NYU CTSI CLINICAL & TRANSLATIONAL SCIENCE INSTITUTE
NYU LANGONE HEALTH • NYC HEALTH+HOSPITALS • NEW YORK UNIVERSITY

Health Literacy in Research Best Practice Brief

Overview

Health literacy is defined as a person's ability to use and understand health information in a way that allows them to make informed decisions regarding their health.[1] According to the Centers for Disease Control and Prevention (CDC)'s Healthy People 2030 initiative, there are 2 types of health literacy: personal health literacy and organizational health literacy.[2] Personal health literacy is 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.[2] 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 (see *figure 1)*.[2]

What is health literacy?

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.

Figure 1. Two definitions of health literacy[3]

Health literacy is one of many kinds of literacies that are also helpful to keep in mind when engaging with patients and research participants, including:[4]

- Reading and Writing
- Numerical Literacy
- Digital Literacy
- Financial Literacy
- Media Literacy
- Cultural Literacy
- Emotional/Physical Literacy

The Office of Disease Prevention and Health Promotion's *Health Literacy Online* is a research-based guide that helps researchers understand and develop intuitive health websites and digital tools to address health literacy. Similarly, Digital Media Fundamentals offers a Best Practices guide on facilitating digital media literacy.

Background

9 out of 10 adults struggle to understand and use health information when it is filled with medical or research jargon or complex terminology.[5] Approximately 36% of adult Americans have only basic or below basic health literacy skills.[6] Only 12% of Americans are considered proficient in their health literacy skills.[6]

Individuals that are at high risk for low health literacy include[6]:

- People with less than 5th grade reading level (limited education)
- The elderly
- Populations experiencing health disparities (for instance, a study found that 66% of Latina/o adults have basic or below basic health literacy skills[7])
- Limited English proficient speakers

Why is health literacy important?

Health literacy is necessary to find, understand, and use health information and services, which is essential in taking care of one's health.[4] Health literacy helps manage and treat any expected or unexpected health challenges, prevent health problems, and ensure the health and well-being of individuals and communities alike. Using health literacy best practices can additionally help care providers and researchers build trust with patients and participants and help close the gaps in access to care.[1]

Without health literacy, patients and participants can be subject to[1,4,8] :

- Unfamiliarity with medical terms, diagnoses, and treatment recommendations
- Poor or mismanaged health resources
- Misunderstanding risks and benefits of a study
- Overpaying for healthcare and hospital visits
- Overuse or underuse of medications
- Poor health outcomes
- Little to no engagement with researchers
- Lack of interaction with research or clinical trial opportunities

With respect to clinical research specifically, a health literacy is beneficial in all stages[9] (see *figure 2)***:**

- Recruitment: health literate recruitment materials as a form of engagement to encourage reach to all populations
- Consent: understandable consent process
- Communication: staff communication strategies that make participation meaningful for patients involved
- Retention: clear data collection forms and accurate data collection
- Results: patient-friendly summaries that help patients understand their role in the trial
- Evaluation: collection of insights grounded in patient values

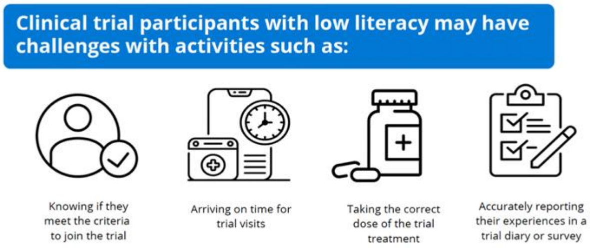


Figure 2. Challenges that clinical trial participants with low health literacy may face[8]

General Strategies for Addressing Health Literacy

There are steps that clinicians and researchers can use to address different levels of literacy in health-related research communication to ensure that participants understand the information. Some strategies include:

- Not assuming a participant's level of health literacy; err on the side of explaining and adapting to the participant's level of health literacy (universal caution)
- Using pictures and other visual aids such as numbered images or diagrams showing and acting out health issues
- Using shorter, easy to understand verbiage (e.g. using plain language)
- Using audio or video products
- Get to know your participant audience
- Find examples of written materials that resonate with your audience
- Connect with your participants and write content in plain language
- Match your words to your audience
- Construct simple, concise sentences
- Presenting your information
  - Visually appealing and well-organized documents are easier to read and understand[10]
  - Consider documents' formatting and visual clarity in using design elements, such as font, text size, white space, etc.[10]
- Put main messages at the beginning (primacy effect)
- Define technical words
- Limit medical jargon; explain each medical term and how it affects patients
- Guide your participants through material to make sure they understand
- Integrate plain language into research study and recruitment materials

NYU's Clinical and Translational Science Institute (CTSI) has created a three-part Health Literacy in Research Training, accessible with a Kerberos ID through NYU Langone's RISE platform:

- Part 1
- Part 2
- Part 3

CDC Clear Communication Index is a research-based tool to help researchers develop and assess public communication materials. National Institutes of Health's Plain Language Toolkit is a collection of step-by-step modules that help researchers learn how to write in plain language. Further information on plain language can be found in Appendix A.

Engaging Low Health Literacy Patients & Populations

As researchers, it is imperative that we and our colleagues are intentional and mindful of health literacy and use talking points that allow for clear and open communication – especially to successfully engage and reach all participants and populations in research.[4] Centering culture and language can further bridge gaps and reduce health system level challenges to increase the capacity of health care programs to promote health for all populations[5]. Here are some general considerations to increase health literacy across the research continuum[11]:

- **Improve cultural and linguistic competence by utilizing adequate translation and interpretation services, as well as culturally appropriate educational materials.**
    - Adopting a transcreation approach – the process of adapting a message from one language to another while maintaining its intent, style tone, and context – can enhance acceptability and receptivity of the message (see *figure 3)*[12]
    - Infusing culturally relevant themes, images, and context
    - Meeting the health literacy and informational needs of the population of focus
    - Make sure all educational materials meet the National Standards for Culturally and Linguistically Appropriate Services (CLAS)

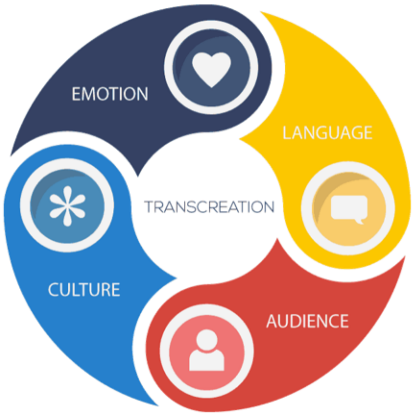


Figure 3. Fundamentals of the Transcreation Approach. Learn the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care here.

- **Consider co-developing and user-testing research study materials** (such as consent forms) with participants, community partners, and other organizations familiar with the participant population(s) being studied to ensure that they are clear, relevant, and culturally and linguistically appropriate.

  - Materials created using a translator, translation services or translation software (e.g. Google translation & AI) should only be used after its reviewed by a bilingual/bicultural reviewer
- **Build trust by proxy through community-engaged research can help to address barriers to health literacy**. Some examples include:
  - Employing representative researchers that conduct outreach to the participant population
  - Utilizing certified language interpreters
  - Working with trusted community partners, such as community health workers (CHWs), to address potential social needs and provide linkages to needed community-based social services in addition to engaging them in research
- **Utilize plain language, define and explain terms, and use visual aids**.
  - Plain language dictionaries, linguistically accessible brochures, and visual data representations (such as infographics) are several tools that researchers can use to improve health literacy and infuse education into all steps of the research process (such as in obtaining informed consent).
- **Build engagement points into the participant education and informed consent process to ensure continual learning, understanding, and information sharing**.
  - Incorporate interactive elements like a frequently asked questions section or checklists to support learning

See *table 1* below for a summary of considerations for engaging low health literacy communities:

Consider:	**How?**	**Example:**
Improving cultural and linguistic competence	Utilizing adequate translation and interpretation services, as well as culturally appropriate educational materials.	Use transcreation approach to enhance acceptability and receptivity of the message
Co-developing and user-testing research study materials	Working with participants, community partners, and other organizations familiar with the participant population(s) being studied to ensure that they are clear, relevant, and culturally and linguistically appropriate	Review Consent forms with community members and ask for input on ways to address pain-points or confusion that may arise in future
Building trust by proxy through community-engaged research	Employing representative researchers and working with trusted community partners to conduct outreach among participant population	Include Community health workers (CHWs), interpreters to create introductions between research staff and participants
Utilize plain language, define/explain terms, and use visual aids	Use Plain language dictionaries, linguistically accessible brochures, and visual data representations	Use bold colors, common language, “layman’s terms”, clear charts and infographics as visual aids
Infuse education into all steps of the research process	Build in engagement points into the participant education and informed consent process to ensure continual learning, understanding, and information sharing	Stop at different points of the consent process or study overview to ask how well participants are understanding the material, create teach-back moments

Table 1. Considerations for engaging low health literate communities and recommended steps for implementation.

Health Literacy in the Digital Era

The relationship between digital literacy, health literacy, and digital health literacy is a multi-dimensional one, where each competence domain of digital and health literacy may affect one or more competence domains of digital health literacy.[13] For instance, poor language access, trust in sources of information, and lack of information on or experience with using electronic health devices (health literacy) play into digital literacy.[14] Groups previously identified as being at higher risk for low health literacy also have difficulty accessing electronic health information.[13]

Presenting Information in digital formats to participants pose unique challenges for researchers and thus require communication strategies tailored for digital formats to ensure participant understanding. For example, site design, complexity of navigation, amount of data entry, and confusion with app usage can all be obstacles to information access.[15] Researchers working with digital materials should consider the following "universal design" strategies in digital health[15]:

- Encourage development of materials and tools in line with universal precautions (accessible health information)
- Make materials available in video and audio formats for participants with limited general literacy
- Ensure any test results are given along with a health literate interpretation of those test results
- Solicit questions from participants to ensure understanding and reinforce learning and communication
- Minimize features that are work-intensive or time-consuming
- Designate employees to support patients using eHealth services

Effective data translation and visualization helps researchers explain and communicate their findings with participants.[16] Some considerations to effectively translating data and creating visualizations include:

- Use bolded words, lists and headers to help readers skim documents[10]
- Use visual tools (see *figure 4*)
- Infographics: provide clear representation of data, relationships or ideas
- Tables: useful for making comparisons and showing relationships
- Lists: grouping similar items to make it easier to read
- Organize content with headings
- Provide table of contents for longer documents
- Consider formatting (font, white space, margins, space between sections)

