

Health Literacy Toolkit

2nd Edition, 2023

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Introduction and background

What is health literacy?

The definition of health literacy has changed since its beginning in the 1970s. At first, it meant that someone had good enough skills in reading and understanding to get the health information they needed. This could be about illness, health risks or how to use health services. It also meant they could act on this information to improve their health. An expert in the field, Professor Don Nutbeam, called this **FUNCTIONAL HEALTH LITERACY**.¹

But there is more to health literacy than being able to read a leaflet or arrange a repeat prescription. Sourcing your own health information and being able to act on it independently is empowering. Nutbeam called this INTERACTIVE HEALTH LITERACY. This means people have the skills and confidence to find and understand health information from social media and also from newspapers, TV and other forms of mass media. And they have the self motivation to apply it without needing to be told to by a doctor or nurse. So people are able to act independently to improve their health. Their greater understanding may also increase their confidence in discussions with health professionals.

Nutbeam's final level is **CRITICAL HEALTH LITERACY**. 1 This means someone can analyse and appraise health information. When combined with social skills, this may include people or organisations taking part in community action to promote health more widely.

A broader definition for the 21st Century

In 2014, the World Health Organization (WHO) defined health literacy as "the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health." WHO goes on to say that health literacy includes being able to communicate and act on these decisions.²

A more recent definition of health literacy from the US Center for Disease Control (August 2020) covers both the personal and organisational:³

"Personal health literacy – being able to find, understand, and use information and services to inform health-related decisions and actions for yourself and others.

Organisational health literacy – organisations enabling people to find, understand, and use information and services to inform health-related decisions and actions for themselves and others."

By including both the personal and the organisational, this definition shows that health literacy covers the skills and confidence of individuals and the resources provided by society to support health literacy.

Why is health literacy important?

To maximise their health and wellbeing, people need to be able to understand health information, make decisions based on their understanding, and use health services effectively. So those with lower levels of health literacy are more likely to have poorer health outcomes.

If you are less able to make healthy lifestyle choices or take part in screening or health promotion programmes, you are more likely to have a disability, have trouble managing long health term conditions and die younger.

As we've seen, health literacy is a broader issue. Health information (written and spoken) and the way the healthcare system is set up can be complicated. The needs of those with lower health literacy levels are not always considered.⁴ In a UK study, more than 40% of people did not have the skills to interpret health information materials. And those most at risk of socioeconomic deprivation were more likely to be in this group. When numeracy was added to literacy, more than 60% did not have the required skills.⁴ The European Health Literacy Survey looked at health literacy in eight European countries. They found that nearly half of all adults had inadequate literacy skills.⁵

People with higher literacy and numeracy are able to understand a wider range of health information materials.⁴ But health literacy is not set in stone. Your ability to understand and make health decisions can change according to your circumstances.⁶ For example, the shock of hearing a new diagnosis can reduce confidence and health literacy skills.

As well as understanding information, people have to be able to use it to make good health decisions. This can be affected by individual circumstances - lack of money or time, preferred language, level of social support and difficulties accessing health systems.⁷

The University of Southampton mapped where people in England are likely to struggle with health literacy. They based this on local literacy and numeracy levels.

You can find it on this link: http://healthliteracy.geodata.uk

What is digital health literacy?

Health information and health services are increasingly provided online. To access these, people need to have computer and online skills as well as health literacy. These computer and online skills are referred to as digital skills. The World Health Organization published their <u>Global strategy on digital health</u> in 2021. They describe "digital determinants of health" as including "literacy in information and communication technologies, and access to equipment, broadband and the internet".8

So, digital health literacy covers both digital skills and the ability to apply these to health information. People who are digitally health literate have the skills and knowledge to use a computer, phone or the internet. And using them, they can find and use health services and information. They can:

- book appointments
- order repeat prescriptions
- manage telephone or virtual appointments
- work out whether information they find on the internet is right for them and apply it to their own health.

Those without the required digital skills may be left out. Barriers include¹⁰:

- Lack of interest in technology
- Lack of confidence and fear of technology ("I don't want to break it")
- Language difficulties (including English as a second language)
- Not understanding common technical instructions ("scroll down", "go to www.. and click on...")
- Lack of familiarity with processes (using apps, registering for online services and managing and using passwords)
- Money (cost of equipment, broadband and smartphone contracts)
- Lack of trust (privacy and confidentiality fears, fear of online scams)
- Traditional reliance on family or other helpers
- Disability.

As of 2022, 6 in every 100 UK households (6%) had no internet access at home. A further 5% relied solely on mobile internet access. Those without internet access are most likely to be older, poorer, unemployed, living alone or with a hearing or visual impairment.¹¹

There are around another 2 million households who do have home internet access, but have trouble paying for it.¹¹

Among those who do have access to a computer (or digital device) and the internet, around 8 out of 100 people (8%) say they are not confident in using it.¹¹

How does it relate to information literacy?

