

# Health Literacy and Patient Centred Research

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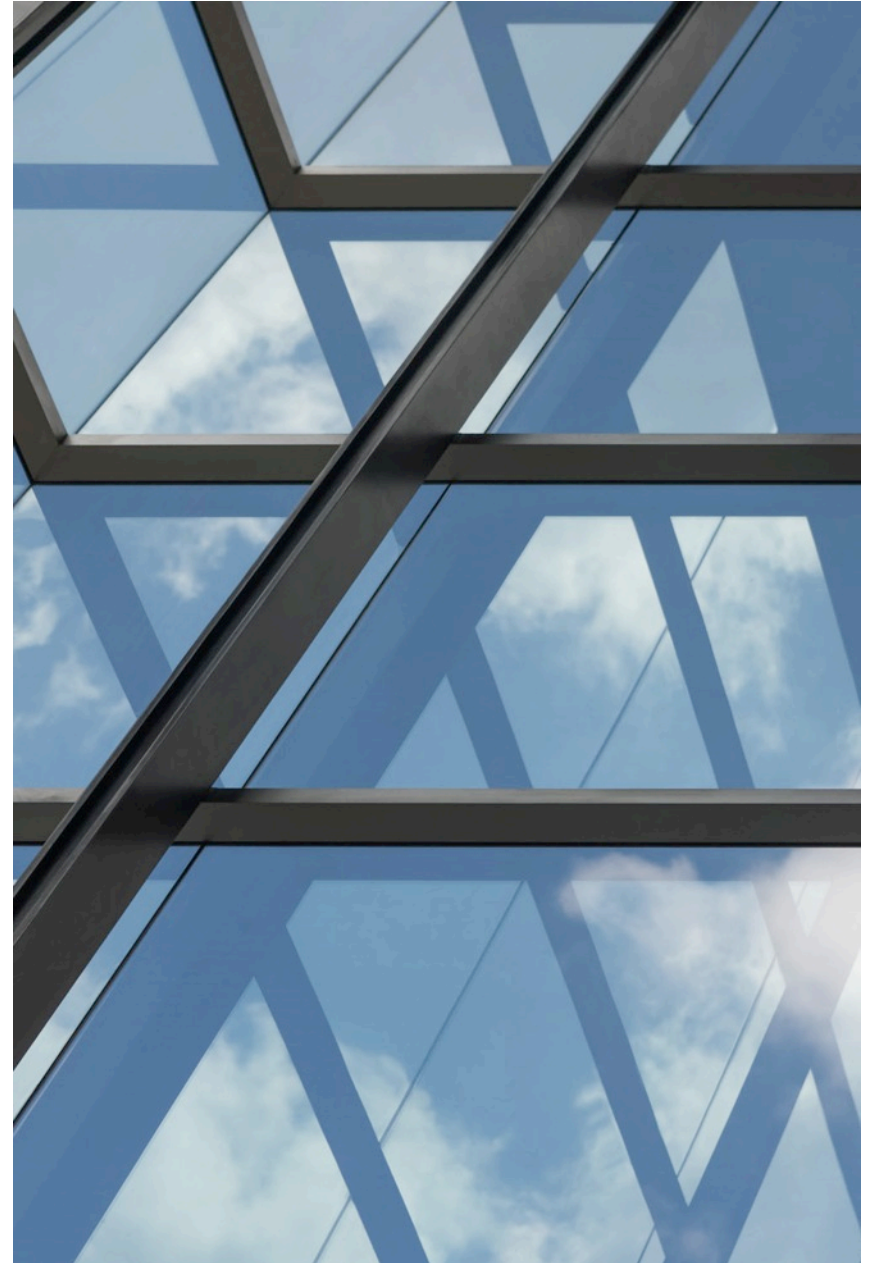
The University of Sydney, Faculty of Medicine and  
Health, School of Public Health, Sydney Health  
Literacy Lab



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Sydney  
Health  
Literacy  
Lab



# Sydney Health Literacy Lab

Director: Prof Kirsten McCaffery

Westmead Lead: Dr Danielle Muscat



# WSLHD Health Literacy Hub

Professor Don Nutbeam

Dana Mouwad

Dr Danielle Muscat

+ growing Community of Practice



# Outline

- What is health literacy?
- Why do we care about health literacy?
- Conceptualising health literacy
- Health literacy and patient-centred research
  - Important considerations
  - Potential benefits

# Defining health literacy



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# What is literacy?

- Functional literacy is defined as a tangible set of **skills in reading and writing and the capacity to apply these skills in everyday situations**



- Literacy skills enable people to **better develop their knowledge and improve their potential to achieve personal goals.**
- Individuals are able to participate more fully in society and the economy.

# Literacy skills are significantly moderated by the context in which they are applied

- More accurate to talk about literacies for example:
  - Financial literacy,
  - Science literacy
  - Media literacy,
  - IT literacy (new literacy) and,
  - Health literacy

# What is *health literacy*?

- ...the cognitive and social skills that enable individuals to gain access to, understand and use information to make decisions about health<sup>1</sup>.
- Content and context specific



(Nutbeam, 1999)

# Why do we care about health literacy?



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# Why do we care about health literacy?

