Making Government Biomedical Information Understandable for Everyone

Shauna Bennett and Karen Eddleman

November 7, 2019
Sexual fact or fiction?

1. In one study, around 70% of girls 15 to 19 who had sex said they wish they had not.
   - True
   - False

2. Most teens think about the risk of getting pregnant.
   - True
   - False

3. You can't get pregnant having sex your first time. It's impossible.
   - True
   - False

4. You can't get pregnant having sex standing upright.
   - True
   - False

5. Three out of 10 teen girls in the United States get pregnant before they turn 20.
   - True
   - False

6. Most teens who become pregnant marry the father of their baby.
   - True
   - False
Today’s Goal

1. **What is federal contracting?**
   - Why does it exist?
   - What’s it like?

2. **What is our role as writers?**
   - Plain language practices
   - Section 508 compliance
Who are we?

*Karen Eddleman, BS, MT, Senior Science Writer*

- 15 years as federal contractor/science writer
- BS medical tech + Grad work in molecular bio
- 10 years in clinical and research labs
- 15 years as freelance science writer/editor
- Superpowers: covering meetings and translating scientific information into lay language
Who are we?

Shauna Bennett, PhD
Science Writer

• 2 years as federal contractor/science writer
• PhD cell and molecular bio
• 10 years academic research
• 2 years freelance technical writer/adjunct professor
• Superpowers: Interpreting scientific information and covering genetics
Working for a Federal Contractor
What is a government contractor?

- Contractors: a large part of government workforce

The U.S. government workforce

- Contractors
- Federal Employees

Federal government spends ~14% of the budget on private-sector contractors (CNN Money, 2012)

Data: Paul Light, New York University
What is a government contractor?

- Contractors are private companies that produce goods or services for government.
- Compared to private parties, contracts with federal government are well defined, with less freedom.

**Top contracting departments:**
1. Defense
2. Energy
3. Health and Human Services
4. Veterans Affairs
5. NASA

**Top 100 contractors (2015):**
1. Lockheed Martin
2. Boeing
29. CalTech
38. Merck
84. FedEx
Why contracting? The history

- U.S. government has used contractors since the beginning.
- During war, needs arise quickly. No time for approval process.
- Early 1800s: Many contracting practices came into being.
Why contracting? The need

• Structure of government (positions) is defined and difficult to change.
• Hiring full-time federal employees is a long-term commitment.

• Contractors can:
  • Be on the job faster
  • Be terminated more easily
  • Offer skills and expertise that fill the gaps
How does contracting work?

1. Agency puts out “request for proposals”
2. Companies submit proposals to bid
3. Government agency chooses which companies win or lose contract
4. Contracts about 3–5 years for our work

Contracts give government special rights, such as right to:
- Change contract terms
- Terminate contract
What is it like to be a contractor?

• Are working for a client
• Have a variety of work that can change each year
• Can work on one contract or many or be embedded at agency
• Can be affected by government funding
• Support research by writing internal documents and public-facing content
Doing government health communications

• What gap do we fill?
  • Full-service communications

• What do we provide?
  • Writing and editing
  • Content strategy
  • Digital strategy
  • Graphic design
  • Conference services
What do writers produce?

- Meeting reports
- Web content
- Evidence-based health content
- Social media posts
- Congressional justifications
- Exhibit displays
Communication and the Law

1. Plain Language Act
2. Section 508 Compliance
Plain Language Writing
Plain Language Definition

When the **wording, structure, and design** are so clear that the **intended audience** can easily:

- **Find what they need**
- **Understand what they find**
- **Use that information**

- International Plain Language Federation
History of Plain Language

- **1963**: Movement toward plain language legal writing
- **1972**: President Nixon decreed "Federal Register be written in layman's terms"
- **1978**: President Carter signed Executive Order for regulations to be "written in plain English"
- **1998**: President Clinton issued memorandum for plain language in government documents
- **2010**: President Obama signed Plain Writing Act
Plain Language Act of 2010 says:

Agencies must:

• Designate officials
• Train staff

Agencies must use plain language in documents related to:

• Benefit or service
• Filing taxes
• Complying with a requirement
Plain Language Considerations

1. Audience (and purpose)
2. Structure
3. Design
4. Expression (the words)
5. Evaluation
Plain Language: How-to

1. Audience (and purpose)
   • What do they want to know?
   • What do they need to know?
   • Education level? Profession? Skills?

Professionals? Families?
Plain Language: How-to

1. Audience (and purpose)

2. Structure

• Put main idea first.

• Use headings, topic sentences, and transitions.