Information literacy underpins both health literacy and digital health literacy. The <u>Chartered Institute of Library and Information Professionals</u> (<u>CILIP</u>) gives the following definition:

"Information literacy is the ability to think critically and make balanced judgements about any information we find and use. It empowers us as citizens to develop informed views and to engage fully with society."¹²

If you can think critically, you can assess whether information is likely to reliable. This includes assessing information on social media. Organisations such as public libraries help people to develop information literacy skills. They are therefore well placed to be involved in health literacy and digital health literacy programmes in local communities.

Where do we go from here?

When individuals improve their health literacy skills and organisations improve the ways that they communicate, this has two key benefits: Firstly, people take steps to stay healthier; and secondly, people's health improves.^{13,14}

This toolkit contains details about practical tools and techniques that can support you in implementing health literacy initiatives. Wherever you work, it should help you to support people with low levels of health literacy. In turn, this will help your patients or service users to develop the knowledge and confidence they need to improve their own health and wellbeing.

The guide can be used as part of a training programme or as a standalone resource. It can apply to clinical and non-clinical settings in health, social care, housing and other services. Our collective aim should be to:

- provide written information that is easier for everyone to read
- improve the quality and accessibility of spoken communication
- recognise who may have lowered health literacy and that this level may vary with circumstance
- ensure that those who are digitally excluded are able to (and know how to) access services.

Health Literacy: Guidance and tools

1. Communicating with people

To communicate well, anyone working in health care must provide information that can be understood. This can be written or spoken. It includes information on accessing services as well as clear medical information. So, this covers everyone from those working on reception desks to health professionals working with a patient to gain consent for treatment or a procedure.

In England, more than 4 out of 10 adults (43%) cannot routinely understand health information because their literacy skills are not good enough. And more than 6 out of 10 adults (61%) can't understand health information because their numeracy skills are too poor.⁴

Functional literacy means having good enough skills in reading and understanding to manage daily life. To be 'functionally literate', people must have a literacy level at or above the equivalent of GCSE grade 1, 2 or 3 (was D-G). About 15 in 100 adults (15% or around 1 in 6 adults) in England and Northern Ireland have a literacy level at or below that.¹⁵

Functional numeracy means being good enough at basic maths to manage daily life. That means numeracy at key stage 2-3 or above (or as good as the average 11 year old). Around 24 out of 100 people (24% or nearly 1 in 4 people) in England are below this level.

Tool 1 gives a comparison of educational levels and abilities in relation to health information. It provides a guide to what people at various levels of health literacy will be able to understand and do.

Being able to assess someone's literacy and numeracy level can be helpful. But it's best if we aim to make all health communication accessible to as many people as possible, by making it easy to understand.¹⁷ To be health literacy aware, we also need to ensure that people have understood what they've been told and not just assume that they do.

The World Health Organization recommends taking "universal precautions".¹⁸ This means offering support to everyone, rather than assuming some people will understand and others won't.

It is also helpful to think about different formats of information. People do not necessarily want written information as a substitute for verbal information.¹⁹ Often good communication is not a case of using one method or another, but rather multiple methods.

Tool 1: Levels of literacy and numeracy in the UK population and how this relates to health information

The literacy levels below are defined in the Government 2011 Skills for Life Survey¹⁵. This estimates that:

- 43 in 100 adults in the UK (43%) are below level 2 that's just under half of all adults¹⁵
- 15 in 100 adults in the UK (15%) are at or below entry level 3 that's nearly 1 in 6 of all adults15

Literacy level	In a health setting, adults at each literacy level will be able to:
That of a typical 5–7-year-old (Literacy entry level 1)	 Understand pictures on a health promotion poster Read and understand 'way in' and 'way out' signs but not entrance or exit signs Tell a doctor they don't feel well, but not describe types or levels of pain
That of a typical 7–9-year-old (Literacy entry level 2)	 Understand the words on a simple poster, such as 'smoking is bad for you' Understand the words of a routine appointment letter, but not necessarily the numbers Tell a clinician in simple language about the type and level of pain they have
That of a typical 9–11-year-old (Literacy entry level 3)	 Understand the words on a more complicated poster and simply worded leaflets Understand a short, formal letter, note or form. Undertake a call to 111 Describe types and levels of pain in more detail. Understand what they've been prescribed by a clinician
Lower grade GCSE - grade 1 - 3 or F – D (Literacy level 1)	 Understand more complicated information, e.g. health promotion information on diet, or simple clinical information if delivered with help and support Confidently describe types and levels of pain Understand simple spoken instructions, but not the importance of following them or ability to clarify what they've been told
Higher grade GCSE - grade 4 -9 or C – A* (Literacy level 2)	 Understand and interpret more complicated health information, as above Volunteer information about pain without being asked Ask simple questions to understand why a particular course of treatment has been prescribed

The numeracy levels below are defined in the Government 2011 Skills for Life Survey. This estimates that:

- 78 in 100 adults in the UK (78%) are below numeracy level 2 that's just under 4 in 5 of all adults¹⁵
- 49 in 100 UK adults (49%) are at or below entry Level 3 that's almost half of all adults¹⁵

