

How to develop good content and patient materials – print, online, and video or “Seeing through the SMOG”

SmartStart 2019, Session 0104, 13:00-14:00 hours
Frankfurt, Saturday 6 July 2019

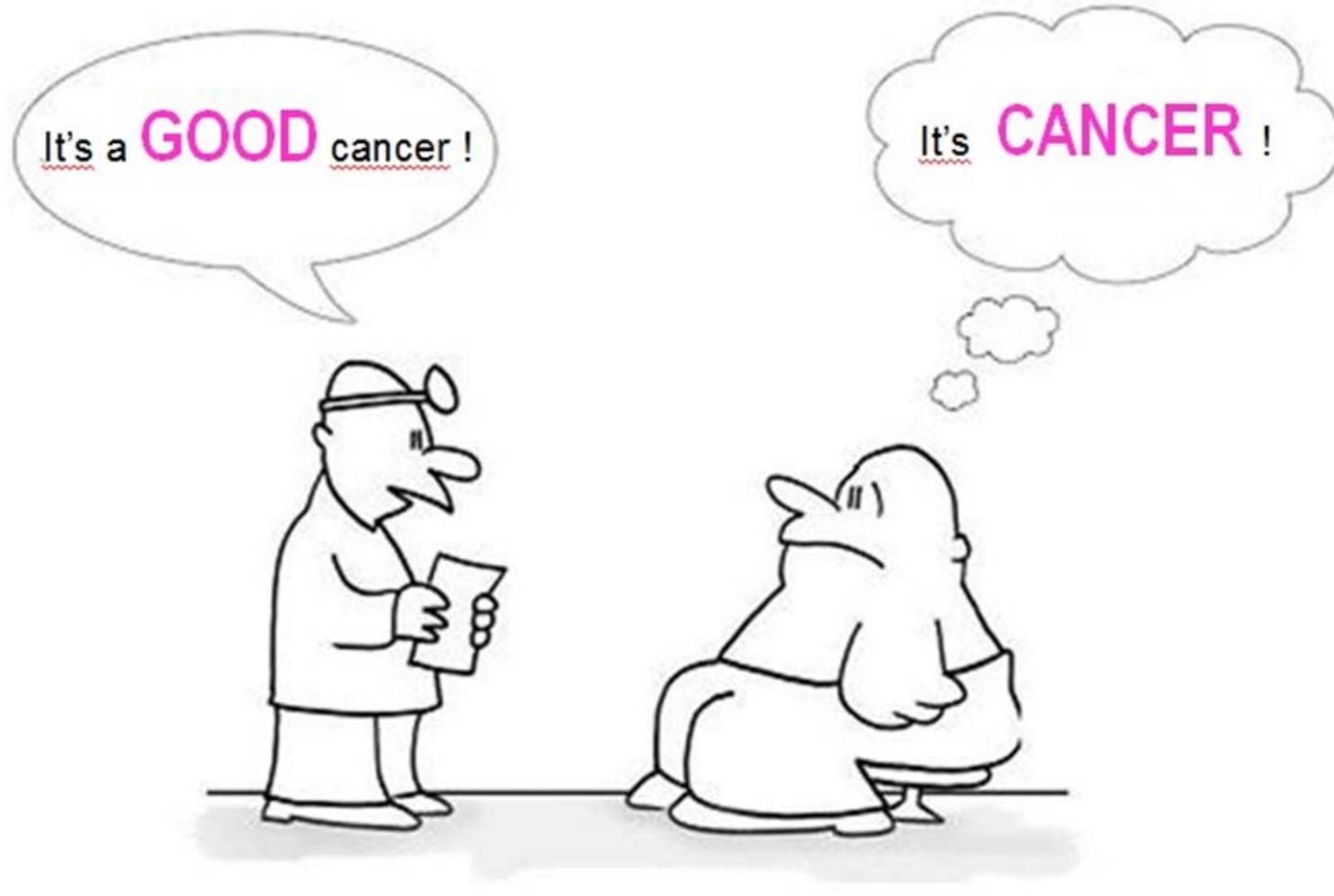
Judith Taylor

Thyroid Cancer Alliance, The Netherlands and The Thyroid Trust, UK

Writing/editing experience

- Former Acquisitions Editor/Publishing Director, Elsevier Science, Amsterdam (1974-2008)
- Volunteer writer/editor web and print patient materials (newsletters, case studies, patient leaflets), for
 - **British Thyroid Foundation** (BTF) (2005-2015)
 - **Hypopara UK** (2009-2016), and
 - **Thyroid Cancer Alliance** (2011-)
- Freelance science-to-public writer, 2012 → present
- Patient representative and co-author, British Thyroid Association (BTA) Thyroid Cancer Guidelines (3rd revised edition 2014) and Editor, BTA patient information (2014)
- Occasional reviewer for Macmillan Cancer Support
- Patient reviewer, *British Medical Journal*
- Patient representative and author patient information tools, ElaTION trial

Drawing courtesy of Beate Bartes (Vivre Sans Thyroïde)



WHAT do we want to know and WHY?

Jenkins (Royal Free Hospital, London, UK)* surveyed over 2,000 cancer patients in a multi-centre study in 1999-2000 and found:

- 98 percent preferred to know whether or not their illness was cancer
- 87 percent wanted all possible information, both good and bad news
- the vast majority of patients with cancer want a great deal of specific information concerning their illness and treatment

“Failure to disclose such information on the grounds that significant numbers of patients prefer not to know is untenable.”

*V. Jenkins, L. Fallowfield, J. Soul Information needs of patients with cancer: results from a large study in UK cancer centres *British Journal of Cancer*, 84 (2001)

Accessibility of thyroid cancer information

- **Banach et al (Thyroid Cancer Alliance)** surveyed 2,398 thyroid cancer patients worldwide in 2010 about their patient experience and found **63 percent received no clear written disease/treatment information**, and 84 percent were not referred to a patient organization*.
