Health Information Security and Privacy Collaboration

Creating Consumer Education and Engagement Tools: A Guide to Literacy and Language Considerations

Prepared for

RTI International
230 W Monroe, Suite 2100
Chicago, IL 60606

Jodi Daniel, JD, MPH, Director
Steven Posnack, MHS, MS, Policy Analyst
Office of Policy and Research
Office of the National Coordinator for Health IT
200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

Prepared by

Consumer Education and Engagement Collaborative
Colorado, Georgia, Kansas, Massachusetts, New York, Washington, West Virginia

Contract Number HHSP 233-200804100EC
RTI Project Number 0211557.000.007.100
Health Information Security and Privacy Collaboration

Creating Consumer Education and Engagement Tools: A Guide to Literacy and Language Considerations

Prepared for

RTI International
230 W Monroe, Suite 2100
Chicago, IL 60606

Jodi Daniel, JD, MPH, Director
Steven Posnack, MHS, MS, Policy Analyst
Office of Policy and Research
Office of the National Coordinator for Health IT
200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

Prepared by

Consumer Education and Engagement Collaborative
Common Project Lead, Dawn Bonder, Oregon

Collaborative Members
Phyllis Albritton, Colorado
Peggy Evans, Washington
Ellen Flink, New York
Victoria Wangia, Kansas
Jerilyn Heinold, Massachusetts
Alicia McCord-Estes, Georgia
Patricia Ruddick, West Virginia
Identifiable information in this report or presentation is protected by federal law, section 924(c) of the Public Health Service Act, 42 USC. § 299c-3(c). Any confidential identifiable information in this report or presentation that is knowingly disclosed is disclosed solely for the purpose for which it was provided.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Introduction</strong></td>
<td>1-1</td>
</tr>
<tr>
<td>2. <strong>Lessons Learned</strong></td>
<td>2-1</td>
</tr>
<tr>
<td>2.1 What Is Plain Language?</td>
<td>2-1</td>
</tr>
<tr>
<td>2.2 Why Is Plain Language Important?</td>
<td>2-1</td>
</tr>
<tr>
<td>2.3 Writing in Plain Language—Quick Tips</td>
<td>2-2</td>
</tr>
<tr>
<td>3. <strong>Literacy Level Assessment</strong></td>
<td>3-1</td>
</tr>
<tr>
<td>3.1 SMOG Readability Formula</td>
<td>3-1</td>
</tr>
<tr>
<td>3.2 Assessing Pre-Existing Communication Materials</td>
<td>3-1</td>
</tr>
<tr>
<td>3.2.1 Content</td>
<td>3-2</td>
</tr>
<tr>
<td>3.2.2 Organization</td>
<td>3-2</td>
</tr>
<tr>
<td>3.2.3 Source Credibility</td>
<td>3-2</td>
</tr>
<tr>
<td>3.2.4 Language and Tone</td>
<td>3-2</td>
</tr>
<tr>
<td>3.2.5 Cultural Competence</td>
<td>3-3</td>
</tr>
<tr>
<td>3.2.6 Design</td>
<td>3-3</td>
</tr>
<tr>
<td>3.2.7 Overall Impression</td>
<td>3-3</td>
</tr>
<tr>
<td>4. <strong>Language Translation Guidelines</strong></td>
<td>4-1</td>
</tr>
<tr>
<td>4.1 The Right Interpreter</td>
<td>4-1</td>
</tr>
<tr>
<td>4.2 Recreate the Tool</td>
<td>4-1</td>
</tr>
<tr>
<td>4.3 Use Credible Depictions</td>
<td>4-1</td>
</tr>
<tr>
<td>5. <strong>Testing Materials</strong></td>
<td>5-1</td>
</tr>
<tr>
<td>6. <strong>Conclusion</strong></td>
<td>6-1</td>
</tr>
<tr>
<td>7. <strong>Resources</strong></td>
<td>7-1</td>
</tr>
</tbody>
</table>
1. INTRODUCTION

In this document, “e-Health” is a broad term for the heterogeneous and evolving digital resources and practices that support health and health care. Consumer-oriented e-Health resources are meant to help consumers manage the heavy demands of health management. Indeed, it may be difficult for consumers to meet some of the demands without e-Health tools. The category of e-Health items referred to as “health care tools” covers the means of maintaining or accessing health records and interacting with health care providers.