Numeracy level	In a health setting, adults at each numeracy level will be:
That of a typical 5–7-year-old (Numeracy entry level 1)	 Unable to understand appointment times in a letter Unable to read medicine doses and schedules e.g. 5ml three times a day Unable to measure their own weight Unable to take their own temperature
That of a typical 7–9-year-old (Numeracy entry level 2)	 Able to understand appointment times in whole hours using 12-hour clock e.g. 9am, but not parts of an hour or a 24 hour clock e.g. 9.15am or 13.00 hours Able to understand simple medicine doses and schedules e.g. take one teaspoon 3 times a day Able to measure their own weight in kilos Able to take their own temperature, but not understand the reading
That of a typical 9–11-year-old (Numeracy entry level 3)	 Able to understand appointment times using 12-hour clock e.g. 9.15 but not 24 hour clock e.g 14.15 Able to measure their weight, height and temperature Able to understand simple instructions about medicines including dose and timing e.g. take 5ml three times a day after food
Lower grade GCSE - grade 1 - 3 or F – D (Numeracy level 1)	 Able to understand appointment times using 12 and 24-hour clock Able to understand instructions about medication timings and dosages e.g. take 5ml every 4 hours, three times a day
Higher grade GCSE - grade 4 -9 or C – A* (Numeracy level 2)	 Able to describe and calculate their own weight loss or gain Able to give a percentage of time that they have been pain free in the previous 24 hours

2. Spoken communication

Everyone involved in healthcare needs to be able to communicate effectively with their patients or clients and their families. This may be during phone conversations, enquiries at reception desks or responding to requests for information. They can be one to one conversations or group discussions. They can be part of medical examinations, treatment discussions or during conversations about consent for procedures.

Principle 4 of the **NHS Constitution** says:

'Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment'.²⁰ This is commonly called 'shared decision making'. The <u>National Institute</u> for Health and <u>Care Excellence</u> (NICE) have produced guidance on this. They acknowledge that people don't always want to take an active role in making decisions about their healthcare. But they should be offered the opportunity to take as much of a part in the decision as they wish. If they feel involved, people are more likely to²⁰

- be satisfied with their healthcare
- trust their health team
- communicate better with their health team
- have a greater understanding of treatment risks and benefits.

NICE acknowledge that health literacy is a fundamental component of shared decision making. Two tools they recommend are Teach-Back and Chunk and Check.

Tool 2: Teach-Back

Teach-Back is a tool you can use to confirm that a patient or carer has heard and understands what they've been told. The US Agency for Healthcare Research and Quality report that patients immediately forget 40-80% of the medical information they've been given and nearly 50% of the information they do 'remember' is incorrect.²¹

Essentially, Teach-Back means asking someone to repeat what you've just told them in their own words. You can use it to check that you've explained something in a way that the patient or client can understand. It's important to phrase questions in a way that doesn't make people feel they are being 'tested'. Examples of how this might sound include:

- We've discussed a lot today. What was it that you thought most important?
- Just to check that I've explained everything clearly, could you tell me how you are going to take your medicines?
- To make sure the instructions I've given you make sense, could you tell me how you are going to...?

It is helpful to tell the person **beforehand** that you are going to ask them to repeat the information back to you and explain why.

So, this tool involves more than asking 'Have you understood?'. Depending on the person's response, you can clarify or change the way you've explained something. Then you use the Teach-Back approach again as necessary until they can repeat back correctly.

There is a related technique called 'Show me' that asks a patient to demonstrate an action, such as using an inhaler or applying a cream, dressing or appliance.

There is a useful <u>video showing Teach-Back in action</u> that you may find helpful.

Tool 3: Chunk and Check

This technique goes hand in hand with 'Teach-Back'. It means providing information in small sections or 'chunks'. After each chunk, you can check understanding with Teach-Back before moving on to the next.²¹

An example of how to use the 'Chunk and Check' technique Pharmacist: So, Mrs Smith, I have your tablets here. There are two lots of tablets. You take these 3 times a day, with water after a meal. And these smaller ones twice a day on an empty stomach or several hours after eating. You might find this leaflet useful.

This could be split into smaller chunks, using Teach-Back between chunks where appropriate.

- So, Mrs Smith, I have your tablets here. There are two lots of tablets.
- You take these 3 times a day, with water after a meal.
- You take these smaller ones twice a day on an empty stomach or several hours after eating.
- You might find this leaflet useful.

There is <u>more about Teach-Back</u> and about <u>Chunk and Check</u> on <u>The Health Literacy Place</u> website. This was developed as the main source of health literacy information and resources in Scotland.

Tool 4: Health Literacy eLearning

The <u>Health Literacy eLearning course</u> provides information on what health literacy is, how it impacts everyone and what tools are available to help. It was developed jointly by the NHS knowledge and library services leads and public health specialists in NHS Education for Scotland and Health Education England (now part of NHS England).

The course contains a mixture of videos, written information, and activities to help you understand and reflect on health literacy. It allows you to identify simple actions that you could take to make health information clearer.

At the end, the eLearning programme creates a personalised Action Plan based on your inputs. This can assist you to put changes into place.

Guides to good communication

Good communication does not just depend on the words you use. Non verbal cues are key to giving the right impression and encouraging people to engage with you. These may be particularly important during virtual appointments. Positive non verbal cues include making eye contact, using appropriate tone of voice and facial expressions and the lack of a physical barrier between you (such as a desk). There are other potential barriers such as an inappropriate setting or an anxious client.