## 1. Prevalence

60% of Australian adults lack functional health literacy skills (e.g. interpreting medicine dosage information).

(Australian Bureau of Statistics, 2008)

# Why do we care about health literacy?

## 2. Impact on health

Associated with poor health independent of all other known risk factors:

- Higher rates of chronic illness (e.g. CVD, diabetes, obesity)
- Higher rates of mortality (all cause)
- Higher hospitalisation rates and use of emergency services
- Lower rates of preventive services such as screening
- Poorer self management skills
- Greater medication errors
- Lower levels of knowledge about disease

(AHRQ Systematic reviews: DeWalt et al 2004; Berkman et al 2011)

# Why do we care about health literacy?

## 3. Social gradient

Lower levels of health literacy more common among the socially and economically disadvantaged.

# Why do we care about health literacy?

## 4. Policy

National requirements of the Australian Commission for Safety and Quality in Healthcare (Standard 2)

NSW Health Pillar organisations (Agency for Clinical Innovation [ACI]; NSW Clinical Excellence Commission [CEC])

NSW Health Strategic Priorities 2017-18.



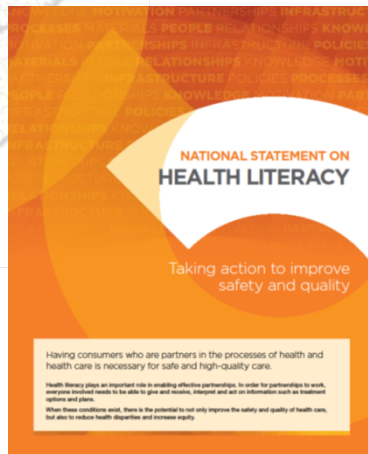
# Why do we care about health literacy?

## Documents for Promoting Health Literacy in China

“中国公民健康素养促进行动”  
资料汇编

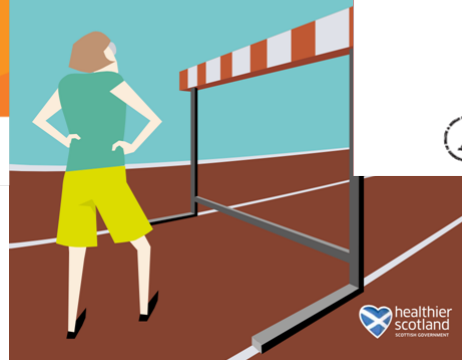
Issued by the Ministry of Health  
the People's Republic of China  
中华人民共和国卫生部 编

April, 2009  
二〇〇九年四月



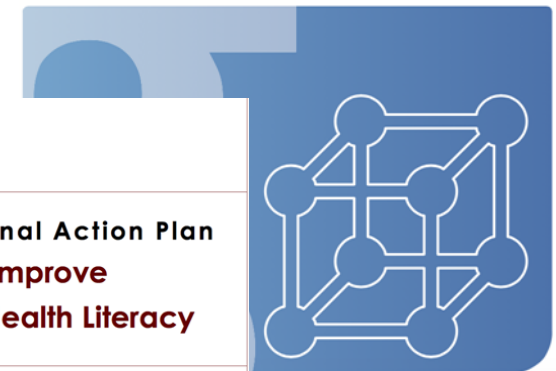
AUSTRALIAN COMMISSION  
on SAFETY and QUALITY in HEALTH CARE

## Making it Easy A Health Literacy Action Plan for Scotland



## Health Literacy erhöhen

Capacity Building bei VertreterInnen von PatientInnen  
und KonsumentInnen von Gesundheitsleistungen



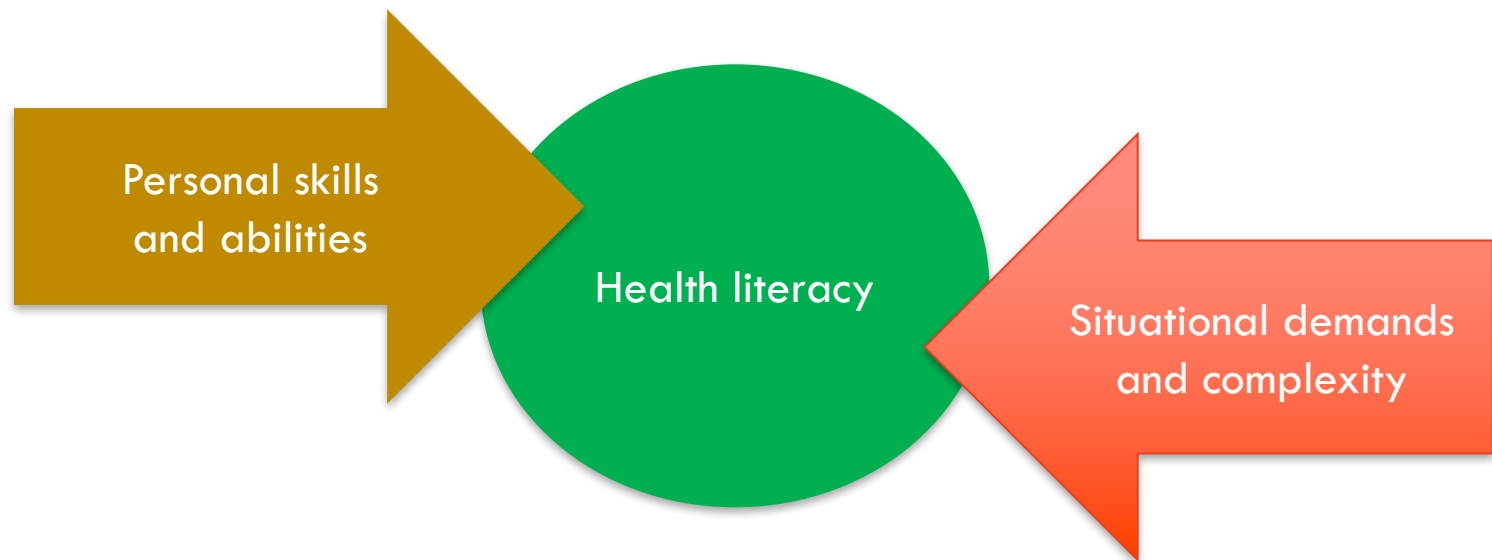
U.S. Department of Health and Human Services  
Office of Disease Prevention and Health Promotion

