

# Readability of HIPAA Privacy Notices

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## Summary

Readability analyses of 31 HIPAA privacy notices (which are supposed to be written in plain language) found that they were actually written at a 2nd-3rd year college reading level. Patients will have a hard time understanding the notices because the writing style uses too many words per sentence, too many complicated sentences and too many complicated words. A one-page “Summary of HIPAA Privacy Practices” may help readers deal with the information overload created by the many elements required by HIPAA.

## How readable are HIPAA Privacy Notices?

I downloaded and analyzed 31 HIPAA privacy notices using several software programs including Prose, WStyle 1.6, Grammtik 6.0 and Reader 1.2. These programs calculated reading grade level, the Flesch Reading Ease Score, writing style, sentence and vocabulary complexity and word commonness.

Instead of being written in plain language as required by the HIPAA regulations, the 31 privacy notices average a 2nd-3rd year college (grade 14.5) reading level, rating them as “difficult” on the Flesch Reading Ease Score. Average readers will find these notices hard to understand, especially the elderly and those whose primary language is not English.

Recent Census data shows that about 85% of adults have a high school degree. About 25% have one or more college degrees. Despite these levels of educational attainment, literacy research shows that many people read three-to-five grades lower than their highest level of educational attainment. Thus, it's not unusual for someone with a high school diploma to be reading at a 7th to 9th grade reading level. Because of that gap, literacy experts recommend that materials written for the general public be at about a junior high reading level.

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## Readability Analysis Summary

The following table shows the results of my readability analyses of 31 HIPAA privacy notices. The policies are ranked from “best” to “worst” in terms of Flesch’s “Reading Ease.” Only one of the notices scored any better than “difficult,” since the scores ranged from 19 to 60. Rudolf Flesch calculated Reading Ease based on the following scoring system:

- 0 - 29 = Very Difficult
- 30 - 49 = Difficult
- 50 - 59 = Fairly Difficult
- 60 - 69 = Standard
- 70 - 79 = Fairly Easy
- 80 - 89 = Easy
- 90 - 100 = Very Easy

	<b>Flesch Reading Ease (60+ is best)</b>	<b>Reading Grade Level (8 is best)</b>	<b>Sentence Complexity (100 = most complex)</b>	<b>Vocabulary Complexity</b>	<b>Writing Style</b>
<b>Average--31 notices</b>	<b>39/Difficult</b>	<b>14.5</b>	<b>72</b>	<b>58</b>	<b>Weak</b>
*****					
1. Cimarron Health	60/Standard	10	46	42	Satisfactory
2. University Neuro- logical Associates	49/Difficult	13	73	46	Weak
3. Pediatrix Med Grp	48/Difficult	13	79	45	Satisfactory
4. Horizon Health	48/Difficult	13	83	42	Weak
5. Delta Dental	47/Difficult	13	67	50	Weak
6. Ark Regional Svc	44/Difficult	14	67	58	Weak
7. Arkansas Childrens’ Hosp	42/Difficult	14	63	59	Weak
8. York Neurosurg- ical Associates	43/Difficult	14	74	56	Poor
9. Memorial Sloan- Kettering Hosp	43/Difficult	14	84	49	Weak
10. Cook Children’s Health Care Syst	41/Difficult	14	68	56	Weak
11. Rural/Metro Corp	40/Difficult	15	76	47	Weak
2. Immanuel Luth- eran Corp.	39/Difficult	14	64	65	Poor
13. Hospice of the Valley	39/Difficult	14	73	50	Weak
14. Colon Rectal Surg Assoc	39/Difficult	14	68	64	Poor
	<b>Flesch Reading Ease (60+ is best)</b>	<b>Reading Grade Level (8 is best)</b>	<b>Sentence Complexity (100 = most complex)</b>	<b>Vocabulary Complexity</b>	<b>Writing Style</b>