The e-Learning for Healthcare website includes a <u>Principles of Communication module</u>. This looks at how anyone can facilitate good communication in healthcare, whether you are a patient, carer, health professional or social care professional.

The Centre for Pharmacy Postgraduate Education (CPPE) provides a consultation skills learning programme for pharmacy professionals. This link will take you to their <u>guide to good communication skills for the pharmacy setting</u>.

Communicating risk or any information that involves numbers can be particularly difficult for people to understand. The <u>NICE guideline on Shared Decision Making</u> includes a section on <u>communicating risk and discussing numerical information</u>.

3. Written information – how you write

People are often given factsheets or booklets when they are diagnosed with a condition or to help them make informed choices about their health and wellbeing. These will only be helpful if they are written in a way the reader can understand.

Almost half the adult population in England have a reading ability at or below level 1, which is the level expected of an average 11-14 year old.¹⁵ But a lot of health information is written at a higher reading level than this. So however useful and accurate the information may be, many adults won't be able to understand it. To be sure that it's accessible, written information really needs to be aimed at reading age 11 or below.²²

Almost half the adult population in England have a reading ability at or below level 1, which is the level expected of an average 11–14-year-old.

This means writing in simple language, or what is often called 'plain English'.

There are readability tools you can use to measure the reading age of your writing, and these are covered in this section. There are also guides to writing information that is easy to read and in plain English.

It's also important to think about what your patients want and need to know. Understandably, health professionals often focus on what they think they need to tell patients and this is not always the same as what an individual wants to know. For example, information about tests may not include whether they are painful or uncomfortable (or not). Try asking your patients what they think they need to know – you may be surprised.

Think about the **flow** of your information. It will be easier for people to follow if it's in a logical order. Think about 'before', 'during' and 'after'. Also consider what your patients' are likely to think is most important, and make sure those points stand out.

A key part of creating written information is checking that your intended audience can understand it. This is called 'user testing' and is covered in the later section on involving service users.

Writing in plain English

The first step in plain English writing is to choose words that your reader is most likely to understand. Some of the tools below include lists of alternative wording. There are also lists of words and phrases that it's best to avoid.

If you're stuck, try typing the word you want to replace, followed by 'synonym' into Google (or another search engine). Or if you're working in Word, you can right click on a word and choose synonyms from the drop down list to find alternative ways of saying something. It isn't easy to write health information in plain English. You may have to use a complicated term or words that people will have difficulty understanding. However, if you explain these well, it is helpful for the reader as they are likely to come across these terms when talking to their healthcare team.

The way you write

This is also important for increasing understanding. For example, it is harder for less confident readers to read very long sentences. Try not to write sentences longer than 25 words.

Using 'active' verbs makes writing simpler. Health information is often written in a 'passive' style. In the following examples, the passive and active forms of the verbs are highlighted:

- Passive: The test results will be sent to you by the hospital within a week.
- Active: The hospital will send you the test results within a week.
- Passive: The medicines will be given to you by the pharmacist before you go home.
- Active: The pharmacist will give you the medicines before you go home.

As well as the words and writing style you use, the way the words look on the page can make a big difference. Dense text is much harder to read. There is more about this in the section on design. But when you are writing, think about where you can put bullet lists to break up the text.

Tool 5: How to write in plain English

This free <u>How to write in plain English guide</u> is produced by the Plain English Campaign. It explains what plain English is and then runs through the main ways you can make your writing clearer:

- choosing the simplest words that you can
- using short sentences
- using active verbs
- using 'you' and 'we'
- using bullets for lists
- being direct.

There is also a short section on dealing with complaints and a list of words that it's best to avoid.

Tool 6: A-Z of alternative words from the Plain English Campaign

This <u>A-Z of alternative words</u> provides plain English alternatives to more complex terms that are often used in official writing. It isn't specific to health information but includes many words that are commonly used and that you may want to try and avoid, such as 'deficiency' ('lack of'). Some words that could be used medically are not defined in those terms. For example 'discharge' is defined as 'carry out'.

Tool 7: Plain English Lexicon from the Plain Language Commission

The <u>Plain English Lexicon</u> provides a searchable list of almost 3,000 words. These are arranged alphabetically, with simpler alternatives.

It may look confusing at first glance, as there are several columns. The most relevant for us is the UK column, which gives the lowest reading age at which the average person will understand the word. There is a description of all the column headings on page 4 of the Lexicon.

The Lexicon is not aimed specifically at health information but includes many medical and health-related terms. You may have to use your judgement with some - for example, 'abdominal' is defined in the Lexicon as 'about the stomach', which may not always be a suitable alternative in medical information.

Tool 8: Care and Support Jargon Buster from Think Local Act Personal

The <u>Care and Support Jargon Buster</u> explains commonly used terms in health and social care. These are arranged alphabetically and are searchable. It doesn't cover many medical terms. But it does include a lot of words and phrases related to care systems and services. These may be useful for extending your own knowledge as well as in producing health information. There are useful 'see also' suggestions for many of the terms.

