Patient information leaflets (PILs) currently require graduate level literacy levels: equivalent to The Guardian or The Telegraph newspapers



Simon Collins [1], Matt Williams [2], Liam Martin [1], Robin Jakob [1] Marta Boffito [3]

1. HIV i-Base; 2. UK-CAB; 3. Chelsea & Westminster Hospital

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Informed consent

- Informed consent (IC) as an ethical concept is a cornerstone of medical research.
- Patient Information and consent forms are part of the IC process.
 - What the study is for.
 - What is involved and expected.
 - Possible risks and benefits.
 - That taking part is voluntary.
- i-Base talks with individuals about joining studies and works with research groups.

Readability scores

- Recommended in NHS guidelines. [1]
- How difficult is text to read?
- What percentage of people will easily understand or be excluded.
- Usually include average word, sentence and paragraph length.

 Readability increased with shorter words, sentences (10-12 words), using the active tense, and common words.

1. NHS. Information Sheets & Consent Forms. Guidance for Researchers and Reviewers. March 2011, Annex 9. http://www.hra.nhs.uk

Methods

- Evaluate the body text of patient information leaflets from 9 ongoing studies: phase I-IV.
- Text was copied from PDF files into MS Word. Minor edits to help scores. Punctuation added after headings and in bullet lists. Tables were excluded.
- Primary outcome was Reading Ease. Scores calculated online. ^[1] Results compiled in Excel.
- Two community-written patient leaflets were used as comparisons.

1. www.readabilityscore.com and www.read-able.com

Choice of scores

- Flesch reading ease (Plain English)^[1]
 Target: >70 for general public; higher score is better
 Practical range 0 100 (but can be <0 and >100)
- Flesch-Kincaid reading grade ^[1]
 Adapted for US school grade: lower is better,
 Target: grade <8 = reading age 13-14; grade >12 = graduate
 Microsoft Word caps highest grade at 12.
- SMOG grade score ^[2]

May have advantages for health information. Stricter criteria for higher comprehension. Used for cancer patients in US.^[3]

1. Wikipediia: Flesch–Kincaid readability tests; 2. Wikipediia: SMOG index 3. Friedma DB, Health Educ Behav. (2006).

Reading scores

Equations are objective estimates.

Flesch reading ease score ^[1]

$$206.835 - 1.015 \left(\frac{\text{total words}}{\text{total sentences}}\right) + 84.6 \left(\frac{\text{total syllables}}{\text{total words}}\right)$$

Flesch-Kincaid reading grade ^[1]

$$0.39\left(\frac{\text{total words}}{\text{total sentences}}\right) + 11.8\left(\frac{\text{total syllables}}{\text{total words}}\right) - 15.59$$

SMOG index ^[2]

grade =
$$1.0430\sqrt{\text{number of polysyllables} \times \frac{30}{\text{number of sentences}} + 3.1291$$

1. Wikipediia: Flesch-Kincaid readability tests; 2. Wikipediia: SMOG index.

Target literacy

Reading ease score 80-90: similar to tabloids.^[1]

| | Score | % of pop |
|-------------------|-------|----------|
| Easy tabloids | 95 | 70-80% |
| Standard magazine | 80 | 50-60% |
| Broadsheet | 77 | 30-50% |
| Academic | 31 | <30% |

UK literacy ^[2] Level 2 - 57% or higher - GSCE grade A-C Level 1 - 27% - GSCE grade D-E Below Level 1 - 16% - reading age 11

1. NHS. Information Sheets & Consent Forms. Guidance for Researchers and Reviewers. March 2011.

2. Department for Business, Innovation and Skills. Skills for Life Survey (2011)

Let's make the unreadable readable

Online scores

| Test by URI | Test by Direct Input | Test by Referer | |
|--|--|---|------------------------|
| Test by Dir | ect Input | | |
| Enter text to check | k the readability: | | |
| age of foolishness season of Light, it winter of despair, going direct to Hea so far like the pres | a, it was the epoch of belief, it w was the season of Darkness, it we had everything before us, we aven, we were all going direct the | a, it was the age of wisdom, it was was the epoch of incredulity, it was t was the spring of hope, it was the e had nothing before us, we were a ne other way – in short, the period siest authorities insisted on its be egree of comparison only. | the e all was |
| HTML is allowed - | it will be stripped from the text. | | |
| Calculate Reada | hility | | |

Free service, unlimited text, instant results.

