

# Welcome to the Community Engagement Learning Network!

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**Community engagement** refers to the different ways in which health (& social) care organizations can reach out to, engage, and partner with people with lived experience, with the goal of working together to improve healthcare and achieve positive health outcomes.



Please join us for our next session on **May 27<sup>th</sup>** from **3-4:30pm ET**

Session topic: How to Have Inclusive and Productive Conversations about Data and Outcomes with PWLE (and Everyone Else)



[www.consumerpartnership.org/assessment](http://www.consumerpartnership.org/assessment)

## Welcome to INSPIRE's Community Engagement Assessment & Practice Library

This self-assessment takes less than 10 minutes to complete and offers customized suggestions, including 'easy wins' for your organization and community!

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### Start Your Assessment

Start Now

Your responses will be used to provide recommendations about specific ways your organization can strengthen partnerships with PWLE.

We strongly recommend that you start with the self-assessment so we can help point you in the right direction, but you can choose to skip the self-assessment and explore our full Practice Library on your own.

What is this self-assessment? +

Who should take this self-assessment? +

How to take this self-assessment: +

Click to filter by practice category

Building authentic and impactful relationships with PWLE

Building organizational infrastructure for engaging PWLE

Creating strategies and goals for engaging PWLE

Measuring and evaluating your work with PWLE

Search resources...



#### Articulating A Clear Statement Of Purpose

Creating strategies and goals for engaging PWLE



#### Creating Engagement Opportunities

Building authentic and impactful relationships with PWLE



#### Engaging Executive Leaders

Building organizational infrastructure for engaging PWLE



#### Ensuring Representation

Creating strategies and goals for engaging PWLE



#### Establishing Feedback Loops That Support Action

Building organizational infrastructure for engaging PWLE



#### Hiring And Training Dedicated And Skilled Staff

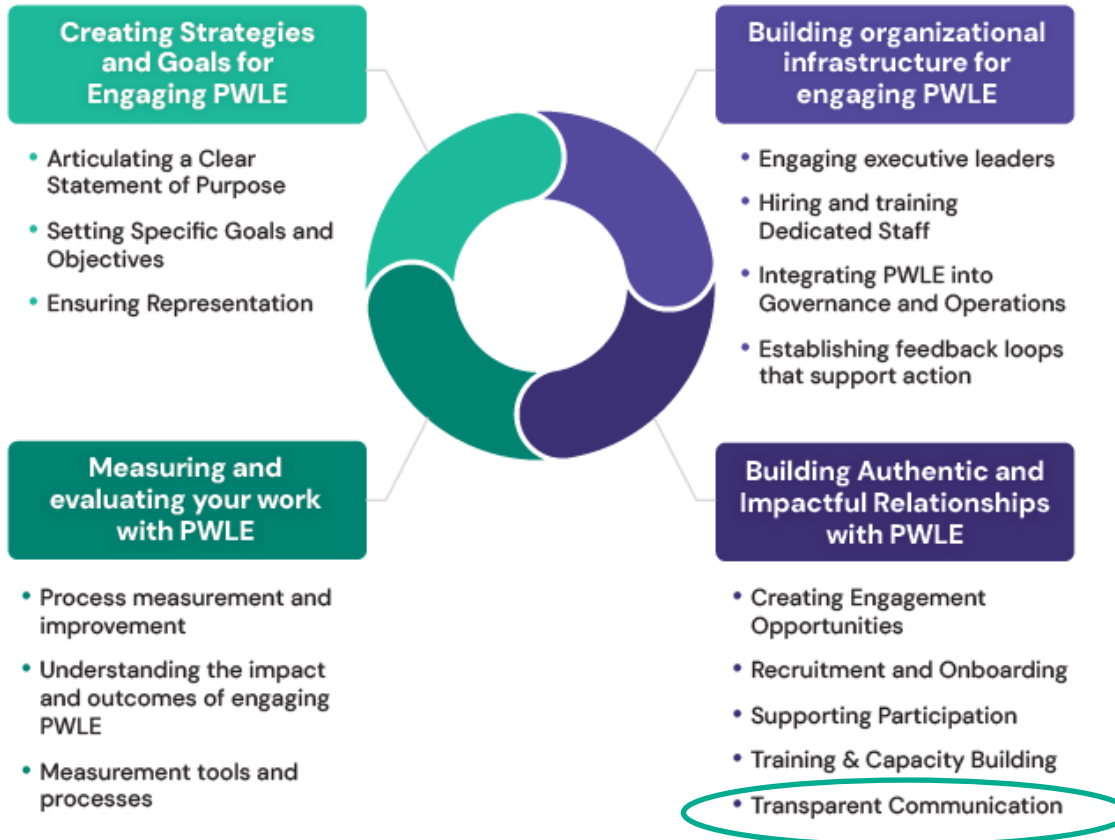
Building organizational infrastructure for engaging PWLE



