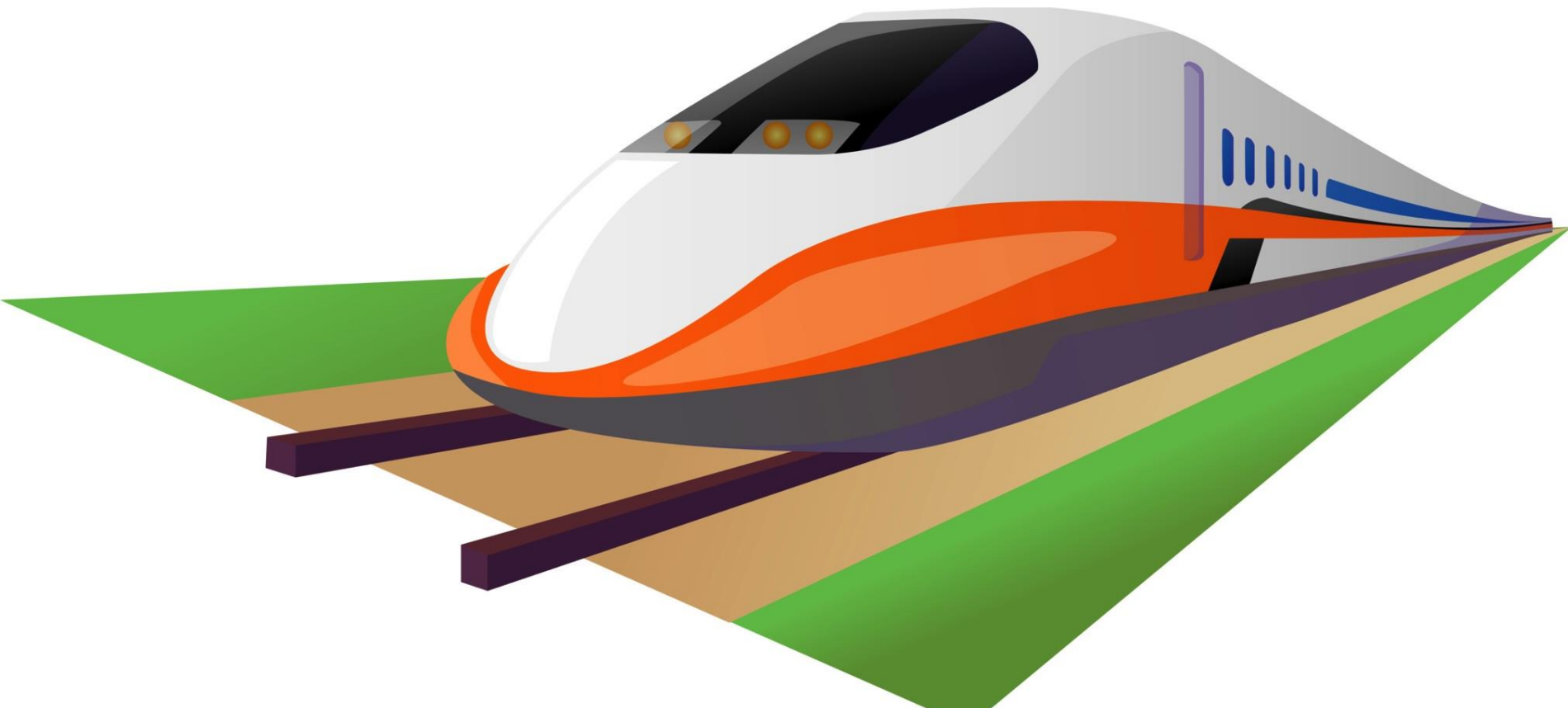
Catch the Moving Train

- Patient engagement



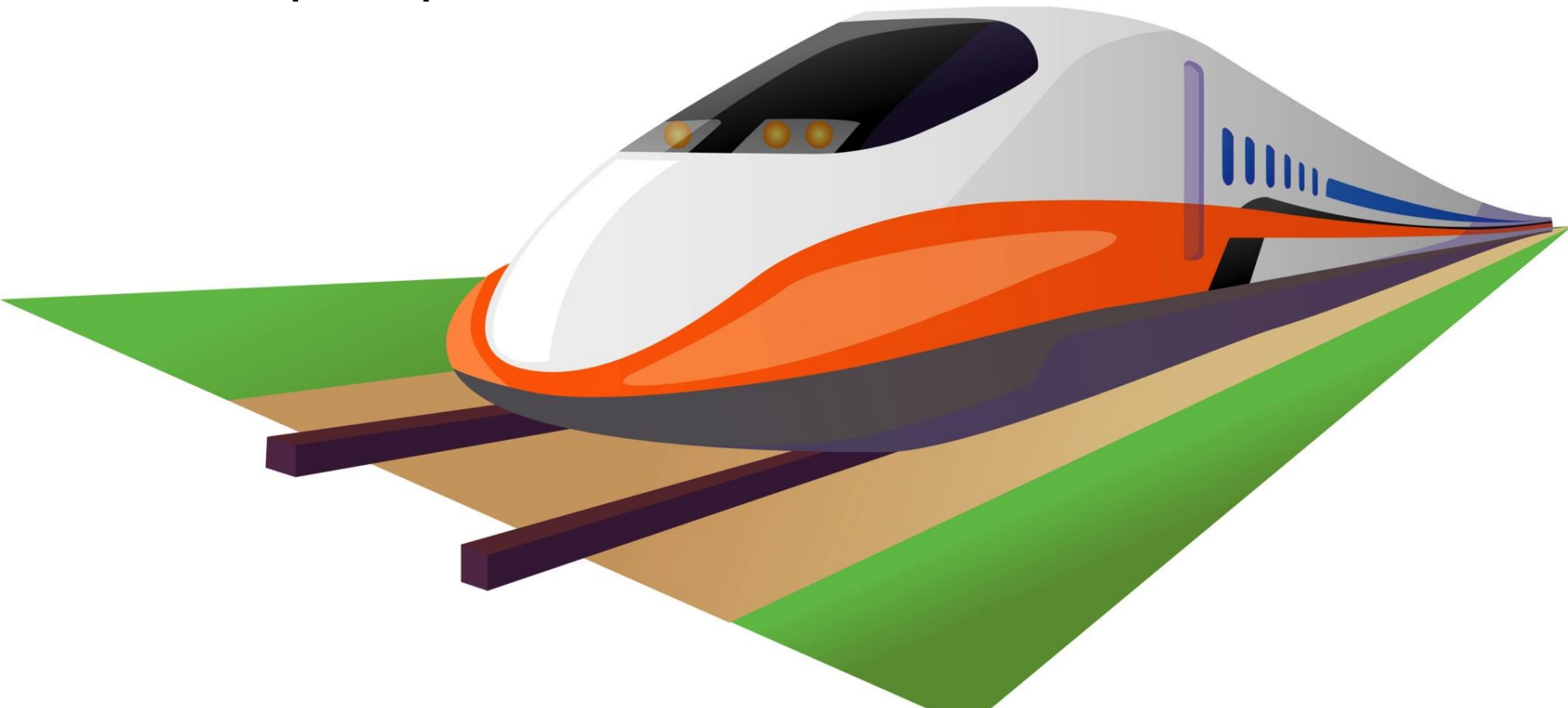
Catch the Moving Train

- Patient engagement
- Shared decision-making



Catch the Moving Train

- Patient engagement
- Shared decision-making
- Complex patients



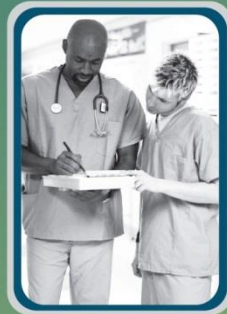


Research Impact: RE-AIM

- **R**each into the target population
- **E**ffectiveness or efficacy
- **A**doption by target settings, institutions and staff
- **I**mplementation - consistency and cost of delivery of intervention
- **M**aintenance of intervention effects in individuals and settings over time.

What Potential Adopters Want to Know

Will It Work Here? A Decisionmaker's Guide to Adopting Innovations



- Does the innovation *fit*?
- *Should* we do it here?
- *Can* we do it here?
- *How* will we do it here?