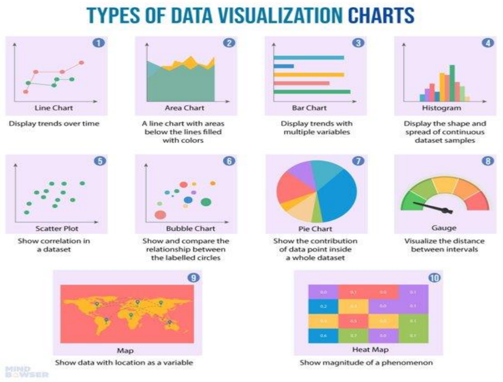
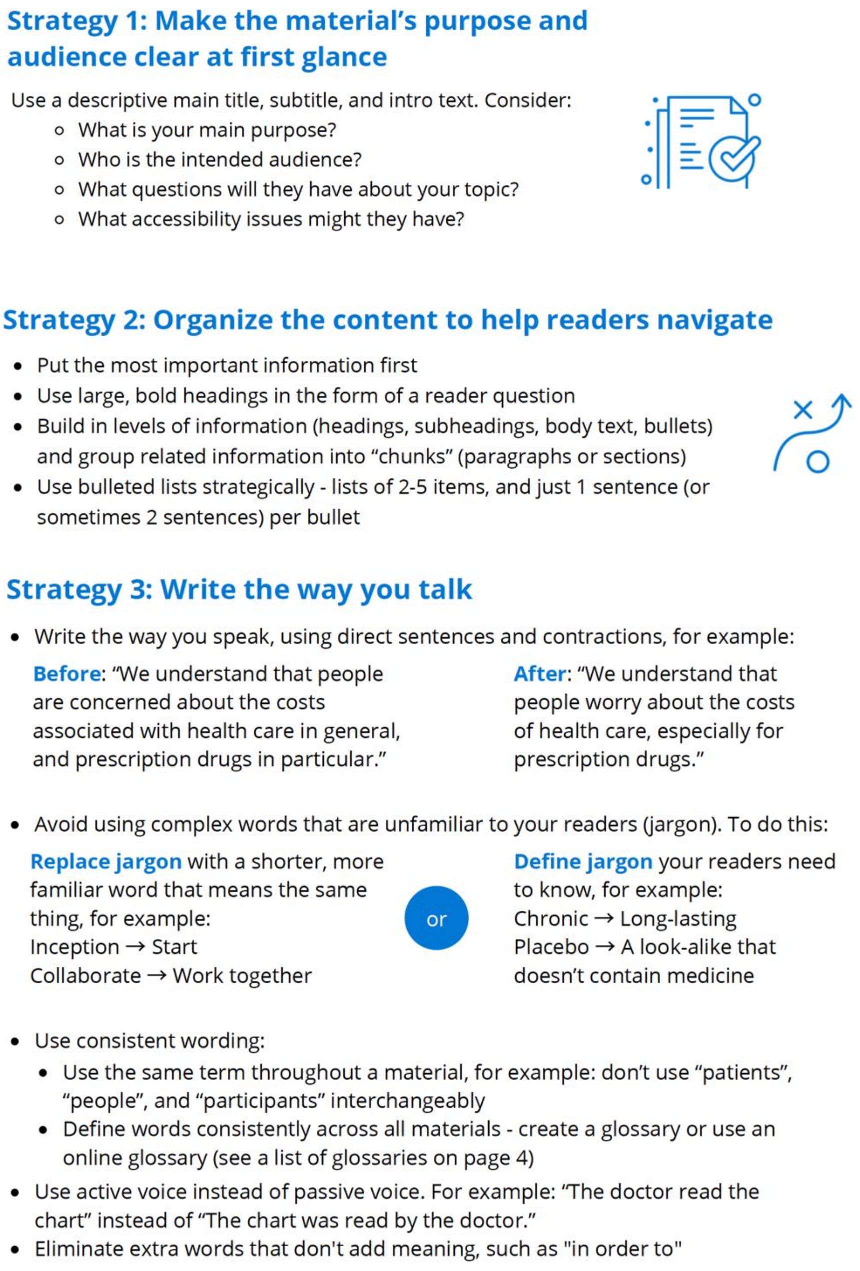


Figure 4. 10 Types of Data Visualization Charts[16]. See the NYU Health Science Library's Data Visualization Guide for additional resources on data visualization.

Appendix

Appendix A: Plain Language Considerations and Resources

The figures below further detail concrete steps that researchers can take to ensure that health-related communication and research material are understood by participants.



Strategy 1: Make the material's purpose and audience clear at first glance

Use a descriptive main title, subtitle, and intro text. Consider:

- What is your main purpose?
- Who is the intended audience?
- What questions will they have about your topic?
- What accessibility issues might they have?

Strategy 2: Organize the content to help readers navigate

- Put the most important information first
- Use large, bold headings in the form of a reader question
- Build in levels of information (headings, subheadings, body text, bullets) and group related information into "chunks" (paragraphs or sections)
- Use bulleted lists strategically - lists of 2-5 items, and just 1 sentence (or sometimes 2 sentences) per bullet

Strategy 3: Write the way you talk

- Write the way you speak, using direct sentences and contractions, for example:

Before: "We understand that people are concerned about the costs associated with health care in general, and prescription drugs in particular."	**After**: "We understand that people worry about the costs of health care, especially for prescription drugs."