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# The INSPIRE Framework for Engaging PWLE

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# Creating Health Information People Can Use

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## Best Practices for Plain Language Writing

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# Overview

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1. Understanding How People Read
2. Health Communication and Plain Language
3. Plain Language Best Practices: Before You Start Writing, Writing, and Confirming Understanding
4. Wrap Up

# Skills Involved in Reading

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- Reading is an **active process** that involves constant decision-making, prediction, and attention shifts
- Core reading skills
  - **Decoding skills** (recognizing words)
  - **Language comprehension** (making sense of text)
- Reading behaviors varies based on individual differences, such as
  - Prior knowledge and vocabulary
  - Language background
  - **Reading fluency** (ability to read text accurately and quickly)
  - **Cognitive load tolerance** (amount of mental effort a reader can process before comprehension breaks down)

# How People Read (In Print and Online)

- Rarely read word-for-word or full paragraphs
  - Jump around the text
  - Spend more time on unfamiliar or complex words
  - Skip easy words
- Scan for structure – look first at headings, bullets, bold text, first lines of paragraphs
- Stop reading quickly if the text feels dense or confusing

The screenshot shows the website **smokefree.gov** with a search bar. The main content is titled "Benefits of Quitting". The text includes:

The benefits of quitting are far better than the discomforts of recovery! Stay with it and find your freedom. Once you do, you'll never let it go.

**The Good News...**  
 But it won't be done. Millions of people just like you have become former smokers. But cravings will pass. Most cravings only last a few minutes, and over time the urges to smoke will get weaker and come less often. But it isn't painful. It's for a short time and it's manageable. Gaining a few extra pounds after quitting is normal, but exercise and healthy eating can stop most of this weight gain, if not all of it. Smoking has been part of your daily life, like drinking coffee and waiting for the bus. But every day that you spend as a non-smoker will help make new routines that don't include cigarettes. Smoking feels good because you've had lots of practice being a smoker. But you have years ahead of you to practice being a non-smoker.

**Many people who quit are surprised by how good they feel!**

**They feel less stressed**

- They don't need to smoke
- They don't need to smoke
- They don't need to worry about their smoke bothering others

**They smell good**

- Their clothes, and breath don't smell like smoke
- Their cars, homes, and cars don't smell like smoke
- They can better smell and enjoy good smells

**They feel more relaxed**

- They don't have to make sure they always have cigarettes
- They have more money
- They are not as worried about their health

**They look and feel better**

- They're good about being able to quit
- Their skin looks better
- They have more energy when they walk, play with their kids, or do something active

At the bottom, there is a testimonial from a woman: "My grandkids are proud of me."

Office of Disease Prevention and Health Promotion: Health Literacy Online

# Health Literacy

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- Communicating and understanding information related to wellness and health promotion, disease prevention and detection, diagnosis and decision making, treatment and self-care, and access to care
- Implications for health outcomes, safety, use of health services, health care costs

## How does Healthy People define health literacy?

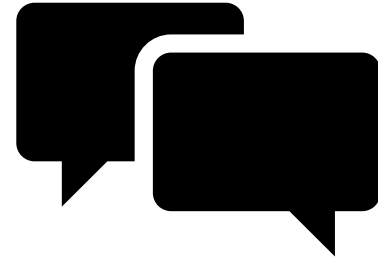
Healthy People 2030 addresses both personal health literacy and organizational health literacy and provides the following definitions:

- **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.
- **Organizational health literacy** is the degree to which organizations enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

# Strengthen Health Literacy Through Better Communication

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- Ways health information can be communicated:
  - Conversations
  - Written materials
  - Websites
  - Text messages
  - Podcasts
  - Pictures
  - Videos
  - Phone calls
  - Classes
  - Social Media



**Plain language is one way to improve communication**

# What is Plain Language?

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A communication is in plain language if its **wording**, **structure**, and **design** are so clear that the intended audience can easily **find** what they need, **understand** what they find, and **use** that information.