Research Translation

- Report Context
 - ▶ Consolidated Framework for Implementation Research (CFIR)
- Build translation activities into grants
- Beyond the peer-reviewed article
 - ▶ Create tools & guides
 - ▶ Write trade press articles
 - ▶ Train others, leverage opinion leaders, groom champions

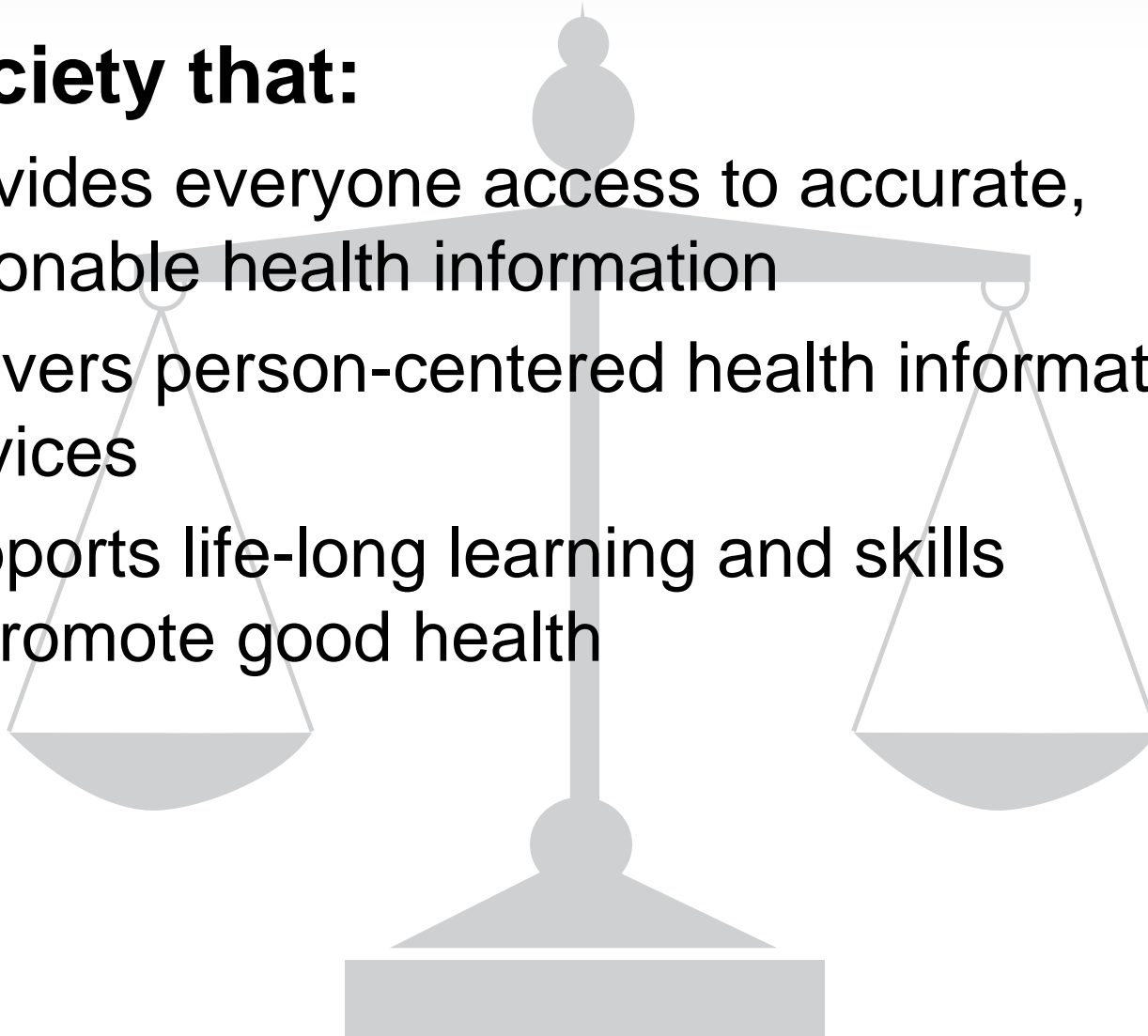




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Ask Me 3 for Health Literacy Researchers

- Will my findings provide information on **what** to do to increase health equity?
- Will my findings provide information on **how** to do it?
- Will it provide information about **why its important** to do it?

Win Hearts and Minds