# Conceptualising health literacy



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# Health literacy is determined by personal skills and context in which those skills are to be applied



Adapted from Ruth Parker, *Measuring health literacy: What? So what? Now what?* In Hernandez L, ed. *Measures of health literacy: workshop summary, Roundtable on Health Literacy*. Washington, DC, National Academies Press, 2009:91–98

# Conceptualising health literacy

- Two different conceptualisations of health literacy<sup>1</sup>

Risk/ deficit approach	Asset approach
<ul style="list-style-type: none"><li>• Reifies health literacy as an individual deficit</li><li>• Health literacy seen as a static patient characteristic that needs to be managed in the process of providing clinical care</li></ul>	<ul style="list-style-type: none"><li>• Health literacy is seen as a personal asset which offers consumers greater autonomy and control over healthcare decisions.</li><li>• Health literacy seen to be a modifiable health determinant</li></ul>

<sup>1</sup> Nutbeam, D. 2008. The evolving concept of health literacy. Social Science and Medicine. 67. 2017-78



# Patient-Centred Research



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# Patient-centred Research

- **Patient involvement** refers to patients being active partners in research who contribute their experiences and perspectives across the stages of the research process – setting the research priorities, designing, conducting, reporting, and disseminating research. → *partnership*
- **Patient-centred research** generates evidence that helps patients and their caregivers communicate and make informed decisions about their health. Understanding their values, goals, and priorities are needed to inform patient-centred care. → *evidence*

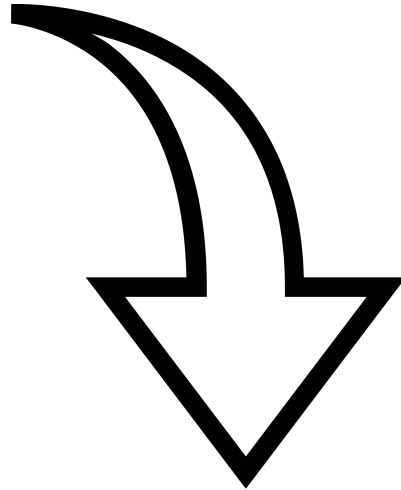
# Health literacy and patient centred research



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# Important considerations

1. NHMRC (2006) emphasises the diversity of consumer representatives



Remember: 60% of Australian adults lack functional health literacy skills

- Know the health literacy of your population
- Use multiple engagement strategies and approaches
- Purposively sampling for lower health literacy

# Identifying those with lower health literacy

- There are a number of tools to measure and screen for health literacy, including:
  - Rapid Estimate of Adult Literacy in Medicine (REALM)
  - Short Test of Functional Health Literacy in Adults (S-TOFHLA)
  - Newest Vital Sign (NVS)
  - Chew et al., Screening Questions
  - Single Item Literacy Screener (SILS)
  - Health Literacy Questionnaire (HLQ)

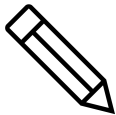
# Newest Vital Sign (NVS)



6 questions based on a nutritional (ice-cream) label



3-5 minutes



Not self-administered (presented verbally to patient)



3 categories:

- High likelihood of limited literacy
- Possibility of limited literacy
- Adequate literacy

## Nutrition Facts

Serving Size  $\frac{1}{2}$  cup  
Servings per container 4

### Amount per serving

Calories	250	Fat Cal	120
			%DV

<b>Total Fat</b>	13g	20%
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Sat Fat	9g	40%
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<b>Cholesterol</b>	28mg	12%
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<b>Sodium</b>	55mg	2%
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<b>Total Carbohydrate</b>	30g	12%
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Dietary Fiber	2g	
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Sugars	23g	
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<b>Protein</b>	4g	8%
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\*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.