–[Plain Language Association International](#)

- Plain language is not “dumbing down.” It is evidence-based communication design that aligns with:
  - How the human brain processes information
  - How people actually read – not how we *wish* they would read
  - Health literacy and the goal of making sure all people can understand and use health information

# Best Practices: Before You Start Writing

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- Define communication goals
- Establish a team
- Understand the intended audience

# Before You Start: Define Communication Goals

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- Determine purpose of materials and the main message to convey
  - Explain a diagnosis
  - Inform a treatment decision
  - Explain instructions, such as for medicine or procedure
  - Complete a form
  - Communicate a public health message
  - Summarize findings from a research study
- Ask what readers should **know**, **do**, or **feel** after reading

# Before You Start

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## Establish a Team With Expertise in:

- Plain language →  
Advocate for readers
- Content →  
Determine accuracy and what information must stay
- Lived experience →  
Represent intended audience in terms of literacy level, language, age, culture, and familiarity with the subject
- Copyeditor
- Graphic Design

## Understand the Intended Audience

- Determine the intended audience
- Figure out what your intended audience knows and wants to know
- How?
  - Partner with people who have lived experience
  - Conduct interviews or focus groups
  - Identify commonly asked questions via email or other platforms
  - Look at what people search for or where they spend their time on a website
  - See what people are saying on social media
  - Observations

# Best Practices: Writing

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- Content and organization
- Words and sentences
- Numbers and risk
- Design

# Content and Organization

- Differentiate between “need to know” and “nice to know”
- Put most important information first
- Group information in sections that make sense to readers
- Use clear headings to identify new sections
- Frame information in positive, and honest ways

## PROJECT INFORMATION

January 2026

### Comparing Ways to Treat High Blood Pressure in Children and Youth with Chronic Kidney Disease -- The PRESERVE Study -- A PCORnet® Study

#### Principal investigator

Christopher B. Forrest, MD, PhD

#### Organization

Children's Hospital of Philadelphia

#### What was the research about?

Chronic kidney disease is a health problem in which the kidneys don't work well to filter the blood. About half of all children and youth with this condition also have high blood pressure. High blood pressure increases these patients' risk for kidney failure, where the kidneys stop working. When this happens, patients need dialysis or a kidney transplant. Managing high blood pressure can help lower the risk of kidney failure.

In this study, the research team compared how well two types of medicines for treating high blood pressure worked to protect kidney function in children and youth with chronic kidney disease:

- Calcium channel blockers, or CCBs
- Renin-angiotensin-aldosterone system inhibitors, or RAASi

#### What were the results?

After two years, compared with patients who received CCBs, patients who received RAASi had:

- A lower risk of needing dialysis or a kidney transplant
- A lower risk of major loss of kidney function
- Better blood pressure control

- Fewer adverse events, like depression

Patients who received the two types of medicines had a similar and low risk of death.

#### Who was in the study?

The study included data for 2,762 patients ages 2–20 with chronic kidney disease and high blood pressure. Among patients, 46% of parents or patients reported the patient's race or ethnicity as White, 25% as Black or African American, 18% as Hispanic, 4% as Asian, 2% as more than one race or ethnicity, and 5% reported another race or didn't report race. The average age was 13, and 50% were female. All received care from a pediatric kidney doctor at one of 13 clinics taking part in PCORnet® across the United States. Of the 2,762 patients, 1,005 received CCBs and 1,757 received RAASi.

#### What did the research team do?

The research team looked at patient electronic health record, or EHR, data from PCORnet® Network Partners. EHR data were from January 2009 to December 2020. The team linked the EHR data to data in the United States Renal Data System to provide data on dialysis and kidney transplants in youth and children.

Then the research team compared data for patients who received CCBs and patients who received RAASi.

[WWW.PCORI.ORG/FORREST567](http://WWW.PCORI.ORG/FORREST567)

[INFO@PCORI.ORG](mailto:INFO@PCORI.ORG) | [WWW.PCORI.ORG](http://WWW.PCORI.ORG) | [@PCORI](https://twitter.com/PCORI)

# Words

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- Use common 1-2 syllable words.
  - Define unfamiliar, yet necessary, words and terms.
  - Be consistent, using the exact same wording each time.
  - Avoid or explain acronyms, jargon, idioms, and needlessly “stuffy” words.
  - Use acronyms sparingly
- **Use everyday words for these terms (put in chat):**
    - Multidisciplinary treatment team
    - Risks
    - Adequate fluid intake
    - Negative test result
    - Primary care provider

# Sentences

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- Reduce unnecessary words
- Write short sentences (about 15-20 words), each with only one idea.
- Use active voice, identifying who is doing the action.
- **Simplify a sentence (put in chat)**
  - The focus of this updated clinical practice guideline is to address the evaluation, management, and monitoring of individuals with dyslipidemia.
  - Although telemedicine has expanded access to care for many patients in rural communities, its effectiveness still depends on reliable internet connections and the ability of clinicians to adapt their communication strategies to a virtual environment.”