Tool 9: A guide to producing written information in 'easy read' from North Yorkshire County Council

Easy read is a style of producing information developed for people with learning disabilities. But it's also useful for people who speak English as a second language, people with memory problems or those with low literacy levels. It includes many of the principles of plain English information, but is simpler and generally uses more images.

This <u>guide to producing information in easy read</u> provides many 'top tips' that were developed in partnership with people with learning disabilities. It continues with a step by step guide to producing easy read documents.

Producing easy read documents is not easy! If someone else has already produced the information you need, it makes sense to use that, rather than reinventing the wheel. Gloucestershire NHS Foundation Trust have produced an extensive <u>list of existing easy read resources</u> that you may find useful.

More information

The Patient Information Forum also have a <u>guide to using plain language</u> <u>in health information</u>. The link will take you to a summary, but you have to be a PIF member to see the full guide.

The Plain English Campaign produce a <u>guide to writing medical</u> <u>information in plain English</u>.

4. Readability

This is a way of measuring how easy a document is to read and understand. Readability tests were first developed in the USA in the 1920s. They use maths to work out the reading age of a piece of writing. The tests take into account the length of sentences and the number of syllables in each word. So, in general, writing that has short sentences and short words score better.

As they are based on maths, the tests can't show whether writing is interesting and enjoyable. And most can't tell whether writing can be understood. Some tests give good scores with gobbledygook, as long it has short sentences and words with one syllable. More recent readability tests are better at checking understanding, as they can spot passive verbs and complicated sentences.

Design and layout also make a difference to how easy something is to read. These tests don't measure that. So, readability tests can be useful. But it's most important to stick to good writing style guidelines when creating any health information.

A note about US school grades

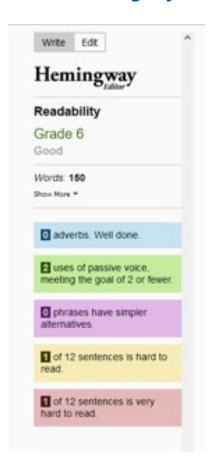
The readability tools give reading age as a US school grade. This is one less than the UK school year system. So, US grade 6 is the same as UK year 7, or age 11-12. Grade 7 is the same as Year 8, or 12-13, and so on.

Information that scores as 6th grade (age 11-12) is easy to read. Information at 8th or 9th grade is said to be plain English and anything above that more difficult for people to read.

Comparing results

All the descriptions of the tools below include the results they gave for exactly the same piece of writing. As you'll see, they are all different. They're all useful in their own way but using several could be confusing. So, it's probably best to find one that suits you and then stick to that. You will get used to the scores it gives and be able to fine tune your writing and make it more accessible.

Tool 10: Hemingway



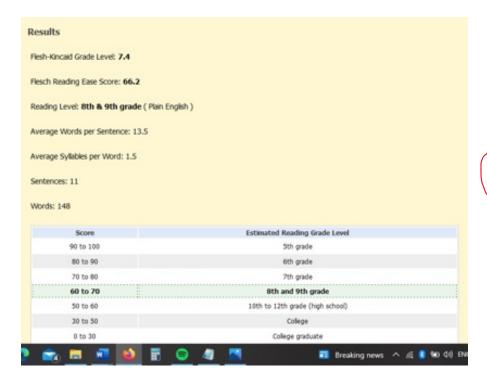
The <u>Hemingway Editor</u> is an online readability tool. Use of the webpage is free. There is also a desktop app you can buy to download.

Hemingway gives your writing a reading grade, rating and word count. The grade is the US school grade that someone would need to reach to be able to understand the piece of writing. Hemingway also tells you how many adverbs and passive verbs you've used. And picks out sentences that are hard or very hard to read. This is how it shows your scores.

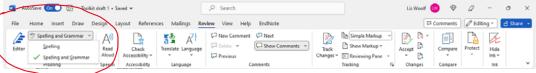
You paste your own text onto the webpage and then edit it within the tool to sort out issues. Or you can write directly on the webpage and then copy your finished text into your document.

As a readability tool, Hemingway is easy to use and gives you quite a bit of good information about your writing. It can improve your writing over time, by showing you clearly where you can improve. The only downside is cutting and pasting in and out of the webpage.

Tool 11: Flesch-Kincaid



The <u>Flesch-Kincaid calculator</u> combines two tests – the Flesch Readability Ease score and the Flesch-Kincaid Grade Level score. It gives your writing a reading ease score between 1 and 100, where 100 is very easy to read. The grade level is the US school grade that someone would need to reach to be able to understand the piece of writing. It also gives you the average sentence length and average syllables per word. This is how it shows your scores.

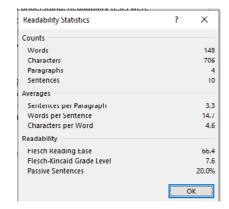


As with Hemingway, you paste your text into the web page. You can make changes and then recalculate the score if you wish.

An advantage of Flesch-Kincaid is that you can use it in Microsoft Word. Choose the 'Review' tab and find 'Spelling and grammar' on the lefthand side of the top menu. Click the drop down and make sure 'spelling and grammar' are ticked.