# Chew et al., Screening Questions

- "How confident are you filling out medical forms by yourself?"
- Possible responses:
  - 0-Extremely
  - 1-Quite a bit
  - 2-Somewhat
  - 3-A little bit
  - 4-Not at all
- Higher scores reflect greater problems with reading

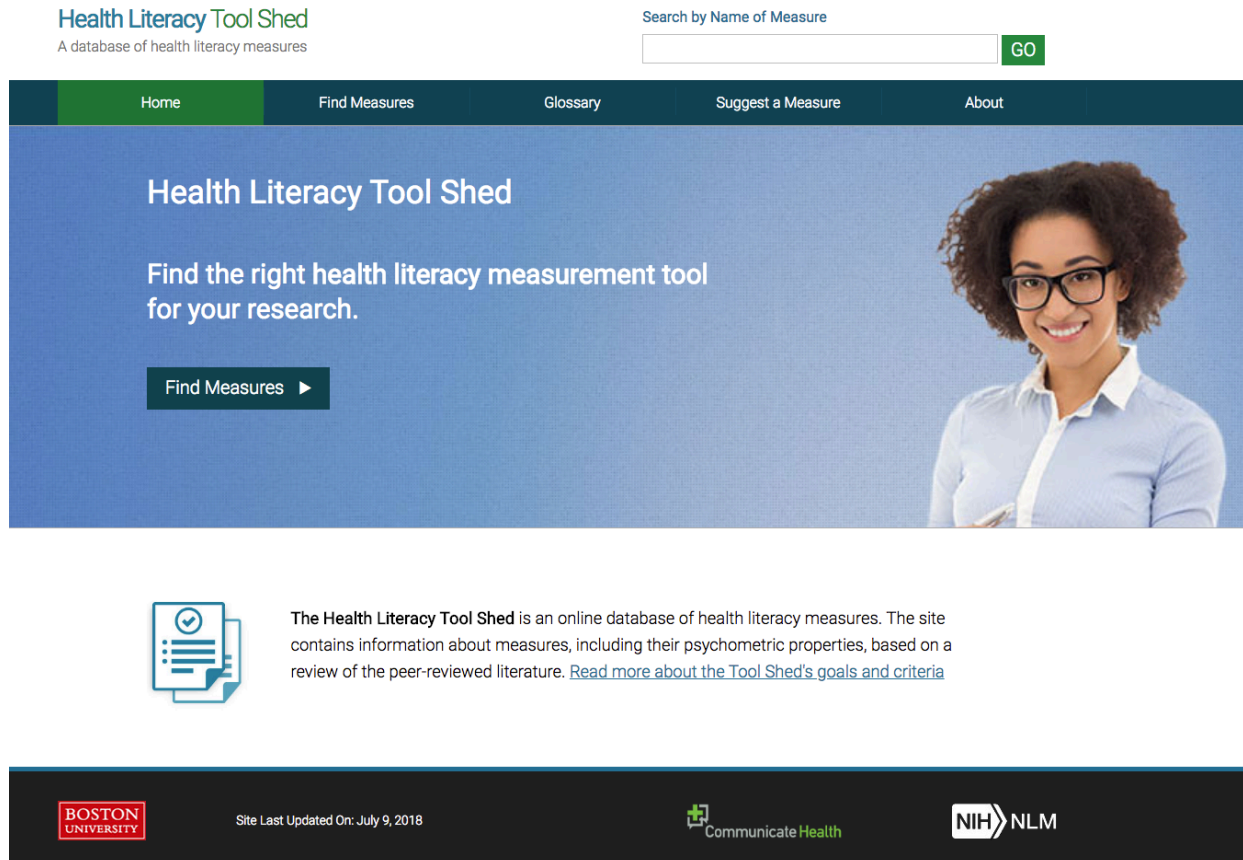
# Identifying those with lower health literacy

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# Identifying those with lower health literacy

- Health Literacy Toolshed: <https://healthliteracy.bu.edu/>



The screenshot shows the homepage of the Health Literacy Tool Shed. At the top, the logo "Health Literacy Tool Shed" is displayed with the tagline "A database of health literacy measures". To the right is a search bar labeled "Search by Name of Measure" with a "GO" button. Below this is a navigation menu with links: Home, Find Measures, Glossary, Suggest a Measure, and About. The main content area features a large blue banner with the text "Health Literacy Tool Shed" and "Find the right health literacy measurement tool for your research." A "Find Measures" button with a right arrow is positioned on the left. On the right side of the banner is a photograph of a smiling woman with curly hair and glasses. Below the banner, there is a document icon with a checkmark and a paragraph of text describing the tool shed as an online database of health literacy measures, mentioning psychometric properties and a link to "Read more about the Tool Shed's goals and criteria". The footer contains the Boston University logo, the text "Site Last Updated On: July 9, 2018", the "Communicate Health" logo, and the "NIH NLM" logo.

Health Literacy Tool Shed  
A database of health literacy measures


Search by Name of Measure  
 GO




Home Find Measures Glossary Suggest a Measure About

## Health Literacy Tool Shed

Find the right health literacy measurement tool for your research.