# Numbers

- Appreciate that many people have difficulty with numbers – are they necessary to include?
- Do not require readers to do math
- Help the reader understand whether a number is good or bad
- Use numbers paired with, or instead of, vague terms, like common, rare, high risk
- Using numbers may be a way to build trust with reader



# Risk Information

- **Options for risk that an event will occur:**
  - Percentages (40%)
  - Fractions (2/5)
  - Simple frequencies (2 in 5)
- **Risk can be:**
  - Relative (Medicine will reduce your risk of X by 50%)
  - Absolute (Medicine will reduce your risk of X from 6 in 1,000 to 3 in 1,000)

## Considerations for presenting risk

- Some studies suggest people understand simple frequencies better than percentages
- When using simple frequencies, use same denominators (compare 3 in 200 with 24 in 200 rather than 3 in 25)
- Avoid 1-in-X format as people over-identify with 1 (say 3 in 1,000 versus 1 in 300)
- Show both relative and absolute risk. Systematic review showed people understand both, but risk may appear larger with relative risk.

# Design

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## Formatting

- Have adequate white space so pages do not look crowded
- Use short, bulleted lists. Limit lists to 5 items
- Include graphics to show key ideas or actions (carefully)
- Line up (justify) the left margin, but not the right or center

## Font

- Use consistent font styles and size throughout the document.
- Use bold font rather than italics or underline for headings.
- Use upper and lower case. Avoid writing in all capital letters.
- Use dark text on a white or light background.

# Best Practices: Confirming Understanding

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# Assessing Reading Level

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- Different readability formulas are available: Flesch-Kincaid, Flesch Reading Ease, SMOG, Fry Formula
- Results are often a grade level and based on the average length of words and sentences
- Can be a tool to give general sense of complexity:
  - 4-6<sup>th</sup> grade → easy to read
  - 7-9<sup>th</sup> → average difficulty
  - Above 10<sup>th</sup> grade → difficult
- Different formulas provide different grade levels
- Formulas do not tell you whether
  - Words are familiar
  - Sentences are clear
  - Information is organized logically
  - People can understand and use the information

# Getting Feedback from the Intended Audience

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- Determine how and when to best get feedback:
  - Throughout the writing process versus specific time points
  - In person versus virtual
  - One-on-one versus group
  - Verbal versus written
- Make it clear that you are asking for feedback on the writing (and not testing literacy skills):
  - I want to make sure that I explained this clearly
  - What do you think the authors meant by [X]? How would you explain this information in your own words?
  - How would you use this information?
  - What do you think of the overall format and design?

# Reflection Questions

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- What challenges have you faced with creating written materials?  
What helped you address those challenges?
- What could you do this week to improve your communication?

# Plain language makes it easier for everyone to find, read, and use information

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- Aligns with how people read
- More than just simplifying words:
  - Need to know versus nice to know
  - Put most important information first and organize info logically
  - Use common words, short sentences, and clear headings
- People with lived experience improve the usefulness of health information

# Resources: Literacy

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Agency for Healthcare Research and Quality (AHRQ). (March 2024). *AHRQ Health Literacy Universal Precautions Toolkit, 3<sup>rd</sup> Edition*. <https://www.ahrq.gov/health-literacy/improve/precautions/toolkit.html>

Center for Disease Control and Prevention. (July 2025). *Plain Language Materials & Resources*. <https://www.cdc.gov/health-literacy/php/develop-materials/plain-language.html>

Center for Health Care Strategies. (March 2024). *Health Literacy Fact Sheets*. <https://www.chcs.org/resource/health-literacy-fact-sheets/>

Centers for Medicare & Medicaid Services. (March 2026). *Guidelines for effective writing*. <https://www.cms.gov/training-education/learn/find-tools-to-help-you-help-others/guidelines-for-effective-writing>

Helen Osborne. (2022). *Health Literacy from A to Z: Practical Ways to Communicate Your Health Message 3<sup>rd</sup> Edition*. <https://healthliteracy.com/>

OASH. Office Of Disease Prevention and Health Promotion. (July 2025). *Health Literacy Online 3<sup>rd</sup> Edition*. <https://odphp.health.gov/healthliteracyonline/about-third-edition>

# Resources: Presenting Risk

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American Academy of Family Physicians. (2018). Five Ways to Communicate Risks So That Patients Understand. <https://www.aafp.org/pubs/fpm/issues/2018/1100/p28.html#fpm20181100p28-b8>

American College of Cardiology. (2020). Improving Cardiovascular Risk Communication with Your Patients. <https://www.acc.org/-/media/Non-Clinical/Files-PDFs-Excel-MS-Word-etc/Tools-and-Practice-Support/Risk-Communications/1-Quick-Reference-Guide.pdf>

Bonner et al. (2021) Current Best Practice for Presenting Probabilities in Patient Decision Aids: Fundamental Principles. *Medical Decision Making*. 41(7).  
<https://journals.sagepub.com/doi/10.1177/0272989X21996328#core-bibr20-0272989X21996328-1>

Peters et al. (2025). Communicating Numeric Risk Information to Patients. *Journal of General Internal Medicine*. 40: 3228-3231. <https://link.springer.com/article/10.1007/s11606-025-09520-8>