Then when you click on 'Spelling and grammar' on the top menu, Word will spellcheck your document and give readability scores. This is how the results look.

If you don't see the Readability statistics, you'll need to switch that on. Click on 'File' on the top menu. Choose 'Options' (at the bottom of the list on the left). Choose 'Proofing' (3rd option down) and lastly, find and tick 'Show readability statistics'. You may have to restart Word before it will work.



Tool 12: Drivel Defence

Summary

- . Total sentences with 20 or more words= 0.
- . Longest sentence has 18 words (2 sentences).
- Total potential alternative words= 0.
- . Total words=148.
- Total sentences=10.

[Average sentence length = 14.80 words].

Details

[17] Readability This is a way of measuring of how easy a document is to read and understand.
[11] Readability tests were first developed in the USA in the 1920s.
[14] They use maths to work out the reading age of a piece of writing.
[17] The tests take into account the length of sentences and the number of syllables in each word.
[13] So, in general, writing that has short sentences and short words score better.
[16] As they are based on maths, the tests can't show whether writing is interesting and enjoyable.
[9] And most can't tell whether writing can be understood.
******** | Your Longest Sentence (1 of 2) | *******
[18] Some tests give good scores with gobbledygook, as long it has short sentences and words with one syllable.
******* | Your Longest Sentence (2 of 2) | *******
[18] More recent readability tests are better at checking understanding, as they can spot passive verbs and complicated sentences.

End of report.

<u>Drivel Defence</u> is computer software developed by the Plain English Campaign. It counts the number of words in each sentence and suggests alternative plain English terms for complicated words.

The link will take you to the online text version. You paste in text as you do for the previous readability tools. Then you click 'analyse' and the results appear in a separate window. This is how they look.

You can download <u>Drivel Defence</u> to your own computer, but it works just as well online. There is also a version called <u>Drivel Defence for Web</u>. Web developers can use this to check the content of their webpages. To use this, you have to download it to your own computer.

An advantage of Drivel Defence is that there is a handy A-Z of alternative plain English words on the same page. A disadvantage is that it shows the results in a new window. If you have a pop-up blocker active on your web browser, you will need to turn it off before Drivel Defence will work.

[15] But design and layout also make a difference to how easy something is to read.

Tool 13: NHS Medical Document Readability Tool

The <u>NHS Medical Document Readability Tool</u> calculates the estimated UK reading age of your text. It highlights complex sentences, passive sentences, complex words and long words. It also tells you the average reading time for your text. You can choose whether to include medical terms in reading age scores.

Copy and paste your text, or write directly into the tool. Use the options on the right to analyse your writing. Hover over complex words to see suggested replacements. Edit your text and see how the reading age changes. Aim for as close to 11 as you can.

This tool is simple to use. The UK reading age makes it easy to understand the readability score. Excluding medical terms from the score helps you to write healthcare information. The tool doesn't check your spelling and grammar. It doesn't change your sentences for you. But it shows you where you can write more clearly.

5. Involving service users

To make sure that your target audience will understand the information you produce for them, it's best to involve them in the production process. This can range from getting feedback on the final draft before you publish or print it to full 'co-production'.

Co-production means producing patient information alongside the people it's intended for. This includes consulting on and respecting how people wish to be described, e.g. an autistic person or a person with autism. Full co-production means involving them from planning to publication. So, from the first discussions about what information they need, right up to the final printing or publishing of the finished information.

Levels of user involvement

The Patient Information Forum say that full co-production is the 'gold standard' that all patient information producers should aspire to.²³ However, it is time consuming and therefore expensive and you may not have the resources to do this where you work. Don't worry – try to involve users as much as you can.

- Feedback on a finished piece of information is the most basic level of involving users. You can collect the feedback and keep it for the next planned update. To collect feedback from your readers, you could include a form on your website or a tear-out slip in printed information. Complaints can be a good source of feedback too – keep it and take it seriously.
- User testing a final draft of your information should really be the minimum level of involvement. It should include the finished design (colours, type and images) for people to comment on, as well as the text. If a website, you need to test that users can find information using the navigation and layout.
- Input into the writing and design process, through individual or group involvement can be as much or as little as you can manage. At the least, you could carry out a round of service user feedback at the same time as your information is going out for professional medical review.
- Full co-production means engaging and involving service users from the outset of the planning process. They can identify gaps and then guide production of information users are likely to need and want.

Co-production includes a wide range of activities, such as running workshops and review sessions. <u>To find out more see these details from NHS England</u>.

Website user testing can be highly technical, with specialist eye tracking software and video filming. But you can get good results much more simply. Whatever your resources allow you to do will be of benefit.

The cheapest and simplest way to user test web content is to sit with a service user while they use your website. You give them pre-defined tasks to complete. While they do, an observer in the background takes notes about where they go on the site and what they look at.

Remember that user testing is a circular process – you test, identify problem areas, make adjustments and then test again.

A few things to be aware of...

If you are contacting service users, you need to make sure you are aware of data protection regulations. If you keep their contact details (digitally or on paper), you will need their permission.