Find Measures ►

 The Health Literacy Tool Shed is an online database of health literacy measures. The site contains information about measures, including their psychometric properties, based on a review of the peer-reviewed literature. [Read more about the Tool Shed's goals and criteria](#)

 Site Last Updated On: July 9, 2018  

# Important considerations

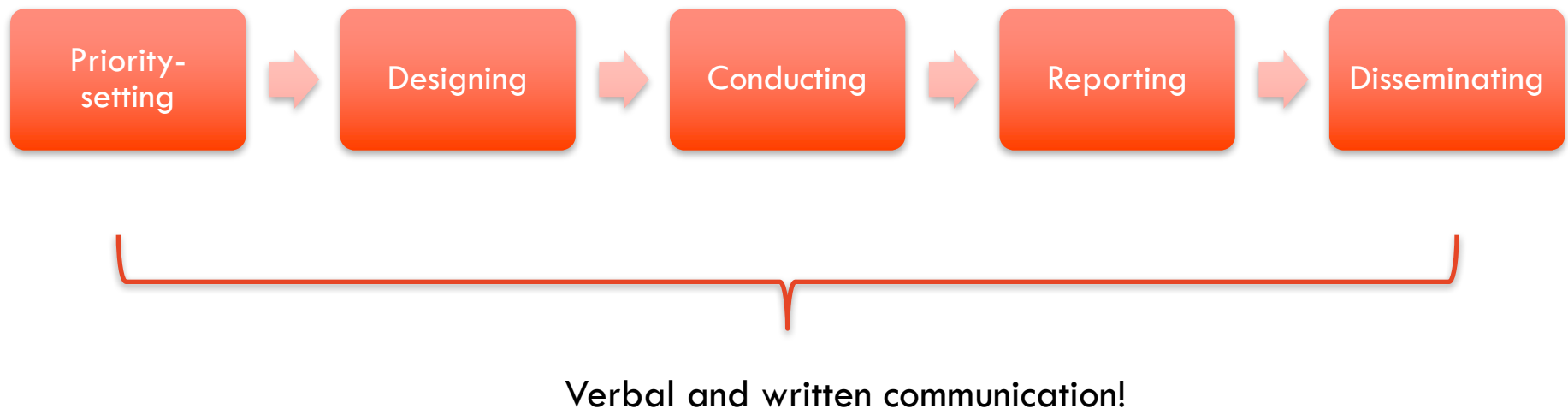
2. Supporting consumers (with lower health literacy) to be involved
  - a. A risk approach



Image source: <https://www.keepcalm-o-matic.co.uk/p/keep-calm-and-use-universal-precautions/>

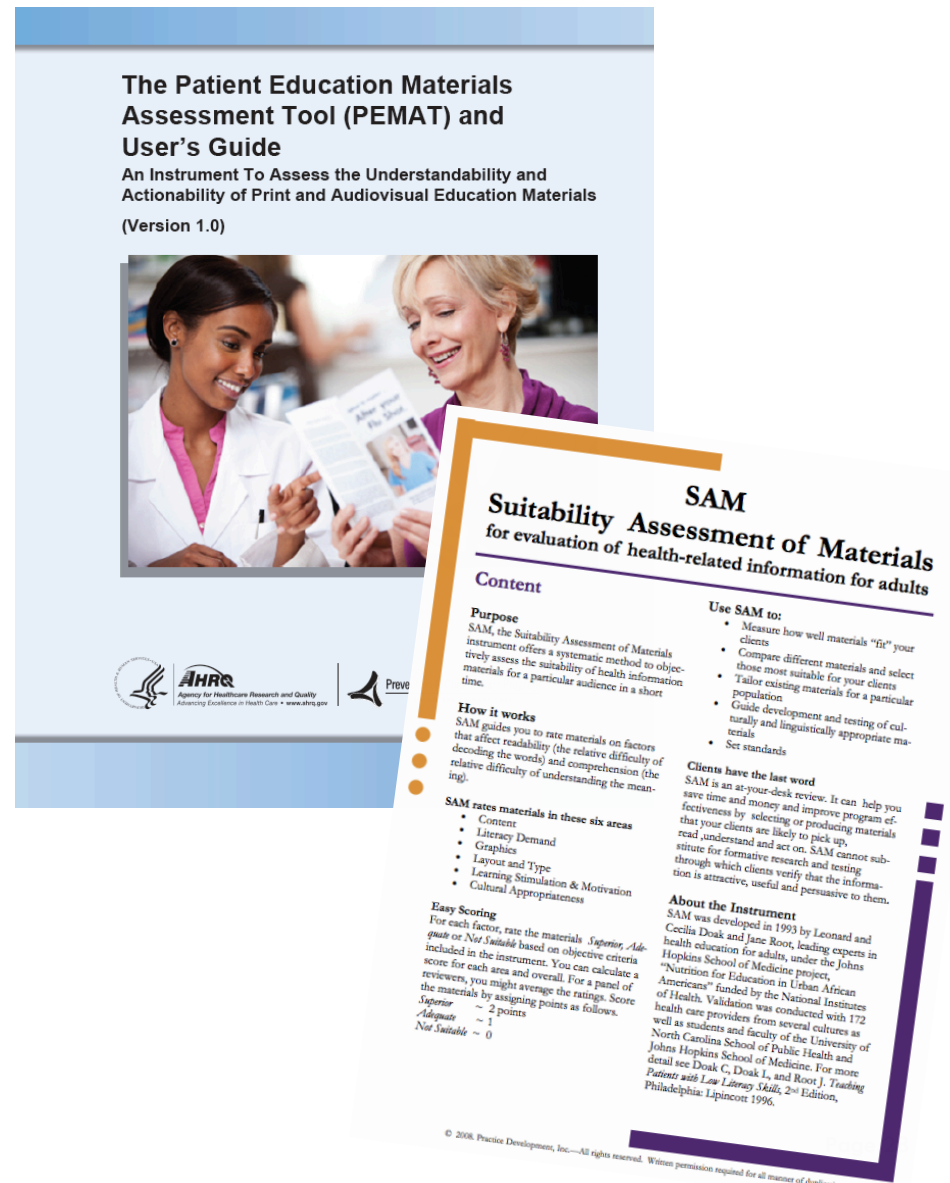
# Supporting consumers to be involved: A risk approach