- Avoid using complex words that are unfamiliar to your readers (jargon). To do this:

Replace jargon with a shorter, more familiar word that means the same thing, for example: Inception → Start Collaborate → Work together	or	**Define jargon** your readers need to know, for example: Chronic → Long-lasting Placebo → A look-alike that doesn't contain medicine

- Use consistent wording:
  - Use the same term throughout a material, for example: don't use "patients", "people", and "participants" interchangeably
  - Define words consistently across all materials - create a glossary or use an online glossary (see a list of glossaries on page 4)
- Use active voice instead of passive voice. For example: "The doctor read the chart" instead of "The chart was read by the doctor."
- Eliminate extra words that don't add meaning, such as "in order to"

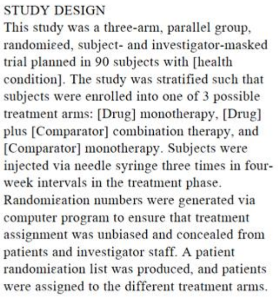
Strategy 4: Highlight actions readers should take

- Give detailed action steps and resources such as contact info or websites
- Focus on actions readers should take and not what they shouldn't
- To motivate readers, tell them why they should do it

Strategy 5: Use design and layout to make materials easier to read

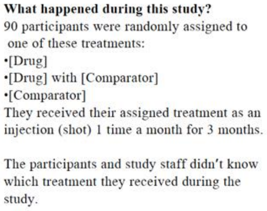
- Leave 20-30% white space so the pages don't look crowded
- Use clear fonts such as Arial, Calibri, Verdana, and Trebuchet
- Avoid ALL CAPS, *italics*, underlining, and condensed fonts
- Use bold formatting, color, and visual cues such as arrows or boxes to highlight important information
- Where appropriate, use photos that represent your audience
- Use visuals that are culturally appropriate for your intended audience

Original:



STUDY DESIGN
This study was a three-arm, parallel group, randomized, subject- and investigator-masked trial planned in 90 subjects with [health condition]. The study was stratified such that subjects were enrolled into one of 3 possible treatment arms: [Drug] monotherapy, [Drug] plus [Comparator] combination therapy, and [Comparator] monotherapy. Subjects were injected via needle syringe three times in four-week intervals in the treatment phase. Randomization numbers were generated via computer program to ensure that treatment assignment was unbiased and concealed from patients and investigator staff. A patient randomization list was produced, and patients were assigned to the different treatment arms.

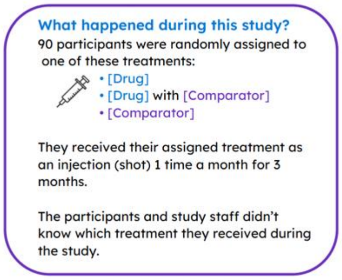
Plain language revision:



What happened during this study?
90 participants were randomly assigned to one of these treatments:
•[Drug]
•[Drug] with [Comparator]
•[Comparator]
They received their assigned treatment as an injection (shot) 1 time a month for 3 months.

The participants and study staff didn't know which treatment they received during the study.

Designed version:



What happened during this study?
90 participants were randomly assigned to one of these treatments:
• [Drug]
• [Drug] with [Comparator]
• [Comparator]

They received their assigned treatment as an injection (shot) 1 time a month for 3 months.

The participants and study staff didn't know which treatment they received during the study.

Strategy 6: Use essential numbers and do the math for readers

- Only use numbers that are necessary
  - Example: "1 in 20 people (5%) will have side effects from this medicine"
- Do the math for readers
  - Example: To lose 5% of your body weight, you will need to lose 7 pounds if you weigh 140 pounds.
- Give numbers meaning and context
  - Example: Use labels such as "Low," "Normal," and "High" on a chart
  - When you use a percentage, also give the natural frequency. Example: "1 in 3 people (30%) will have some side effects"
- Use visuals to support numbers
  - Example: Use bar graphs or pie charts to help illustrate percentages

Finally, use audience testing to see if your material is clear

- **Test materials with your intended audience** to identify gaps in understanding through focus groups and one-on-one interviews with 5-8 people. After you get their feedback, incorporate it into your materials and retest.