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Let's make the unreadable readable

Online scores

Test by URI Test by Direct Test by Direct Input Enter text to check the readability: It was the best of times, it was the wors age of foolishness, it was the epoch of b season of Light, it was the season of Da winter of despair, we had everything before going direct to Heaven, we were all going so far like the present period, that some

Text statistics

| No. of sentences | 1 |
|------------------------|-------|
| No. of words | 120 |
| No. of complex words | 10 |
| % of complex words | 8.33% |
| Av. words per sentence | 120 |
| Av. syllables per word | 1.4 |

received, for good or for evil, in the superlative degree of comparison only.

HTML is allowed - it will be stripped from the text.

Calculate Readability

Statistics are provided in addition to calculations

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Let's make the unreadable readable

Online scores

Readability Indices

| Flesch Kincaid Reading Ease | -34.8 | |
|-----------------------------|-------|--|
| Flesch Kincaid Grade Level | 47.9 | |
| Gunning Fog Score | 51.3 | |
| SMOG Index | 18.2 | |
| Coleman Liau Index | 7.5 | |
| Automated Readability Index | 57.2 | |

Let's make the unreadable readable

Online scores

| Readability Indices | |
|---|--|
| Flesch Kincaid Reading Ease -34.8 | |
| Fleso Guni Readability Test Results SMO | |
| Cole Auto Ooh, that's probably a bit too complicated. Have you thought about using smaller words a sentences? | |

A Tale of Two Cities (110 words). Reading ease: -34 Reading grade: 47

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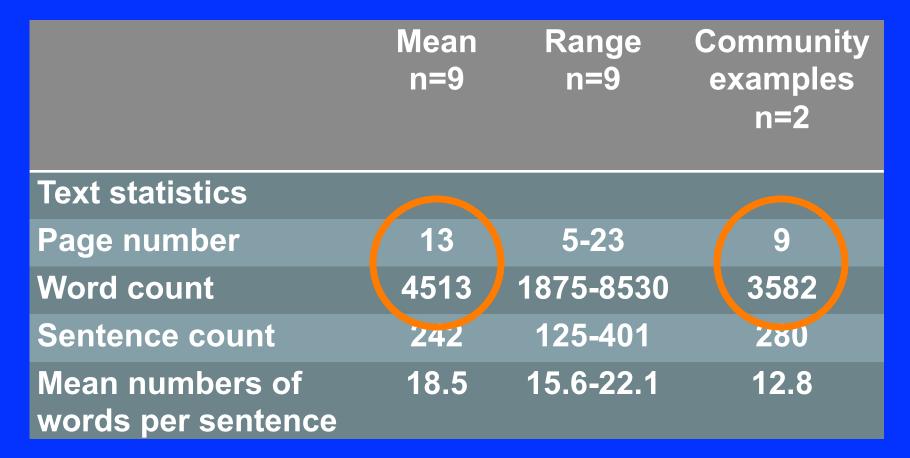
| | Mean n=9 | Range n=9 | Community examples n=2 |
|------------------------------------|-------------|--------------|------------------------------|
| Text statistics | | | |
| Page number | 13 | 5-23 | 9 |
| Word count | 4513 | 1875-8530 | 3582 |
| Sentence count | 242 | 125-401 | 280 |
| Mean numbers of words per sentence | 18.5 | 15.6-22.1 | 12.8 |

Community examples matched for complexity. Document length is a literacy factor (START substudy)

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Results: readability scores

| | Mean scores n=9 | Range of mean scores n=9 | Community examples n=2 |
|---------------------------------|-----------------------|--------------------------------|------------------------------|
| Readability scores | 5 | | |
| Flesch Reading Ease | 55.4 | 47.1-63.1 | 70.3 |
| Flesch-Kincaid Reading Grade | 10.1 | 9.0-12.0 | 6.6 |
| SMOG index | 9.2 | 7.9-10.4 | 6.9 |

Community examples show targets are achievable.

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Limitations and discussion

- Small number of protocols.
- Other factors of readability were not assessed:
 i.e. text content and layout (font size, use of space and headings).
- However, text heavy layouts and results probably underestimated true readability scores.
- Patient leaflets are not used in isolation. Talking through a study is essential – but readability enables independent engagement.