- **Vivre Sans Thyroïde** surveyed 1,142 patients in France about their quality of life (QoL) after thyroidectomy in Spring, 2015. Only 63 percent of the patients said they received sufficient information, which contributed efficiently to the decision-taking process about surgery; **35 percent felt they did not receive sufficient information**.
- **AECAT - The Spanish association for patients with thyroid cancer** - conducted a survey of 360 thyroid cancer patients in 2015. Nearly 60 percent were dissatisfied with the information they received through the healthcare system and **81 percent said they needed more detailed written information**, including reliable information on the internet.

*Banach et al for the Thyroid Cancer Alliance. Results of the Thyroid Cancer Alliance international patient/survivor survey: Psychosocial/informational support needs, treatment side effects and international differences in care. *Hormones*, 12 (2013)

WHY do we want to know?

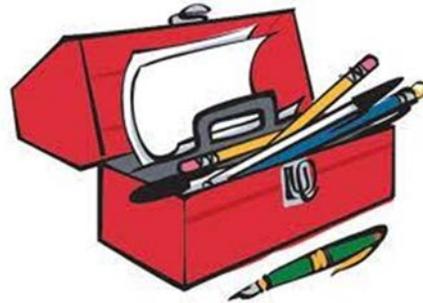
- An informed patient is better placed to **make decisions** about their care and wellbeing and **manage changes** in their health status.*
- Information gives people the **power** and **confidence** to become partners in their care.*
- It helps them to regain a sense of **control** over their lives and can reduce the fear and loneliness that the diagnosis of a life-threatening or long-term condition can bring.*

What other reasons can you think of?

*Derived from a National Health Service England website for Information Prescriptions.

The patient information toolkit

- Developing a template
- Best practice and characteristics of (a) print/online and (b) video content
- Testing the reliability and readability of patient information
- Accreditation of patient information materials
- The six pillars of content production quality
- Tips for managing layout
- Tips for managing text
- Tips for making a good video
- SMOG and other readability tools
- Further reading



Breakout #1 – WHAT do we want to know?