15. UnumProvident	39/Difficult	15	78	56	Weak
16. W. Wash Univ Student Health	37/Difficult	15	69	58	Poor
17. MetLife Dental	36/Difficult	15	67	67	Poor
18. Dublin Hematol/ Oncology Care	36/Difficult	15	75	62	Weak
19. United Regional Hlth Care Syst	36/Difficult	15	72	66	Poor
20. Metlife Long Term Care	35/Difficult	15	70	66	Poor
21. Manchester Manor Health Care	35/Difficult	15	75	62	Weak
22. Metlife Medical Insurance	34/Difficult	15	68	66	Poor
23. TriCare	34/Difficult	15	74	57	Poor
24. Internal Medicine Associates	34/Difficult	15	66	57	Poor
25. Pocono Health System	34/Difficult	15	76	54	Poor
26. Mobile Medical Industries	34/Difficult	15	82	66	Poor
27. Medica	32/Difficult	15	61	73	Poor
28. Western Carolina Center	32/Difficult	16	77	62	Poor
29. Zeeba Surgery Center	30/Difficult	16	80	66	Poor
30. Intermountain Health Care	28/Very Difficult	16+	88	65	Poor
31. U Michigan Hlth Care System	19/Very Difficult	17	83	64	Poor

### Why elderly patients will have a hard time understanding HIPAA notices

Across all age groups, people 65 and older have the lowest literacy scores, with an average educational attainment between 11th and 12th grade. Seventy year-old patients (born in 1933) with an average 11th-12th grade education completed their education about 1951. The following table shows the educational attainment of the population across the age span based on March 2000 US Census Data.

Educational attainment (2000)	Total	Age					
		25-54	55-59	60-64	65-74	75-84	85+
Less than 9th grade	7%	4%	7%	10%	13%	19%	29%
9th - 12th grade (no diploma)	9%	7%	9%	12%	13%	15%	14%
High school graduate	33%	32%	35%	36%	37%	35%	30%
Some college/Associate degree	25%	28%	24%	21%	19%	18%	14%

Bachelor's degree	17%	20%	14%	12%	10%	9%	9%
Advanced degree	9%	9%	11%	9%	7%	5%	4%

## Some plain language criteria

### *Words per sentence: 24*

One plain language factor is the number of words per sentence. Research suggests that to be easily understood, documents should average about 15-20 words per sentence. When sentences get too long (over 40 words), readers may forget the beginning of the sentence by the time they get to the end. The 31 HIPAA privacy notices averaged 24.2 words per sentence, with a range from 19 to 33 words per sentence.

### *Concrete everyday words: Above average*

Word "commonness" was calculated by Reader 1.2 software, in which a normal score is 1,450. A lower score means that the notice has many common words, a higher score that the notice has many uncommon words. The average score for the 31 notices was 1,594 (above average), with a range of 866 to 3,398.

### *Sentence Complexity: 72/100*

Grammatik 6.0 measures "sentence complexity" based on the number of words and clauses in a document--with a maximum "very complex" score of 100. The 31 notices averaged a sentence complexity score of 72, with a range of 46 to 88.

### *Vocabulary Complexity: 58/100*

Grammatik 6.0 measures "vocabulary complexity" based on the number of syllables in a document and a comparison to a word list of unusual or difficult words--with a maximum "very complex" score of 100. These 31 privacy notices averaged a vocabulary complexity score of 58, with a range of 42 to 73.

### *Writing Style: Weak*

WStyle writing analysis program listed 2 notices as "satisfactory," 13 as "weak," and 16 as "poor."

### *A document design problem*

Our health plan sent us a "Member Privacy Notice." It's 3 1/2 pages long (single-spaced), but does not have any page numbers. The notice refers to the health plan simply as "Provider" (not "the Provider") so there are sentences such as:

- What types of personal information does Provider collect?
- When you enroll or renew with Provider, the consent provided on your enrollment application
  - allows Provider and its business associates to collect, maintain, use and share your personal; information to provide service to members, manage our business, or conduct related activities.
- With whom does Provider share information?

How many people will read this and think that they're members of the "Provider health plan?"

