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Health Literacy: Plain and Inclusive Language

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Learning objectives

- Describe the rationale for emphasis on clarity and inclusivity in research focused communication
- List some best practices for inclusive and clear research language
- Describe 3 principles of cultural humility

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Why we need clear communication in research

What happens if communication with research participants fails?

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Personal health literacy

The degree to which individuals have the ability to **find**, **understand**, and **use** information and services to inform health-related decisions and actions for themselves and others.

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.

U.S. DHHS, Office of Disease Prevention and Health Promotion. Healthy People 2030. https://health.gov/our-work/healthy-people-2030/about-healthy-people-2030/health-literacy-healthy-people

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Proficient health literacy requires many skills

Prose

Document

Quantitative

Oral

Digital

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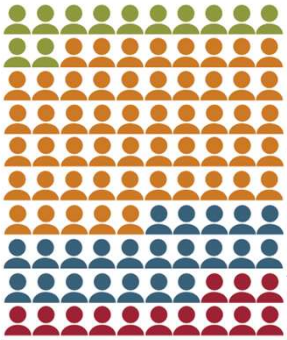
US adults and health literacy



At each health literacy level, 2003

Proficient
Intermediate
Basic
Below Basic

About 35 out of 100: Basic/Below Basic

Source: National Assessment of Adult Literacy

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Groups at risk for poor health literacy

Advanced age

Minority race

Chronic disease status

Low education

Low income

Source: National Assessment of Adult Literacy

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Limited health literacy is a hidden problem

- Context influences ability to learn
  - Stress
  - Pain
  - Feeling ill
- You cannot tell by looking at someone
  - Should treat everyone as if they may have difficulty understanding

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Communication across the research study life cycle

MULTI-REGIONAL CLINICAL TRIALS
THE MRCT CENTER of BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

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Informed consent

3. CONSENT

- Communication goal:
  - Understanding of responsibilities, risks, benefits…
  - Participant has accurate information to support decision-making
- Problems:
  - Too much information
  - Information not written in understandable terms
  - Process may not support confirming understanding

Source: https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/informed-consent/index.html

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New Common Rule – key information

3. CONSENT

"Informed consent must begin with **a concise and focused presentation** of the key information that is most likely to assist a prospective subject or legally authorized representative in understanding the reasons **why one might or might not** want to participate in the research."

82 Fed Reg 12 at p. 7265

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Plain language informed consent form (ICF) navigator

3. CONSENT

Web-based utility to create plain language ICF

- IRB approved plain language ICF template
- Key information template
- New plain language HIPAA template

https://healthliteracy.uams.edu/health-literacy-research/resources/
https://irb.uams.edu/new-study-tools/

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During study

4. ON STUDY

Communication goals: What actions do you need participants to take while on your study?

- Problems:
  - Instructions may not be fully actionable
  - May result in inaccurate or unhelpful information
  - May result in frustration and dropout

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After study

5. END OF STUDY

- Communication goal:
  - Share outcomes with participants and communities
- Problems:
  - Spoken and written reports may not be in plain language and people may not speak up (may lead to lost opportunities for future study participants and support)

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After study

5. END OF STUDY

Practice activity: Explain your research to a potential donor in 2 minutes in "living room" language.

Plain language tip sheet for sharing your research summary with lay audiences

https://healthliteracy.uams.edu/wp-content/uploads/sites/94/2019/10/Using-plain-language-to-share-your-research-summaries-with-lay-audiences.pdf

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Solutions for improving clarity

across the research study life cycle

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Plain language

- Information people understand the first time they see or hear it
- Plain language is:
  - Readable (written only)
  - Understandable
  - Actionable
- Plain language is not "dumbing down"

Readable

Understandable

Actionable

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Avoid or define jargon

Instead of	Use
Ambulatory	Walk-in
Approximately	About
Hypertension	High blood pressure (?)
Implement	Begin or start
Medical condition	Health problem
Eligibility criteria	Who can join
Inform	Tell
Suffer from	Have
Provider	Doctor or nurse
Medication	Medicine
Sphenopalatine Ganglioneuralgia	"Brain freeze"* or "ice cream headache"

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Organize content logically

- Share most important information first
- Keep like information together (use an outline)
- Use helpful headers
- Avoid using ALL CAPS
- Emphasize key messages (choose one method)
- Summarize action steps

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Make it actionable with action steps

- Clearly identify action the participant needs to take
  - What
  - How much
  - When
- Provide step-by-step instructions to complete the action

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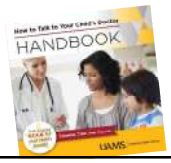
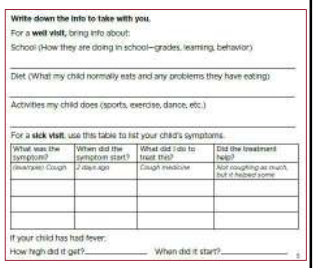
Make it actionable with tools

- Activity logs
- Medication lists and dosing calendars
- Food journals
- Symptom diaries





Write down the info to take with you.

For a **well visit,** bring info about:

School (How they are doing in school—grades, learning, behavior)

Diet (What my child normally eats and any problems they have eating)

Activities my child does (sports, exercise, dance, etc.)