Established in June 2006 by RTI International through a contract with the Office of the National Coordinator for Health Information Technology, the Health Information Security and Privacy Collaboration (HISPC) was originally comprised of 34 states and territories. As phase three of the HISPC began in April 2008, HISPC was comprised of 42 states and territories, and aimed to address the privacy and security challenges presented by electronic health information exchange through multi-state collaboration. The third phase was comprised of seven multi-state collaborative privacy and security projects focused on different issues. The HISPC Consumer Education and Engagement Collaborative (HISPC CEE) developed tools and strategies to educate and engage consumers on the privacy and security issues related to HIE.

The HISPC CEE found that designing and disseminating tools with an eye to the diverse experiences, requirements, and capacities of the intended audience is a key to effective communication.
2. LESSONS LEARNED

The HISPC CEE designed and disseminated consumer education and engagement strategies and tools. We attempted to bring some focus to tools geared for particular target populations within our home states. This involved analyzing culture, language, and literacy levels for the target audiences chosen within each state. This guide is intended to provide background on literacy and language consideration for others designing consumer education and engagement strategies. There were a number of overarching general lessons learned:

- It is often impossible to take existing materials and adapt them for literacy levels. Create the material with the target literacy level in mind.
- While literacy experts are a great benefit, it is possible to create appropriate materials using the suggestions in this guide.
- Test your materials with the target audience.
- Using plain language whenever possible will increase the ability of the communication tool to be used with multiple target audiences.

2.1 What Is Plain Language?

Plain language is text and speech characterized by easy words and short sentences to accommodate consumers who are poor readers or have trouble understanding hard words, as well as individuals who don’t have a working knowledge of the expertise area.

The goal of plain language information is to provide clear, simple, and streamlined communication. This concept is especially valuable in the jargon-filled world of health care, where it is crucial that communication between health care providers and their patients is very clear. This need is further impacted by discussions around technology. It is important to use plain language with all consumers, not just those with limited literacy skills.

2.2 Why Is Plain Language Important?

Most adults have limited time and limited technological and medical backgrounds. Many adults have limited literacy skills. Plain language allows consumers to easily understand forms and instructions for taking prescriptions, providing consent, preparing for visits or procedures, caring for a chronic condition, etc.

Our research and work has shown that consumer education and engagement is extremely important to the promotion of electronic health information exchange. However, if you are not communicating with your target audience in a clear and understandable manner, it will be impossible to achieve the benefits of a good education and engagement campaign.

The two golden rules of communicating in plain language are:

1. Know your audience—who are you writing for? Take into consideration age, gender, ethnic background, education, etc.
Section 2 — Lessons Learned

2. Identify your main message and key points—and stick to them!

Once you have mastered the golden rules, try out some of the following tips to make your materials more reader-friendly.

2.3 Writing in Plain Language—Quick Tips

1. **Put the most important information at the beginning.**
   The beginning is a place of honor and your reader will still be focused. Put your main message right up front.

2. **Use short words and short sentences.**
   Try to keep sentences to 20 words or less. Instead of using semicolons and dashes, try breaking a long sentence into two or more shorter sentences.

3. **Create short paragraphs or sections with one major idea in the first line.**
   Try to place your main message in the first sentence. Group similar ideas together and remove information that overlaps.

4. **Use the active voice.**
   Avoid using the verb “to be” (is, was, were, will be). Instead, make your sentences come alive with action.
   - **Use:** Ask your doctor if he or she uses electronic health records.
   - **Avoid:** Patients should ask their doctors if electronic health records are used.

5. **Talk directly to the reader.**
   - **Use:** You have the right to not have your information included in an exchange.
   - **Avoid:** Patients have the right to request that their information not be included in an exchange.

6. **Provide concrete examples.**
   - **Use:** Electronic health information exchange can save your life in an emergency by providing your doctor with accurate information about the medications you take and the conditions you have.
   - **Avoid:** Electronic health information exchange can save your life in an emergency.

7. **Use short, bulleted lists.**
   - **Use:** There are a number of different ways health information can be exchanged:
     - personal health records,
     - record locator systems, or
     - data warehousing.
   - **Avoid:** There are a number of different ways health information can be exchanged, such as through personal health records, record locator systems, or data warehousing.

8. **Use headers or subtitles that group information.**
   Large blocks of text are hard to read and can be intimidating to low-literacy clients. Headers break up these large blocks and help consumers to find the information they
are looking for. It also helps to keep your writing organized and logical. For example, when designing a brochure, rather than writing in continuous paragraphs (like you were writing a novel), try listing one or two paragraphs underneath a subheading. Another good tip is to use questions as subheadings, such as “Where can I find more information?”