- Communication with consumers should be guided by best-practice health literacy principles.



# Written information

- Readability scores
- Patient Education Materials Assessment Tool (PEMAT)
- Suitability Assessment of Materials (SAM)
- Universal Precautions (Toolkit)

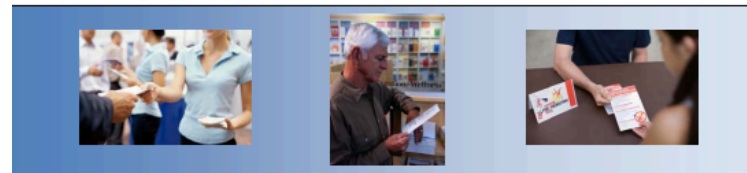


# Written information

- Toolkit to Make Written Materials Clear and Effective
- Health Literacy Online: A Guide for Simplifying the User Experience
- Simply Put: A guide for creating easy-to-understand materials
- Everyday Words for Public Health Communication

## Simply Put

*A guide for creating easy-to-understand materials*



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

May 2016

### Everyday Words for Public Health Communication



Centers for Disease  
Control and Prevention  
Office of the Associate  
Director for Communication

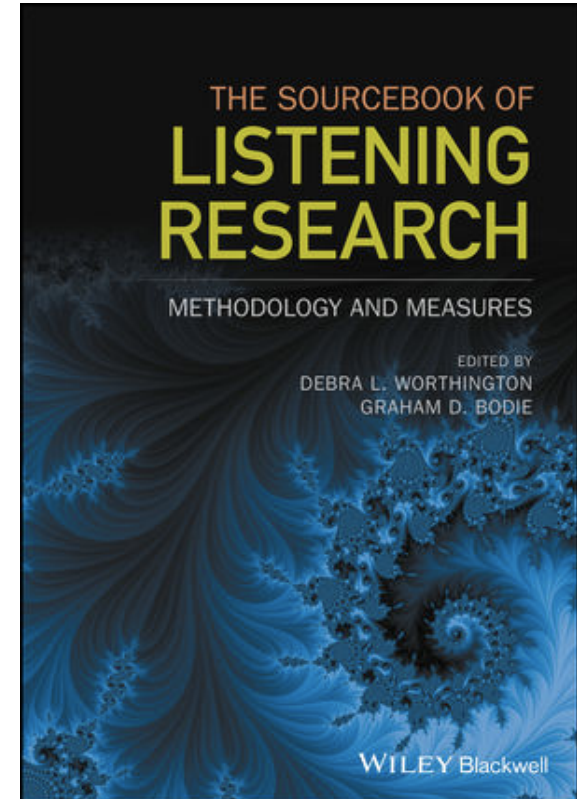
# PEMAT

Item #	Item	Response Options	Rating
<b>Topic: Content</b>			
<b>1</b>	The material makes its purpose completely evident.	Disagree=0, Agree=1	
<b>Topic: Word Choice &amp; Style</b>			
<b>3</b>	The material uses common, everyday language.	Disagree=0, Agree=1	
<b>4</b>	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
<b>5</b>	The material uses the active voice.	Disagree=0, Agree=1	
<b>Topic: Organization</b>			
<b>8</b>	The material breaks or “chunks” information into short sections.	Disagree=0, Agree=1, Very short material*=N/A	
<b>9</b>	The material’s sections have informative headers.	Disagree=0, Agree=1, Very short material*=N/A	
<b>10</b>	The material presents information in a logical sequence.	Disagree=0, Agree=1	
<b>11</b>	The material provides a summary.	Disagree=0, Agree=1, Very short material*=N/A	

Shoemaker SJ, Wolf MS, Brach C. The Patient Education Materials Assessment Tool (PEMAT) and User’s Guide. (Prepared by Abt Associates, Inc. under Contract No. HHS A29020090001 2I, TO 4). Rockville, MD: Agency for Healthcare Research and Quality; November 2013. AHRQ Publication No. 14-0002-EF.

# Verbal communication

- Listenability Style Guide (Rubin, 2012, 2018)
  - *Repeat content nouns and verbs across sentences. Don't aim for diverse vocabulary for its own sake (low lexical diversity).*
  - *Give listener's "advance organizers" to help them predict what information will follow.*
  - *Use internal summaries.*



Rubin DL. Listenability Style Guide (LSG). In Worthington, D.L. & Bodie, G. 2018, *The sourcebook of listening research: methodology and measures*, John Wiley & Sons, Inc, Hoboken, NJ.