Working in groups, compile a **question-led** template for a patient information leaflet

<h3>Breakout group 1A</h3>	<h3>Breakout group 1B</h3>
<p>What questions would you ask if you or a family member/friend has just been given a cancer diagnosis?</p> <p>What other templates could you use?</p>	<p>What (additional) questions would you ask if you or a family member/friend has been diagnosed with advanced/metastatic cancer?</p> <p>What other templates could you use?</p>

Solutions - some questions to use in a question-led template – using mesothelioma as an example

- What is mesothelioma?
- What causes mesothelioma?
- What are the symptoms of mesothelioma?
- What are the tests for mesothelioma?
- What is the treatment for mesothelioma?
 - Surgery
 - Radiotherapy
 - Chemotherapy
 - Other
- Will I have to take medicine? What are the side effects?
- What is the outlook for mesothelioma?
- Does mesothelioma run in families?
- Where can I find a support group for people with mesothelioma and their families?
- Is there a clinical trial for mesothelioma?

Solutions – other types of content

- FAQs
- Patient stories
- Celebrity stories
- Conference highlights
- Booklets
- Drug information leaflets
- Videos: about <name of cancer>
- Video patient stories
- Video interviews with experts
- “Easy to Read” versions

Breakout #2 – Best practice and characteristics of patient information



Breakout group 2A	Breakout group 2B	Breakout 2C	Breakout group 2D
What is the process for producing good written content?	What are the ideal characteristics of good written content?	What is the process for producing good video content?	What are the ideal characteristics of good video content?
Does your PO need to produce printed content and if so, why?	How do you source writers, designers, printers? Do you have these skills in your PO?	What can video content add to a patient's understanding?	How do you source film makers and film editors? Do you have these skills in your PO?

Can we trust it? Building a reputation for reliable material



National Health Service UK Information Standard is a “Kite Mark” for accrediting POs in the UK as responsible producers of patient information. The IS is closing down this year but some of its workshop materials are still available on line - <https://www.england.nhs.uk/tis/about/the-info-standard/>

British Medical Association annual patient information awards are given each year to new patient information materials, including leaflets, booklets, websites, and videos. The list of highly commended materials (over 100 in 2018) is itself a helpful resource for POs seeking ideas and inspiration. <https://www.bma.org.uk/library/patient-information-awards>

Health on the Net Foundation Code of Conduct (HONcode) is an accreditation system for medical and health web sites <https://www.hon.ch/HONcode/>

Can you think of other ways to get your information endorsed?

Six pillars of content production quality

Derived from the National Health Service England "Information Standard"

#1 Information production

- Does your PO have a defined process for producing information?
- What does this process consist of?
- Do all individuals concerned have the necessary training/skills?
- Do you have the budget?

#2 Evidence sources

- Is your content relevant and from recognised peer-reviewed sources?
- Can you provide copies of these sources if you are asked?
- Is it reviewed by relevant professionals?
- Is it endorsed by relevant professional organisations?

#3 User involvement

- Do you ensure, through user testing, that it reflects the needs of those using it?
- Do you involve users throughout the process?
- Do you check for readability and avoid jargon?

Six pillars of content production quality

#4 End product

- Do you have a quality control process in place?
- Does an authorized approver check that the process has been followed?
- Does your product include the date of publication, review date, references to the sources used, and contact details?

#5 Feedback

- Do you encourage people to give ongoing feedback and act on this after it has been published?

#6 Review

- Do you review your information products regularly?
- Do you review them within a timeframe appropriate to the type of information (not normally more than every three years?)

Tips for managing layout

Adapted from The Information Standard Workshop Handout: Understanding Health Literacy (10 October 2013)

	Harder to read	Easier to read
Text density	High	Lots of white space, short chunks of text, short paragraphs, spaces between chunks of text
Line spacing	Single spacing	1.5 or greater
Font	Gothic, Italic, size less than 12	Distinct, clear e.g. Calibri, Arial, Helvetica. Size 12-14
Headings	CAPITALS	Upper and lower case
Highlighting	CAPITALS	Bold or boxed, bullet points
Layout	Sentences running over pages, no page numbering	Headings, new sections etc. at top of pages. Sentences not running over pages. Pages numbered
Illustrations	Separated from relevant text, used as background	Next to relevant text, at end of paragraphs.