References

1. Centers for Disease Control and Prevention. (2021). What is Health Literacy? Centers for Disease Control and Prevention. U.S. Department of Health and Human Services. https://www.cdc.gov/healthliteracy/learn/index.html.

2. Centers for Disease Control and Prevention. Health Literacy in Healthy People 2030. U.S. Department of Health and Human Services. https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030.

3. Centers for Disease Control and Prevention. (2021). Understanding Health Literacy. Centers for Disease Control and Prevention. U.S. Department of Health and Human Services. https://www.cdc.gov/healthliteracy/learn/Understanding.html.

4. Gaspésie Literacy Council. Types of Literacy. Gaspésie Literacy Council. https://gaspelit.ca/types-of-literacy/.

5. Centers for Disease Control and Prevention. (2021). Talking Points about Health Literacy. Centers for Disease Control and Prevention. U.S. Department of Health and Human Services. https://www.cdc.gov/healthliteracy/shareinteract/TellOthers.html

6. Pfizer. (2021). How prevalent is low health literacy? Pfizer Inc. https://www.pfizer.com/health/literacy/healthcare-professionals/how-prevalent-is-low-health-literacy

7. White RO, Osborn CY, Gebretsadik T, Kripalani S, & Rothman RL. (2013). Health literacy, physician trust, and diabetes-related self-care activities in Hispanics with limited resources. *Journal of health care for the poor and underserved*, 24(4), 1756–1768. https://doi.org/10.1353/hpu.2013.0177

8. Cary L, O'Leary C, HLM (2023). NYU CTSI Health Literacy for Research Materials Workshop Summary. Health Literacy Media. Summary takeaway - NYU workshop Sept 2023.pdf

9. Catina O'Leary, Casey C, Webb D, Collyar D, & Pleasant A. (2020). How Health Literacy Can Enhance the Design and Conduct of Clinical Trials from Consent to Conclusion. *Studies in Health Technology and Informatics*, 269, 275 – 284. https://doi.org/10.3233/SHTI200042.

10. NIH. (2017). Formatting and Visual Clarity. U.S. Department of Health and Human Services, National Institute of Health. https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language/formatting-visual-clarity.

11. The National Academies of Sciences, Engineering, and Medicine. (2022). Adoption of Health Literacy Best Practices to Enhance Clinical Research and Community Participation. National Academies Press. https://nap.nationalacademies.org/catalog/26506/adoption-of-health-literacy-best-practices-to-enhance-clinical-research-and-community-participation.

12. Piñeiro B, Díaz DR, Monsalve LM, Martínez Ú, Meade CD, Meltzer LR, Brandon KO, Unrod M, Brandon TH, Simmons VN. (2018). Systematic Transcreation of Self-Help Smoking Cessation Materials for Hispanic/Latino Smokers: Improving Cultural Relevance and Acceptability. *J Health Commun*. 23(4): 350–359.

13. Van Kessel R, Wong BLH, Clemens T, & Brand H. (2022). Digital health literacy as a super determinant of health: More than simply the sum of its parts. *Internet interventions*, 27, 100500. https://doi.org/10.1016/j.invent.2022.100500.

14. Centers for Disease Control and Prevention. (2022). eHealth Literacy. Centers for Disease Control and Prevention. U.S. Department of Health and Human Services. https://www.cdc.gov/healthliteracy/researchevaluate/eHealth.html#print.

15. Smith B, & Magnani JW. (2019). New technologies, new disparities: The intersection of electronic health and digital health literacy. *International Journal of Cardiology*, 292, 280–282. https://doi.org/10.1016/j.ijcard.2019.05.066.

16. LaPolla F. (2020). Data Visualization. NYU Langone Health, NYU Health Sciences Library. https://hslguides.med.nyu.edu/dataviz.

This research is supported in part by an NYU CTSA grant (UL1 TR001445) from the National Center for Advancing Translational Sciences, National Institutes of Health.

Updated April 2025