Plus, the notice includes a "Medical authorization letter" that's written at about a 3rd year college reading level. Neither the "Member Privacy Notice" nor the "Medical Authorization Letter" came with any type of introductory letter or explanation; indeed, there was no logo and no corporate letterhead on either document. One section should have been placed elsewhere in the Notice; additional grammatical

errors suggest that the documents were not written or proofread very carefully. Or maybe they bought a generic HIPAA privacy notice and neglected to replace the generic “Provider” with the name of the health plan.

### Comparing HIPAA privacy notices to other privacy notices

In 2001, I analyzed 60 financial privacy notices that were distributed to consumers as a requirement of the Gramm-Leach-Bliley (GLB) Act. The HIPAA notices are written only slightly better than the GLB notices.

	<b>31 HIPAA Notices</b>	<b>60 GLB Notices</b>
Flesch Reading Ease	Difficult/39	Difficult/34
Reading Grade Level	14.5	15.6
Sentence Complexity	72	70
Vocabulary Complexity	58	62
Writing Style	Weak	Poor

*What rights do patients have if they don't understand their rights?*

HIPAA privacy notices may be given to patients along with other written materials. For example, in Minnesota, patients are given a 10-page, 4,221 words “Minnesota Patient Bill of Rights” booklet that describes patient rights under Minnesota and federal law. However, this booklet is not well written, making it difficult (if not impossible) for most patients to understand. And will patients take the time to read three documents totaling 6,500 words describing their patient “rights?”

### Readability of Minnesota patient documents

	<b>Bill of Rights</b>	<b>Rights Under Federal Law</b>	<b>Average HIPAA Notice</b>
Length	2,752 words	1,469 words	2,269 words
Flesch Reading Ease	15/Very Difficult	31/Difficult	39/Difficult
Reading Grade Level	Graduate School	4th-Year college	2nd-3rd year college
Writing Style	Poor	Poor	Weak
Sentence Complexity	84	83	72
Vocabulary Complexity	66	54	58

Re-writing such documents in plain English may be almost impossible. A patient representative at a Minneapolis hospital told me that the Minnesota Association of Patient Representatives tried to have the patient “Bill of Rights” written in more understandable language. Because that had to be done through the legislative process, they were told that patient representatives could not provide a more understandable document without also providing the original as written by the legislature. The Association could not get help to re-write it in a way that would assure accuracy--as determined by the legislature. Even if they could, that might mean giving patient an original version and a revised version. If both Minnesota and federal laws were re-written, would patients read all four documents? If HIPAA Notices were re-written, would patients read all six documents?

### When less information = more understanding

Legislators, policy makers, and writers believe that HIPAA Notices written in plain language will be easier to understand than if written in legal and bureaucratic language. But that may not be true. Plain English may help readers understand fairly short, non-technical documents, but the HIPAA privacy regulations are very complex. Communication problems may have less to do with plain language than

with information overload. There are so many required elements in HIPAA that writing the Notice in plain language won't help comprehension much, since readers still have to understand all of the required elements. The amount of information may be more important than the grade level at which it's written.

One way to increase understanding is to use a "layered" approach, which includes a one-page HIPAA summary and the longer HIPAA privacy notice. Here's an example of what a HIPAA Privacy Notice Summary might look like.

### **Summary Notice of HIPAA Privacy Practices**

**THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.**

#### **SUMMARY OF YOUR PRIVACY RIGHTS**

##### **We may use and give out your health information to:**

- treat you
- get paid
- run the hospital
- tell you about other health benefits & services
- raise funds
- include you in the hospital directory
- tell family and friends about you
- do research

##### **We may use and give out your health information for:**

- health and safety reasons
- organ and tissue donation requests
- military purposes
- worker's compensation requests
- lawsuits
- law enforcement requests
- national security reasons
- coroner, medical examiner or funeral director use

##### **You have the right to:**

- get a copy of your medical record
- change your medical record if you think it's wrong
- get a list of whom we share your health information with
- ask us to limit the information we share
- ask for a copy of our privacy notice
- write a letter of complaint to the hospital if you believe your privacy rights have been violated