Some examples of patient materials from the British Thyroid Foundation



BTF News
The newsletter of the British Thyroid Foundation
1 issue 1st October 2017

Thyroid Cancer For Patients - By Patients
Third Revised Edition

Living Positively

BMA
Patient information awards
Highly commended

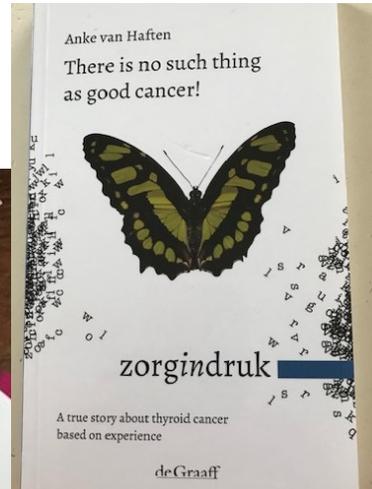
Thyroid Foundation
Thyroid disorders affect one in twenty people in the UK. Could you be one of them?

Tips for managing text

Adapted from The Information Standard Workshop Handout: Understanding Health Literacy (10 October 2013)

	Harder to read	Easier to read
Sentence length	Long sentences	Short sentences and “bullet points”
Word length	Words more than 3 syllables	Words less than 3 syllables
Medical terms, jargon	Not defined	Define first or include a “glossary”
Abbreviations	Lots of abbreviations	Define first or preferably include a definitions “box”
Numbers	1,2,3, 100, 1,000,000, 365,351 etc.	One through ten, twenty, one hundred, one million, round numbers “more than”, “nearly”, etc
Units	%, ml, cm, etc.	Percent, milliliter, centimeter etc.
“Voice”	Passive voice	Active voice

Some examples of patient information materials produced and/or distributed by the Thyroid Cancer Alliance

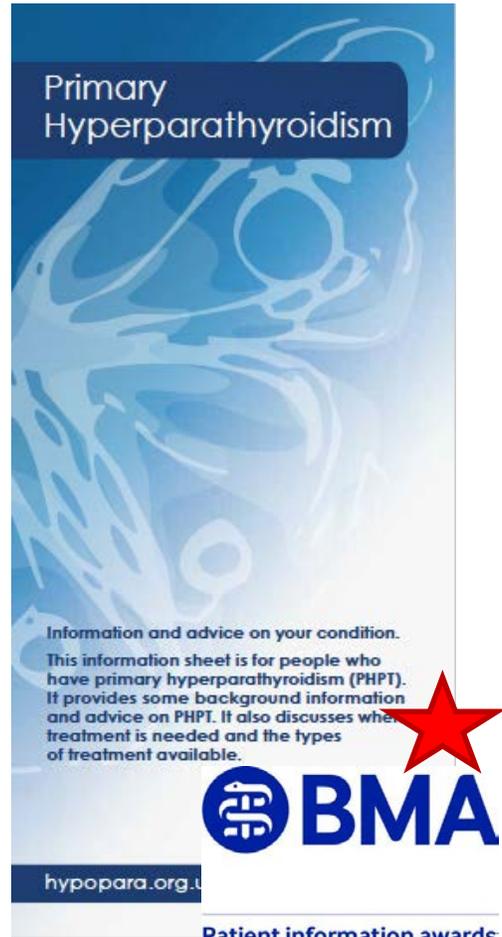


Some examples of patient materials from Hypopara UK



Hypoparathyroidism

hypopara.org.uk



Primary Hyperparathyroidism

Information and advice on your condition. This information sheet is for people who have primary hyperparathyroidism (PHPT). It provides some background information and advice on PHPT. It also discusses when treatment is needed and the types of treatment available.

BMA

hypopara.org.uk

Patient information awards
Highly commended



HYPOPARA UK NEWS
Issue number 12, Winter 2016

HYPOPARA UK NEWS
Issue number 11, Spring 2016

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Liz is Britain's Best Volunteer!