9. **Eliminate unnecessary words.**

   **Use:** Talk to your doctor about the benefits and risks of electronic health information exchange.

   **Avoid:** We encourage you to talk with your doctor about the benefits for you and the possible risks to you of electronic health information exchange.

10. **Don’t use abbreviations.**

    **Use:** 8:00 in the morning, Health Information Technology

    **Avoid:** 8:00 am, HIT

11. **Repeat your central message.**

    Repeating your main point at least once is a good practice. It helps get your message across because it will stick in the reader’s memory.

12. **Create a form of reader interaction.**

    This can be as simple as asking a question at the end of a section, like “Have you thought about what to ask your doctor?” It could also take the form of a checklist, a fill-in-the-blank, or a trivia question. By taking an active role, the reader is more likely to recall the information later.

13. **Use concrete examples to explain key concepts.**

    **Use:** When you take this medicine, be sure to eat a piece of bread or crackers at the same time.

    **Avoid:** Take with food.

14. **When possible, pretest newly created materials with consumers in the target audience.**

    For example, if you want to communicate a message to a Latino population, test your materials with Latino consumers to gauge the efficacy of the tools you are using.

15. **Make sure there is a lot of white space on your page.**

    This makes the task of reading feel less overwhelming and makes it easier for the eye to follow to the next line.

16. **Use at least 12-point font in an easy-to-read typeface.**

    Such as:
    - Georgia
    - Times New Roman
    - Veranda

17. **Avoid italics.**

    Instead try bolding words or bulleted phrases to which you want to draw attention.
18. **In general, do not use all capital letters.**
   Writing in capitals makes your reader feel that you are YELLING at them, and no one likes to be yelled at. “All Caps” is also harder to read.

19. **Use diagrams and pictures to explain the text.**
   When appropriate, use a picture that reflects your message. For example, use diagrams to explain how health information will flow in an exchange. However, the pictures should relate to the subject and not have excess detail in order to not distract from the message.

20. **Remember—reading and understanding are two different things.**
   Ask consumers to state back to you the information they read. This is one of the best ways to check that they have understood it.
3. LITERACY LEVEL ASSESSMENT

There are a number of formulas to assess the literacy level of printed communications; however, the **SMOG Readability Formula** (Simple Measure of Gobbledygook) is a very popular method to use when dealing with health literacy. Because communication tools for health information exchange will usually be disseminated in the health care context, the SMOG formula offers an opportunity to align health IT communications with other communications related to health care.

### 3.1 SMOG Readability Formula

1. Count 10 consecutive sentences near the beginning of the text to be assessed, 10 in the middle, and 10 near the end. Count as a sentence any string of words ending with a period, question mark, or exclamation point.

2. In the 30 selected sentences, count every word of three or more syllables. Any string of letters or numbers beginning and ending with a space or punctuation mark should be counted if you can distinguish at least three syllables when you read it aloud in context. If a polysyllabic word is repeated, count each repetition.

3. Estimate the square root of the number of polysyllabic words counted. This is done by taking the square root of the nearest perfect square. For example, if the count is 95, the nearest perfect square is 100, which yields a square root of 10. If the count lies roughly between two perfect squares, choose the lower number. For instance, if the count is 110, take the square root of 100 rather than that of 121.

4. Add 3 to the approximate square root. This gives the SMOG Grade, which is the reading grade that a person must have reached if he or she is to understand fully the text assessed.

The general rule of thumb is to aim materials for a 6th-grade reading level or lower.

\[
\sqrt{\text{total complex words} \times \left(\frac{30}{\text{total sentences}}\right)} + 3
\]

Online calculators will do this assessment for you. Just go to [http://www.wordscount.info(hw/smog.jsp](http://www.wordscount.info(hw/smog.jsp)) and cut and paste your text into the calculator.

### 3.2 Assessing Pre-Existing Communication Materials

Although it is often easiest to create materials for specific literacy levels, it is also likely there will be existing materials you may want to adapt for your own use. The following assessment guide should be used when you are trying to determine whether to use an existing material or to develop one yourself. It is also a helpful tool to refer to as you develop your own materials.
3.2.1 Content
- Is the information accurate and up-to-date?
- Does it focus on the key, most necessary information? (And avoid extraneous information?)
- Have any important points been left out?
- Are concrete examples given to illustrate general ideas?
- Does the content take the audience’s culture and circumstances into account?
- Does the material call on the reader to take some specific, appropriate action?

3.2.2 Organization
- Is there a clear core message, supported by a few (3-4) main points?
- Is the information presented in easy-to-understand “chunks” or sections?
- Are the main points presented in a logical order that will make sense to the audience?
- Are headers used to direct the reader to the main points?
- Is there a summary of key points?