• Chronological order? Chapters?
If you are taking drug products or therapies that contain certain non-glucose sugars, such as maltose, galactose, and xylose, these sugars will produce a falsely elevated glucose result if you are measuring your blood glucose using a GDH-PQQ test strip.
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Do you test your blood sugar with GDH-PQQ test strips?  
Do you take drugs or treatments that have maltose, galactose, or xylose?  
These are sugars, but are not the same as the blood sugar you test (glucose).  
If you answer “yes” to both questions, you could have a problem with your blood sugar test results.
Plain Language: How-to

1. Audience (and purpose)

2. Structure

3. Design
   - Layout: white space, tables
   - Typography: fonts, styles
   - Information graphics
Example: Structure and design

**Signs and Symptoms of High Blood Pressure**

High blood pressure usually has no warning signs or symptoms, so many people don't realize they have it. There's only one way to know whether you have high blood pressure: Have a doctor or other health professional measure it. Measuring your blood pressure is quick and painless.

**What Blood Pressure Numbers Mean**

Blood pressure is measured using two numbers. The first number, called **systolic** blood pressure, represents the pressure in your blood vessels when your heart beats. The second number, called **diastolic** blood pressure, represents the pressure in your blood vessels when your heart rests between beats. Blood pressure is measured in millimeters of mercury (mmHg).

The chart below shows normal, at-risk, and high blood pressure levels. A blood pressure less than 120/80 mmHg is normal. A blood pressure of 140/90 mmHg or more is too high. People with levels from 120/80 mmHg to 139/89 mmHg have a condition called prehypertension, which means they are at high risk for high blood pressure.

<table>
<thead>
<tr>
<th>Blood Pressure Levels</th>
<th></th>
</tr>
</thead>
</table>
| Normal                                    | systolic: less than 120 mmHg  
diastolic: less than 80 mmHg        |
| At risk (prehypertension)                 | systolic: 120–139 mmHg     
diastolic: 80–89 mmHg                |
| High                                      | systolic: 140 mmHg or higher  
diastolic: 90 mmHg or higher       |

☑️ Headings  
☑️ Table  
☑️ Image
Plain Language: How-to

1. Audience (and purpose)

2. Structure

3. Design

4. Expression
   
   • Everyday words—no jargon
   • Conversational tone—use pronouns.
   • Active voice
   • Short sentences
Example: Everyday words

Which sentence below would you prefer to read?

1. The myriad symptomatic permutations of the abovementioned disease exacerbate misdiagnosis potential.

2. This disease is often misdiagnosed because it has many symptoms.
Example: Active voice

Which is active voice?

1. The documents were shredded yesterday.

2. The documents were shredded yesterday by Dr. Smith.

3. Dr. Smith shredded the documents yesterday.
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Plain Language: How-to

1. Audience (and purpose)

2. Structure

3. Design

4. Expression

5. Evaluation
   - Check readability
   - Editing
   - User testing
Readability

Based on:

- Length of words (syllables)
- Length of sentences
- Number of sentences per paragraph

Formulas:

1. Flesch Reading Ease/ Flesch–Kincaid Grade level
2. Fry Readability Test
3. SMOG (Simplified Measure of Gobbledygook test)
4. Lexile® Framework for Reading
1. Flesch–Kincaid Grade level

→ in Microsoft Word!
*Under options for spelling and grammar, check box that says “Show readability statistics.”*

**Formula:**

\[ 0.39 \times \text{(words/sentences)} + 11.8 \times \text{(syllables/words)} - 15.59 \]
A prior study, also published in the Journal of the American College of Cardiology in 2019, showed that early conversion to a maintenance sirolimus-based immunosuppression regimen with complete withdrawal of calcineurin inhibitor therapy was associated with attenuation of cardiac allograft vasculopathy progression.
Migraine is a medical condition. A migraine headache is usually an intense, throbbing pain on one, or sometimes, both sides of the head. Migraine pain and symptoms affect 29.5 million Americans. About three out of four people who have migraines are women.
Use multiple readability formulas

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<table>
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<th>Test</th>
<th>Grade level</th>
<th>Reading ease</th>
</tr>
</thead>
<tbody>
<tr>
<td>SMOG</td>
<td>15.0</td>
<td></td>
</tr>
<tr>
<td>Flesch-Kincaid</td>
<td>16.2</td>
<td>35% (very easy to read)</td>
</tr>
<tr>
<td>Fry</td>
<td>college</td>
<td>very long sentences</td>
</tr>
<tr>
<td>Lexile**</td>
<td>Graduate school</td>
<td></td>
</tr>
</tbody>
</table>
Use multiple readability formulas