We're thrilled to announce that Chief Executive **Liz Glenister**, who is the founder of Hypopara UK, has been named the winner of Britain's Best Volunteer award. Liz faced stiff competition from hundreds of nominations for volunteers across Britain and reached the final alongside four other remarkable charity workers.

The finalists were selected by award judges **Judith Miller**, Trustee of Small Charities Coalition, **Andy Partington**, the Director of Market UK and **Vicky Browning**, Director of CharityComms.

Liz was named the winner following a public vote and was presented with a cheque for £1,250 for Hypopara UK, as well as £1,000 in holiday vouchers for her own personal use.

On finding out she had won the award, Liz said: "I'm absolutely thrilled to have won this award which I see as a fantastic opportunity to raise awareness about the rare condition, hypoparathyroidism, and our small but far-reaching charity, Hypopara UK.

"We are raising funds for vital stem cell research at the moment so this prize will really help. Thank you to everyone who voted, to my committee who nominated me and well done to all the finalists who all work so hard and represent such worthy causes."

Liz founded Hypopara UK in July 2005 after her experience of living with undiagnosed brittle hypoparathyroidism following surgery for thyroid cancer in 1992.

She was inspired to do something to help others after spending many years without support or information about her condition and being told by doctors that she must be "bringing it on herself".

Today, with over 1600 members, Liz has brought together a team of ten dedicated volunteers and a highly regarded team of medical specialists who work closely to improve the lives of patients living with all types of parathyroid conditions. Patient support is her priority and she has set up telephone helplines, an online forum, Facebook and local groups and is in daily communication with members.

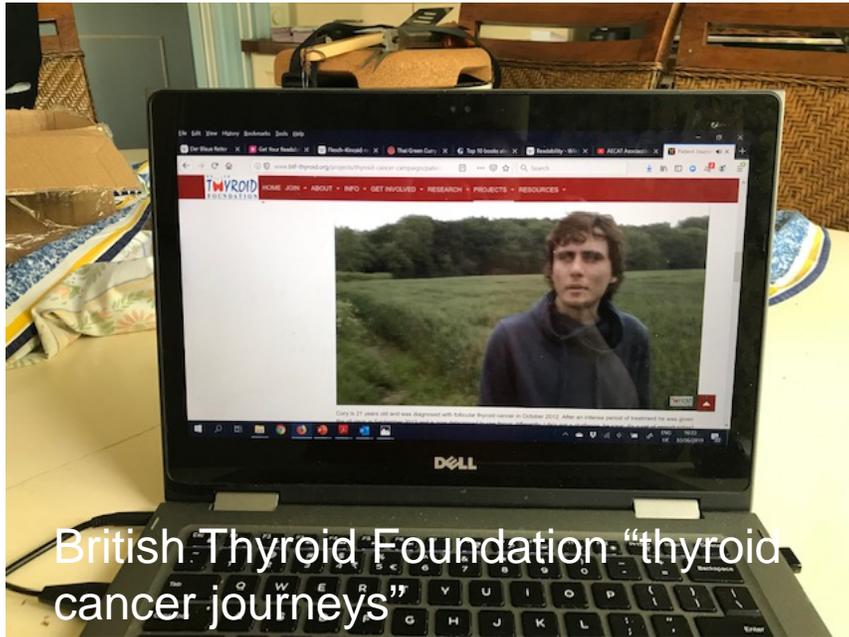
Continued on page 14...

Wednesday 1 June is World Hypopara Awareness Day - join the Facebook campaign by posting your own mug shot!
See page 3 for details