For a **sick visit,** use this table to list your child's symptoms.

What was the symptom?	When did the symptom start?	What did I do to treat this?	Did the treatment help?
(example) Cough	2 days ago	Cough medicine	Not coughing as much, but it helped some

If your child has had fever:

How high did it get?_____ When did it start?_____

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Use health numeracy best practices

- Avoid or explain calculations
- Simplify numbers
  - 91.2% (difficult)
  - 91 out of 100 (better)
  - About 9 out of 10 (best)
- Avoid relative risk statistics
  - ...your risk doubles…(accurate but misleading)
  - If you smoke: 2 out 100; If you do not smoke: 1 out of 100

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How to promote inclusive communication

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Cultural humility principles

- Lifelong learning and critical self-reflection
- Recognize and challenge power imbalances for respectful partnerships
- Institutional accountability – Working to develop mutually beneficial partnerships

Tervalon and Murray-Garcia in 1998 video: https://www.youtube.com/watch?v=_Mbu8bvKb_U&list=PL879555ABCCED8B50

Tervalon M, Murray-García J. Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. J Health Care Poor Underserved. 1998 May;9(2):117-25. doi: 10.1353/hpu.2010.0233. PMID: 10073197.

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Aim for inclusive language

- Use person-centered words rather than labels
  - "Person diagnosed with Down Syndrome" rather than "Downs person"
- Avoid victimizing words
  - "Person with muscular dystrophy" rather than "Person crippled by muscular dystrophy"
- Choose adjectives over nouns
  - "I met a transgender person" rather than "I met a transgender"
- Self-identification

https://s3.amazonaws.com/s3.sumofus.org/images/SUMOFUS_PROGRESSIVE-STYLEGUIDE.pdf
https://www.who.int/publications/i/item/9789241512459

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Inclusive language: Race

- Capitalize Black and White, which is aligned with race and ethnic categories.
- Avoid using *brown* to characterize a specific racial or ethnic category.
- The word *minority,* on its own can be demeaning, vague, and imply lower social position.
  - Alternatives depending on context: racial/ethnic minority group, underrepresented group (be specific to the representation in the region), or people of color.

https://www.amamanualofstyle.com/page/live-updates

Christiansen SL. Inclusive language: race and ethnicity. Sci Ed. 2020;43:95-96.https://doi.org/10.36591/SE-D-4303-95

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Inclusive language: Gender

- Singular "they" is preferred over he/she
  - More inclusive
  - Easier to read
- Use personal pronouns
  - More inclusive and personal
  - Promotes action

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Inclusive language: Gender

- Avoid using "the opposite sex," (ignores the reality of a gender spectrum). Instead use "of a different gender."
- Avoid "guys" to refer to a mixed-gender group of people.
- Ask survey questions based on what you want to know (sex at birth vs current gender identity).
- Ask people what name they want to be called (use pronouns).

https://s3-us-west-2.amazonaws.com/uw-s3-cdn/wp-content/uploads/sites/98/2020/04/20111848/UMAC-Equitable-Language-Guide-v.1.pdf

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Inclusive language: ability

Promotes that all bodies have value, and all people should be treated with dignity and respect.

Specific suggestions:

- Ask the preferred terminology.
  - For example, "blind" vs "person with low or limited loss of vision"
- Avoid stereotyping phrasing that equates "thin" or able-bodied" with health
- Remember that many chronic conditions and disabilities are invisible.

https://s3-us-west-2.amazonaws.com/uw-s3-cdn/wp-content/uploads/sites/98/2020/04/20111848/UMAC-Equitable-Language-Guide-v.1.pdf

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Strategies for addressing implicit bias

- Self awareness (know your bias)
- Exposure
- Individuation
- Perspective taking
- Counter-stereotyping
- Reducing stress, getting sleep, complex cognitive encounters can trigger reliance on bias

Source: 2020, TRI CBPR Scholars program: Stewart, K., Hale,R., Hayne, T., Huff-Davis, A.

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Online templates and resources

- Plain language Informed consent form template
- Plain language HIPAA form template
- Tips for plain language presentations
  https://healthliteracy.uams.edu/health-literacy-research/resources/
- Key information template
  https://irb.uams.edu/new-study-tools/
- In development: Informed consent form navigator
  Contact us for more information
- Plain language tips for research teams
  https://mrctcenter.org/health-literacy/

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October Health Literacy Month

- Take the Plain Pledge
- Join us:
  - Plain language training for research
    January 2022 (email)
  - Interprofessional Education Plain Language Competence Workshop
    September 24, 2021
  - Interprofessional Education Quadruple Aim Project
    October 8, 2021

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Plain language assessment, editing

Offered by UAMS Center for Health Literacy

- Recruitment materials (flyers, scripts), informed consent documents, other instructions or education
- Assessment and editing for improved readability, understandability, actionability
- Support from TRI for small projects
- Request through TRI Request Services portal

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How to request CHL services through TRI portal

- Visit the TRI Services Request portal:
  https://tri.uams.edu/request-services-2/
- Select "Plain Language Assessment/Spanish translation"

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Other UAMS CHL services

- Field testing, new materials development (English, Spanish)
- Contact us for inclusion in proposal budgets

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