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<th>Test</th>
<th>Grade level</th>
<th>Reading ease</th>
</tr>
</thead>
<tbody>
<tr>
<td>SMOG</td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Flesch-Kincaid</td>
<td>4.5</td>
<td>84.6 (very easy to read)</td>
</tr>
<tr>
<td>Fry</td>
<td>6th (5th)</td>
<td></td>
</tr>
<tr>
<td>Lexile</td>
<td>5-6th Grade</td>
<td></td>
</tr>
</tbody>
</table>
Evaluation

1. Audience (and purpose)
2. Structure
3. Design
4. Expression
5. Evaluation

→ What about audience members who have vision impairment?
Accessibility and Section 508 Compliance
Section 508: It’s the right thing to do, and it’s the law.

- Section 508 of **29 U.S.C § 794 (d)** mandates that “agencies must give disabled employees and members of the public access to information comparable to the access available to others.”
- The law also specifies that disabled federal employees must have access to information and tools to be able to do their jobs.
- The law applies to all federal agencies.
Section 508 compliance

A Section 508–compliant document or Webpage allows people with low vision to use screen reader software.
Computer screen readers allow blind and visually impaired users to access content.

Probably the most used screen reader programs are:

- JAWS® (Job Access with Speech)
- NVDA (NonVisual Desktop Access)
The writer’s role in Section 508 compliance

• We have a team of Section 508 specialists at our company.
• The Section 508 staff “tag” elements in the document, and they write and insert descriptive alt-text for any photographs, charts, graphs, and figures.
• But, we writers can make the job of our Section 508 compliance staff a walk in the park or pure he**.
How writers can help with Section 508 compliance: Tagging text

Original document:

βCTX a marker of bone resorption, was evident at doses of 125 and 175 mg QD (125 mg achieves plasma levels of ~5 × IC50 at Cmin steady state)

How the screen reader interpreted the text:

Beta C-T-X; M-G; tilde 5 times I-C 50 at semen steady state

How I interpreted it for the screen reader tags:

Beta cross-laps; milligrams; about 5 times I-C 50 at C min steady state
How writers can help with Section 508 compliance: Formatting

• Stick with a few basic fonts in your documents.
• Always use standard hyperlink blue for hyperlinked text.
• Everybody loves a bulleted or numbered list, right? (Um, no.) Limit bullets.
• Use Word styles for your headings, respecting the hierarchy of headings in your document.
• Do not use color as the only means of conveying important information.
Qualitative Analysis of the Survey Data and Data from Electronic Health Records

Availability in public dataset or on the Internet

Very low risk

High risk

Other

Lifestyle

Demographics

Medical History

Family History
Qualitative Analysis of the Survey Data and Data from Electronic Health Records

Availability in public dataset or on the Internet

Very low risk

High risk
How writers can help with Section 508 compliance: Contrast checking

• Ensure that diagrams have sufficient levels of contrast for screenreaders.
• The minimum contrast ratio should be 4.5 to 1.
• Contrastchecker.com
How writers can help with Section 508 compliance: Alt-text

We can help create alt-text (alternative text) for photos and figures.

• Alt-text is a short description of an image that’s embedded in a document or Webpage.
• Keep Alt-text as short as possible. Don’t bother including wording such as “This is a photograph of...”
Suggest some alt-text for this image.
Now it’s your turn!

Study sites. The largest marker shows the location of the data center.
Study sites. The largest marker shows the location of the data center.
Enrollment Numbers

- **Participants**
- **Participants who have completed the initial steps of the program**
Take-Aways
Take-aways

• Federal contracting is an interesting career option.
  • Particularly if you live in DC!
  • Freelancers rarely contract directly.

• Writing for federal government requires plain language and Section 508 compliance.
  • Plain language writing makes it easier to understand.
  • Accessibility practices help get your message out to more of your audience.
A day in the life: Karen

- **Writing** Web content on hypercholesterolemia
- **Notetaking** for 1-hour Web conference
- **Emailing** about my availability and interest in writing some summaries of published papers
- **Writing** summary of 2-day meeting of an NIH advisory board
- **Emailing** back and forth with an editorial supervisor about style decisions for a report
A day in the life: Shauna

• **Writing** social media posts on heart disease prevention
• **Meeting** about gene therapy graphics
• **Reading** and reviewing literature on interstitial lung disease
• **Writing** plain language content on lung disease
• **Notetaking** for 1-hour teleconference, writing up summary
Thank you!

Questions or Comments?

List of resources will be available on the AMWA conference website

Thank you to our colleagues at Palladian Partners who helped us develop, review, and edit our presentation.