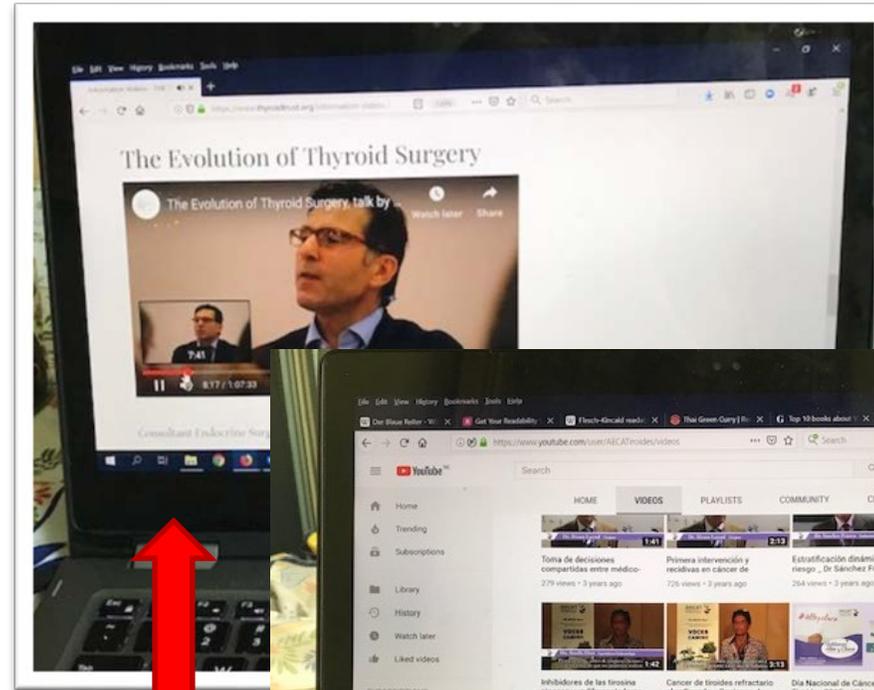
Tips for making a good video

	Don't	Do
Camera position and background	“Talking heads”	Vary the distance from the speaker, use different backgrounds – indoor, outdoor
Length	Over 4 minutes, unless it's a complete lecture	Ideally no more than 3 minutes
Interviewer questions	Include interviewer questions	Edit them out, the result will be shorter, snappier
Voice quality	Mumbling, interviews with non-native speakers	Get it as clear as possible, add subtitles for extra clarity
Language (see readability tips)	Long words and sentences	Short sentences, avoid jargon
Science	Long technical words, no pictures	Graphics, animated cartoons
Overall presentation	Messy, complicated	Make it nice!
Distribution	DVD, mail order only	Website, You Tube

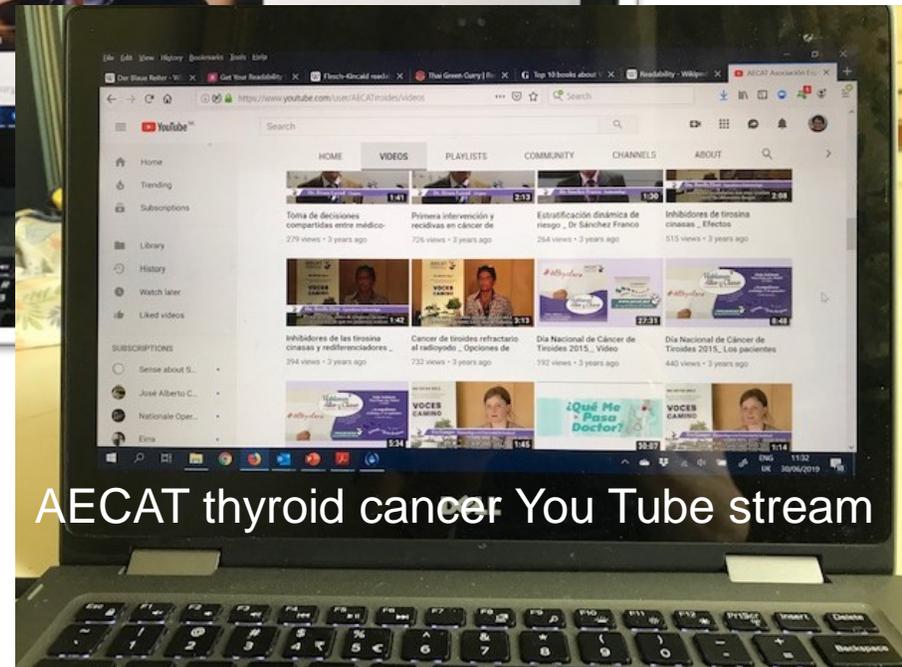
Some examples of online videos and You Tube streams