Service users shouldn't be out of pocket. You will need to factor in any travel costs, postage costs and provide refreshments if they are attending meetings or events. You may wish to provide vouchers as a thank you, but be aware that this can affect benefit payments (see More Information below).

Everyone needs to be clear about the level of service user involvement. Are you just collecting opinions or will people have an active role in suggesting what is included in your information? Sorting this out from the beginning means avoiding disappointment and potential conflict later on.

Try to get a mix of people involved. They need to be from your target audience of course. But they should also reflect the diversity of that audience in terms of social background, cultural group or disability, as well as in health and digital literacy. You could exclude people if you only have meetings online.

It's best if your group includes people who have recently used your service as things can change over time. You can find people from your own group of service users or contact patient organisations or support groups.

There are many different methods of gathering feedback—questionnaires, surveys, structured interviews—and constructing these is a skill. You may simply send a draft text for comments. But if you're having multiple feedback sessions and/or sending information to a number of people for comment, you'll need something standardised.

For final user testing of an online or hard copy resource, you'll need around 6 people per round of testing. Fewer and you may miss something, but more than that isn't likely to bring up much new information.

Remember to feed back to your participants. Let them know how things have gone and the improvements that involving users have brought to your project – and thank them for their help.

Tool 14: Co-production

The Patient Information Forum (PIF) have produced a <u>poster on coproduction</u>. This summarises how to involve service users in developing health information. There is also a PIF full guide to co-production but this is only available to PIF members.

More information

Think local, act personal (TLAP) have a <u>poster explaining the different</u> <u>steps in co-production</u>.

NICE has information on <u>how payments to service users can affect</u> <u>benefit payments</u>. There is similar <u>information on co-production affecting</u> <u>benefits</u> from the Social Care Institute for Excellence.

There is a useful <u>pubmed article about designing and validating a</u> <u>questionnaire</u>. Some professional survey hosting companies have hints on their websites - type 'designing a questionnaire' into a search engine.

An <u>article about patient engagement</u> by David Gilbert – an expert in patient engagement from a patient perspective.

6. Design

How information looks on a page makes a huge difference to how easy it is to read and understand. A leaflet or web page that looks cluttered, complicated or confusing will put off less confident readers from even trying to read it. User testing on medicines leaflets has shown that the way information is laid out is as important as the words that you use.¹⁹

The sections below cover information in print, additional tips for digital information design, and a section on pictures and other images.

Information in print

As well as following plain language guidelines for the way you write, you need to pay attention to the design of your information, whether it will be a printed hard copy or digital information online. There has been a lot of research into basic design principles for health information, which form the basis of the following lists.^{19,24}

Issues around the overall 'look'

- White space should make up about half the page.
- Make sure there is enough spacing between lines of text or it will look crowded.
- Have good contrast between the colour of the text and the background – preferably black or dark blue on white.

Issues around type and text

- Choose a plain font (typeface), such as Arial or Helvetica.
- Use as large a type size as you can at least 12 point.
- **Don't** use 'justified' text. (Justification means ending the lines evenly at the righthand margin by adjusting the spacing between words).
- Don't use capitals, italics or underlining they are all harder to read.
- Lines of text that are too long or too short can make reading harder. Aim for 10-12 words per line.
- Don't wrap words round a picture or other image.

Organising your information

- Use short headings that stand out at least 2 points bigger than your main type size.
- Try not to phrase headings as questions writers like them but they may not always be helpful.
- Use bullet points for lists.
- Use bold text to help something important stand out.

Using text boxes

Text boxes can be useful in breaking up text and making important information prominent. Make sure there's enough white space round the text so it's not crowded.

Additional tips for digital information

Almost all of the points for print apply to digital/online information. There's more to think about with digital information. Some of this will be in your control as you put the information together. Other issues are dealt with by the web designers.

What you need from the designers

The web designer should make sure that the pages of your website display as intended, whether people are looking at it on a computer, tablet or mobile phone.

A web browser is the programme people use to view the internet. Websites may look different on different browsers (for example, Chrome, Firefox or MS Edge), particularly on older versions. Your web designers should check, but you may want to make your digital information displays well on the web browsers at work if your Trust uses an older version.

Assume that your readers will want to print your information. Ask the web designers for a print version, which strips out all the unnecessary stuff from the screen. Try to make sure there won't be any blank pages printed.

Remember that people can come into your website on any page, not just the home page. So you and the designers need to make sure they'll know where they are, and how to get to your home page and other important pages.

As of September 2020, under the Equality Act, all public sector websites and apps must be accessible to everyone. So for those with vision problems, they must work with screen readers and have good contrast between the text and the background.

Design issues when you're writing online information

There are some things to watch out for when you're putting information together:

- As with printed hard copies, make sure there is enough contrast between the background and the text. Black text is really best
- Don't use blue text link text is traditionally blue on websites so it could confuse.
- Only link text should be underlined
- Links should have descriptive text e.g. using more information about breast cancer tells the user exactly where the link goes.
- Never use generic link text such as <u>click here</u>. People with vision problems using screen readers will only hear 'click here' and have no idea where the link goes
- Colour can make your pages attractive, but don't overdo it.