3.2.3 Source Credibility
- Does the material’s author/producer have credibility with the target audience?
- Does the spokesperson or other source shown in the material have credibility with the target audience?

3.2.4 Language and Tone
- Is everyday language used?
- Are action words and the active voice used?
- Is the tone friendly and conversational, with the reader treated as a partner?
- Does the material use short words and short sentences, without sounding choppy?
- Are unfamiliar terms, abbreviations, and acronyms defined?
- If slang or figures of speech are used, does the target audience know their meaning?
- What reading level does readability testing show?
- Does the material avoid preaching, condescending, or blaming?
- Does the material avoid using fear tactics?
3.2.5 Cultural Competence

- Is the material written in the preferred language of the target audience?
- If translated, is the translation accurate and well-done?
- Are demeaning labels or stereotypes avoided?
- Is the material appropriate for the audience’s age and gender?
- Does the material show respect for the target audience’s values, customs, beliefs, and prior knowledge?
- Are the people depicted representative of the target audience?

3.2.6 Design

- Do design elements (like headers, bullets, and boxes) help draw attention to the main points?
- Does the material have an accessible, open look with plenty of white space?
- Is the font (typeface) clear and clean, and large enough (12 points or larger)?
- Do visuals support the text and are they placed close to the text they relate to?
- Do visuals show the correct way to do something?
- Are confusing graphs, charts, and statistics avoided?
- Is there good contrast between paper and ink?
- Is the material visually attractive?

3.2.7 Overall Impression

- What are the strengths of the material?
- What are the weaknesses of the material?

Other comments?
4. LANGUAGE TRANSLATION GUIDELINES

There is no set formula for determining whether communication pieces should be translated into another language. Each organization and group will need to determine if there is a significant size population speaking another language that requires the information you wish to disseminate.

Once the decision to translate materials is made, however, how that is accomplished is very important.

4.1 The Right Interpreter

There are many dialects and variations of each foreign language. For example, do you want a Spanish translation to Latin American Spanish, Northeastern Spanish, or European Spanish? Each of these translations calls for different vocabulary and different phraseology to be understood and credible with your target audience.

4.2 Recreate the Tool

It is also recommended that the translator start with the original source communication, but not do a “word for word” translation. It is important that the concepts translate—the words are the vehicle to communicate the concepts. Allow your translator to choose the best vocabulary to convey your messages.

4.3 Use Credible Depictions

And lastly, ensure that pictures or photos used in materials depict people who look like the people you are trying to reach. Communication tools intended for a Hispanic community which depicts only Caucasians, in settings unfamiliar to the target audience, will not be effective in conveying your message. Words are only one way to communicate; your pictures, photos, and diagrams should also be translated.
5. TESTING MATERIALS

It is important to pretest your materials before finalizing and distributing them. The purpose of testing the materials is to assess whether they are understandable, relevant, attractive, and acceptable to the target audience.

The best way to see if your materials are easy for your target consumers to understand is to conduct a focus group. By holding a focus group, you get feedback to help your materials be even more understandable, relevant, attractive, and culturally competent. Ideally, your focus group would be 5–7 people who are in the target audience for the publication (in terms of gender, ethnicity, primary language, etc.).

If you are unable to hold a full focus group, then try to ask individuals to critique your materials. Again, it is ideal to have people from the target audience do this. At the very least, have 2 or 3 co-workers review the materials. You can ask the same questions as you would for a focus group, but keep in mind that individuals may not be as open with criticism as they might be in a group setting.
6. CONCLUSION

Today, more and more decision makers are interested in e-Health tools as critical components of personal health management and health care reform strategies. Decision makers are seeking viable approaches to reduce health care costs, improve the quality of care, and increase consumers’ ability to manage their own health. Conditions are favorable for a greater investment in consumer-oriented e-Health tools. The technology marketplace is dynamic; the public is increasingly turning to information and communication technologies for a better life; health care organizations are adopting and offering health information technology; and government policy is placing great emphasis on both health information technology and personal health management for consumers. Such activities are now part of everyday news.

A central message from the HISPC CEE is that no single tool or strategy will work for a national population with highly diverse interests, experiences, conditions, and capacities. Our work introduced us to the challenges that the well-documented diversity in this country present to consumer education and engagement efforts in the e-Health arena, with special emphasis on the challenges presented by privacy and security issues related to electronic health information exchange. This is the case for e-Health tools themselves as well as the policies, funding, and program priorities that influence their development, evaluation, and dissemination.
7. RESOURCES