# Verbal communication

- Teachback
  - Iteratively asking the patient to summarise or restate the important points in a consultation using their own words
  - Impact greatest for those with low health literacy (Morony et al., forthcoming)

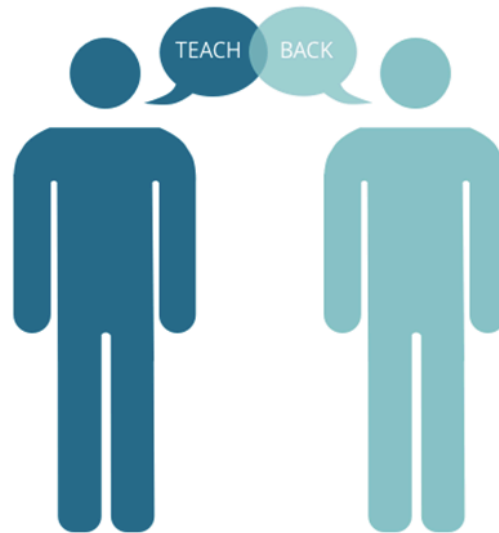


Image source: <http://www.healthliteracyplace.org.uk/tools-and-techniques/techniques/teach-back/>



# Important considerations

2. Supporting consumers (with lower health literacy) to be involved
  - b. Training and skill building

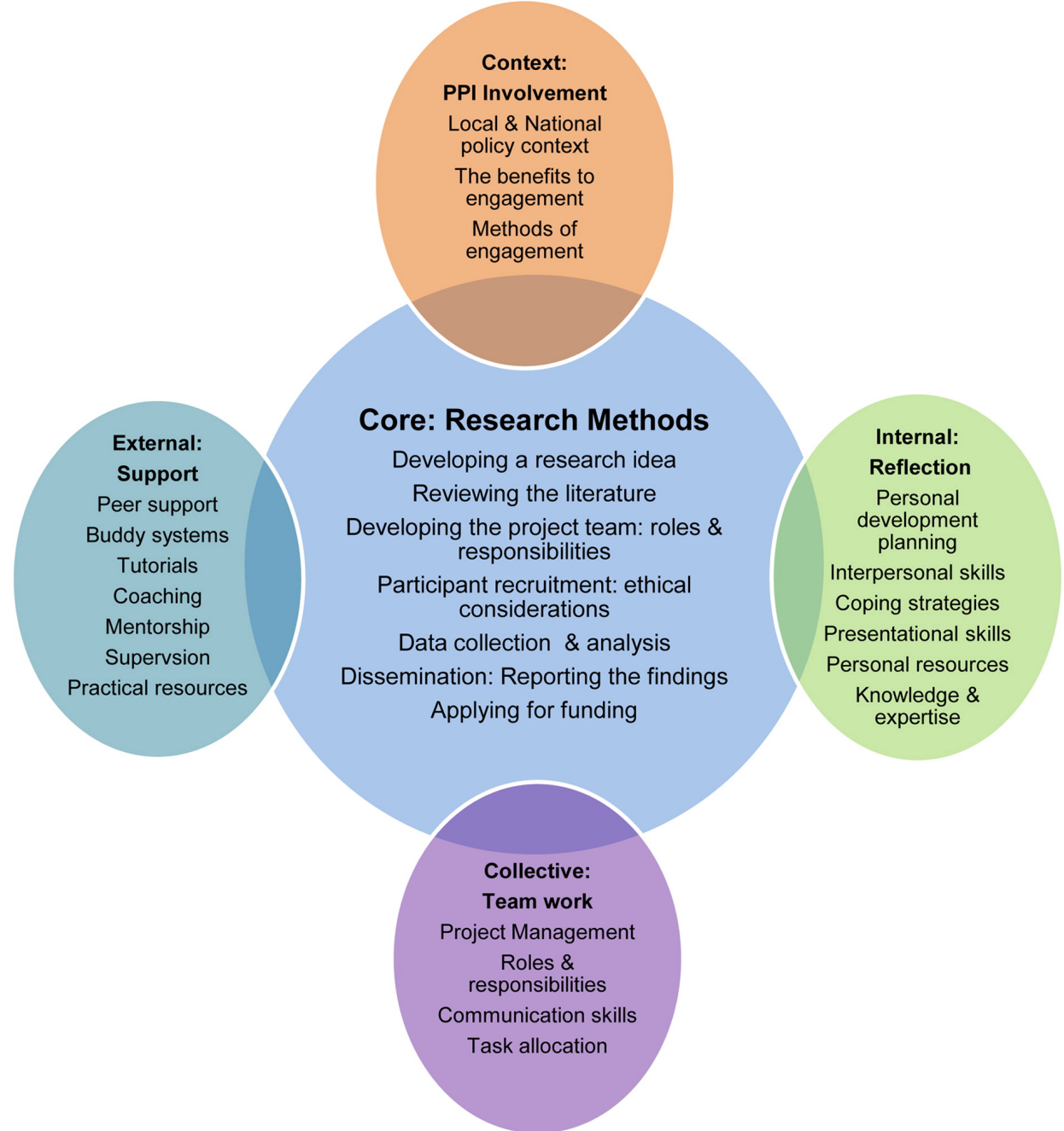
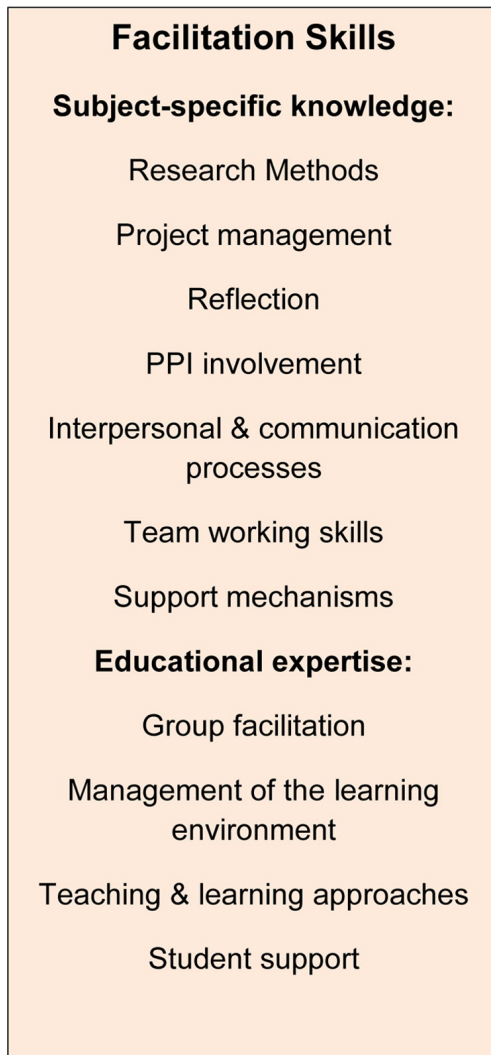