More information

The Plain English Campaign produce <u>tips for clear websites</u>, covering page design, text and technical display issues. They also produce a <u>guide</u> <u>to design and layout</u> for printed information.

The RNIB have a <u>guide to choosing colour and contrast in print materials</u> <u>for people with sight problems</u>. This link takes you to the guide on a Scottish disability organisation's website.

https://pifonline.org.uk/resources/how-to-guides/web-accessibility-a-quick-quide

If you are producing information for the NHS, you also need to take into account the NHS style quide.

Pictures, graphs and other images

Images in health information can include photographs, drawings, tables, graphs and infographics. Tables and graphs can be difficult for people to follow. So try to make sure that the information you are providing in a graph or table is summed up in the text. An infographic uses images to communicate evidence-based information in a way that is easy for people to understand. There is more about infographics below.

In health information, people like images that have a purpose - a picture or diagram that helps explain the text. Images that are added to break up the text are also helpful as long as you don't use too many. People may be less likely to print digital documents with a lot of photos, as they'll use more printer ink.

Chosen well, images can also reinforce your message. Images should be of good quality and large enough for people to see them properly in your finished document. Poor quality images may make your information look unprofessional and less trustworthy.

It can be surprising how differently people can interpret the same image. In one project, a healthy eating leaflet with an apple icon for fruit intake was thought to mean apples were the only fruit you should eat!²⁵ Select your images and put in place **before** doing any user testing. You can ask your testers what the images 'say' to them, which will help rule out anything that is misleading, confusing or inappropriate.

Reflecting your audience

Images should reflect the diversity of your audience. **NHS Identity** Guidelines say they should be representative of²⁶:

- gender
- race
- disability
- age
- sexual orientation
- religion
- belief
- gender reassignment
- pregnancy and maternity
- marital and civil partnership status.

Clearly you wouldn't have images covering all those areas in a single leaflet! But the point is to show a range of people **appropriately**. For example, a leaflet with only images of white people may lead to people from different ethnic backgrounds thinking it's not for them.

The NHS Guidelines also say it's best to use real patients and staff where you can.²⁶ If you do, make sure you have (and keep) their written consent in your records.²⁶

Copyright

Images are protected by copyright, so if you use anyone else's, you have to make sure you have permission.²⁷ Images that have a 'creative commons' licenses are free for anyone to use, as long as they credit where they came from. You can <u>find out more about creative commons</u> licenses here.

Infographics

These visual representations of information or knowledge have become increasingly popular.²⁵ They can be very helpful if well thought out and put together. But they can also be complicated and confusing if they are visually too busy and contain too much information.

Creating a good infographic is highly skilled. Both the images and the accompanying text need thorough user testing to make sure people can easily understand the finished product.

Many organisations produce infographics that they are happy for you to use as long as you credit them. These links to <u>Prostate Cancer UK</u> and <u>Cancer Research UK</u> will take you to some good examples. Search online for 'infographics' and the health area you're interested to find others.

More information

The <u>Chelsea and Westminster Hospital Healthcare Information</u> <u>Resource</u> has a range of simple images that are useful for people with communication difficulties.

7. Next Steps

There are some steps you can take more or less straight away to help those with lower levels of health and digital literacy.

- Start using Teach-Back and Chunk and Check as a format for your interactions with patients and clients – it's a relatively easy technique to pick up. Watch the video we link to in section 2 and practice.
- Routinely ask people if they need help filling in digital forms or accessing information sent to them digitally. Low digital literacy can affect people of any age and background. They may simply not have access to a computer or much experience using one.
- Review your and your team's verbal communication skills. There are links to help in our section on good communication.
- If you've recently written information for patients, put it through a readability checker to give you an idea of how you might need to improve your plain language writing skills.
- Do some user testing by asking your patients of clients for their views on your existing leaflets - particularly if there's anything that's not clear.
- User test your online information check that patients can find the information they need and that they can understand it.
- Organise some health literacy training for yourself or your team

You can also make plans for the future. Prepare for the next time your information needs updating. Have a look at your hard copy and online information and make sure it is accessible. How does it read? Is there enough contrast between the text and the background? Is the text used for links descriptive? Does it reflect the diversity of the audience in image and tone?

Attention to health literacy is key in improving health outcomes for everyone. We need to adopt a 'universal precautions' approach across healthcare. That means always checking whether patients or clients need help in understanding health information or accessing services. This is both an individual and an organisational responsibility. It is critical in involving patients in shared decision making and engaging them in maximising their health through illness prevention and managing any health conditions they already have.

Acknowledgements and Further Reading

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Further Reading

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ISBN 978 1 78592 538 2 eISBN 978 1 78450 932 3

Guide to Health Literacy

Council of Europe Published January 2023 https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75

International Handbook of Health Literacy

Okan O, Bauer U, Levin-Zamir et al Policy Press Published 2019 file:///C:/Users/eawoo/Downloads/9781447344520_webpdf.pdf

National Adult Literacy Agency

Literacy audit for healthcare settings Published 2009 ISBN: 1-871737-87-7 https://www.nala.ie/publications/literacyaudit-for-healthcare-settings

Shared Decision Making (NICE guideline NG197)

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