Advantages of readability

- Increase the pool of potential participants.
- Engage people in research.
- Reduce the chance that people leave the study later.
- More likely to enable real informed consent.

Conclusion

- This small study showed that literacy levels are commonly too high for most HIV positive people to be actively included in research.
- Given the care, detail and costs involved in HIV studies, similar attention is needed for patient information. It should not be an afterthought.
- This is neither a recent or UK-specific issue.*
- These skills are easy to learn and the tools are easy to use.

* See: Grossman SA et al. Jour Oncology (1994); Sugarman J et al. Hastings Centre Report (1999); Paasche-Orlow et al. NEJM (2003) etc.

Readability in Microsoft Word

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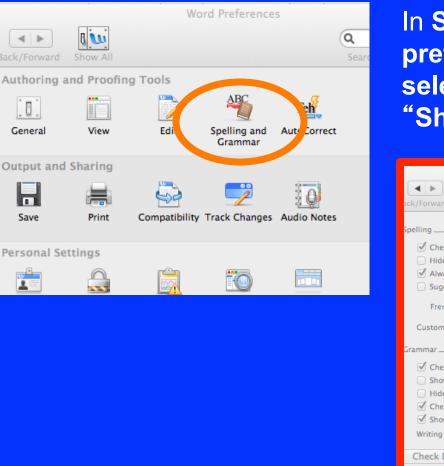
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Readability in Microsoft Word



In Spelling and Grammar preferences, check the box to select: "Show readability statistics"

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| French Modes: Traditional and new spellin Custom dictionary: Custom Dictionary | gs ÷ | |
| Grammar | | |
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| Check Document | | |

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Readability in Microsoft Word

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| Spelling and Grammar |
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| French Modes: Traditional and new spellings + |
| Grammar |
| Check grammar as you type |
| Hide grammatical errors in this incument ✓ Check grammar with spelling ✓ Show readability statistics Writing style: Standard error Settings |
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Readability in MS Word

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|---|---|----------|---|
| 1/2 1 | Word Count AutoSummarize AutoCorrect Track Channes IOad faster than other n • Adherence. Drugs can only take your meds on time quickly. Viral load should drop by at This is sometime referred to not, your doctor will ask you other tests. If viral load is still detectable change treatment. | Averages | 148 691 9 15 1.9 9.1 4.5 6% 77.1 4.7 |

Thank you

HIV positive people who contacted i-Base. Researchers who collaborated with patient leaflets. Marta Boffito, Matt Williams, Liam Martin, Robin Jakobs

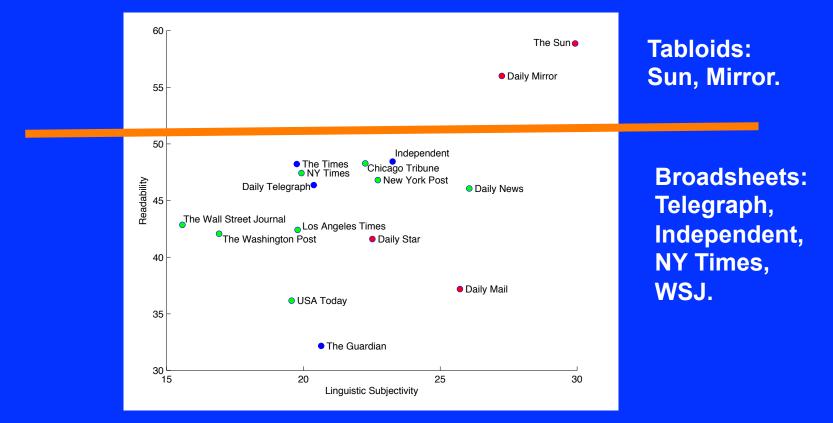
Further information i-base.info/guides/about www.plainenglish.co.uk www.hra.nhs.uk

Additional slides

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Newspaper readability

Comparison of selection of US and UK journals based on writing style (Flesch reading ease and subjectivity).



Cristianini N et al. Digital Journalism 1(1)102-116 (2012) 10.1080/21670811.2012.714928.