# Supporting consumers to be involved: An asset approach

- National Framework for Consumer Involvement in Cancer Control<sup>1</sup>
  - Consumers receive training specific to the area of participation and involvement.
  - Training and mentoring of consumers is essential if consumers are to acquire the levels of expertise required for their roles.
  - Opportunities that enable consumers to develop expertise in areas of interest...are considered a necessary component of effective consumer engagement.

<sup>1</sup>Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.

## B



# Important considerations

## 2. Supporting consumers (with lower health literacy) to be involved

### c. Addressing power imbalances

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- Adults with lower literacy are more likely to perceive a greater power imbalance
- Ask fewer questions (during consultations)

...compared to higher literacy patients (Katz et al., 2007).

# Important considerations

## 3. Benefits

- Patient/consumer involvement can result in products that meet the needs of target populations (ACI, 2015)
- Information was more relevant, ‘readable’ and understandable when consumers were involved than when clinicians produced written materials alone (Nilsen et al., 2006).



# Integrating health literacy principles and consumer engagement

- Case study 1: Development of mass communication for Medicaid beneficiaries (Neuhauser et al., 2009)
  - Aim: To support highly vulnerable populations participating in Medicaid to make complex choices to select a health plan given that only 25% made active, informed choices.
  - Methods:
    - Identified and engaged user subgroups; established an 24-member advisory group
    - Conducted focus groups and interviews with purposive sampling
    - Developed a guidebook; set health literacy standards and performed usability and readability testing
    - Adapted final 'guidebook' into 13 languages

# Integrating health literacy principles and consumer engagement

- Case study 1: Development of mass communication for Medicaid beneficiaries (Neuhauser et al., 2009)
  - Results of an RCT:
    - Intervention participants showed gains in knowledge, positive attitudes, and intentions to enroll in Medicaid managed care that were statistically significant compared with control participants.
    - Nearly all (97.9 percent) participants found the guidebook somewhat or very useful.

# Health literacy and consumer engagement

- Case study 2: Designing infographics for community members with varying levels of health literacy (Arcia et al., 2016)
  - Aim: To identify best practices for health information visualisations
  - Methods:
    - Purposively sampled consumers based on language and health literacy (adequate, marginal, inadequate)
      - Chew et al., 2008 single item health literacy screener
    - Iterative infographic refinement process
  - Results:
    - Identified infographics that will be meaningful, culturally relevant, and actionable for future testing in research studies.



# Health literacy and consumer engagement

Case study 3: The experience of teenage pregnancy (cited by Parkes et al., 2014)

- Aim: To explore the experience of teenage pregnancy
- Methods:
  - Six young mothers and their youth worker were trained in how to design an interview schedule and conduct focus groups with their peers.
  - With the support of the research team, trainees then conducted focus groups with other young mothers, young offenders and Children Looked After.
  - The groups were facilitated in pairs of teenagers who had been trained by the research team.

# Health literacy and consumer engagement

Case study 3: The experience of teenage pregnancy (cited by Parkes et al., 2014)

- Results:
  - Consumers' advice and experience enhanced the wording of the focus group schedules
  - Consumers were very successful in building rapport with participants who were of a similar age.

# Summary

- High proportion of people with lower health literacy → support diversity in consumer participation
  - Target and tailor communication
  - Training and skill-development
- Established evidence for impact of including diverse range of patients/consumers in the research process.



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