British Thyroid Foundation “thyroid cancer journeys”



Thyroid Trust video of talk by trustee Fausto Palazzo on “The evolution of thyroid surgery”



AECAT thyroid cancer You Tube stream

“Seeing through the SMOG”

Simple Measure of Gobbledegook (SMOG) and other readability tools



- **SMOG** is a measure of readability that estimates the years of education needed to understand a piece of writing. It uses sentence complexity (number of words per sentence) and word complexity (number of words of three or more syllables) to give a **readability score**.
- Shorter sentences with simpler words will give better readability. The lower the readability score, the more accessible the document.
- A 2010 study* described the SMOG index as the “gold standard” and stated, “SMOG should be the preferred measure of readability when evaluating consumer-oriented healthcare material.”
- **US Department of Health and Human Services (USDHHS) recommends that patient-orientated health literature be written at or below the 6th-grade level (UK reading age of 11–12 years).**
- The SMOG index recommends writing for people with a reading age of 12-13 years.
- Other readability tests are the **Gunning-Fog index** and the **Flesch-Kinkaid formula**. Organisations such as **Macmillan Cancer Support UK** use Flesch.

*Fitzsimmons, P.; Michael, B.; Hulley, J.; Scott, G. (2010). "A readability assessment of online Parkinson's disease information". *J R Coll Physicians Edinb.* **40** (4): 292–6. [doi:10.4997/JRCPE.2010.401](https://doi.org/10.4997/JRCPE.2010.401). [PMID 21132132](https://pubmed.ncbi.nlm.nih.gov/21132132/).

The SMOG table

Reading age level (US grade)	Able to fully understand and use	Unable to fully understand and use
Based on UK adult working population of 35 million people	Number (percentage)	Number (percentage)
10-11 (5 th grade)	32.5 million (93 percent)	2.5 million (7 percent)
12-13 (7 th grade)	29.8 million (85 percent)	5.2 million (15 percent)
14 and over (9 th grade)	20 million (57 percent)	15 million (43 percent)



Where would you aim your content?

Flesch reading ease table

Adapted from https://en.wikipedia.org/wiki/Flesch%E2%80%93Kincaid_readability_tests

School level	Score	Notes
College graduate	0-30	Best understood by university graduates
College	30-50	Difficult to read
10 th to 12 th grade	50-60	Fairly difficult to read
8 th and 9 th grade	60-70	Plain English. Easily understood by 13- to 15-year-old students
7 th grade	70-80	Fairly easy to read
6 th grade	80-90	Easy to read. Conversational English for consumers

**Macmillan and some other POs in the UK
strive for a score of >70.**

What score would you aim at? Why?

Test your website or content at
<https://www.webfx.com/tools/read-able/>

(it works for other languages too)

But keep your sense of perspective!

Further reading

- The Information Standard (UK) - <https://www.england.nhs.uk/tis/about/the-info-standard/>
- BMA Patient Information Awards <https://www.bma.org.uk/library/patient-information-awards>
- Macmillan Cancer Support: How we produce our information - <https://www.macmillan.org.uk/about-us/what-we-do/how-we-work/award-winning-cancer-information/how-we-produce-our-information.html>
- Cancer Research UK: Checklist for information production and review - <https://www.cancerresearchuk.org/about-cancer/about-our-information/checklist-writing-review>
- A-Z of NHS health writing - <https://beta.nhs.uk/service-manual/content/a-to-z-of-NHS-health-writing>
- MedlinePlus: How to write Easy-To-Read materials <https://medlineplus.gov/etr.html>

Tools

- Grammarly - <https://www.grammarly.com>
- Readability test tool - <https://www.webfx.com/tools/read-able/>
- Readability test tools for French, Italian and Spanish texts - <https://visual-seo.com/SEO-Software-Features/Readability-Analysis>



Thank you!

THYROID CANCER
ALLIANCE



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www.thyroidcanceralliance.org

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