### **Examples of complicated language from 31 HIPAA Privacy Notices**

"Examples of these activities include obtaining accreditation from independent organizations like the Joint Commission for the Accreditation of Healthcare Organizations, the National Committee for Quality Assurance and others, outcomes evaluation and development of clinical guidelines, operation of preventive health, early detection and disease management programs, case management and care coordination, contacting of health care providers and patients with information about treatment alternatives, and related functions; evaluations of health care providers (credentialing and peer review activities) and health plans; operation of educational programs; underwriting, premium rating and other activities relating to the creation, renewal or replacement of health benefits contracts; obtaining

reinsurance, stop-loss and excess loss insurance; conducting or arranging for medical review, legal services, and auditing functions, including fraud and abuse detection and compliance programs; business planning and development; and business management and general administrative activities, including data and information systems management, customer service, resolution of internal grievances, and sales, mergers, transfers, or consolidations with other providers or health plans or prospective providers or health plans.” (169 words)

“At [XYZ] we may use or disclose Protected Health Information for purposes of treatment, obtaining payment, and our health care operations without Your Consent or Your Authorization under the following three circumstances; (1) when you require emergency treatment; (2) when we are required by law to treat you and we attempt to obtain Your Consent, but are unable to obtain it and (3) when we attempt to obtain Your Consent but are unable to obtain it due to substantial barriers to communicating with you (e.g., you are unconscious or otherwise incapacitated) and we reasonably infer that you would have consented in the absence of the barriers.” (106 words)

“Your health information may be used for research purposes, but only if (1) the privacy aspects of the research have been reviewed and approved by a special Privacy Board or Institutional Review Board and the Board can legally waive patient authorizations otherwise required by the Privacy Regulations; (2) the researcher is collecting information for a research proposal; (3) the research occurs after your death; or (4) if you give written authorization for the use or disclosure.” (76 words)

“This will occur to the extent the disclosure is (a) required by law (b) agreed to by you or your personal representative or, (c) authorized by law and we believe the disclosure is necessary to prevent serious harm to you or to other potential victims, or, if you are incapacitated and certain other conditions are met, a law enforcement or other public official represents that immediate enforcement activity depends on the disclosure.” (69 words)

“This right applies to disclosures made by us except for disclosures to carry out treatment, payment, or health care operations as described in this Notice or incidental to such use to you or your personal representatives pursuant to your authorization for our directory, or other notification purposes, or to persons involved in your care or for certain other disclosures we are permitted to make without your authorization.” (67 words)

“An accounting of disclosures does not describe the ways that your health information has been shared within and between the hospital and the facilities listed at the beginning of this notice, as long as all other protections described in this Notice of Privacy Practices have been followed (such as obtaining the required approvals before sharing your health information with our doctors for research purposes).” (64 words)

“If you do not object to these disclosures or we can infer from the circumstances that you do not object or we determine, in the exercise of our professional judgment, that it is in your best interest for us to make disclosure of information that is directly relevant to the person's involvement with your care, we may disclose your protected health information as described.” (64 words)

“Before we use or disclose medical information for research, the project will have been approved through this research approval process, but we may, however, disclose medical information about you to people preparing to conduct a research project, for example, to help them look for patients with specific medical needs, so long as the medical information they review does not leave the hospital. “ (62 words)

“We will mail you a list of disclosures in paper form within 30 days of your request, or notify you if we are unable to supply the list within that time period and by what date we can supply the list, but this date will not be exceed a total of 60 days from the date you made the request.” (60 words)

“You may request in writing that Provider give you an accounting of the entities to whom your personal information was discloses in the past two years, and for the past six years if the disclosure was not for treatment, payment, health care operations, authorized by your signature, or other situations as required by law.” (54 words)

“If you choose to sign an authorization to disclose your PHI, you can later revoke that authorization in writing to stop any future uses and disclosures (but only to the extent that we haven't already taken any action relying on the authorization).” (42 words)

“We are permitted to use PHI without your written authorization, or opportunity to object, in certain situations, and unless prohibited by a more stringent state law, including:...(27 words)