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UK adult literacy & numeracy

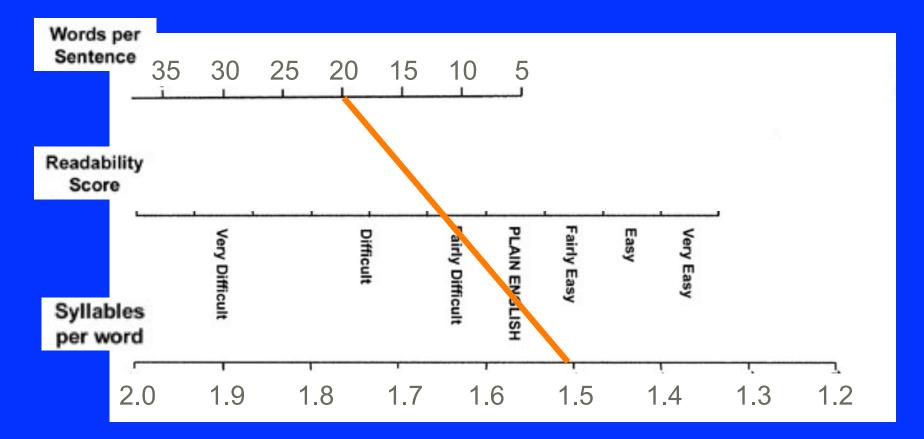
| | Literacy | Numeracy | Comment |
|------------------------|----------|----------|---------------------------|
| Level 2 or higher | 57% | 22% | GCSE A-C |
| Level 1 | 28% | 29% | GCSE D-E |
| Below level 1 | 15% | 49% | "functionally illiterate" |
| Entry level 3 | 8% | 25% | Reading age 9-11 |
| Entry level 2 | 2% | 17% | Reading age 7-9 |
| Entry level 1 or lower | 5% | 7% | Reading age 5-7 |
| | | | |

Based on representative sample of > 7000 adults (16-65 years old). Not all participants included in all modules.

Department for Business, Innovation and Skills. Skills for Life Survey (2011). Tables 4.1 and 4.4 https://www.gov.uk/government/publications/skills-for-life-survey-2011-important-findings

Flesch reading ease

The intersection of the line joining average words per sentence to average syllables per word show the readability score. The minimum score for Plain English is 60.



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Green eggs and ham

Do you like green eggs and ham?

I do not like them, Sam-I-am. I do not like green eggs and ham!

Would you like them here or there?

I would not like them here or there. I would not like them anywhere.

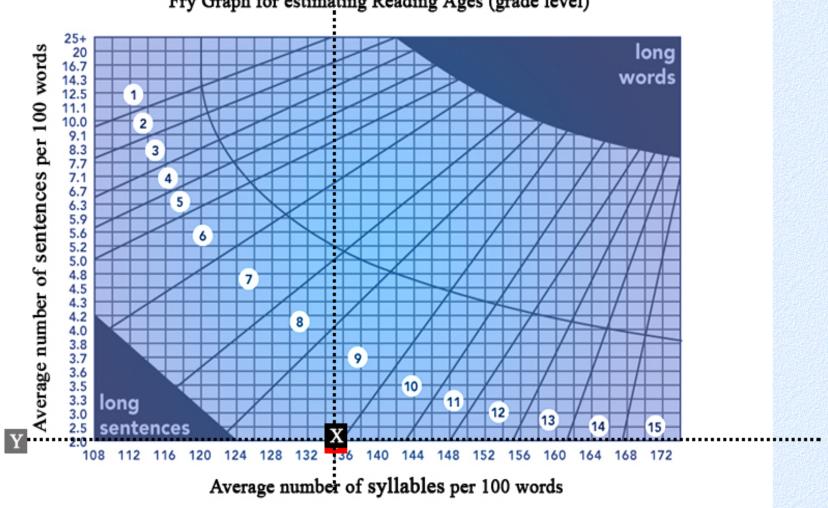
I do so like green eggs and ham! Thank you! Thank you, Sam-I-am!

FK reading ease: +112; Reading grade: -0.8

A tale of two cities

It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to Heaven, we were all going direct the other way – in short, the period was so far like the present period, that some of its noisiest authorities insisted on its being received, for good or for evil, in the superlative degree of comparison only.

The opening sentence of A Tale of Two Cities has 110 words. It has a reading ease: -34 and reading grade: 47



Fry Graph for estimating Reading Ages (grade level)

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